PROGRESS OF RECOVERY AND ITS ASSOCIATED FACTORS IN RECENT-ONSET PSYCHOSIS: A MIXED-METHODS STUDY

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Progress of Recovery and Its Associated Factors in Recent-Onset Psychosis: A Mixed-Methods Study

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CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor materials that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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ABSTRACT

Abstract of dissertation entitled: Progress of recovery and its associated factors in recent-onset psychosis: a mixed-methods study.

Submitted by: Temesgen Worku Animaw *for the degree of Doctor of Philosophy at the Hong Kong Polytechnic University in Ju12019.*

Background: Recovery from psychosis is a major concern to patients, families and health care providers. Symptomatic recovery, functional recovery and subjective recovery are the three common types of recovery in mental illness. Subjective recovery is a relatively recent view of recovery that is conceptualized as an individualistic process towards self-defined goals through the endeavours of the individual and assistance from important others. Studies showed that recovery levels are different in countries with different developmental levels, being influenced by several individual, cultural and contextual factors. However, evidence from low-income, particularly African countries is scant. This makes the topic among the principal issues to be studied in the region to have a more conclusive understanding of subjective recovery; which is essential for the development of recovery-oriented mental health services.

Objective: This study was conducted in order to: a) investigate the levels and progress of subjective recovery from recent-onset psychosis; b) examine its predictive factors and; c) explore the conceptualizations of recovery and describe perceived challenges and opportunities affecting recovery.

Method: To address these objectives a sequential explanatory mixed-methods study design was employed (quantitative followed by qualitative approaches). For the

quantitative part, a nine-month longitudinal study approach was employed with three time-point measurements (baseline, third-month and ninth-month). Predictor variables for subjective recovery from recent-onset psychosis were identified by hierarchical multiple linear regression tests. Following the quantitative survey, qualitative data were collected, transcribed and thematically analysed. Finally, the findings from the two approaches are integrated and discussed together.

Results: From three referral hospitals in North-western Ethiopia 263 service users with recent-onset psychosis participated at baseline, while 190 completed the nine-month follow-up. High mean subjective recovery scores were recorded throughout the study (Questionnaire about the Process of Recovery (QPR) score ranging from 44.17 to 44.65). Quality of life, internalized stigma, disability, hopelessness, satisfaction with social support, and central obesity were the significant predictors of subjective recovery across the three time-points.

Nineteen participants were involved in qualitative in-depth interviews. Their conceptualizations of recovery were summarized in four main 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*". Participants' perceived challenges affecting their recovery were categorized into four main themes; "*altered health, psychiatric treatment and side effects of antipsychotics*", "*collective understanding and social process to psychosis management*", "*opportunities and challenges of working*" and "*faith, hope and determinations*".

Discussion: Consistently high mean subjective recovery scores and the related variables in the quantitative approach were found to be complemented and explained

by the qualitative findings. Getting a meaningful improvement in psychotic symptoms within a short treatment period and having optimistic view towards the treatment for the illness could be among reasons that contributed to the high perceived recovery level. Close interdependence within the family and utilization of care from both spiritual and modern treatment modalities could also make substantial contributions. Factors that predicted subjective recovery in the quantitative approach were also explained by the interview findings of altered physical and mental health, antipsychotic side effects, strong familial interdependence, strong faith and reliance on spirituality, impaired functioning, challenges in working environment and related economic constraints

Implications and conclusions: In low-income countries like Ethiopia, a low percentage of individuals with SMIs initiate psychiatric treatment and the majority of them visit spiritual healing sites, most by discontinuing their psychiatric treatment. Stakeholders should work on the mental health literacy of the community by informing that mental illness is treatable and illnesses like psychosis often require long term follow-up treatment. Devising mechanisms to integrate the two sectors (spiritual healing sites and Western treatment modalities) is suggested. Participants were found to believe that they would only need a limited period of treatment and once finished they would be cured. This misunderstanding needs appropriate interventions. Future research should include participants from different settings, adopt and develop different interventions to suit the local context.

PUBLICATIONS ARISING FROM THE THESIS

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

- BHS: Beck's Hopelessness Scale
- BMI: Body Mass Index
- CMD: Common Mental Disorders
- COREQ: Consolidated criteria for Reporting Qualitative research
- FEP: First Episode Psychosis
- GAF: General Assessment of Functioning
- ISMI: Internalised Stigma for Mental Illness
- PANSS: Positive and Negative Syndrome Scale
- PolyU: The Hong Kong Polytechnic University
- QPR: The Questionnaire about the Process of Recovery
- SMI: Severe Mental Illness
- SPSS: Statistical Package Social Studies
- SSQ-6: Social Support Questionnaire
- STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
- WHO: World Health Organization
- WHODAS 2.0: World Health Organizations Disability Assessment Schedule

CHAPTER 1. BACKGROUND

1.1. Introduction

Mental health is a state of wellbeing in which individuals maintain and promote their mental and emotional functioning and live an autonomous, satisfying and successful life (World Health Organization, 2004). Galderisi, Heinz, Kastrup, Beezhold, & Sartorius, (2015) emphasized that mental health is the ability to maintain one's own state of dynamic equilibrium in his/her changing universe. Conversely, mental illness is characterized by experiences of symptoms affecting mood, thought and behaviour which interferes with social and role functioning in daily living (Sumskis, 2013). The WHO's suggestion of "no health without mental health" has been acknowledged by many health care organizations and countries. It implies that stakeholders working in health care services need to make due consideration for mental health too (Federal Democratic Republic of Ethiopia Ministry of Health, 2012).

Serious/severe mental illness (SMI) is often defined by the duration and severity of illness symptoms and resulting disability. It is a behavioural and psychological syndrome in which an individual experiences distress with a significantly increased risk of suffering, disability and death (Bye & Partridge, 2004). Psychotic, depressive and bipolar disorders are among the prevalent SMIs (Bye & Partridge, 2004; World Health Organization, 2013c). Psychosis is defined as loss of contact with reality as manifested by delusions, hallucinations, lack of insight and behavioural abnormalities (Sadock & Sadock, 2011). The American Psychological Association, (2013) in its fifth diagnostic and statistical manual for mental disorders (DSM-V) and the World Health Organization, (1993) in its tenth International Statistical Classification of Diseases and

Related Health Problems (ICD-10) gave very structured and useful clinical diagnosis and classifications for mental disorders, including psychotic disorders. These influential documents considered psychosis as a set of symptoms like the distortion of perceptions and behaviours. In the ICD-10 most psychotic disorders are included under the category named "Schizophrenia, schizotypal and delusional disorders (F20-F29)" (World Health Organization, 1993). Whereas, in the DSM-V, which mostly used in Ethiopia, psychotic disorders are under the category called "Schizophrenia spectrum and other psychotic disorders" (American Psychiatric Association, 2013).

Early psychosis, recent onset psychosis, or first episode psychosis (FEP) are terms often used to express the similar earlier conditions or stages of the illness, psychosis. Recent-onset psychosis is the term used to describe individuals who experienced psychosis for up to five years of illness onset. Early psychosis refers to the early stage or condition of psychotic disorder that occurred in a younger population. First-episode psychosis is used to describe the first time of a person experienced a psychotic episode or occurrence of acute psychotic symptoms, thus often having their first treatment or service contact (Breitborde, Srihari, & Woods, 2009; Crespo-Facorro, Pelayo-Teran, & Mayoral-van Son, 2016). For this study, the term "recent-onset psychosis" is used to describe all individuals with continuous or episodic psychotic symptoms up to five years.

The prevalence of mental illness and its related burden is increasing through time due to increasing population size, crowdedness, stressful life and substance use (World Health Organization, 2015). It has been estimated that about one-quarter of the global population would suffer from mental illness (American Psychiatric Association, 2013). In the 66th World Health Assembly, it has been reported that 13% of the global

burden of disease was due to mental, neurologic and substance use disorders in 2004 (World Health Organization, 2013c) which increased to 28.6% by 2010 which caused it to be the leading cause of disability worldwide (Whiteford et al., 2013; Whiteford, Ferrari, Degenhardt, Feigin, & Vos, 2015). A community-based survey among 2180 adult Ethiopians using a self-reported questionnaire (SRQ-20) found that 17.7% of the participants had mental health problem (Gelaye et al., 2012). A study conducted among Ethiopian mothers also found that about one-thirds (32.8%) had Probable Common Mental Disorders (CMD) (Baumgartner et al., 2014).

Globally over about two-thirds (66.0%) of people with mental illness receive no treatment. The treatment gap in low and middle-income countries (LMICs) is even worse (American Psychiatric Association, 2013; Hanlon et al., 2015; Thornicroft et al., 2010). More than three-quarters of people with serious mental disorders in LMICs receive no treatment (Demyttenaere et al., 2004). The problem of low treatment coverage is even much worse in Ethiopia.

The main reasons repeatedly mentioned for the treatment gap in developing countries are service unavailability, low accessibility and lack of knowledge about the service and its use (Tesfay, Girma, Negash, Tesfaye, & Dehning, 2013). Coupled with service unavailability and inaccessibility, societies' perception towards mental illness and preference of handling the problem also affects mental health service utilization. It is very common that many people from developing countries link or relate mental illness to supernatural and prefer to deal with it in their own traditional way. In Ethiopia, commonly practised approaches used to diagnose, treat or prevent illnesses including mental disorders are spiritual therapies, written scriptures, holy water, and herbs (Hailemariam, 2015; Teferra, Hanlon, Beyero, Jacobsson, & Shibre, 2013). In these

traditional and spiritual practises, mental disorders are generally explained as resulting from disturbances in the relationship between people and divinity (Kassaye, Amberbir, Getachew, & Mussema, 2006) which influences treatment seeking and illness outcomes.

1.2. Perceived Causes of Psychosis

In biomedical models, psychotic disorders are primarily contemplated in relation with genetic factors followed by brain injury in early ages (Broome et al., 2005; Freeman et al., 2013). Although the biomedical models attempted to explain the pathogenesis of psychosis, the human brain has not yet been fully understood; there are queries not yet clearly answered about psychosis, that lets the community have different understandings about the illness (Broome et al., 2005; Crow & Harrington, 1994).

The most commonly mentioned causes of mental illness in the UK community were environmental factors such as stress, heredity, organic causes, accident and substance abuse (Wolff, Pathare, Craig, & Leff, 1996). The perceived causative factors of mental illness in Vietnam were pressure/stress and studying/thinking too much (Ham, Wright, Van, Doan, & Broerse, 2011). A study in Pakistan found that a large number of participants perceived God's will, superstitious ideas, loneliness, and unemployment were the main causes of mental illness (Zafar. et al., 2008). Guineans, South Africans and Malaysians perceived evil spirit, witchcraft and supernatural forces are the causes of mental illness (Ham et al., 2011; Koka, Deane, & Lambert, 2004; Razali, Khan, & Hasanah, 1996). Ethiopians also shared what have been mentioned above with few additional causes like exposure to the wind, evil spirit attack in postnatal women, poverty, infection, alcohol and substance use like "Khat" (Deribew & Tamirat, 2005; Hailemariam, 2015; Monteiro & Balogun, 2014).

Even though there have been much increased scientific knowledge and understandings about the pathology and organic mechanisms of mental illness and its symptoms, psychosis is perceived in relation with spirituality in various parts or societies of the world. Mitchell (2010) stated that meaning and purpose in life are at the core of both psychosis and spirituality. Psychosis often arises when an individual is developing a sense of self, questioning established certainties, myths and beliefs about the truth/reality constructed within the community. It often occurs in the younger population when they start to question constructed realities, explore and experiment new beliefs, and seek their own meaning of life. Researchers in this paradigm argued that psychosis predominantly occurs in a person whose internalized spiritual belief has been opposed by their external world. In this perspective psychosis is a result of disturbed spirituality (Hutchinson & Haasen, 2004; Mitchell, 2010).

Many stories have been reported about delusional beliefs of individuals with psychosis. For example, a case narration from the United States clearly depicted how spirituality and symptoms of psychosis, particularly positive symptoms are related, "*…man … believed himself to be Messiah … tourists that filled his town in the summer were pilgrims…"* (Mitchell, 2010). This and more stories strengthened the earlier beliefs that psychosis is the result of disturbed spirituality and/or vice-versa (Deegan, 1996); undeniably, some may still have the same views.

Although there are differences in naming, the perceived process of acquiring it and the handling mechanisms, mental illness, particularly those causing perceptual and behavioural alterations is perceived in relation with spiritual possession in different regions of the world. An earlier publication from China reported that spirit possession was diagnosed as yi-ping (hysteria) by health professionals, but community perceived

it as possession by spirits of deceased individuals, deities, animals and devils (Gaw, Ding, Levine, & Gaw, 1998). A commonly believed type of spirit that possesses humans and causes illness, in Northern and Eastern African countries including Ethiopia and Middle-Eastern countries is known as "Zar"" (Mianji & Semnani, 2015).

The general public in African and Middle-Eastern countries often perceived the signs and symptoms of acute psychosis as spirit or Zar possession. An early study among Ethiopian origin Jews reported that being possessed by Zar was the cause of almost all somatic and mental disturbances (Arieli & Aychen, 1994). A case of Eritrean, similar in sociocultural and religious beliefs with Ethiopian, immigrant to the UK has demonstrated how cultural conflicts and distress interpreted as sprit possession (Chartonas & Bose, 2015). In societies where spirit possession is believed and practiced, people associated acute psychotic symptoms with spirit possession (Mianji & Semnani, 2015).

The general notion of the above discussion is that societies for traditional and in low-income countries such as Ethiopians have deep-rooted belief in spirit possession with diverse names like Zar, Evil eye, curse with scripture and other more. The syndromes of these things are similar with psychosis as the American Psychiatric Association (2013) also give recognition for this kind of disturbances by saying “culture bounded syndrome”. The community approaches these problems in various ways. As reported from Israel (Arieli & Aychen, 1994) and UK (Chartonas & Bose, 2015) traditional and religious practises significantly contributed to mental health condition of traditional societies. The majority of societies in the developing countries like Ethiopia perceived mental illness different from other societies in developed countries where most studies about recovery from mental illness have been conducted. This difference

may cause different health care preferences and seeking behaviours that subsequently affects the outcomes of the problems arising from the illness.

1.3. Health Care Preferences and Health Care Seeking Behaviours

When people face disabling health problems such as mental illness, they attempt to manage it based on their understanding towards it. If they succeed on their attempt of managing the disorder, their current understanding would be kept or get strengthened and more communicated and shared to the community. The majority of people in developing countries usually start to contact or use health care services from the traditional and/or religious healing modalities (Jirom, 2000). Many developing countries in Africa, Asia and Latin America use traditional medicines and spiritual practises to meet their health needs. About 80% of the African populations use traditional medicine for primary health care (Bhuiyan et al., 2013; World Health Organization, 2000, 2003).

In Ethiopia, it is not possible to differentiate traditional, spiritual and religious healing practises; each healing practise complement eachother and they are interlinked (Andualem & Oyekale, 2012; Hailemariam, 2015). More than half of the Ethiopian population prefer traditional and religious healing services for its better capacity to cure than the modern medicine (Andualem & Oyekale, 2012). The preference of traditional healing services over modern/western treatment is for any illness and the preference for modern medicine is much less if the disorder is mental health. It is because, as modernized health care services are less accessible, expensive and not affordable; above all, people also perceived that mental illness is not treatable by modern medicine (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999).

People also prefer the spiritual and traditional healing practice for its holistic and contextual acceptance of human nature (body, spirit, mind, social being, and culture), culture and its convenience than those wester style treatment sectors. Indeed, it is not only convenience and acceptability, perceived causes of mental illness may also influence health care seeking behaviours and the type/s of health care being sought (Hailemariam, 2015). In addition to individual treatment preferences, the treatment gap in biomedical care provision is another reason why people with SMI visit traditional and religious healing sites in the country (Fekadu et al., 2019). Some people also visit both to benefit from the two treatment paradigms.

Early diagnosis and intervention have significant benefits for several favourable outcomes such as symptomatic improvement and functioning. Studies reported that delay in diagnosis and treatment of psychotic disorder causes increased length and frequency of hospitalization, and poor symptomatic and functional outcomes (Merritt-Davis & Keshavan, 2006; Yeo, Berzins, & Addington, 2007). It has been repeatedly reported that only a few proportions of population seek health care from the conventional health care system for mental disorders. The WHO estimated that only 20 psychotic cases treated in specialist service per 100,000 population in low-income countries, while 324 treated in high-income countries (World Health Organization, 2015). Among those reported factors that delay access to modern treatment were low mental health literacy, beliefs about the cause of the illness, stigma, financial problems, and accessibility of the psychiatric service (Marthoenis, Aichberger, & Schouler-Ocak, 2016).

Different health care seeking behaviours for mental illness were reported from various parts of the world. The majority (70%) of the UK participants would contact a general

practitioner for mental illness (Wolff et al., 1996). About half of Indian participants reported their first contact for psychiatric problems was hospitals and/or clinics (Grover, Nebhinani, Chakrabarti, Shah, & Avasthi, 2014). A study in Pakistan found, 60% looked for either traditional healing services or do nothing for mental illness (Zafar. et al., 2008). Many Indonesian families of patients with psychosis expressed that mental illness was a "village sickness" not to be treated in hospital (Marthoenis et al., 2016). For mental health problems, Nigerians preferred prayer house over modern health care for its curing ability (Nonye & Oseloka, 2009).

In Ethiopia, like most other low-income countries, a small proportion of people with mental illness (5 to 10%) received modern health care, despite these conditions could be eminently treated at low cost (Fekadu & Thornicroft, 2014). A case study report from Amanuel Hospital, the only Psychiatry Specialized hospital in the country/Ethiopia, described the story of a woman with psychotic illness "*Mrs A with acute severe psychosis…'chained' … 3-day journey to … the only specialised mental hospital … admitted … her condition gets completely well and was discharged … she has not returned … for clinical follow-up*" (Fekadu & Thornicroft, 2014, p. 25447). Indeed, this is the story of many individuals with mental illness who started treatment in modern health care system. Even these people, who started psychiatric treatment and disengaged from it after sometimes of treatment, are very few among patients with similar health problems. A 5-year longitudinal study in 321 individuals with schizophrenia in rural Ethiopia found that 20.0% of the participants missed their treatment follow-up (Teferra et al., 2012). Another hospital based cross-sectional survey among 422 individuals with psychiatric illnesses found that 41.2% of patients were not adherent to their drug treatment (Tesfay et al., 2013). Commonly reported reasons for non-adherence in low-income countries are: not having trust on the

medications, expecting cure, not getting expected improvement and/or feeling better, having medication side effects, fear of stigma, and lack of food to counter increased appetite (Teferra et al., 2013; Tesfay et al., 2013; Tareke, Tesfaye, Amare, Belete, & Abate, 2018). The concern is not solely treatment initiation and adherence, even for those who adhere to the psychiatric follow-up their improvement in their symptoms and functioning is not given due attention.

The goal of antipsychotic treatment in psychotic disorder is to control the symptoms, bring functional improvement and sustain it to the best possible state. However, contradicting evidence are emerging on the importance of maintaining the antipsychotic treatment for a long time. Some reports have even indicated those patients who were less treatment adherent and closer to traditional and spiritual healings had better and sustained recovery status (Grover et al., 2014; Menezes, Arenovich, & Zipursky, 2006; Wunderink, Nieboer, Wiersma, Sytema, & Nienhuis, 2013). This also raises a concern if better recovery level for developing countries reported by WHO still holds true and if it really is because of low treatment coverage, adherence and integration of modern treatment with traditional healing practises (Hopper, 2007; Jaaskelainen et al., 2013).

1.4. Levels and Percentages of Recovery from Psychosis

Nowadays, recovery from psychosis and other mental illnesses is the main concern for the service users, service providers and researchers. Fuelled by this interest several qualitative studies have been conducted. Findings from these exploratory (qualitative) studies raise interests to quantify recovery and measure its progress. In response to this demand, recovery measuring tools have been developed by different authors. A systematic review in 2013 broadly categorized recovery measurement instruments in

to three: instruments measuring recovery as a process, as an outcome at one time point, and recovery as dimension (recovery domains/constructs) (Sklar, Groessl, O'Connell, Davidson, & Aarons, 2013). As to the nonlinear nature of recovery, instruments measuring recovery as a process would have a superior advantage to record how recovery is progressing and sustained through time and determine which factors predict the change in it. Another systematic review identified 33 instruments measuring recovery, which categorized them into two: instruments measuring personal recovery and those measuring recovery-oriented services, i.e., tools measuring the successes of the services in enhancing recovery (Burgess, Pirkis, Coombs, & Rosen, 2010). Using these tools in either category, the prevalence, the level and/or the progress of recovery have been reported in different studies, while almost all of them are from developed countries.

Varied levels of recovery are reported in various studies conducted in different countries and/or settings. A review work found that a majority of individuals with SMI remained with a functional disability; over 80% of people with SMI were unemployed indicating most people with SMI were facing problems with functioning and some of them were highly vulnerable to homelessness, stigma, and victimization (Drake & Whitley, 2014). Another systematic review summarized that among individuals with schizophrenia 22.0% to 97.0% of them had symptomatic remission and 10% to 68% had functional recovery (Valencia, Caraveo, Colin, Verduzco, & Corona, 2014). A broader systematic review incorporating both the symptomatic and functional recovery found that median recovery level from schizophrenia was 13.5% (Jaaskelainen et al., 2013). A report of full recovery, both symptomatic and functional recovery, varies from 14.0% in ten years follow-up in Denmark (Austin et al., 2013) to 29.4% in Singapore of two years follow-up (Verma, Subramaniam, Abdin, Poon,

& Chong, 2012). A study from Hong Kong found 17.4% of individuals with psychosis had full recovery in three years follow-up (Chang et al., 2012). Percentage of recovery among 255 individuals with first episode psychosis was 15.7% after 5 years follow up (Albert et al., 2011). The six-month follow up study among 110 individuals with psychosis in the UK found that the mean score of the 15-item questionnaire about the process of recovery (QPR) was improved from 47.46 at baseline to 56.65 at the sixth-month from possible maximum score of 75 (Law, Shryane, Bentall, & Morrison, 2016).

Some cross-cultural studies and review reports agreed that recovery outcome from psychotic disorders and other SMIs is better in low-income countries (Isaac, Chand, & Murthy, 2007; Jaaskelainen et al., 2013; Myers, 2010). However, this understanding is being questioned by some contrasting findings. Although only a few studies have been conducted in low-income countries, they recorded lower recovery level than what were reported in previous cross-cultural studies. A five-year longitudinal study among 321 individuals with schizophrenia in Ethiopia reported that only 20.0% had continuous remission while nearly half were continuously symptomatic (Teferra et al., 2012). Another study from the same study area reported 27.4% were in complete remission for a month while 5.7% had continuous remission for six years (Shibre et al., 2015).

In low-income countries like Ethiopia, no study that measures full recovery (personal/subjective, functional and clinical) from psychosis can be found. A study that measured the functional level of individuals with bipolar disorder in Ethiopia reported that 52.0% to 86.0% of individuals with recent-onset bipolar disorder had

physical and social functioning restriction as measured by items of the short form, SF-36 (Kebede et al., 2006).

Generally, it is understandable that recovery from psychosis is possible. However, wide-ranging percentages of recovery are recorded from different countries. Almost all studies measuring recovery level are from the developed countries, which showed an evidence gap from low-income countries. Factors related to recovery have been identified, though only from high-income countries. These studies have also demonstrated that recovery can be enhanced by evidence-based recovery-oriented psychiatric services and working on modifiable factors.

The variations in the levels of recovery may not be real differences on the ground. Lack of internationally agreed robust definition let the authors give their own definitions which are different among studies and make it difficult to compare findings from different studies. For example, Austin et al. (2013) adopted definition of recovery from severe mental illness or psychosis given by Liberman, Kopelowicz, Ventura, and Gutkind (2002), which considers total control of symptoms, no hospital admission, living in a non-supported accommodation for the past two years, engaged in work or study and an improvement general functioning score which is different in other studies. Another study in Hong Kong by Chang et al. (2012) used definitions of recovery as no psychiatric admission, functional remission, and CGI-S (Clinical Global Impression – Severity of Illness Scale) score less than 3 for both negative and positive symptoms for the last 12 months simultaneously. Whereas other studies used other definitions, some even without considering either the symptomatic level or duration of symptom-free period (Law et al., 2016) or some selected items of PANSS (Verma et al., 2012). Not only the operational definitions and the instruments used to

measure it, but there also no clear agreement on the terms to be used while referring to the desirable outcomes from SMIs including psychotic disorders.

1.5. The Meaning and Importance of Recovery from Psychosis

Recovery from mental illness is an idea that arose in recent decades, though still struggling to fight the "old" belief that such a thing is not possible. The perception of how people see mental illness reflects the way the person with mental illness is treated. This negative perception leads to an enduring stigma and discrimination for people diagnosed with a mental illness (Siqueira, 2011). The old idea that a person could not recover from mental illness resulted in institutionalization and exclusion from normal life in the community. However, it has been revealed that recovery from psychosis is possible and individuals with psychosis can live a meaningful, productive and successful life even if they have continued symptoms (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008).

The two most desired outcomes showing improvement in manifestations and functioning of psychosis patients are remission and recovery. Numerous definitions about remission and recovery have been given, nonetheless there is no internationally agreed single definition. Authors operationally defined to their studies' context; indeed, there are major commonalities and few contextual differences on each definition.

1.5.1. Definitions of clinical recovery and symptomatic remission

Some authors use the term remission and clinical recovery for the same concept. Andreasen et al. (2005) give the definition as "*remission is a state of improvement in core signs and symptoms to the extent that any remaining symptoms are of such low*

intensity that they no longer interfere significantly with behaviour and are below the threshold typically utilized in justifying an initial diagnosis" (Andreasen et al., 2005, p. 442). Davidson et al. (2008) have given a relatively brief definition, if a person's condition for the diagnosis of schizophrenia has improved to the point at which it would no longer meet criteria for the diagnosis previously made, then it is called remission.

Both definitions mentioned above are focusing on subjective understandings for manifestations of mental illness which make them biased for measurement. Hence, authors tried to define remission in an objectively measurable way. A common approach towards defining remission is through assessment of eight items of the Positive and Negative Syndrome Scale (PANSS) and at least 50.0% reduction of the total baseline score and must be sustained for a minimum of six months (Valencia et al., 2014). In their systematic review Jaaskelainen et al. (2013, p. 1298), defined recovery in a broader way considering functioning also "*living independently for 2 years, no psychiatric hospitalization in 5 years, and currently in full clinical remission, psychosocial functioning in the normal range, and no/low antipsychotic medication".* Definitions given above are what recovery is conceptualised from the perspectives of biomedical model; however, these definitions do not consider service users' perspectives.

Generally, remission is about improvement in clinical signs and symptoms, however, it is not that easy to put clear and defining boundary between recovery and remission. Although remission can be defined independently from recovery, it is also among the main pillars of recovery.

1.5.2. Models of recovery and their definitions

People often confused the concept of recovery with remission, cure, or rehabilitation (Noiseux et al., 2009). Various definitions have been given for recovery; however, there is still no common consensus in terms of having a unique definition for recovery. Shepherd, Boardman, and Slade (2008) mentioned that recovery is building a meaningful life, with or without the presence of symptoms. Recovery in mental illness is staying in control of one's life, not returning to the premorbid state of functioning. The approach that emphasizes resilience and control over problems and life without focusing on full symptom resolution is referred to as the recovery model (Noiseux et al., 2009; Shepherd et al., 2008).

The concept of recovery can be traced back to 1830s when John Perceval wrote about his story of personal recovery from psychosis. Hence, this was the initiation of the concept of recovery and recovery models. Following this, several pieces of literatures about personal experience in the journey of recovery from mental illness appeared, though not strong enough to influence policy and not robust enough to be a model of practise for more than a century (International Mental Health Collaboration Network (IMHCN), 2002).

In parallel with the individuals' movements, the medical model has been dominantly practised which drives the clinical view of recovery. The medical model views recovery as objective and understood it to be a return to a former state of health with expected outcomes such as reduced symptomatology, hospitalization and medication use (NSW Consumer Advisory Group, 2009). A similar meaning for recovery also appeared in another report which says; recovery is relatively being free from disease-related psychopathology. Nonetheless, Andreasen's definition considered ability to

function in the community over a prolonged period of time in addition to symptomatic control (Andreasen et al., 2005). As discussed earlier the definition given by medical model has many similarities with current definitions given for remission.

A more criterion-based definition of recovery from the context of medical recovery model has been given in a systematic review with the following proposed recovery criteria (Valencia et al., 2014):

- A reliable diagnosis of mental illness during the early phases of the illness
- Not meeting the diagnostic criteria for the illness at the time of assessment
- Not having been hospitalized for at least five years
- Psychosocial function "within normal range" and
- Antipsychotic medications are not being taken, or if they are, they are at very low doses (less than half of what would be considered as a usual daily dose).

In the definitions mentioned above, though objectively measurable, the criteria are inflexible and may not motivate patients who are continuously symptomatic (or symptomatic if not taking medication) but functional and recovering in a different way.

Another relatively persuasive definition with criteria to be considered is: 1) moderate presence of psychotic symptoms, 2) an independent life, 3) working or studying at least part-time, and/or 4) participating in social and recreational activities. These criteria should be met for a minimum of two years (Liberman et al., 2002; NSW Consumer Advisory Group, 2009). Duration of recovery that should be considered are also varied from months to years among authors.

In 2003 Andresen and colleagues proposed five stages of recovery for the person with

schizophrenia (Andresen, Oades, & Caputi, 2003). Bearing in mind that process of recovery is nonlinear process happens for most patients (Deegan, 1996), the stages of recovery at below are getting highly acceptable by other researchers and organizations working in psychiatric rehabilitation (Andresen et al., 2003; NSW Consumer Advisory Group, 2009):

1) Moratorium: a stage of denial, confusion, hopelessness, confusion and withdrawal.
2) Awareness: reflecting sparks of hope for better life, sense (aware and start to feel/appreciate) recovery is possible.
3) Preparation: mobilizing resources that can promote recovery.
4) Rebuilding: recovery takes and taking place.
5) Growth: the final anticipated stage with or without symptom but knowing much better how to manage the illness and to stay well.

These stages of recovery can be useful assets for recognizing stage of recovery and plan and provide appropriate care for further recovery. However, recovery is a unique, personal and nonlinear journey that each individual has his/her own way and stage of recovery and they may not necessarily pass through or in the sequence of these stages.

The main drawback of the medical model is its paternalistic approach to the clients. This paternalistic approach within the medical profession often dismissed service users' perspectives and did not take kindly to different view-points (Jacob, 2015). Another problem of the medical model and health care practises under this principle is that, labelling of mentally ill individuals and related stigma which emerge as major barriers for the service users. There is an agreement that the existing medical model for mental illness has a substantial negative effect (Beresford, Nettle, & Perring,

2010). Therefore, this contradictions between medical practises and social and individual values led to a re-examination of the medical model. The empowered and vibrant survivors' movement in Europe and America struggled for different perspectives and approaches; this gave birth to the recovery model in late twentieth century (Jacob, 2015).

Application of recovery models to mental illnesses is comparatively recent. The main drive for the development of recovery model came from the ex-patients' movement in the USA during the 1980s and New Zealand early 1990s and more recently followed by nearly all developed countries (International Mental Health Collaboration Network (IMHCN), 2002). Since then, it is getting more acceptance, as it enabled patients to cope with symptoms, gain an acceptable identity and also fuelled by research evidence showing improvement in patients' condition (Jacob, 2015).

The subjective view of recovery is driven by individuals' lived subjective experiences of their illness and recovery, that latter challenges the notion of permanent mental illness. Outcomes of personal/subjective recovery model focused on hope, empowerment, choice, self-defined goals, healing, well-being and control over symptoms (NSW Consumer Advisory Group, 2009). Another clarification in line with subjective view model is by Slade (2009); recovery is about building a meaningful and satisfying life, as defined by the persons themselves, with or without symptoms. It seems that this concept, building a new identity with meaningful life and hope in whatever the symptom level, is getting more acceptance nowadays.

In the subjective recovery model, the process of recovery provides a holistic view of the patient as a person not only focusing on the symptoms he/she has. The recovery model asserts that recovery is a journey rather than a destination. The model helps

individuals with mental illnesses to look beyond mere survival and existence. Recovery is about looking beyond the limits, it is self-helping to achieve own goals, aspirations and dreams. Recovery is viewed as the journey of self-discovery and personal growth (Anthony, 1993; Deegan, 1996; Jacob, 2015). The other important concept in another definition is being able to live a meaningful and satisfying life and having control over one's own life. Recovering from mental illness is a vision; individualized vision and individuals achieve it at different level through their own journey (Scottish Recovery Network, 2009).

In several definitions given for recovery from mental illness, major concepts raised include: hope, new accepted identity, living meaningful life, being responsible and autonomous in own life, demonstrate self-respect and dignity, integration with community, and resuming normal development (Andresen et al., 2003; Jaaskelainen et al., 2013; NSW Consumer Advisory Group, 2009; Valencia et al., 2014). Recently, the American Psychological Association (2012) also suggested 10 core principles of recovery, which are similar to the above concepts but with few additional concepts. The additional concepts are those which characterize the significance of patients' active involvement in the mental health care service such as self-directed (i.e., consumers determine the way of recovery), person-centred and nonlinear approach. These two concepts, self-direct and person-centred, correct the paternalistic approaches of medical model (American Psychological Association, 2012). Service users decide the way they treated and recovered, and health care providers are required to provide individualistic person-centred care based on the needs and plans identified together with the service user. Recovery is not always the upward progress rather setbacks are also common. Learning from the experiences goals and meanings of recovery should be updated individually. Each of the concepts, particularly the

subjective recovery from the perspectives of the individuals with recent-onset psychosis, are further discussed in the next chapter, i.e. Chapter two.

In conclusion, the definitions of recovery vary in terms of the theoretical and conceptual approaches used. If the term “recovery” is used alone it may embrace symptomatic, functional, and/or personal/subjective recovery. Symptomatic remission is a commonly accepted criterion of service users’ recovery from mental illness in ‘clinical recovery’ from the medical model perspective. Most of the definitions about recovery considered period of being symptom-free and functioning, though the durations used are different among researchers. Most definitions agreed that recovery is nonlinear process and self-optimizing journey (American Psychological Association, 2012; Andresen et al., 2003; Davidson et al., 2008; Deegan, 1996). Subjective recovery is an individualistic journey of changing one’s attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life. It is the struggle of developing new meaning and purpose in life through discovering or rediscovering one’s identity (Anthony, 1993, 2000). Personal recovery and subjective recovery are terms used for equivalent concept.

Particular to the conceptualisations of subjective recovery from recent-onset psychosis, a systematic review was conducted to examine and synthesise literature pertaining to the concept of subjective recovery from recent-onset psychosis from both qualitative and quantitative studies. In order to know what have been already done about subjective recovery from recent-onset psychosis, identify the gaps in the topic, and pinpoint the appropriate methods for further study, a systematic review was conducted. In the systematic review, as discussed in the next chapter, subjective recovery was understood differently among individuals, factors affecting recovery

were different among countries, studies used different designs, and studies about the topic are limited in high-income countries showing evidence gap in societies having low-income.

CHAPTER 2. SUBJECTIVE RECOVERY FROM RECENT ONSET PSYCHOSIS: A SYSTEMATIC REVIEW

2.1. Introduction

Early diagnosis and effective interventions for individuals with psychosis result in significant recovery benefits (Merritt-Davis & Keshavan, 2006; Yeo et al., 2007). However, there seems to be no clear consensus on the definition/concept of recovery and thus there are different views about the process or mechanism of enhancing or achieving recovery from psychosis and other SMIs. Therefore, it is important to understand the conceptualization of recovery from the users' perspective and identify modifiable factors which are associated with successful recovery. Few systematic or critical literature reviews were conducted about recovery from psychosis, while almost all were focused on schizophrenia and clinical recovery only (Jaaskelainen et al., 2013; Jose et al., 2015; Tew et al., 2011). No systematic review was yet done about subjective recovery from recent-onset psychosis; therefore, the existing evidence had yet to be collated and synthesised in order to have a comprehensive and deep understanding about recovery and the factors related with it.

The objectives of this review on both qualitative and quantitative studies were two-fold: (1) to examine and synthesise literature pertaining to the concept of subjective recovery from recent onset psychosis; and (2) to summarize factors relating to subjective recovery from both qualitative and quantitative studies.

2.2. Methods for Systematic Review

An integrated systematic review was conducted according to the protocol prepared following the recommendations of Preferred Reporting Items for Systematic Meta-

Analysis Protocol (PRIMSA-P; (Moher et al., 2015), which is registered in an international prospective register of systematic reviews (PROSPERO; registration number: CRD42017064192) to enhance transparency of the review process.

2.2.1. Searching strategy

Searching terms and their combinations were; (“Subjective Recovery” OR “Personal Recovery”) AND (“First Episode Psychosis” OR "Early-Onset Psychosis” OR “Recent-Onset Psychosis”). The search was done from Medline via EBSCOhost, CINAHL Complete via EBSCOhost, PubMed, PsychInfo via ProQuest, ProQuest Dissertations and Theses, and Scopus databases. Electronic databases from the inceptions of each database to 12-April 2017 were searched. Hand searches, google scholar enquiry and searches from reference lists of the identified studies were also employed.

2.2.2. Inclusion and exclusion criteria

Studies were eligible for inclusion if they involved at least 50% of participants with recent-onset psychosis (i.e., having a diagnosis of psychotic disorder up to 5 years) and were mainly pertaining to subjective recovery. Studies were included irrespective of the study settings (i.e. inpatient, outpatient and community). Systematic reviews and studies utilising qualitative, observational quantitative, and mixed-methods research designs were included. Articles published in English in peer reviewed journals and PhD dissertations were eligible for inclusion. However, intervention studies, studies measuring only clinical and/or functional recovery, commentaries, conference abstracts, discussion papers and those involving participants with psychosis secondary to other mental health problems were excluded.

2.2.3. Article selection procedures

All articles identified from database searches were exported to Endnote 8, and duplicates were removed. Articles that did not fulfil the above-mentioned inclusion criteria were excluded by reading from the titles and abstracts, and if necessary, the full texts. If the findings from PhD dissertations were also found in published articles; their article versions were included in the screening process. Article screening was conducted by the first and checked by the third reviewers, and if the two reviewers could not agree about inclusion or exclusion of articles, a second reviewer was consulted in order to reach consensus.

2.2.4. Qualities of reviewed studies

The methodological quality of studies included were assessed using the Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2017). The quality scores of the reviewed articles are presented in Table 13.1 and attached in Appendix 13. The overall qualities of the studies reviewed were judged to be generally of good quality. As to the nature of the topic, most studies used qualitative designs, particularly interpretive phenomenological analysis (IPA) method, which enabled studies to address the issues well from the participants' experiences and perspectives. However, the levels of relationships between researcher and participants were not clearly mentioned in some of the studies (Connell, Schweitzer, & King, 2015; Eisenstadt, Monteiro, Diniz, & Chaves, 2012; Romano, 2009). In the reviewed studies, participants were recruited/invited by their clinical care providers which might influence their willingness/consent and the data they gave. A study by Bourdeau, Lecomte, and Lysaker (2015) used mixed research methods; while the qualitative part was robust enough, the quantitative part and the way the data from these two sources

combined and compared was not presented in a convincing or clear way. Generally, as all the studies reviewed except one (Norman, Windell, Lynch, & Manchanda, 2013) are qualitative studies, authors' reflexivity in each study are hardly recognizable.

2.2.5. Data extraction and analysis

A data extraction form was prepared by adopting and modifying from previously published works (Coleman, Stevelink, Hatch, Denny, & Greenberg, 2017; Jaaskelainen et al., 2013). Using this form, data pertaining to the conceptualization of subjective recovery, the contributing factors for subjective recovery, study and participant characteristics were extracted. The analysis strategies for the integrative review suggested by Whittemore and Knafl (2005) were followed. According to the recommendations, data were ordered (done by ordering types of the article), coded (done by data extraction), categorized (done by thematically analysing the conceptualization of subjective recovery and factors contributing towards subjective recovery) and summarized (done by making interpretations and discussions on identified themes). Commonalities and differences in the conceptualizations of subjective recovery in studies reviewed are discussed.

2.3. Results and Discussions

2.3.1. Selected Studies and their characteristics

A total of ten eligible studies were identified from the electronic databases and hand searches. Among these articles the majority (n=6) of them were from Canada, one was conducted in two countries (Australia and Canada), and each of the remaining were from Hong Kong, Brazil, or Australia. Eight of the identified studies were qualitative studies in which most of them used a phenomenological approach. A total of 298 participants were involved in the studies reviewed, with the majority (n=214, 71.8%)

being male. The number of participants involved in each study ranged from 6 to 84. The mean age of participants ranged from 21 to 28 years old. Participants in the reviewed studies were recruited from early psychosis intervention programmes/centres, first episode programmes, inpatient and outpatient psychiatric clinics, and community mental health services.

2.3.2. Conceptualizations of subjective recovery from recent onset psychosis

In this systematic review, the conceptualization of subjective recovery from the perspectives of service users particularly with recent onset psychosis was synthesized. From this review, subjective recovery is conceptualized in 3 themes as presented Table 2.1. “Recovery as outcome”, “Recovery as process” and “Endeavours during recovery”, were the main themes identified.

Table 2-1: Concepts of subjective recovery from recent onset psychosis

Themes	Subthemes	Illustrators/Verifiers
Recovery as outcome	Bounce back	Absence or decrease of symptoms[1, 3, 5 & 7] Renewed identity, autonomy and independence[1, 2 & 4] Re-engage in life[10] Restoration of self-reliance[1 &2] Achievable goal [9] Trust in others[1]
	Be in self-control	Social relationships and functional improvement[1&2] Able to take responsibility in family and occupation roles Control over symptoms[3, 5 & 9] Participate in treatment/decision (medication (opposing ideas raised)[9] Confidence in self [9] Help seeking and get support from others when in need[9]
	Have vision	Prospect[4] Hope[4& 9] Vision[4 & 10] Goals and purpose[9] Have meaning in life[4]
Recovery as process		Multidimensional and personalized[2 & 4] Slow and gradual [1 & 2] Transition from experiences of self- estrangement to self-consolidation [2] Change in self[10] Not all participants went through same stages [2 & 4] Nonlinear [2 & 4] Beyond symptom control and medication compliance [6] Have positive features that the experience of illness had brought [6]
Endeavours during recovery		Reconciling with illness experience [4, 7 & 10] Understand recovery[7, 10] Maintain optimistic view of recovery[7] Value in self [10] Control over chaos[6] Treatment negotiation and acceptance[5, 7 &9] Negotiating for success[5] Social participation [1, 5] Engaging in services and support[10] Self-help, help from others [9] Fight Stigma [6 & 7] Supress/defeat disabling factors [6]

[1-] (Eisenstadt et al., 2012), [2-] (Connell et al., 2015), [3-] (Windell et al., 2012), [4-] (Bourdeau et al., 2015), [5-] (Windell et al., 2015), [6-] (Woodside et al., 2007), [7-] (Lam et al., 2011), [8-] (Windell et al., 2013), [9-] (Norman et al., 2013), [10-] Romano, (2009)

2.3.2.1. Recovery as outcome

In the reviewed studies subjective recovery was conceptualized as an outcome. In this concept, subjective recovery was defined as an outcome that individuals with recent-onset psychosis should achieve or fulfil to regain optimal health or well-being. Although not particular to subjective recovery, in other studies not included in this review, recovery was conceptualized as an outcome of overcoming psychosis causing impairments (Andreasen et al., 2005; Hassan & Taha, 2011; Menezes et al., 2006). Under this theme, "bounce back" was one of the sub-themes ascertained. Regaining the premorbid symptom free level (Eisenstadt et al., 2012; Lam et al., 2011; Windell, Norman, & Malla, 2012), autonomy, identity, self-reliance and social relationships (Bourdeau et al., 2015; Connell et al., 2015; Eisenstadt et al., 2012) were among the reported illustrators that attested "bounce back". Its' expression was blurred though, individuals also perceived that not relying on medications for the symptom control was among the indicators of their recovery (Norman et al., 2013). Indeed, this sub-theme is not limited to getting back to the pre-morbid state, rather it is also viewed as being in a productive and acceptable condition by society and the self. Individuals with recent-onset psychosis perceived that subjective recovery was a bounce back to the healthy and acceptable state and maintaining this state by staying in control over symptom and self while having a vision for better future.

"Self-control" and "have vision" were the other sub-themes identified under "recovery as outcome" theme. Gaining hope and living a meaningful life were among the repeatedly reported illustrators in defining vision as one concept of subjective recovery. Although many studies attempted to explain recovery as an outcome, it is not merely an outcome and it is rather a process of achieving several desirable

outcomes such as regaining autonomy, self-reliance, symptom control, and others mentioned above.

2.3.2.2. Recovery as process

The "recovery as process" theme reflects the fact that subjective recovery is also conceptualized as a process of overcoming disabilities that the illness brought and getting self-consolidation through learning from experiences (Connell et al., 2015; Lam et al., 2011; Romano, 2009). In accordance with the potentially enduring nature of psychosis with highly possible symptom relapses, many service users agreed that "recovery is a process". Subjective recovery was conceptualized as a multidirectional, individualistic, and nonlinear transition to self-consolidation (Bourdeau et al., 2015; Connell et al., 2015). It is not only controlling the symptoms with or without drugs, rather it is a process of building positive futures through learning from experiences (Woodside, Krupa, & Pocock, 2007). Some individuals even perceived experiencing psychosis and their journey of recovery was a good thing that happened in their life. They perceived that it helped them to see the world in different "better/correct" perspective which makes their life meaningful; "*I am now generally smarter"*(Lam et al., 2011, p. 254)*; "it [*psychosis*] gave me my adulthood"* (Connell et al., 2015, p. 363). Generally, subjective recovery from recent-onset psychosis was perceived as progression to positive future through different efforts.

2.3.2.3. Endeavours for recovery

Endeavours for recovery was another theme that appeared in the review. During the process of recovery from psychosis, struggling to develop new meaning and purpose in life was also mentioned by Anthony (2000) and Sumskis (2013); and the backward

and forward processes involved in the recovery journey were also given emphasis by Deegan (1996). Reconciling with illness and getting new identity are the starting actions of subjective recovery. With new perceptions of self, an understanding of recovery and know how to overcome the challenges in the process of recovery are required. In the initial phase of recovery understanding what the problem is, what the individual is capable of and what other resources are required and available are among the situations needed to be analysed by service users and others working for their recovery (Bourdeau et al., 2015; Lam et al., 2011). Synthesizing and overcoming stigma and other challenges are among the endeavours needed to be taken (Lam et al., 2011; Woodside et al., 2007). Possible resources like family and peer support, gaining something meaningful to do, health care, and peer groups could be vital assets for subjective recovery (Eisenstadt et al., 2012; Lam et al., 2011; Norman et al., 2013; Windell, Norman, & Malla, 2015; Woodside et al., 2007). Another important issue raised at the efforts of recovery is that treatment should not just be accepted and adhered to, rather it should be negotiated (Lam et al., 2011; Norman et al., 2013; Windell et al., 2015). Service users with psychosis should be involved actively in their treatment, health professionals should allow service users to make informed decisions, help them to be competent enough to take risks which would boost their motivation and self-confidence that subsequently enhance recovery (Jacobson & Greenley, 2001).

Generally, from the systematic review about conceptualization of subjective recovery from recent-onset psychosis, it was concluded that service users with recent-onset psychosis perceived that subjective recovery differently; some perceived it was an outcome to achieve while the others perceived it was a process and endeavours of betterment.

2.3.3. Factors associated with subjective recovery from recent-onset psychosis

In the systematic review conducted to identify factors related to subjective recovery from recent-onset psychosis, the related factors were categorized into 4 themes: “treatment-related”, “illness-related”, “individual-related” and “social environment related”. These themes with their sub-themes and illustrators and citations are presented in Table 2.2. Under these themes, factors identified by studies included in the systematic review and also other studies not included in the systematic review are discussed jointly to avoid reappearances in some of the factors identified from both reviews.

Table 2-2: Factors associated with subjective recovery from recent onset psychosis

Themes	Subthemes	Illustrators
Treatment related factors		Medication (positive and negative effects) [1, 3, 7, 8 & 10] Psychoeducation[1] Treatment (duration, dosage & adherence) related factors[3 & 10]
Illness related factors		Duration of untreated psychosis [3 & 4] Symptom level (Both negative and positive symptoms but negative symptoms have higher impact) [4, 7]
Individual related factors	Physical	Family history of mental illness [6] Physical health [6] Education level [4] Substance use[6] Learning problem[4]
	Psychological	Hope, Prospects[1, 10] Personal effort[1] Narrative development (alienation, agency and social worth)[4] Experience of abuse[6] Meaningful activity and life style [8& 10] Ability to learn from experience, Personal Capacity [1, 2 & 6] Uncertainty about the future[10] Important Insight [10] Sexual Orientation problem[6] Psychosocial functioning[4]
Social environment		Immigration[6] Social engagement[4] Social Support[1,7, 8, 9] Stigma[7, 8, 10]

[1-] (Eisenstadt et al., 2012), [2-] (Connell et al., 2015), [3-] (Windell et al., 2012), [4-] (Bourdeau et al., 2015), [5-] (Windell et al., 2015), [6-] (Woodside et al., 2007), [7-] (Lam et al., 2011), [8-] (Windell et al., 2013), [9-] (Norman et al., 2013), [10-] Romano, (2009)

2.3.3.1. Treatment related factors

The effects of treatments on subjective recovery have been well acknowledged in many studies (Eisenstadt et al., 2012; Lam et al., 2011; Romano, 2009; Windell et al., 2012; Windell & Norman, 2013). Individualistic and phase-specific intervention was another issue that clearly substantiated this theme. The importance of antipsychotic medications in controlling symptoms that initiated and maintained clinical and subjective recovery was also well documented; however, drugs side effects were also too visible. Among factors included under this theme, the most visible factors are the

duration of untreated psychosis and duration of treatment and adherence to drug treatment, which are discussed together for their conceptual proximity.

Duration of Untreated Psychosis (DUP) is the time between onset of first psychotic symptoms like hallucinations, delusions, disorganized behaviour, and the time when a definitive diagnosis is made and initiation of treatment for the psychosis (Connell et al., 2015; Gee et al., 2016; Verma et al., 2012). Studies reported that the duration of untreated psychosis is related with clinical recovery; the shorter the duration the better the remission; whereas, its' relationship with functional recovery is controversial (Gee et al., 2016; Verma et al., 2012). Boden and colleagues found if DUP was less than 3 months there were better remission status (Boden, Sundstrom, Lindstrom, & Lindstrom, 2009). Whereas, a 10-years prospective study in 101 Indians with first episode schizophrenia reported that patient with longer DUP (12 months and above) had higher recovery percentage (68.1%) than that of patients with lower DUP (53.7%) though not statistically significant p=0.141) (Shrivastava et al., 2010).

There is a conflicting evidence about the role of continuation of antipsychotic drug treatment and recovery from psychosis. In a randomized trial, drug dose reduction and/or discontinuation after symptomatic remission had a significant positive consequence for recovery rate than continuation of antipsychotic drugs (40.4% vs 17.6%) (Wunderink et al., 2013). A 20-years naturalistic follow-up study in the United States reported that patients with schizophrenia who were not on antipsychotics for prolonged periods were significantly less psychotic, had no relapse and had more periods of recovery (Harrow, Jobe, & Faull, 2012). The importance of antipsychotic drug treatment continuation is questioned; rather it hinders recovery and even causes physical health complications and early death (Harrow, Hansford, & Astrachan-

Fletcher, 2009; Harrow et al., 2012; Wunderink et al., 2013).

Conversely, a five-year cohort study among Ethiopians with schizophrenia found that being non-adherent for more than half of the follow-up period was associated early death (Teferra et al., 2011). Contradictions about the importance of antipsychotic drug treatment on symptom remission and functional recovery and its effect on physical illnesses causing early death have been discussed, though not vigorously quantified (Bressington & White, 2015).

2.3.3.2. Illness related factors

Symptom level, particularly negative symptoms were reported as affecting subjective recovery. In addition to symptom level, duration of illness was also a verifier of the "illness-related" theme (Bourdeau et al., 2015; Lam et al., 2011). The level of psychotic symptom is the main factor boldly visible under this theme.

Though clinical remission, functional and personal recovery have been expressed in different defining characteristics, these desired outcomes do have a strong relationship. A study on 76 patients with first-episode schizophrenia in 2009 reported that 73% of the remitters attained functional recovery, while only 17% of non-remitters had good functioning (Boden et al., 2009). This finding clearly indicated that symptom control should be given due emphasis in order to have further recovery in other aspects of recovery.

Most longitudinal studies found that severity of negative symptoms at onset of psychosis symptoms and starting of follow up significantly hinders recovery (Albert et al., 2011; Alvarez-Jimenez et al., 2012; Fraguas et al., 2014; Gonzalez-Blanch et al., 2010; Kebede, Alem, Shibre, & Beyero, 2004). A cohort study in 271 Ethiopian

patients with schizophrenia who had 10 years follow-up reported that lower negative and positive symptom scores at baseline significantly predicted functioning level (Kebede et al., 2005).

2.3.3.3. Individual related factors

It is, perhaps, not surprising that most of the factors affecting subjective recovery were under the theme of individual related factors; since subjective recovery was conceptualized as unique to everyone. Substance use was among clearly stated factors that affect recovery. Substance use causes psychosis, individuals with psychosis are at risk of using substance that further worsens the psychosis and causes physical, social, economic and mental health problems; which finally results in poor patient outcomes (Liberman et al., 2002; Woodside et al., 2007). Other related factors were hope, gaining meaning in life and self-empowerment in social and personal development (Eisenstadt et al., 2012; Romano, 2009; Windell & Norman, 2013).

Though not appeared in studies that systematically reviewed, spirituality was among the factors reported by other individual studies. Religion, where spirituality is predominantly exercised, plays a central role in reconstructing a sense of self and recovery. The mainstay of religion is the belief, the one who is a member of a religion believes in supernaturalism of God/gods who is believed as in control of everything, which serve as the source of hope for most individuals. The one who has hope in whatsoever the source, will recover earlier and better (Deegan, 1996; Mitchell, 2010).

Nonetheless, the comprehensions made about spirituality and religion as sources of hope do not work for everybody. Individuals with mental illness and psychiatric care providers note that religion and spirituality are sometimes burdensome to individuals

with SMI and to the health care system. Some believers may consider their illness as God's punishment which may intensify the anxiety and depression and lower the self-esteem. Reports also indicated that increased mental health problems are often found amongst those with a strict religious background (Cornah, 2006; Fallot, 2007; Gall, Charbonneau, Clarke, & Grant, 2005).

However, the majority findings are in favour of religion and spirituality for the better recovery process. In the USA, among people diagnosed with severe mental illnesses, more than 80% used religious beliefs to cope with their daily difficulties (Tepper, Rogers, Coleman, & Malony, 2001). Majority interviewed participants in a psycho-social rehabilitation program said that spirituality or religion was their source of comfort and hope (Fallot, 2007). Moher and colleagues also found that, though social and clinical recovery do not vary among individuals with different level of religiousness, patients became more religious/spiritual when they face schizophrenia (Mohr et al., 2010). It was not only patients' reports on religion attachment preference and level; a study found that those individuals who had the greater reliance on religious coping mechanisms had fewer hospitalizations (Gall et al., 2005).

The possible reasons may include religious beliefs allowing a person to reframe events that are uncontrollable, social support from the members and religious leaders, and spiritual buildings' architecture, arts, music (song), and above all the dogmas taught in religious institutions. These can give hope to the individuals and family members in which the sum of these spiritual and social contributions can enhance recovery from a mental illness (Cornah, 2006).

Problems of severe mental illness are not only limited to mental health problems but concurrent suffering from physical health problems are also significantly higher than

the general population (Yasamy, Cross, McDaniell, & Saxena, 2014). Advancement of technology in health care helps the general population to live longer and healthier. However, for individuals with SMI, studies continue to report that they are suffering from physical health problems, and die up to three decades early than their none-SMI counterparts (Bressington & White, 2015; Das-Munshi et al., 2016; Slade & Longden, 2015), mainly due to cardio-metabolic health problems (Yasamy et al., 2014).

The relation of mental health and physical health problems are interwoven. Altered thoughts and behaviours have an impact on physical health conditions, and physical health problems also significantly affect mental health conditions. Problems in either of these can trigger negative impacts in another. Depression induces heart problem, manic attack triggers asthma, psychotic disorders are linked with substance use, SMI patients have higher risk of HIV, they have less physical treatment access and utilisation, treatment for mental illness causes for physical health problems, and vice versa (Coyne & Schwenk, 1997; World Health Organization, 2008).

In Australian psychotic patients, the prevalence of metabolic syndrome is reported to be 60.8% also having higher risks smoking, alcohol and other substance consumption and sedentary lifestyle (Morgan et al., 2014). Another study from the USA reported that SMI patients had lower physical activity than recommended (Jerome et al., 2009). White, Gray, and Jones (2009) justified the need for the new approach in addressing physical health need of individuals with SMI as routine health services failed to address physical health needs of individuals with SMI.

A 5 years cohort study in 307 patients with schizophrenia in rural Ethiopia reported that people with schizophrenia live about three decades shorter than their healthy counterparts (Teferra et al., 2011). A 10-year cohort study in the same study area also

reported 18% of patients with schizophrenia in the cohort were deceased (Shibre et al., 2015), mainly from problems other than mental health (Fekadu et al., 2015). Death is often due to physical health problems like metabolic syndrome and cardiovascular diseases which are triggered by antipsychotic drugs and sedentary/inactive lifestyle, poor health services and being ignored by themselves and health care system (Robson & Gray, 2007; Thongsai, Gray, & Bressington, 2016). Half (49.6%) of causes of death in Ethiopian with schizophrenia were reported to be from infectious disease (Fekadu et al., 2015).

Recovery and physical health status of psychosis patients have been studied in fragmented or exploratory manner in developed countries. To my knowledge, their interaction is not yet studied. No report can be accessed on the relation between these two important (recovery and physical health) concepts in SMI patients. In almost all definitions of recovery, physical health is not even considered. Perhaps one may argue if recovery definitions incorporate patients' functioning, it may directly or indirectly encompass physical health. Interactions of these two important factors need to be tested and to my knowledge, this study will be the first to study it.

In order to be engaged in their own health care, service users need to have appropriate insight about the illness, treatment and recovery matters (Smith et al., 2004). Insight about the illness was one of the contributing factors reported in one of a reviewed study (Romano, 2009). Romano (2009) emphasised insight to recovery and mentioned it as an enhancing factor for recovery. The positive impacts of insight on outcomes in mental illness were also reported in other studies not included in this review (Keshavan, Rabinowitz, DeSmedt, Harvey, & Schooler, 2004; Smith et al., 2004). However, another study, not included in this review, indicated that insight into

chronicity and staying on medication for life, as taught by medical model perspective, have significant hindering effects on recovery. In the study by Carroll et al. (1999), it is interesting to note that poor insight to illness was positively correlated with better psychotic symptoms and less depression. This was justified that getting insight about the reality of individuals with psychosis might damage their self-esteem, and thus this may hinder subjective recovery (Carroll et al., 1999). Indeed, in the studies reviewed, insight is particularly termed as "important insight" (Romano, 2009), suggesting that the author was also acknowledging there were insights that would not be positive to subjective recovery. Overall, it seems that insight to illness/symptoms should be used in a more constructive way, rather than a pessimistic manner that can negatively affect an individual's hope and prospect in recovery.

2.3.3.4. Social environment related factors

Social environment was a very important factor associated with recovery. Most studies mentioned that social support was the pillar for recovery. In contrast, stigma could significantly hinder recovery (Lam et al., 2011; Romano, 2009; Windell & Norman, 2013).

Premorbid social functioning, adaptation and the overall status/quality of life are the other factors that affect psychotic patients' recovery. Studies which tested for it reported that those psychotic patients who had better premorbid functioning and/or social adjustment have better recovery status (Albert et al., 2011; Fraguas et al., 2014; Gonzalez-Blanch et al., 2010; Liberman et al., 2002).

Illness affects functioning, social interaction and quality of life. A cohort study in Ethiopia reported that mentally ill individuals experienced less quality of life, less

social interaction and functioning as compared to the general population (Kebede et al., 2006). However, the more individuals with SMI get involved in social interaction and physical activity, the better the recovery status they had (Hendryx, Green, & Perrin, 2009). Another study also found that individuals with larger network size and better satisfaction with interactions had higher recovery levels (Corrigan & Phelan, 2004). In societies of low-income countries, familial and social interactions and their supports are much more intimate and intensive than those in developed countries (Isaac et al., 2007; Myers, 2010), perhaps this may be among the reasons that better recovery status in low-income countries were recorded in previous studies.

Stigma is a negative mind-set of devaluing a person being stigmatize reprehensibly and differently from others (Pescosolido & Martin, 2015; Ralph & Corrigan, 2007). In a systematic review by Livingston and Boyd (2010), it was reported that there are three levels of stigma: social, structural, and internalized stigma. Social stigma is a discredit, stereotype, prejudice or discrimination towards someone or some group of people for being labelled with something; for the case of this document for being labelled with “mentally ill” (Livingston & Boyd, 2010; Ralph & Corrigan, 2007; Vass et al., 2015). When the stigma occurred at the institution level Livingston and Boyd (2010) referred it as “structural stigma”.

Mentally ill, particularly individuals with psychotic disorders are highly stigmatized members of the society they live in (Guner, 2014; Wood & Irons, 2016; Woodside et al., 2007). SMI patients, even at the periods with no symptom, are considered as irresponsible and criminals (Hopper, Harrison, Janca, & Sartorius, 2007). Compounded to mental disabilities, physical health problems like weight gain, self-care problems, not engaged in productive activities, and poor social interaction

increases the stigmatisation (Habtamu et al., 2016; Robson & Gray, 2007). In developing countries, especially in rural areas, mental illness is viewed as being related to evil spirits that worsen stigmatisation (Hopper et al., 2007). In Ethiopian society living with mental illnesses like schizophrenia are highly stigmatizing for the patients and family members (Teferra et al., 2013).

The problem of stigma is not limited to the patient suffering from mental illness. A report from WHO's international schizophrenia outcome study indicated that majority of mentally ill patients live with their families letting the family members stigmatized by society (Hopper et al., 2007). A qualitative study reported carers of mentally ill persons faced stigma due to presence relative with schizophrenia (Harison, 2008).

The stigma against individuals with SMI usually drives a family to keep the person at home, rather than taking them for treatment (Hopper et al., 2007). A study in Hong Kong reported fear of stigma could be the possible cause of late treatment seeking practises (Chien & Leung, 2013). A quarter of Ethiopian patients with schizophrenia reported they had been stigmatised by the family members (Assefa, Shibre, Asher, & Fekadu, 2012). Stigmatization is not only from the community and family members, health professionals and even religious leaders may also discriminate mentally ill patients (Chien, Chan, Yeung, Chiu, & Ng, 2015; Parle, 2012; Robson & Gray, 2007). SMI patients deny the symptoms they have by fear of discrimination and shame (Smith et al., 2004).

Stigma from the society and institutions against individuals with SMI causes for self-stigma that the latter becomes internalized stigma. Internalized stigma is the internalization of stigmatizing attitudes, beliefs and behaviour that are being perceived and practised by the others around (Vass et al., 2015). Livingston and Boyd (2010)

defined internalized stigma as the endorsement of stereotype and negative social reactions, that characterized by negative feelings, maladaptive behaviour and identity transformation because of their mental illness.

Studies in Ethiopia reported that stigma is a major problem for mentally ill individuals. A cross-sectional study among 212 individuals with schizophrenia in the country's only specialised psychiatry hospital Amanuel reported that nearly half the participants had moderate to high level of internalised stigma; in this study the worse stigma score was recorded among rural residents where about 85% of the country's population resides (Assefa et al., 2012). A study by Girma and Tesfaye (2011) found about half of mentally ill participants in treatment of their illness sought traditional treatment before they attempted modern health care; another facility based study reported that patients with history of traditional treatment had higher self-stigma level (Girma & Tesfaye, 2011; Girma et al., 2013). Internalised stigma has multiple ways of hindering recovery not limited to delay in treatment seeking, poor medication adherence, suicidal ideation and attempt and social withdrawal (Assefa et al., 2012; Girma et al., 2013). In developing countries like Ethiopia many people with severe mental illnesses, like psychosis, are kept in chains and hidden away for years mainly due to fear of stigma and discrimination (Fekadu & Thornicroft, 2014). Obviously, all these issues will affect recovery.

Previous studies reported that mentally ill patients experiencing stigma have poor recovery (Guner, 2014). A longitudinal study among psychotic patients found that stigma predicted both symptomatic and subjective recovery, and effects being mediated by hopelessness and self-esteem (Vass et al., 2015). In Hong Kong, SMI patients' perceptions of stigmatisation with other factors predicted illness relapse

(Chien, Chan, et al., 2015) and self-stigma was found to be the significant predictor of living skills functioning (Chien, Lam, & Ng, 2015). A similar finding is also reported from the community-based study in Ethiopia (Habtamu et al., 2016).

Though it comes following other types of stigma, internalised stigma is the most important concern to be looked while studying subjective recovery (Livingston & Boyd, 2010). When stigma is internalised it causes depression, negative feelings about self, avoidance of help seeking, misuse of alcohol and drugs, less satisfaction in life, that again results in poor quality of life that finally hinders recovery (van Zelst, 2009; Vass et al., 2015). Particularly, it hinders personal recovery by affecting ones' self-esteem, hope and motivation to the future, help seeking and social engagement which these factors are mandatory components/factors affecting personal recovery. Vass et al. (2015) described it as "vicious circle"; which means the more stigma and the more it is internalised the worse symptom and disability and the less recovery level which again worsens stigma.

The other factor repeatedly reported from the cross-cultural studies was one country's developmental status (Harrison et al., 2001; Isaac et al., 2007). As summarised in a recent systematic review, the medians of recovery (in both symptomatic and functional components) were estimated to be 13.0% in high-income countries and 36.4% in low or lower middle-income countries which was significantly different (Jaaskelainen et al., 2013). A clear and scientific justification of how and why better recovery rates are observed in some low-income countries is yet to be proven. In fact, it is also questioned if better recovery rates in developing countries really exist. The methodological quality of studies in many of these countries is questionable; there are issues of poor representativeness (at individual and country levels), high dropout rates

including high rates of early death, non-contextualized diagnoses and invalid outcome measures (Isaac et al., 2007; Menezes et al., 2009). However, if recovery outcomes are truly different across countries with different levels of socioeconomic and health service development, this may relate to issues like tighter social bonds, effective contextual treatments (i.e., traditional healing), less competitive/stressful lives, and a lower degree of urbanization and associated crowdedness (Edgerton, 1980; Harrison et al., 2001; Hopper et al., 2007; Myers, 2010; Purgato, Adams, & Barbui, 2012). However, in this review, all studies were conducted in high-income countries and it is therefore not possible to make such comparison. Given that the development status of a country has been identified as a potential contributing factor to recovery outcomes, this may be an important gap in our current understanding of subjective recovery. Future research in this area should, therefore, consider investigating the perceptions, experiences and outcomes of subjective recovery from recent onset psychosis in developing countries in order to obtain a more comprehensive and global conceptualization.

Though not mentioned in studies on subjective recovery from recent onset psychosis, gender/sex of patients is another factor which affects recovery from severe mental illness particularly psychosis. Most accessed studies reported females do have better recovery status than males (Albert et al., 2011; Chang et al., 2012; Verma et al., 2012). A 5-year longitudinal study by Albert and colleagues found that females have about 2.4 odds of getting recovered than males (Albert et al., 2011). A study in Ethiopia reported female patients were more likely to have episodic illness but no inter-episode residual or negative symptoms however a significantly higher proportion of male were episodic with inter-episode residual symptoms (Shibre et al., 2015). In contrast, a cohort study among Ethiopian bipolar disorder patients reported that males had better

functional outcome (Kebede et al., 2006).

Indeed, factors affecting subjective recovery are intertwined; hope, stigma (Lam et al., 2011; Windell & Norman, 2013), social support (Eisenstadt et al., 2012; Lam et al., 2011; Norman et al., 2013; Windell & Norman, 2013), social engagement (Bourdeau et al., 2015), duration of illness (Bourdeau et al., 2015; Windell et al., 2012), physical health and treatment impact subjective recovery. However, these factors also have eliciting effects to each other. Fear of stigma causes delay in treatment seeking and poor medication adherence (Chien & Leung, 2013; Fekadu & Thornicroft, 2014; Girma & Tesfaye, 2011; Hopper et al., 2007). Though family members stigmatise individuals with psychosis, they are also victims of stigma, which affects their support to the person with psychosis (Harison, 2008; Hopper et al., 2007). This further negatively impacts subjective recovery as identified in the studies (Eisenstadt et al., 2012; Lam et al., 2011; Norman et al., 2013; Sumskis, 2013; Windell & Norman, 2013). From the previous studies, it is also noticeable that with the resources available managing one or some of these factors can significantly contribute to better recovery outcome.

There are a number of limitations of this review; firstly, although we attempted to access all eligible studies through different searching methods, limiting studies to recent-onset psychosis and subjective recovery only might be the reason why no publications from LMICs, particularly African countries, were found. Secondly, publication language was restricted to English so we might have missed some important publications in other languages. Some additional concepts of subjective recovery might exist in intervention or programme evaluation studies and from study participants other than recent-onset psychosis that this review excluded. In all studies

reviewed, the participants were recruited from clinical service sites, which might not represent all individuals with early psychosis. Finally, factors associated with subjective recovery were collated from different study designs; treating statistically tested variables from quantitative studies and exploratory identified variables from qualitative studies equally might cause some bias.

In summary, from the above systematic review and the background in the previous chapter, it is learned that research on subjective recovery from recent onset psychosis is in its early and exploratory stage (earliest publication was in 2007 (Woodside et al., 2007) and almost all are qualitative study design. Recovery, particularly subjective recovery, is mostly a process of improvement in psychosocial aspects in one's own perception. Recovery is possible with endeavours by individuals themselves and important others around them. Early diagnosis and treatment, active engagement in treatment decision and adherence are actions required to be taken. Active engagement in the society and life, maintaining hope, fighting stigma with good social support and high self-esteem are among the factors that enhance recovery. The identified factors in the previous studies could be categorized in illness, treatment, individual and social environment related factors. It is also learned that, though there are factors commonly affected subjective recovery through individuals, there are also factors that affected subjective recovery differently.

In the narrative and systematic review, it is also ascertained that studies conducted about the topic are limited to developed countries. Evidence about subjective recovery from recent-onset psychosis from developing countries is absent. In addition, the concept, process and outcome of subjective recovery from psychosis are different among countries/societies with different developmental levels, which implies factors

affecting recovery may also be different. Therefore, research on the topic of subjective recovery from recent-onset psychosis in a developing country is one of the essential and important social and clinical demands for better and clearer understanding of concepts/constructs, and a pre-requisite to design and provide appropriate evidence-based care to people with early stages of psychotic disorders. The overall report of the systematic review is published in a peer reviewed journal in the field of psychiatry (Temesgen, Chien, & Bressington, 2019a)

2.4. Significance of the PhD Study

Previous studies, though limited in coverage and methods, reported that recovery from recent onset psychosis could be possible. These studies also suggested that by working on the modifiable risk factors such as early diagnosis and treatment, avoiding stigma, engaging in life and society with better social support, and sparking hope, recovery could be enhanced to an optimum level. Epidemiologic studies concretely depicted that patients with psychosis are dying prematurely due to physical illnesses. However, very limited studies have reported the relationship between the level of recovery and physical health state of individuals with psychosis. Similarly, research on subjective recovery from recent onset psychosis is still in its early exploratory stages and is limited to specific societies/countries, making the results difficult to generalize to broader populations.

Nowadays, mental health care systems have shifted towards integrated and recovery-oriented care in developed countries; and developing countries are also adopting this approach of service delivery system in varying levels of application. However, low-income countries are attempting to adopt this kind of service delivery system relying on the evidence generated from the high-income countries. As discussed in the

previous sections the conceptualizations, process and outcomes of recovery are quite different among countries with different levels of development. Hence, the evidence gaps from low-income countries about the level, progress, contributing factors and even conceptualizations of subjective recovery from recent-onset psychosis are yet to be addressed.

The findings of this study would be useful to better understand the concepts of subjective recovery from service users' perspectives. From the systematic and overall literature review, it was learned that only few studies were conducted in low-income countries which could not represent societies in low-income countries. The level and progress of recovery from recent onset psychosis and related factors are determined among Ethiopians where evidence about the topic in the area was nil. Thus, the evidence from this study could be potentially used to inform the development and establishment of a recovery-oriented care service in Ethiopia, and the result may be partially generalizable to other low-income countries with similar socio-cultural characteristics. The findings of this study can therefore significantly contribute to the global evidence about the topic by representing the low-income, particularly African countries.

Due to the individualistic and nonlinear nature of recovery, a quantitative cross-sectional design would not be able to capture the personal concepts, meanings and progress, as well as important factors related to recovery. Therefore, recovery can be better understood and explained with a mixed-methods research design, including both a longitudinal quantitative and a qualitative descriptive approaches. In which, the longitudinal quantitative approach examined the levels of and progresses recovery

over time and identified its related factors; whereas the qualitative part explained and complimented those findings and important issues during the journey of recovery.

2.5. Aim and Objectives of the Proposed Study

2.5.1. Aim of the proposed study

This study aimed to investigate the levels and conceptualizations of recovery self-reported by service users themselves across three measurements over nine months (i.e., at baseline, third months and ninth months), thus examining the progress of recovery over time; and to identify the predictive factors of recovery in patients with recent-onset psychosis in Ethiopia.

2.5.2. Objectives of the study

The objectives of the study are to:

1. Investigate levels of recovery of individuals with recent-onset psychosis who are being followed-up in an outpatient clinic progressing over nine-month at three-time intervals: from baseline to third and ninth-month.
2. Examine predictive factors of the recovery level and its progress over the follow-up period.
3. Describe perceived challenges and opportunities affecting of recovery from psychosis.
4. To understand the concepts about recovery from these service users' perspective and its related factors with both the quantitative and qualitative data.

CHAPTER 3. METHODS

3.1. Introduction

This chapter presents the methods used to address the study objectives in five sections. The first section presents the overall design of the study. The second section presents the methods of the longitudinal quantitative part of the study including the follow-up duration, measurement time-points, sampling, data collection instruments, data collection methods and data analysis techniques. The third section presents the methods and results of translating and validating some of the measures. The fourth section presents the methods of the qualitative part of the study, including sampling, data collection and analysis techniques. In the final section, strategies used to combine and interpret the findings from the quantitative and qualitative study data sources are described. The design, conduct and reporting of this study was guided by recommendations for mixed-methods research provided by Leech and Onwuegbuzie (2010) in addition to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) for the quantitative cohort part (Von Elm et al., 2008) and Consolidated criteria for Reporting Qualitative researc (COREQ) for the qualitative part (Tong, Sainsbury, and Craig, 2007).

3.2. Study Design

This study aimed to investigate the levels of recovery from recent-onset psychosis, examine its predictive factors and explore the conceptualizations, perceived challenges and opportunities for recovery among individuals with recent-onset psychosis. In order to achieve this objective, the study adopted a sequential explanatory mixed-methods (quantitative followed by qualitative) design from the stance of post-positivism paradigm. Sequential explanatory design is most suited for

complex issues to interpret, such as the concepts of subjective recovery and its related factors (Connell et al., 2015; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Polit, 2018)

As discussed in the earlier chapters subjective recovery from SMIs is non-linear and individualistic lending itself more appropriate to be studied with mixed-methods study design. Subjective recovery from recent-onset psychosis demands different perspectives of observations and measurements with different approaches to assess the level, progress and related factors. For the attainment of these kinds of objectives in such type of problem, a post-positivist approach is most appropriate since it advocated methodological pluralism/triangulation (Chilisa & Kawulich, 2012; Wildemuth, 1993). This approach advocates that there could be multiple reality/different understandings that vary depending on the observer's perspectives, which is in-line with what has been mentioned as "subjective recovery is individualistic" (Bourdeau et al., 2015; Connell et al., 2015). Chilisa and Kawulich (2012) clearly stated that using post-positivism paradigm a more reliable/objective findings could be obtained using multiple measures, observations and data triangulation. The current study also used multiple measures/instruments, three time-point observations and triangulated the quantitative and qualitative study approaches. In subjective recovery from SMI, the subjectivity nature of the topic should be maintained, nevertheless, there are also some shared/common points among service users with recent-onset psychosis which could be described objectively. This reality again makes the topic more appropriate to the post-positivism approach which has been emphasised in the post-positivist paradigm as "perfect objectivity cannot be achieved but approachable" (Chilisa & Kawulich, 2012, p. 9).

In the current study, first quantitative data were collected with a longitudinal prospective approach. In consideration of the findings from the quantitative results, a qualitative approach was then employed to gain a more in-depth, humanistic, and individualistic understanding of the topic (subjective recovery) and its relevant issues (Holloway & Wheeler, 2010).

The need for mixed methods is recommended by many researchers in exploratory and explanatory types of study (Bryman, 2011; Spicer, 2011). The findings from one type of study approach can be checked and confirmed or be compared and contrasted by another method; thus, enhancing the validity of findings and confidence in conclusions to be drawn (Bryman, 2011). Holloway and Wheeler (2010) also suggested that the use of a qualitative approach in a quantitative study complements the human dimension of the issue to be studied and humanized nature can be captured through the qualitative part. By employing mixed research methods, it is possible to see the problem from multiple perspectives.

Recovery, particularly subjective recovery from recent-onset psychosis is an individualistic and nonlinear, a quantitative cross-sectional design could not be able to capture the personal concepts, meanings and progress, as well as predictors that affect recovery and its progress. Recovery could be better understood and explained with mixed-methods research design, including both a longitudinal quantitative and a qualitative explanatory approach. In which, the longitudinal quantitative approach examines the level and progress of recovery over time and identified its predictors, whereas the qualitative findings explore the understanding, the process and important issues during the recovery journey.

3.3. Quantitative Part

3.3.1. Study design and period

The quantitative part of this study adopted a nine-month prospective naturalistic study approach. The prospective naturalistic design is a kind of longitudinal design in which, the study subjects are followed over a period of time with continuous or repeated observation/s and monitoring of potentially related factors and changes in variables of interest (Polit & Beck, 2010; Velengtas, Mohr, & Messner, 2012). In a naturalistic prospective approach, the researcher only observes/monitors the progress in variables of interest in its natural setting with no interference with the subjects or phenomena. That is, the natural/routine living condition or treatment is not disturbed for the sake of the study (Velengtas et al., 2012). In the current study, service users' recovery and related variables were measured at three time-points (over nine months) while the participants were attending their routine psychiatric care at outpatient clinics.

The three time-point measurements were done at baseline (December 2017 and January 2018), third month (March and April 2018) and ninth month (September and October 2018). As discussed in the previous chapters, the nonlinear nature of subjective recovery from recent-onset psychosis necessitated repeated measures to have a clear understanding about the level and to determine its predictor variables. Using this method, it was also possible to ascertain if the level of recovery was sustained over the study period. Importantly, adopting this approach it was possible to determine if the associated variables had sustained and long-lasting impacts on subjective recovery which was not possible in other study approaches such as cross-sectional.

Subjective recovery from psychosis and its predictors showed significant change/progress in three to twelve months follow-up periods in previous studies (Law, Neil, Dunn, & Morrison, 2014; Law et al., 2016; Williams et al., 2015). Six (Vass et al., 2015), nine (Zheng, 2003) or twelve (Gee et al., 2016) months follow-up were effectively used to measure the progress of recovery in psychotic patients in the previous studies. A study among Ethiopians with SMI also detected a significant change in disability/functioning score over six weeks (Habtamu et al., 2017). Therefore, in this study, it was anticipated that individuals with recent-onset psychosis who were having psychiatric treatment would have a detectable change in their level of recovery, and its predictor variables in 3rd and 9th months of follow-up. Hence, the nine-month follow-up with three-time points of measurements have been adopted.

3.3.2. Study setting and population

This study was conducted in Ethiopia, where over 25 million people were estimated to have mental health problems. Over 90.0% of people with severe mental health problems are not receiving modern health care for their mental health problems (Alem et al., 2009; Ayano, 2016; Fekadu & Thornicroft, 2014). The majority of the population in the country relied on traditional and religious healing practices for their health concerns (World Health Organization, 2011).

In 2014, the national (Ethiopia) cumulative numbers of health posts/local clinics, health centres and hospitals were 16251, 3335 and 156, respectively (Federal Democratic Republic of Ethiopia Ministry of Health, 2015a). In the country's Health Sector Transformation Plan (HSTP) to be implemented from 2015 to 2020, the health care services were restructured in three tiers system; primary, secondary and tertiary level. The primary level of care includes primary hospitals (serving for 100,000

people), health centres (serving for 25,000 people) and health posts/local clinics (serving for 5,000 people). Secondary care level is provided by general/regional hospitals, each to serve for a population of about one million. The third/tertiary level care system is provided by specialized hospitals (with specialist care/treatment units) while each is expected to serve for 5 million population (Ayano, 2016; Federal Democratic Republic of Ethiopia Ministry of Health, 2015b; Hanlon et al., 2019).

In the country, Ethiopia, there is only one psychiatric hospital, named Amanuel Hospital, located in the capital city, Addis Ababa with about 300 beds serving for over 100 million population. It has been reported that the construction of another psychiatric hospital in the same city is completed and to start service soon (Ayano, 2016; Federal Democratic Republic of Ethiopia Ministry of Health, 2012).

Mental health service decentralisation is one of the strategies being employed to tackle resource scarcity and treatment gaps in the country. The Ethiopian Ministry of Health is practising integration of mental health care to the primary health care level as this approach has been recommended by the Mental Health Gap Action Program (mhGAP) of WHO. Although there are many advantages in providing mental health services that are integrated with general health services at lower level, quality of care is being compromised due to the fact that service providers are not specially trained in caring for people with mental illness and institutions are not designed for such services (Ayano, 2016; World Health Organization, 2013b).

This study was conducted in three tertiary Hospitals, which are located in the North-Western part of the country. These hospitals have a catchment population of about 15 million (i.e., 15% of the total population of the country) and are located in North-Western Ethiopia (Federal Democratic Republic of Ethiopia Ministry of Health,

2015b). The hospitals provide mental health care services in addition to other health services. The psychiatric health services in these hospitals are provided by psychiatrists, nurses and health officers trained to degree and masters level in psychiatry. In these hospitals, individuals with mental health problems are treated in outpatient, inpatient (short period) and follow-up services. About 1500 patients with different types of mental illnesses would have their follow-ups for their mental illness in each of the three hospitals.

3.3.3. Sampling methods and procedures

Three study hospitals in same region of North-Western Ethiopia, namely Debre Markos, Felege Hiwot and Gondar were purposively selected for better representations of the population in the region and also for their convenience. These hospitals are the major teaching and referral hospitals in the North-Western Ethiopia with similar healthcare structure and systems. Other similar tertiary hospitals in the country also have similar health care structure and system, thus likely having similar service-users, treatment and illness prognosis (Federal Democratic Republic of Ethiopia Ministry of Health, 2015b). Hence, the findings from these hospitals could represent the situations about recovery from recent-onset psychosis across the country.

Simple random sampling technique was used to select individual study participants. This technique was selected because simple random sampling is one of the ideal probability sampling methods to give equal chance to the study population to be represented in the study (Polit, 2018). For random sampling, first service users' hospital records were reviewed for eligibility of the study from each of the selected hospitals. From these hospitals, 1195 service users with recent-onset psychosis who fulfilled the inclusion criteria were identified. The lists of these individuals were

recorded into a computer with a unique identification number assigned for each. The required number of participants to be selected/recruited from each hospital was proportionally allocated to the number of eligible attendees' in each hospital to get a representative sample size, Table 3.1 presents this sample distribution. Using the identification numbers given for each, a set of random numbers was generated for potential participants using IBM-SPSS version 23 computer program (IBM Corp, 2015). Figure 3-1 below also schematically presents the sampling procedure and samples in the cohort study.

Table 3-1: Proportional sample selection

Hospital Name	Number of identified eligible individuals	Number of persons allocated	Number of persons randomly selected and participated
Debre Markos	180	50	41
Felege Hiwot	450	100	98
Gondar	565	120	124
Total	1195	270	263

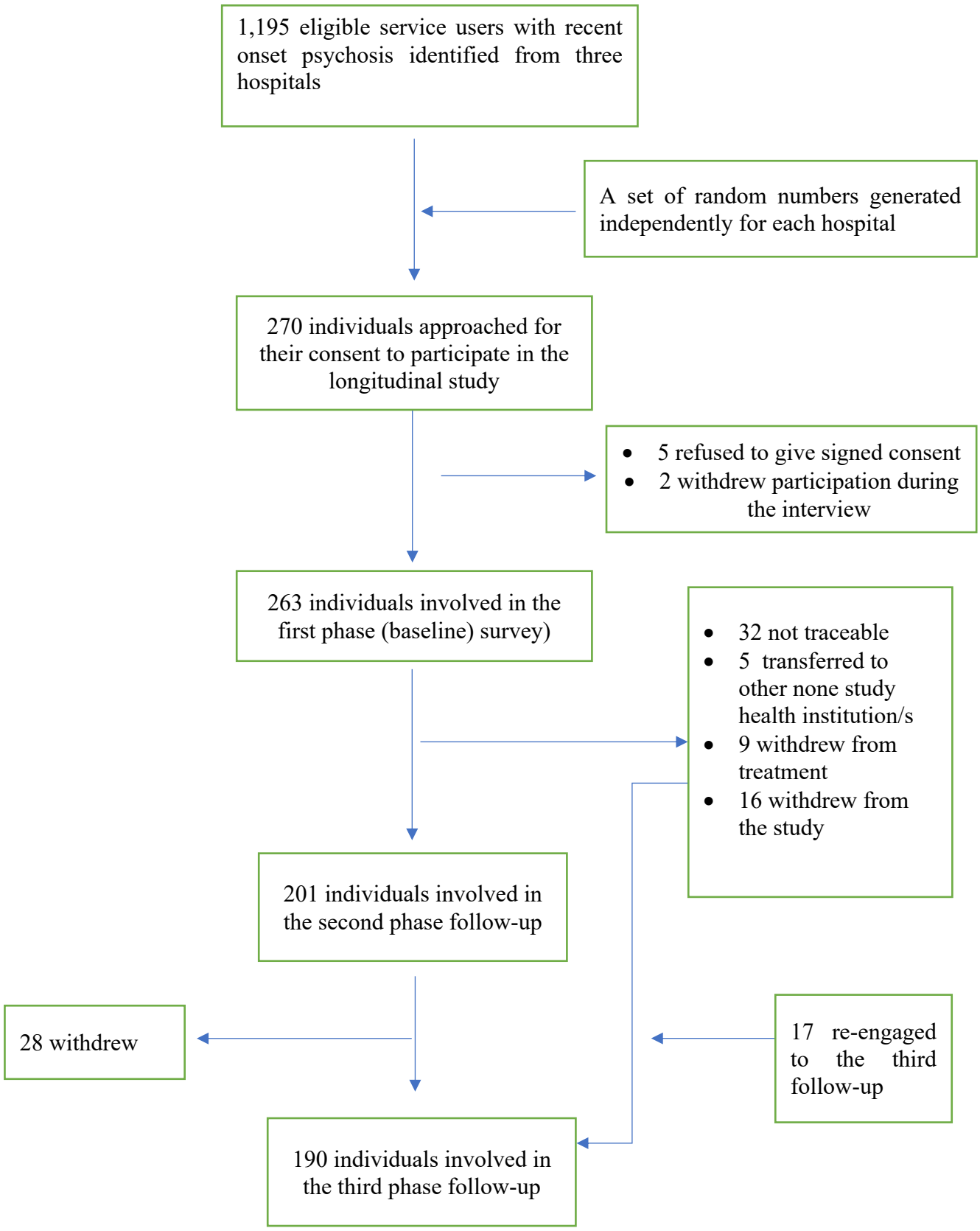


Figure 3-1. Sampling procedure

3.3.4. Inclusion and exclusion criteria

Eligible participants were service users in one of the outpatient clinics under the study who were:

- Diagnosed with recent-onset psychotic disorders (up to 5 years illness duration) "*schizophrenia spectrum and other psychotic disorders*" according to the DSM-5 as recorded in service users' medical records (American Psychiatric Association, 2013) ;
- Having follow-up in one of the selected outpatient departments;
- Ethiopian resident and able to communicate in Amharic
- Aged 16 years and above
- Mentally competent to communicate and have capacity to provide informed consent as judged by the health care provider (psychiatric nurse);

Service users with the following conditions were excluded:

- Severe physical health problems needing emergency or acute care
- Inability to comprehend questions (e.g., items in the questionnaires)
- Acute and/or severe symptoms of psychosis (e.g., strong delusions and disorganised thought, inducing difficulties in having conversations)
- Organic brain syndrome such as dementia and amnesia
- Moderate to severe cognitive impairments, as judged by their psychiatrist (health care professional).

3.3.5. Sample size

Sample size was estimated considering the multiple regression statistical tests computed for examining factors that predict the level of subjective recovery. For multiple regression, the number of cases/participants required are recommended to be 10-20 for each potential predictor variable to be computed (Brooks & Barcikowski, 2012; Stevens, 2002, 2009). For the current study the mean of this recommendation i.e., 15 was taken to estimate the required sample size. In this study, about 15 potential predictive variables *(social support, quality of life, hopelessness, functioning, symptom level, stigma, duration of untreated psychosis, and physical health)* were proposed to be included in the final regression model, and considering about 15.0% none-response rate (Teferra et al., 2012), the required minimum sample size was calculated to be 259. The potentially related variables were identified in a systematic review conducted prior to this study (Temesgen et al., 2019a).

3.3.6. Participant recruitment procedures

Lists of randomly selected service users were printed and distributed to each hospital. Data collectors, document porters and hospital record officers were contacted and discussed how to identify the selected individuals when they attended for their regular follow-up. The potential participants were contacted by the assessors and fully explained about the purpose and procedure of the study, as described in the information sheet and consent form (Appendix 1 and 2). They were then asked to sign a consent form to demonstrate that they fully understood what was required of them and that they were willing to participate in the study. Signed informed consents were kept in a locked cabinet with limited access by the researcher only for follow-up measurements.

3.3.7. Measuring instruments

A set of questionnaires for examining the level of recovery and its potential predictors were used. Permission to translate and use these tools were granted from developers or copyright owners. These questionnaires as study instruments in this study include: Questionnaire about the Process of Recovery (QPR), Social Support Questionnaire (SSQ-6), World Health Organization Quality Of Life (WHOQOL-BREF), World Health Organizations Disability Assessment Schedule (WHODAS 2.0), Positive and Negative Syndrome Scale (PANSS), Internalized Stigma of Mental Illness scale (ISMI- 9), and Beck's Hopelessness Scale (BHS). Some of these instruments such as the QPR measure the level of self-perceived recovery and the other two independent variables (ISMI-9 and SSQ-6) were not validated for the Ethiopian population. Therefore, these instruments have been translated and validated before use in the main study. The findings of the validation tests are described in the next section (Section 3.4). In addition, physical health, diagnostic and treatment related variables and socio-demographic data of the participants were also collected. Details of the study instruments are discussed below.

3.3.7.1. Questionnaire about the Process of Recovery (QPR)

The QPR has been developed by Neil and colleagues in the UK and first published in 2009. The first version of the QPR has 22 items with two subscales (intrapersonal and interpersonal). The tool was developed to assist clients with psychosis to promote their recovery from psychosis by setting and evaluating recovery goals. It showed good construct validity with the General Health Questionnaire (GHQ-28) and Schizophrenia Quality of Life Scale (SQLS), test-retest reliability (intrapersonal subscale r=0.874, interpersonal subscale r=0.769, P<=0.001 for the overall scale) and

internal consistency assessed with Cronbach's α (intrapersonal subscale α=0.94; interpersonal subscale α=0.77) for people with psychosis (Neil et al., 2009). A systematic review by Shanks et al. (2013) found that the QPR has strongest evidence of being favoured by service users, most desired psychometric properties, and strongest match with the overall recovery when compared with the other 13 recovery measuring tools reviewed. It was the only measure, which incorporates all the CHIME components of recovery that are Connectedness, Hope, Identity, Meaning in life, and Empowerment (Shanks et al., 2013; Slade et al., 2012).

The QPR is shown to be a reliable and valid recovery measuring tool in various societies and languages (Law et al., 2014). A Chinese version of the 22-item QPR demonstrated acceptable psychometric properties among individuals with psychotic disorders in Hong Kong in which the measure supported for a three-factor structure (Chien & Chan, 2013). Whereas only two factors were found in the original English version developed in the UK (Neil et al., 2009).

In 2014, the QPR was recommended to be shortened to a 15-item with deletion of seven items. Reasons given were, items deleted were not generalizable to the broader population, lack of items face validity and ambiguousness. By making the QPR a 15-item in a single domain, it became more valid and reliable than the original QPR-22 (Law et al., 2014; Law et al., 2016). Another study also reported that 15-item version of QPR was more robust and less burdensome than the QPR-22 (Williams et al., 2015). Therefore, for the current study, the QPR-15 was used.

Each item is to be scored on five points Likert scale ranging from 0 = strongly disagree to 4 = strongly agree; a higher total score would indicate a higher level of recovery. The QPR-15 was translated and piloted prior to this longitudinal study in service users

with recent-onset psychosis and found to be valid and reliable for Ethiopian service users with recent-onset psychosis; details of the validation results are presented in the next section (Section 3.4).

3.3.7.2. Social Support Questionnaire (SSQ)

The short version Social Support Questionnaire (SSQ) is a six-item instrument used to determine the number of people involved in providing support and to measure the level of satisfaction with the support. The SSQ was initially developed with 27 items, however, the 6-item short version (SSQ-6) was subsequently developed by Sarason, Sarason, Shearin, and Pierce (1987). The 6-item SSQ was found to have strong internal consistency (α=0.93). The satisfaction items are to be rated on a 6-point Likert scale, with the possible total score of 6-36; a higher score indicating more satisfaction with the available social support (Sarason et al., 1987). The Japanese version of SSQ showed Cronbach's α=0.91(Furukawa, Harai, Hirai, Kitamura, & Takahashi, 1999). Chinese version of SSQ showed satisfactory validity, Cronbach's α=0.94, and weighted Kappa's 0.48 - 0.67 (Chien & Norman, 2004). Its' Amharic version showed good content validity, test-retest reliability and internal consistency as piloted prior to this survey which is discussed in the next section.

3.3.7.3. Quality of life (WHOQOL-BREF)

The World Health Organizations Quality of Life (WHOQOL) is an instrument that assesses the quality of life that would be applicable cross-culturally. The WHOQOL assessment is primarily recommended to be used in individuals having health problems where the prognosis is likely to involve only partial recovery in which treatment is not curative, like that of psychosis in this study. The WHOQOL-BREF is

a 26-item version of the WHOQOL-100 to be self or interviewer-administered. It is validated in different languages (World Health Organization, 1996) including Amharic (Lambert, 2014). The WHOQOL-BREF has 4 domains: physical (7 items), psychological (6 items), social (3 items) and environmental (8 items) each item to be scored 1-5 while item number 3, 4, and 26 are to be reverse-coded for analysis and interpretations. The higher score denotes higher quality of life. Question number 1 and 2 are not to be included in domains. Item response rate should be more than 80% in order to compute the total and domain analysis; if an item is missing the mean score of the domain is substituted (World Health Organization, 1996). Internal consistency tests of WHOQOL-BREF showed acceptable scores in the general populations of 23 countries; with values of Cronbach's α for domains of physical health 0.82, psychological 0.81, environment 0.80, social relationships 0.68 (Skevington, Lotfy, & O'Connell, 2004).

The WHOQOL-BREF has been translated and validated to the Amharic language among Ethiopian patients with HIV (Tesfaye et al., 2016), psychiatric (Araya, 2007) and leprosy (Lambert, 2014). All of these studies stated that the WHOQOL-BREF is reliability and validity to be used for Ethiopians with some contextual modifications (Tesfaye et al., 2016). However, only Lambert (2014) reported details of the validity and reliability results. Item internal consistency correlation for items in each domain ranged from 0.4-0.84. The consistency of WHOQOL-BREF domains were within an acceptable range of Cronbach's ($\alpha>0.7$) except for social domain ($\alpha=0.65$); the possible reason mentioned was that among 3 items of this domain, one was about sexual satisfaction which is not openly discussed in Ethiopian culture, omitting this item the Cronbach's α improved to 0.85. Inter-domain correlations coefficients (r) ranged from 0.46 to 0.76 for all domains (Lambert, 2014).

3.3.7.4. Hopelessness scale (HS)

The Hopelessness Scale (HS) also called Beck's Hopelessness Scale (BHS) is a 20 items scale to measure negative attitudes towards the future, loss of motivation, and expectations that initially was developed for patients with depression (Beck, Weissman, Lester, & Trexler, 1974). The BHS has been translated and validated for Ethiopian para-suicide patients. It demonstrated satisfactory concurrent validity with Brief Psychiatric Rating Scale-Expanded version (BPRS-E) at $P<0.001$ and high construct validity with an intention to die ($P<0.001$). The Amharic version of HS demonstrated good item-total correlation coefficients, which ranged from 0.27 to 0.73 (Bekry, 2008). The correct answers for each item are summed up with a possible score of 0 – 20 and the total score is used for analysis, a higher score value indicating more hopelessness.

3.3.7.5. Level of functioning (WHODAS 2.0)

To assess the health and disability status of individuals with any health problem, culture and setting the world health organization developed "World Health Organizations Disability Assessment Schedule (WHODAS). The initial 36-item WHODAS was modified to the WHODAS 2.0 by 2010. The WHODAS 2.0 measures six domains of functioning: cognition, mobility, self-care, getting along, life activity and participation (Üstün, Kostanjsek, Chatterji, & Rehm, 2010).

The WHODAS has been used by previous studies in Ethiopia (Asher et al., 2018). An Amharic version of the twelve items WHODAS 2.0 has been adapted and validated for persons with schizophrenia and effectively used in an Ethiopian context. The overall Amharic version of WHODAS-2.0 demonstrated good convergent validity

with BPRS-E (r=0.52) and excellent internal consistency (α=0.98) (Habtamu et al., 2016). The Amharic version of 12-item WHODAS demonstrated similar psychometric properties with the 36 items WHODAS but superior content validity (Habtamu et al., 2017). Habtamu (2016) suggested that the single factor 12 items Amharic version WHODAS is the preferred version in this rural low-income setting and is thus used in this study. A higher score of WHODAS indicates a higher level of disability due to the health problem.

3.3.7.6. Psychotic symptoms (PANSS)

For recruited participants, the severity of psychotic symptoms was assessed by the Positive and Negative Syndrome Scale (PANSS). The PANSS is a 30-item tool developed by Kay and colleagues in 1987 which assesses the severity of psychotic symptoms in three subscales; positive symptoms, negative symptoms and general psychopathology. Each item is scored on 7-point Likert scale (ranging from 1- 'Absent' to 7- 'Extreme') (Kay, Fiszbein, & Opfer, 1987). The scale demonstrated good concurrent validity with the Brief Psychiatric Rating Scale (total score r=0.84), interrater reliability correlation (r=0.91, and internal consistency of positive, negative, and general scales were (α=0.74, 0.69, and 0.64 respectively) in people with psychotic disorders (Bell, Milstein, Beam-Goulet, Lysaker, & Cicchetti, 1992).

PANSS has been effectively used in several studies in Ethiopia (Fekadu et al., 2013; Shibre et al., 2010; Shibre et al., 2015). Health professionals working in mental/psychiatric units in Ethiopia are trained how to rate such symptoms in their college and in-service trainings. For the current study, the raters (data collectors) were nurses who were trained in psychiatry and have experience in caring for psychotic patients. Items in the PANSS are often used in routine health care for psychotic

patients in Ethiopia. After a full day training about scoring PANSS by a trained psychiatrist, satisfactory interrater reliability among psychiatric nurse raters was established with intra-class correlation coefficient (ICC(*P*)=0.985(<0.001).

3.3.7.7. Internalized stigma (ISMI)

Internalized stigma was measured by the Internalized Stigma in Mental Illness scale (ISMI). The ISMI-29 was developed by Ritshera, Otilingama, and Grajalesa (2003) to measure the subjective experiences of stigma with four subscales. The measure has passed through consecutive modification mainly with item reduction. The 24 items tool has been translated and validated in Ethiopia, showed good interrater reliability (Kappa=0.76), and satisfactory internal consistency, Cronbach's α=0.92 (Assefa et al., 2012). For the current study, the nine-item ISMI was validated for use. Each item is to be scored in four Likert scales from strongly disagree (1) to strongly agree (4) (Hammer & Toland, 2017). The mean score, after reverse coding for item number 2 and 9, is used for analysis and reporting. A sigher score indicates a higher level of internalized stigma.

3.3.7.8. Physical health measurement

Physical health measurements were specifically focused on cardio-metabolic health of participants. There are several invasive and none invasive methods of testing the cardio-metabolic health conditions. Due to long interview time for other main objectives of the study the physical health conditions of the participants were assessed by simple and none-invasive methods including, weight, height, hip circumference, waist circumference, blood pressure, and heart rate.

3.3.7.9. Other measurements

Participants' clinical and socio-demographic data were examined from the patients' clinical records. Diagnosis and medical treatment data were taken from the patients' progress sheet/charts and interview. A data extraction form was prepared for the required variables from patients' medical record charts (Appendix 3).

3.3.8. Ethical considerations

Ethical approval to conduct the study has been obtained from the Human Subjects Research Ethics Sub-Committee at The Hong Kong Polytechnic University attached in the Appendix 15.1, local office in Ethiopia attached in the Appendix 15.2 and permission was granted from each of respective study institutions. Confidentiality of the personal identity of the participants was assured by using anonymous codes and by storing the data securely. Safe storage of the data was ensured by direct handing of the data to a researcher from the data collectors, safely storing the completed questionnaire in a locked cabinet and limiting access to the researcher only. All the questionnaires will be discarded or destroyed after completing the PhD project and publications of the findings.

Written informed consent was obtained from individual participants and parents/legal guardians for individuals under 18 years old after full explanation of the objective and procedures of the study by the data collectors. The voluntary nature of participation was emphasized. Participants were given opportunities to ask questions, and full responses were given to the questions until no further queries raised. In case any emotional or psychological distress happened during or after interviews and/or measurements, psychological support was planned to be provided. If the participants incurred additional expenses to give the data (such as came to the hospital only for

this study purpose) they were reimbursed. Participants were also assured their right to withdraw from the study at any time with no impact on their treatment.

3.3.9. Data collection

Data were collected by two psychiatric nurses in each hospital who have had caring experiences for mentally ill individuals. One room was reserved for interviews in each hospital; these rooms were used for interviews and measurements. Data were collected from patients' hospital charts/records (some demographic, clinical and treatment characteristics including DUP and duration of illness) and face-to-face interviews. Because of the low literacy rate in the study population, all scales were administered by reading each item by data collectors in face-to-face interviews.

A full day training was given to data collectors by a psychiatrist and the principal investigator about taking informed consent, interviewing and scoring the scales. Most of the research instruments used only required the data collectors to read out the questions for the participants' self-rating. The one-day training was mainly focused on the rating method and procedure of the PANSS, following a set of standard instructions and guidelines. The data collectors who are experienced in the field of psychiatry were give adequate time to read the PANSS materials before training. In addition, the psychiatrist trainer and the principal investigator were present at the study sites to answer questions about the PANSS or any other queries related to the study. Inter-rater-reliability was also established. Details of the training schedule and content are presented in Appendix 16. The same assessors were involved in the pilot and main study. The principal investigator closely supervised the data collection process, each assessor was observed while collecting data from some (1-5) first participants, the

collected data checked, feedback given and required corrections were made and thus uniformity among the assessors was ensured.

In the physical health measurements anthropometric measurements were taken without heavy outdoor clothing. Height was measured to the nearest millimetre using an anthropometric rod. Weight was measured on a pre-standardized body weighing scale. The hip circumference was measured at the maximum circumference around the hips and the waist circumference was obtained at the level of the umbilicus at the midpoint between the lower margin of the last palpable rib and the top of the iliac crest (hip bone) using a measuring tape. Blood pressure (BP) was measured using a digital measuring device with participants sitting and resting for at least five minutes. Definitions for normal and abnormal test results were interpreted per WHO recommendation (World Health Organization, 2010, 2013a).

Table 3-2: Operational definitions of the physical health measurements

Blood Pressure (Average of two consecutive measurements)		
	Systolic BP in mmHg	Diastolic BP in mmHg
Normotensive	<120	<80
Pre- hypertensive	120–139	80–89
Hypertensive	≥140	≥90
Weight status in BMI		
Underweight	<18.5 kg/m^2	
Normal Weight	18.5–24.9 kg/m^2	
Overweight	25.0–29.9 kg/m^2	
Obese	≥30.0 kg/m^2	
Central Obesity measured in WTHR		
	Men	Women
Normal	< 0.95	< 0.85
Centrally obese	≥ 0.95	≥0.85

BP: Blood Pressure, mmHG: millimetre of Mercury, WTHR: waist-to-hip-ratio, BMI: body mass index

Measurements were conducted at three time-points. In the baseline data collection, all the study variables were measured. During the baseline assessment, an appointment was made for the second-round measurement at third month. For tracking and reminding the participants in case they forgotten/did not appear in time, their phone numbers were recorded. The participants received either a text message or a phone call as a reminder. Most of the variables were measured in all three rounds of measurements except for a few like socio-demographics which were measured only at the baseline measurements.

3.3.10. Data analysis

About 10.0% of questionnaires from each hospital were randomly selected and checked for completeness and accuracy by the researcher. Data entry and analysis was done in IBM, SPSS version 23 statistical software (IBM Corp, 2015).

Descriptive analysis was done for the data collected. Frequency and percentage for variables like demographic characteristics of participants and other categorical variables at each measurement time are reported. Minimum, maximum, and mean score with standard deviations of numeric measurements (such as QPR, WHODAS 2.0, SSQ6, PANSS, HS and ISMI) at each measurement time and their changes over time are also reported. With descriptions for the important variables such as demographics, clinical and subjective recovery scores, and potentially related factors, the findings of all variables are presented using tables. Repeated measures ANOVA tests were computed to understand whether there were differences in the variables measured in three time-points. Assumptions for the test were fulfilled except for sphericity when checked by “Mauchly's test” and hence the Greenhouse-Geiser results were used (Leech & Onwuegbuzie, 2010; Tabachnick & Fidel, 2007).

To identify significant predictors for subjective recovery and determine the independent contributions of each group of variables, hierarchical multiple regression test was applied (Petrocelli, 2003). This analysis method was found to be most appropriate for the study objective. The study mainly aimed to identify variables associated with the subjective recovery and determine if the associated variables had sustained and/or long-lasting relations with subjective recovery. Accordingly, four regression tests were computed for the whole longitudinal quantitative data. Hence the first three regression tests have tested individual variables that predicted subjective at

different time-points and therefore tested if the associated variables had sustained relationship/prediction on subjective recovery. The last (fourth) regression tests if either of the significantly related variables in any assessment time point had long-lasting associations with subjective recovery at 9th month. In addition, the last regression also tested if the subjective recovery scores in the earlier time (baseline and third month) could predict subjective recovery score in the later months (9th month) and hence tested if the non-linear nature of subjective recovery holds true.

Using these regression tests, the prediction of the independent variables on the dependent variable at each measurement time (T_1, T_2, and T_3) were tested independently. Several potential predictor variables of subjective recovery were identified in the previous studies; these variables were grouped in temporal precedence and entered into the regression models accordingly. Therefore, sociodemographic and substance use variables were entered in the first model followed by physical health states and finally, psychosocial variables were inserted into the regression tests. This analysis method was used for each of the three round measurements. Finally, to identify the significant predictors at ninth month, all significant predictors at any of the measurement time-points were introduced into the last hierarchical regression test in sequence with the round of assessment. The missing data were imputed with the mean values at the time-point of observations to maintain high statistical power and to compute the regression analysis for all cases (Di Franco, 2013).

The total scores of all the measures were used for regression where appropriate (i.e. BHS, ISMI, WHODAS and WHOQOL). However, the subscales/domains of the PANSS and the SSQ6 were inserted in the regressions due to the reported independencies of the subscales/domains (Best, Grossman, Oyewumi, & Bowie, 2016;

Fekadu et al., 2013; Mortimer, 2007; Shibre et al., 2010). Dummy dichotomous variables were generated for the categorical variables such as gender, substance use, weight status, blood pressure and central obesity. In each block, “Enter Method” was used for regression tests. For all the regression tests, the level of significance was set at $p<0.05$.

3.3.10.1. Regression for first-round data

For the first-round data, there was no missing data for the dependent variable but there were 21 cases with missing data for at least one of the 17 independent variables included in the multiple regression. These missing cases were imputed with the mean values in the regression tests. Seven outliers were identified by looking at the standardized values (three and above) and hence were excluded from the regression tests. According to Stevens (2009) and Tabachnick and Fidel (2007), the dependent variable was in the acceptable ranges for normality (Skewness = -0.218 and Kurtosis 1.63). There was no multicollinearity between independent inserted into the regression model (VIF ranges from 1.08 to 2.38) (Stevens, 2009; Tabachnick & Fidel, 2007); and hence the data fulfil the assumptions of linear regression test.

3.3.10.2. Regression for second-round data

To compute the multiple linear regression tests for the second-round data, assumptions for linear regression test were also checked. For the dependent variable (QPR) 14 outlier cases were identified by looking at the standardized values (three and above), and therefore these cases were excluded for the regression. There was no missing data for the dependent variable but there were eight cases with missing data for either of the independent variables inserted into the model. Regression was computed with the

mean values for the missing data for the independent variables. When checked for the assumptions of regression tests, according to Stevens (2009) and Tabachnick and Fidel (2007), it was in the acceptable ranges for normality (Skewness = -0.606 and Kurtosis 1.656) for the dependent variable (QPR). There was no multicollinearity between predictor variables included in the regression model (VIF ranges from 1.11 to 4.03) (Stevens, 2009; Tabachnick & Fidel, 2007).

3.3.10.3. Regression for third-round data

In the ninth month's measurement there was no missing data for the dependent variable (QPR) but for the independent variables inserted into the regression test there were 21 cases with missing data which have been imputed with the mean values. Twelve cases were found to be outlier for the dependent variable by looking at the standardized values (three and above) and visualizing extreme values and therefore were excluded from the regression test. After these corrections the data were in the acceptable ranges for normality (Skewness = -0.457 and Kurtosis 0.634) for the dependent variable (QPR) according to Stevens (2009) and Tabachnick and Fidel (2007). There was no multicollinearity between predictor variables included in the regression model (VIF ranges from 1.10 to 5.66) (Stevens, 2009; Tabachnick & Fidel, 2007).

3.3.10.4. Final regression model

A final regression model was computed to identify variable/s significantly predict the level of subjective recovery from recent-onset psychosis within a nine-month period. In this multiple regression test, variables which showed significant prediction in any of the three-round measurements were included in the model. These variables were

grouped with the rounds of measurements; i.e., the first-round measurements were inserted in the first model, second-round measurements were inserted in the second model and the third-round measurement at third phase were inserted in the last model. Accordingly, WHOQOL-BREF, BHS, WTHR, ISMI, SSQ6-Satisfaction and WHODAS measurements of each phase were inserted in each of three consecutive regression models. The QPR measurements of the first and second phase measurements were also inserted as independent variables in the first and second regression hierarchies/models respectively.

3.4. Pilot Testing the Validity and Reliability of the Study Instruments

3.4.1. Introduction

This section presents the instrument translation and validation processes for the measures used in the main study following suggestions by Sousa and Rojjanasrirat (2011) and piloting the feasibility of the cohort study conducted following this cross-sectional validation and piloting survey. Initially, the measuring tools were translated to the local language, Amharic by a bilingual health professional, reviewed by mental health professionals who spoke Amharic in the study hospitals and tested with participants having same inclusion criteria with the main study. Different statistical tests were employed to assess the validity and reliability of these tools to Ethiopians with recent-onset psychosis. The findings of these steps are presented and discussed below.

3.4.2. Objective

To establish the reliability and validity of study instruments (QPR, SSQ6 and ISMI) in Amharic language for Ethiopians with recent-onset psychosis.

3.4.3. Methods

3.4.3.1. Study Design

A cross-sectional survey was conducted using face-to-face interviews with sixty consecutively sampled individuals in November 2017 before the main study. The measurements for each of the three instruments were repeated after two weeks to assess the test-retest reliability.

Instruments Translations: Initially, measures were translated into the local language, Amharic. Translations were done by a bilingual professional in mental

health. Translated versions were translated back to English by another bilingual public health professional. Two versions of each (original English and back-translated English version) were compared for semantic equivalence by a native English speaker and professional in the field. Discussions between these translators and corrections were also made. Six mental health professionals, who spoke both Amharic and English language, studied to master or bachelor's degree level, working in psychiatric clinical and research appraised the appropriateness of the translation. They compared it with the original English version and gave both written and verbal comments.

Face validity: The translated (Amharic) versions of the instruments were reviewed six experts in the mental health field. They gave both verbal and written comments, discussion between these experts and the principal investigator was also held and required corrections were made. Service users in the piloting phase were also invited to comment on the understandability of the scales.

Content validity: Content validity of the three scales were tested by making each item to be scored by six mental health experts with 4 points Likert scale for relevancy (1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant). The raters also gave any comments and suggestions for corrections about the readability and clarity of the items in the scales. The Scale Content Validity Index Average (S-CVI/Ave) were calculated to determine the level of validity in terms of content. As suggested by Polit and Beck (2006) and Sousa and Rojjanasrirat (2011), 5-10 experts would be appropriate to test the content validity of a translated instrument in behavioural or health care research.

Test-retest reliability: The three instruments' response stability over time was checked by repeating the same measurements over the 14-days interval. The

individuals' level of recovery from psychosis or severe mental illness is expected to be stable over 2 weeks of duration; and the participants were expected not to be able to recall their initial response (Williams et al., 2015).

Concurrent validity: Concurrent validities of the two instruments (QPR and ISMI) were tested with the hopelessness scale. Previous studies by Law et al. (2016) and Law et al. (2014) found that subjective recovery (the QPR) had a significant negative correlation with Beck's hopelessness scale (BHS). ISMI was also found to be positively correlated with BHS (Pescosolido & Martin, 2015). As mentioned in the previous subsection the BHS has been previously validated and used for Ethiopian population (Bekry, 2008). However, for the SSQ-6 it was not possible to identify any other instrument that was validated in Amharic language for Ethiopians with mental illness to test for its concurrent validity, therefore the scale SSQ-6 was not checked for its concurrent validity in the current validation survey.

Internal Consistency: The level of internal consistencies of the items within the scales (QPR, ISMI and SSQ-6) were assessed by calculating Cronbach's α for each scale.

3.4.3.2. Study settings

The study setting is the same as the main study described in the previous section (section 3.3.2).

3.4.3.3. Sample size and sampling

Sixty service users with recent-onset psychosis who had follow-up care in the psychiatric clinics under study were involved in the first measurement of this

instrument validation and 45 of them were involved in the retest. Required numbers of participants (sample size) for validation test was adopted from the suggestions by Anthoine, Moret, Regnault, Sebille, and Hardouin (2014) and Sousa and Rojjanasrirat (2011). Equal numbers of participants were involved from the three tertiary hospitals of North-Western Ethiopia. A consecutive sampling method (recruited in their visit order to the psychiatric clinics) was employed to recruit participants from each hospital.

All three scales validated in this study are unidimensional in the original English or other languages and, therefore, factor analysis was not required for the targeted instruments; and hence sample size estimation was done with this consideration.

3.4.3.4. Inclusion and exclusion criteria

The same inclusion and exclusion criteria were used for the piloting survey and main longitudinal study which were mentioned earlier.

3.4.3.5. Data Collection Methods

Guaranteeing ethical issues as mentioned above and using the instruments also discussed above, data were collected from the three hospitals. Data were collected by two masters or degree level professionals in mental health care in each hospital who were working in the study hospitals. Details of data collection procedures were discussed in the earlier section.

To test the manageability/feasibility of the main study, all instruments to be used in the main study were piloted in this validation study. Therefore, the measurements in the first test of this validation study were not limited to only the three scales (QPR,

SSQ and ISMI) undergoing validation; however, the assessment in the re-test at 14-day interval was limited to the three scales. During the baseline measurements appointments were made on the 14th day with the participants and the first-come 45 participants were involved for the test-retest reliability assessment. Only a couple of participants requested for financial subsidy for transportation, and their expenses for the second visit were reimbursed.

3.4.3.6. Data Analysis

Data were entered and analysed using IBM-SPSS version 23 statistical software (IBM Corp, 2015). Descriptive summary of the study participants and variables was made by calculating percentages, means and standard deviations.

For content validity the Scale Content Validity Index Averages (S-CVI/Aves) were calculated by dividing the number of items ranked relevant (rated 3 or 4) to the total number of items rated for relevance. The total content validity index average for the scale (S-CVI/Ave) of 0.80 or higher was taken as acceptable level as recommended by Polit and Beck (2006).

Test-retest reliabilities of each item were checked by running Intra-class Correlation Coefficient (ICC) as suggested by Vaz, Falkmer, Passmore, Parsons, and Andreou (2013); index points of $r \geq 0.7$ was taken as the acceptable level of reliability (Polit & Beck, 2010; Sousa & Rojjanasrirat, 2011). ICC is preferred over Pearson's correlation test for its measurement of correlation and level of agreement (Koo & Li, 2016). Patients' chart numbers were used to match the test and retest data.

Concurrent validity tests for the two instruments (QPR and ISMI) were tested with the hopelessness scale (BHS). Pearson's Correlation test was used to examine the

correlations of the overall scores of each pair of measures. The correlation coefficient of (r>=0.5) was taken as the minimum acceptable level (Polit & Beck, 2010; Sousa & Rojjanasrirat, 2011).

Internal consistencies of instruments were tested by calculating the Cronbach's α coefficient for the whole items of each scales; the minimum value of 0.7 and above was taken as the acceptable level of consistency (Polit & Beck, 2010; Sousa & Rojjanasrirat, 2011).

3.4.4. Results

3.4.4.1. Sociodemographic, substance use, clinical and psychosocial characteristics

From the three hospitals, 60 individuals (20 from each hospital) with recent-onset psychosis were recruited. The majority of the participants were Orthodox Christians (86.7%) in their religion. The mean age of participants was 27.6 (SD = 7.13) years. Average monthly family income was 2,922.83 Ethiopian birr (1 USD = 27.5 birr). Nearly half (48.3%) of the participants were female and from the rural area. More than half (53.3%) of the participants were single in their marital status while 33.3% were married. Only a quarter (25.0%) of the participants reported they were unemployed/not in study. More than half of the participants reported they were living with their parents (56.7%). Socio-demographic characteristics of the pilot study participants are presented in Table 3.2 below.

Table 3-3: Sociodemographic characteristics of study participants (Pilot Test N=60)

Variable	Category	Freq (%)
Gender	Male	31 (51.7)
	Female	29 (48.3)
Residence	Urban	31 (51.7)
	Rural	29 (48.3)
Marital status	Single	32 (53.3)
	Married	20 (33.3)
	Divorced	8 (13.3)
Education level	Illiterate	17(28.3)
	Primary School	14(23.3)
	Secondary School	19(31.7)
	College diploma and above	10 (16.7)
Occupation	None	15(25.0)
	Student	15 (25.5)
	Have regular work	30 (50.0)
Living with	Parents	34 (56.7)
	Partner	17 (28.3)
	Alone	5 (8.3)
	Other	3 (6.7)
Smoke cigarette	Yes	9 (15.0)
	No	51 (85.5)
Drink alcohol	Yes	16 (26.7)
	No	44 (73.3)
Chew Khat	Yes	9 (15.0)
	No	51 (85.5)
Other drugs	Yes	1
	No	59
	Mean	Std. Deviation
QPR Sum	40.80	9.26
BHS Sum	5.3	5.01
ISMI Mean Value	2.31	0.50
SSQ number	9.6	6.6
SSQ satisfaction	26.10	10.76
WHODAS sum	26.80	11.14
WHOQOL-BREF-overall	3.10	0.72
WHOQOL-Phy	3.33	0.80
WHOQOL-Psy	3.23	0.85
WHOQOL-Soc	2.76	0.96
WHOQOL-Env	2.89	0.76
PANSS-overall	45.65	13.12
PANSS-Positive	12.40	5.07
PANSS-Negative	10.97	4.38
PANSS-General psychology	22.28	7.07

QPR: Questionnaire about the Process of Recovery, BHS: Beck's Hopelessness Scale, ISMI: Internalized Stigma for Mental Illness, SSQ-6: Social Support Questionnaire with six item, WHODAS 2.0: World Health Organizations Disability Assessment Schedule, WHOQOL-BREF: World Health Organization Quality of Life, PANSS: Positive and Negative Syndrome Scale

Substance use practice of the participants was also assessed in this pilot study. Relatively higher proportion of participants reported they consumed alcohol (26.7%) than cigarette smoking and chewing Khat (15.0%).

Duration of untreated psychosis and duration of illness was recorded from patients' hospital charts and the mean duration of untreated psychosis (DUP) was found to be 7.8 months with a large standard deviation (13.0) ranging from one day to 5 years. The mean duration of illness for participants of this pilot study was 22.8 months with SD = 18.7.

Table 3.2 also summarizes the psychosocial, substance use and recovery scores of the participants in the pilot study. In the table, the mean values of the pilot test (*N*=60) for the scales and subscales are presented.

For the scale assessing the process of recovery (QPR) the mean score of participants was found to be 40.8, SD = 9.26; while the measurement was repeated after 2 weeks it only increases by 1 point which was not significant (*P* of ICC test is less than 0.001) as presented in Table 3.2. For the scale measuring level of hopelessness (BHS), the mean value was found to be 5.3, SD = 5.01. After reverse coding for the item number 2 and 9 of ISMI, the mean value was 3.31, SD = 0.5. The social support questionnaire-short form (SSQ) was among the scales assessed both in the pilot and retest. This scale has two domains; items assessing number people involved in support and level of satisfaction with the support. The mean number of people involved in support was found 9.6, SD = 6.6. The level of satisfaction with the support was 26.1, with the broad standard deviations (SD = 10.76).

The mean values of level of disability (WHODAS) 26.80 (SD = 11.14), the overall scale of quality of life (WHOQOL-BREF) was 3.10, and the overall scale of the level of the psychotic symptom (PANSS) was 45.62 (SD = 13.12). The mean scores of subscales and the SDs of all scales are presented in Table 3.2.

The reliability and validity of the instruments were validated in terms of concurrent validity, content and face validity, test-retest reliability and internal consistency/reliability. Previous studies recorded that perceived recovery from mental illness (Law et al., 2014; Law et al., 2016) and internalized stigma (Livingston & Boyd, 2010) were negatively correlated with individual's level of hopelessness and hence concurrent validity of the two instruments were tested with the hopelessness scale (BHS).

The content validity of these instruments was tested with item and scale content validity index average (SCVI-Av) as advised by (Polit & Beck, 2006). The content validity of the items in each scale was scored by six experts in mental health care. Item CVIs were calculated by counting raters scored relevant to the number of raters. The SCVI-AVs of each scales were calculated by summing scales scored as relevant and dividing by the number of items scored for relevance and results are presented in Table 3.3. Three among six assessors rated not relevant for item number 7 (I-CVI = 0.5) of the Amharic version of QPR "*My experiences have changed me for the better*" and item number 2 of ISMI "*In general, I am able to live the way I want to*". In the initial version, raters felt that it would be pointless to ask service users if they benefited from their illness as it (QPR item number seven) used to sound like that. For the ISMI item number two it (the prior Amharic version) used to sound like the overall satisfaction in life which was not referring to internalization of stigma due to mental illness.

Therefore, for these items, revisions of the translation were made in discussion with the raters. The indices of the scales tested indicated that these scales are highly valid in their contents (SCVI-AVs ranges from 0.86 to 0.96).

Table 3-4: Content Validity Index (CVI) for items and scales (A: QPR, B: ISMI, C: SSQ6)

	QPR	ISMI	SSQ6
Scale CVI-AV	0.86	0.89	0.91
Item number	Item CVI	Item CVI	Item CVI
1	1	1	1
2	1	0.5	0.83
3	1	1	0.83
4	1	1	1
5	0.67	1	1
6	1	0.67	0.83
7	0.5	1	
8	1	1	
9	0.67	1	
10	0.67		
11	1		
12	0.67		
13	1		
14	1		
15	0.83		

QPR: Questionnaire about the Process of Recovery, ISMI: Internalized Stigma of Mental Illness, SSQ: Social Support Questionnaire

Reliabilities of the three scales were examined with test-retest reliability test using Intra-class Correlation Coefficient (ICC) and internal consistency using Cronbach's α coefficients. The p - values for all scales it was found that intra-class correlation coefficients (ICC) were below 0.001. The ICC value of SSQ satisfaction was found to be the least (ICC = 0.65) among others and slightly lower than the proposed point,

which is 0.7, but it was still in the moderately acceptable range as suggested by (Koo & Li, 2016). Though the numerical figure of SSQ appeared to be acceptable and most of its items were properly translated and understood by participants, item number 1, 2 and 6 were commented by expert reviewers (health professionals in mental health) to have somewhat similar concepts/meanings.

The extents of internal consistencies of the scales were tested by calculating the Cronbach's α values. As presented in Table 3.4 all the scales were found to be highly consistent, as indicated by Cronbach's α values which are greater 0.7 as proposed to be an acceptable value (Elkin, 2012).

Table 3-5: Reliability and Validity test results

Correlations	Pearson's correlation with BHS *r (P*-value)	ICC (*P*-value)	Cronbach's α
ISMI	0.55 (<.001)	0.74 (<0.001)	0.74
SSQ6-S	-	0.63 (0.001)	0.96
SSQ6-N	-	0.85 (<0.001)	0.92
QPR	-0.63 (<.001)	0.71 (<0.001)	0.95

** Cronbach's α was computed for the whole items of each scales*

QPR: Questionnaire about the Process of Recovery, ISMI: Internalized Stigma of Mental Illness, SSQ6-N(S): Social Support Questionnaire Number (Satisfaction)

The Pearson's correlation coefficients (r) for the correlations of hopelessness scale (BHS) with the nine items internalized stigma of mental illness (ISMI9) and the 15 items questionnaire for the process of recovery (QPR) were 0.55 and -0.63 respectively. These coefficients for both scales are in the acceptable level ($r \geq 0.5$) as proposed while the p-value for both coefficients are below 0.01. Both coefficients showed that both QPR and ISMI are moderately correlated with BHS indicated these scales are concurrently valid to be used for Ethiopians with psychosis.

Table 3-6: Pearson's Correlations r (p-value) of psychosocial statuses of participants (N=60)

	QPR	SSQ6-N	SSQ6-S	ISMI	BHS	WHODAS	PANSS overall
SSQ6-N	-0.01(0.9)	1.00					
SSQ6-S	0.07(0.6)	0.61(<0.001)	1.00				
ISMI	-0.50(<0.001)	0.01(0.9)	-0.08(0.6)	1.00			
BHS	-0.63(<0.001)	-0.06(0.6)	-0.05(0.7)	0.55(<0.001)	1.00		
WHODAS	-0.48(<0.001)	0.05(0.2)	0.17(0.1)	0.45(<0.001)	0.54(<0.001)	1.00	
PANSS-overall	-0.58(<0.001)	-0.05(0.7)	0.01(0.9)	0.43(<0.001)	0.74(<0.001)	0.52(<0.001)	1.00
WHOQOL-overall	0.64(<0.001)	0.18(0.2)	0.18(0.8)	-0.64(<0.001)	-0.67(<0.001)	-0.51(<0.001)	-0.59(<0.001)

QPR: Questionnaire about the Process of Recovery, PANSS: Positive and Negative Syndrome Scale, BHS: Beck's Hopelessness Scale, SSQ6-N(S): Social Support Questionnaire number (satisfaction), ISMI: Internalized Stigma of Mental Illness, WHODAS: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life.

Concerning interrater reliability, all scales used in the study, except PANNS, were to be either self-rated or interviewer-administered i.e., interviewers only recorded what the interviewee reply and therefore variations in rating was not the concern. However, for the PANSS, interviewers were expected to rate the level of psychotic symptoms of the study participants. To have a consistent rating among assessors, different strategies have been used as discussed in the method sections. Consistency among raters has been assessed by ICC (Intraclass Correlation Coefficient) and the rating was found to be highly consistent among raters, ICC (P-value) = 0.985 (<0.001). High level of correlations between raters was also recorded with correlation coefficients (*r*) ranging from 0.89 to 0.97 as presented in Table 3.6.

Table 3-7: Pearson's correlation coefficients (r) between PANSS raters

Rater	1	2	3	4
2	0.967			
3	0.946	0.947		
4	0.915	0.934	0.968	
5	0.942	0.95	0.911	0.889

3.4.5. Discussion

This part of the survey was conducted to establish the reliability and validity of the three study instruments (QPR, SSQ6 and ISMI9) in the Amharic language for Ethiopians with recent-onset psychosis and to pilot the feasibility of the nine months longitudinal study conducted following this survey. Sixty individuals with recent-onset psychosis participated in this instrument validation stage of the study. The three instruments translated and validated were found to be reliable and valid to be used for Ethiopians with recent-onset psychosis as indicated by SCVI-Ave ranges from 0.86 for the QPR to 0.91 for SSQ6, Cronbach's alpha ranges from 0.74 for ISMI to 0.96 for SSQ6, ICC for test-retest ranges from 0.63 for SSQ6-satisfaction to 0.85 for SSQ6-number and concurrently valid with BHS Pearson's *r* 0.55 for ISMI and 0.63 for the QPR. According to Elkin (2012); Koo and Li (2016); Polit and Beck (2006) these figures demonstrated that these scales (QPR, ISMI and SSQ6) are valid and reliable for Ethiopians with recent-onset psychosis.

In this study, it was also learned that some participants, though seeming/assessed to be stable and competent to communicate, had difficulty understanding questions and properly answer each item. Some participants felt repetitions of some items from different scales, such as *"I can find the time to do the things I enjoy?"* in the QPR and *"I have enough time to accomplish the things I most want to do"* in the BHS, however as each scales was aimed for different objectives all items were kept in their scales. Scales like BHS and WHOQOL-BREF were found to have some sensitive items (e.g., items asking about sexual satisfaction in QOL and "*my future seems dark*" in BHS scale) and therefore these scales were put at the end; and hence, the discomforts for the items of these scales would not affect the feelings of participants to complete other scales. Participants had difficulty to speak out their true feeling about social support

(SSQ6) items in front of their family members and therefore more privacy was given in scoring the scales by asking them (guardians accompany the participants to the hospital) to wait outside while completing this scale.

Another challenge faced was that few individuals sent their family members to hospitals while they (the patients) stayed at their home, for medication refill. Service users should have been assessed for their progress of illness rather than keeping the same medications; and participants were advised to visit the hospitals by themselves for their medication refill. Some individuals claimed that financial restraints to escort the patient and the guardian to hospital was the reason for the patients to stay home; for this transportation expenses for the sampled participants if claimed were reimbursed. Indeed, this might not be the only reason, it needs a systematic study to identify the reasons why service users are not visiting hospitals instead get drug refill by their agents/family members.

Although most of the participants were able to complete the interview without any difficulties/complaints few reported too many items and too long interview time; and as solution participants were allowed to take a break any time during the interview, and the questionnaires were arranged with priority from most important and easy-to-answer ones to less important and more complex to respond ones. Generally, from the pilot survey it was learned that all scales could be completed within an average duration of 30 minutes and it would be feasible to conduct the nine months longitudinal study.

3.4.6. Conclusions

The Amharic versions of the scales measuring subjective recovery (15 items QPR), internalized stigma (9 items ISMI) and social support (SSQ) showed acceptable face

and content validities. All the items in the QPR and ISMI were properly translated and well understood by the Ethiopians with recent-onset psychosis. Most of the items in SSQ6 were properly translated and understood by participants, but some of its items perceived to have similar meanings/concepts and hence assessors were required to clarify the questions.

The QPR and ISMI are significantly correlated with the hopelessness scale indicating these scales are concurrently valid. Generally, all the three scales (the 15 items QPR, the 9 items ISMI and the six items SSQ) are valid and reliable to be used for Ethiopians with recent-onset psychosis. In this dual objective survey, it was also learned that it would be feasible to conduct a nine months longitudinal survey using these scales.

3.5. Qualitative Part

3.5.1. Study design and period

The qualitative interviews were conducted during September and October 2018 to describe: a) service users' conceptualizations of recovery; and b) perceived challenges and opportunities during the process of recovery from recent-onset psychosis. A descriptive qualitative research design was employed as it was suitable to describe the nature of phenomena or experiences of something in a particular situation (Seale, 2011). In the current study, the descriptive qualitative approach gave the participants a voice and ensured presentation of their perspectives in detail. Data from this approach gave rich information to further interpret and build on the quantitative findings of the study. In other words, findings from the qualitative approach were used to strengthen the findings of quantitative prospective cohort study by providing deeper naturalistic, contextual interpretations of service users' recovery experiences.

As this study has adopted a sequential explanatory mixed-methods study design, the qualitative part of the study has been informed by the findings of the initial quantitative part (Andrew & Halcomb, 2009; Ostlund, Kidd, Wengstrom, & Rowa-Dewar, 2011; Polit, 2018). Specifically, findings from the quantitative longitudinal study have guided the design of the interview guide questions, selecting/sampling of participants of the subsequent qualitative study.

3.5.2. Sampling method

Nineteen participants from different level of subjective recovery score in the quantitative measurement were purposively selected for the qualitative interview. Hence, individuals with different level of recovery in the quantitative study were represented in the descriptive qualitative study.

3.5.3. Sample size

To decide the number of participants for the qualitative interviews, the principle of data saturation as recommended by renowned qualitative researchers (Dworkin, 2012; Marshall, 1996; Polit & Beck, 2004) was followed. A systematic review by Dworkin (2012) concluded that 5 to 50 participants were commonly used as the adequate number in any kind of qualitative study.

For the current study sample size was determined based on data saturation. By doing concurrent and constant analysis, data were considered as saturated when no new and relevant data seems to emerge, categories and themes were well developed, and the relationships among categories were well established and validated (Bryman, 2011; Lingard, Albert, & Levinson, 2008; Marshall, 1996; Polit & Beck, 2010). In this study, determined data saturation was achieved at 15 participants and to ensure four

more participants were interviewed for member checking and testing the data iteration. Previous studies also found data saturation on subjective recovery from recent-onset psychosis among service users at about 20 participants (Connell et al., 2015; Eisenstadt et al., 2012).

3.5.4. Interview guide questions

The questions for interviews in a qualitative exploratory study are suggested to be open-ended, focused on the objectives of the study, exploring the individuals' experiences and understandings about the topic "recovery" and its related important issues (Larkin & Thompson, 2013). The flow of questions was recommended to be ordered from simple questions asking experiences to more comprehension and understanding questions (Holloway & Wheeler, 2010).

Following this advice, for this study, mainly open-ended semi-structured interview guide questions were developed. Questions inquired about service users' understanding of their mental health state such as, *"Please tell me how you are feeling?"* with follow-up questions that prompt the participants to elaborate on their answers to the wide-ranging questions like *"How does this different mental well-being affect your day-to-day life?*". Their experiences through their recovery journey were also explored with questions such as, *"Please tell me about what has been happening with your mental health since you started treatment?"* and "*What does "recovery" mean for you?"* also with follow-up questions like, *"What indicators do you expect to say you are recovered/recovering/?".* Questions asking interviewees to share their understandings and experiences of the hindering and helping factors such as *"From your experiences, what components/factors do you think most important to get*

better?" were also raised. Details of the interview guide questions are shown in Appendix 12.

The interview guide question preparation was guided by relevant literature on the topic (Bourdeau et al., 2015; Connell et al., 2015; Lam et al., 2011) and based on the clinical experiences of the research team in the care of people with psychosis. For example, in the literature it was learned that individuals have different perceptions/definitions of their recovery and hence, questions enquiring participants' conceptualizations of recovery were included. The questions were revised based on the findings of the quantitative part that was conducted earlier to this qualitative interview (Andrew & Halcomb, 2009). The revisions were mainly about the factors related to subjective recovery. In the cohort study, it was found that quality of life, physical health, hopelessness, internalized stigma, and disability in functioning were significant predictors of subjective recovery. For example, questions enquiring how social support affected recovery were included in the interview guide; because in the quantitative part it was found that satisfaction with social support significantly associated with subjective recovery but not the number of supporters. Therefore, qualitative interview guide questions were devised to prompt interviewees to explain the related factors from their perspective.

The interview guide questions were evaluated/commented on before the actual use by two experts in the qualitative approach and psychiatric rehabilitation care. Beforehand, three service users were also asked to comment on interview guide questions to see if they understood it and were modified accordingly. They commented rather than asking to define recovery, asking them to list/mention indicators of recovery would be easier to understand and respond. Indeed, these questions were

used as only as triggers and guide the interview, whereas additional interview questions and prompts such as "*How do these factors affect your recovery journey?"* were used based on issues raised during the interviews when more elaboration was required.

3.5.5. Data collection methods

With pre-established interview guide questions, the researcher conducted the face-to-face interviews. Audio recording (after obtaining consent) and memo writing were part of data collection during the interviews. The memo/field notes were very important to capture data regarding the behaviours, emotions, gestures, postures and other important nonverbal cues during the interview (Holloway & Wheeler, 2010). These data were used as supplementary material and for reflection and interpretation of the interview data. In the early stage of interviews, the interviewer/researcher suppressed or "bracketed" his pre-suppositions on the topics being discussed. For the last four interviewees, member checking was performed using preliminary analyses results (themes and subthemes) at the end of the interviews.

3.5.6. Thematic data analysis

As described by Joffe (2012) thematic analysis is used to identify, analyse and describe patterns of meaning that finally highlights 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); which makes it appropriate for the current study. The qualitative data collected in this study were thematically analysed to identify and describe the main constellations/themes of the data from interviewees.

Data were analysed through concurrent and constant comparison after each interview. Audio recorded data in Amharic (local language) were transcribed in English for analysis. To check the accuracy of translation the transcripts were appraised by psychiatric nurses by listening to the audio records and reading the transcripts. Hence analysis was done from the English version transcripts. Before starting coding and actual analysis process, familiarization with data was made by reading the transcribed and memo data repeatedly. Scholars call this phase "immersion" or "dwelling" into the data to be analysed, which is very crucial to be able to gain the real meaning and concepts of collected data (Seale, 2011). After getting deep insight into each interview, the coding, categorizing and finally thematising were done as recommended by Glaser BG (1998); Joffe (2012); Maguire and Delahunt (2017). One supervisor checked the appropriateness of the codes, subthemes and themes generated by looking at the quotes for each code and when necessary, referring the whole transcripts. Two other supervisors verified the subthemes and themes by looking at the supporting quotes.

An inductive thematic analysis method was followed. Accordingly, after getting familiarized with the data, transcripts were openly coded into two broad groups; one group contained codes about conceptualizations of recovery and another group encompassed codes about perceived challenges and opportunities related with subjective recovery. After this step, codes having close/similar pattern/meaning were collated/categorized together and gave the subthemes and themes. The themes were reviewed and tightened through iteration of codes from different interviewees (Braun & Clarke, 2006). Themes, subthemes and codes with their selected verifier transcripts are presented using tables and texts. The meaning of each theme has been also defined/discussed.

Identified themes were interpreted and triangulated/checked with memos written during data collection and analysis and quantitative results (Hessen-Biber, 2016) which also enhanced the consistency of the research (Polit & Beck, 2010). Reflections of my perceptions are made throughout the whole process of the study (Polit & Beck, 2010).

3.5.7. Rigour of the study

Rigour of results (codes, categories and themes) were verified by iteration of codes and categories from participants' original transcribed data and finally by cross-checking with other personnel (supervisors). Common points to be considered to maintain the criteria of scientific rigour/trustworthiness of study while conducting qualitative study are credibility, transferability, dependability, and confirmability (Holloway & Wheeler, 2010).

3.5.7.1. Credibility

Credibility is a truth-telling nature of the data collected and the authenticity of conclusions drawn from it (Houghton, Casey, Shaw, & Murphy, 2013). To ensure this, participants with a different level of recovery were involved, data were collected until saturation and memo/field notes were taken persistently throughout interview and analysis (Holloway & Wheeler, 2010). Member checking was also conducted during and at the end of interviews and analysis. This member checking involved asking participants about the accuracy of the researcher's initial interpretation and summary of discussions, which helped to enhance the credibility of the study (Polit & Beck, 2010). As described in the qualitative data analysis section, the analysis method followed in this study also helped to capture the core messages of the data which increased credibility (Larkin & Thompson, 2013). After categories and themes were

developed, we also cross-checked the categories and themes with the original data for their analogy in the organization and interpretation. Furthermore, in the final write up the participants' own voices were conveyed by directly citing/quoting their own words so that readers can also make their own judgement.

3.5.7.2. Transferability

Transferability is the applicability (or generalizability) of the findings to the broader population to be ensured by involving a representative sample (Seale, 2011). Purposively including participants with different levels of recovery increased its representation, iteration and transferability. Conducting interviews until data saturation also enhanced transferability to the topic, area and populations with similar backgrounds. Writing detailed memos and field notes during interview and analysis and explaining each step with a thick reflexive description could also produce dependable and confirmable research report. Triangulating findings from the quantitative part of the study and having supervisors' review/feedback on the analysis/interpretation of findings further augmented the trustworthiness of this research.

3.5.7.3. Dependability

Dependability is about the consistency, repeatability or stability of the qualitative data (Houghton et al., 2013; Seale, 2011). In the current study using semi-structured interview checklist questions prepared referring to previous studies and conducting each interview by the same person strengthen the dependability of the findings. Audio recording and taking field-note and memos during the interview also helped to enhance dependability.

3.5.7.4. Confirmability

Confirmability is the objectivity of the data, its analysis and interpretation. This was confirmed by activities in recruiting participants, conducting interviews and data handling. We documented all activities/steps of the qualitative study in the field notes, which were used for data auditing and reflexivity. Being reflexive in each phase (collection, analysis and interpretation of data) of qualitative research is the main activity to be considered to enhance the confirmability. The data analysis and interpretations were checked by supervisors, and the themes with their illustrators are presented by tables.

3.5.7.5. Reflexivity

Reflexivity is an awareness of a researcher's role and position in the qualitative research process, starting from the conception of the research idea to the final interpretations of the qualitative findings (Seale, 2011). In the current study, the interviews were conducted in a private room of each hospital that interviewees sought their routine psychiatric follow-up care so interviewees might have perceived that I (interviewer and researcher of this study) am a health care provider. Maybe this was why the interviewees were asking questions related to the effects of their antipsychotic medications and the duration of treatment during interviews.

Nurses working in the study hospitals made appointments with interviewees for the qualitative interviews. However, I introduced myself that I was not working in those hospitals and not their health care provider. I clearly mentioned myself as a PhD student and conducting those interviews as part of my PhD project, indeed in addition to the aims of the study. To make participants feel that I was just a researcher in the

hospital, I was not wearing a gown or holding any diagnostic or treatment instruments that would identify me as a health care provider in the hospitals. Although I was not working in those hospitals; I am a professional in the field (mental health nursing).

I was part of the community that the participants came from and hence we might have some shared norms, values and understanding. I felt that it was easy for me to capture their ideas when they were trying to explain their long journey to the health care settings, challenges and opportunities they were facing within the community. I am male of a similar age with many participants who spoke the same language as the interviewees. As a member of the community I knew individuals with mental illness visited spiritual/traditional healing sites for their illness. In the community that I grew up, I was being told that miracles were happening in the spiritual/traditional healing practices, particularly for those who were believed to be possessed with evil spirit/s (individuals with the disturbed mental state). I knew some of the community members perceived that the traditional/spiritual and modern health care were not things to be practised side by side. Not only as a member of the community but also as a health professional who had some exposure to service users, I had some knowledge that service users might interrupt the hospital treatment and adhere to the spiritual/traditional healing practices. As part of the community, I observed that individuals with SMI were controlled, some were even chained by their family members, and therefore most of the treatment decisions were made by their guardians.

After starting my study (PhD) and prior to embarking to this study process, I spent much time on reading previous works on the topic, published a systematic review on this topic and conducted a longitudinal study that I analysed and wrote a report from the data. I, the researcher, had some knowledge about the topic which could have had

an impact on the research process. And hence, all these assumptions that I brought to the study could have its 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 researcher can influence the data collection, analysis and interpretations. However, in the final data analysis and interpretation process, supervisors who are from different cultures and settings, but who are in the field of psychiatric nursing have been involved adding more perspectives to the interpretations of the findings of this study and this could enhance the rigour of the study. Therefore, the interpretations of qualitative findings in this thesis shall be in consideration of these issues.

Generally, the overall rigour of the study is enhanced by the fact that the study has adopted a mixed methods design in which both qualitative and quantitative data were analysed and compared in order to be more likely to confirm the results. Triangulation of data and the involvement of more than one researcher also strengthen the rigour of the study (Holloway & Wheeler, 2010; Shenton, 2004).

3.6. Combined Interpretation of Quantitative and Qualitative Findings

This study has applied a sequential explanatory mixed-methods design (quantitative cohort followed by descriptive qualitative study) to enhance the validity and depth of understanding about subjective recovery (Holloway & Wheeler, 2010). Combination of findings from the two study approaches was to deepen the understanding of the concepts of subjective recovery from service users' perspectives and to explain factors related to recovery from the quantitative and qualitative data. Taking suggestions by Polit (2018) and Ostlund et al. (2011) for sequential explanatory mixed-methods, analysis of quantitative and qualitative data were performed independently. The

findings from the two approaches were summarized (Ostlund et al., 2011) and integrated together at the interpretation phase of the study which is the discussion chapter (Creswell, 2018). Findings from both methods were found either to be complimented or converged but no finding that diverged/opposed each other was found (Ostlund et al., 2011).

Similar to the qualitative data analysis approach, the combined interpretation was also performed dividing into two sections; conceptualizations of recovery and factors related to recovery. For the conceptualizations of recovery, interpretations of the findings from both study approaches have been made by giving priority to the findings from the qualitative data. Hence findings from the qualitative data were used as main data to define service users' understanding/interpretation of recovery from recent-onset psychosis, while data from the quantitative cohort were used to compliment it. Specifically, participants' experiences in the journey of recovery, their expectations of desired outcomes and perceived challenges that affect the journey of recovery were clarified by the findings from the qualitative study (Creswell, 2018; Ostlund et al., 2011). To make this possible, participants with different levels of recovery were purposively selected for the qualitative interviews; and the interview guide questions were revised after completing the longitudinal quantitative study that could add depth of understandings to the quantitative results.

For the factors related to recovery, quantitative data (regression results) were used as the core central data and the qualitative findings were used to explain it (Andrew & Halcomb, 2009). Particularly factors predicted subjective recovery in the quantitative cohort study have been clarified by the themes identified from the qualitative data (Creswell, 2018; Ostlund et al., 2011). Generally, integration of the findings from the

two study approach (quantitative cohort and qualitative) was done at the interpretation phase of the study as advised by many scholars in the field (Andrew & Halcomb, 2009; Creswell, 2018; Holloway & Wheeler, 2010; Ostlund et al., 2011; Polit, 2018). Findings from both approaches were found to compliment/support each other.

In summary of the methods chapter, this study has employed a sequential explanatory mixed-methods (Quan → qual) study design. For the quantitative part a nine months longitudinal study approach was conducted with three time-point (baseline, third month and ninth month) measurements. A set of instruments were identified and used in the study; while most were already in use in Ethiopians, three instruments were translated and validated for the study population. Predictor variables for subjective recovery from recent-onset psychosis were identified by hierarchical multiple linear regression tests. Following the quantitative survey qualitative data were collected from 19 participants with face-to-face interviews. Qualitative data were transcribed and thematically analysed. Finally, the findings from the two approaches were integrated and discussed together.

CHAPTER 4. RESULTS

4.1. Introduction

This chapter presents results from the quantitative and qualitative phases of a mixed methods study. The first phase, a quantitative cohort study, addresses the first two objectives of the study, that is to investigate levels of recovery of individuals with recent-onset psychosis who were being followed-up in an outpatient clinic progressing over nine months at three points of measurements (baseline, third month and ninth month follow-ups); and to examine predictor factors of the level of subjective recovery from mental illness. The demographic characteristics of the participants, who were service users with recent-onset psychosis sampled from three tertiary hospitals of North-western Ethiopia, are presented. Other study variables such as clinical, substance use, physical health and psychosocial characteristics were also analysed and presented for the three time-points measurements in tables and by using the percentage or mean values. The linear regression test results are also presented with tables and descriptions of important findings.

The second part of this chapter presents the findings from the qualitative phase of the study that addresses the third objective of the study, that is to explore the service users' conceptualizations of recovery; and perceived challenges and opportunities related to recovery from psychosis. The demographic and clinical characteristics of the nineteen participants in the qualitative interviews are presented. Finally, the thematic analysis results have been presented into two different subsections, conceptualizations (perceived meaning) of subjective recovery and perceived challenges and opportunities related to recovery.

4.2. Quantitative Results

4.2.1. Sociodemographic and clinical characteristics

From the three hospitals, 1,195 eligible participants with recent-onset psychosis were identified; and 270 were randomly selected. Seven did not participate in the study; they either refused to give written consent (n = 5) or withdrew participation during the interview (n = 2); hence 263 individuals with recent-onset psychosis were finally involved in the baseline measurement. Over half of them (n= 145, 55.1%) were male. The mean age was 29.58 (SD = 9.11) years ranging from 16 to 65 years. About two-thirds (61.7%) of the participants were urban dwellers and over three-quarters (77.2%) were Orthodox Christian in their religion. Only 21.7% of the participants reported they had no job, while others reported they either had a full-time job, private work or were on study.

More than half of the participants (54.0%) were diagnosed with schizophrenia, followed by schizoaffective disorder (21.3%). Most of the participants (78.5%) were taking typical antipsychotics, while nearly half (45.2%) had a history of psychiatric inpatient admission. The mean and median of DUP were found to be 7.61 (SD = 11.6) and 3.0 (SD = 11.59) months, respectively. The mean and median duration of illness were 22.84 (SD = 6.87) and 18.00 (SD = 16.87) months, respectively. Details of the study participants' demographic and clinical characteristics are presented in Table 4.1 below.

Table 4-1: Sociodemographic and clinical characteristics at baseline

Variable	Category	Frequency (%)
Gender (N=263)	Male	145(55.1)
	Female	118(44.9)
Residence (N=261)	Urban	161 (61.7)
	Rural	100(38.0)
Marital Status (N=263)	Single	149 (56.7)
	Married	73(27.8)
	Divorced/Widowed	41 (15.5)
Education Level (N=263)	Illiterate	62 (23.6)
	Primary School	57 (21.7)
	Secondary School	75 (28.5)
	College diploma and above	69 (26.2)
Religion (N=263)	Orthodox Christian	203 (77.2)
	Muslim	50 (19.0)
	Protestant Christian	10 (3.8)
Employment (N=263)	None	57 (21.7)
	Student	53 (20.2)
	Have regular work (Employed or private work)	153 (58.2)
Living with (N=260)	Parents	143 (54.4)
	Spouse	66 (25.4)
	Alone	29 (11.0)
	Other	22 (8.4)
Number of family members (N=252)	[1-3]	93(35.4)
	[4-6]	108(41.1)
	7 and above	51(19.8)
Psychiatric diagnosis (N=263)	Schizophrenia	142(54.0)
	Schizoaffective	56(21.3)
	Other specified schizophrenia Spectrum and other psychotic disorders	16(6.1)
	Schizophreniform	12(4.6)
	Brief psychotic	10(3.8)
	Substance induced psychosis	10(3.8)
	Unspecified schizophrenia spectrum and other psychotic	9(3.4)
	Delusional disorder	4(1.5)
	Psychotic disorder due to another medical condition	3(1.1)
	Catatonia	1(0.1)
Types of antipsychotics (N=261)	Typical	250 (78.5)
	Atypical	56 (21.5)
History of psychiatric admission (N=263)	Yes	119 (45.2)
	No	144(54.8)
	Range	Mean (SD)
Age (N=259)	16 - 65	29.58 (9.11)
Duration of Untreated Psychosis in Months (N=260)	0 - 59	7.61 (11.59)
Duration with illness in Months (N=260)	0.2 - 58	22.84 (11.87)
Family Monthly Income in Birr* (N=246)	200.00 – 20,000.00	2,012.25 (2,1141.56)

*27.5 Birr = 1 USD

In the second round (third month) follow-up measurements 201 of the 263 baseline participants were involved, giving the follow-up retention rate of 76.4%. More than half (N = 145, 57.7%) of the participants were male which is similar to the baseline (55.5%) participants. It was possible to retain nearly three-quarters (N =190, 72.2%) of the baseline participants in the third round (ninth month) assessments, while 58.4% were male. Individuals who were lost from followup seemed to have lower subjective recovery score (QPR = 43.1) as compared to those who engaged to the ninth month assessment (QPR = 44.6), but the difference was not statistically significant (P = 0.057). Presented in Figure 3.1 of the methods chapter, participants who disengaged from the follow-up were either not traceable (32 at second round and 73 at third round), disengaged from their treatment (9 at second round), withdrew from the study (16 at third round) or transferred to other hospitals (5 at second round). Seventeen participants who disengaged at the second round were re-engaged at the third-round measurements.

4.2.2. Substance use and physical health

Presented in Table 4.2 below, the percentages of self-reported substance use were found to be low. Over 95.0% of the participants reported that they did not smoke cigarette. About ten percent of participants reported that they drank alcohol at baseline measurement while the self-reported alcohol use percentage decreased to 4.2% and 4.7% at third and ninth months respectively. The rate of self-reported Khat use (a stimulant plant commonly consumed in East Africa) showed slight increase from the baseline (8.7%) to the third round (ninth month) assessment 10.0%. Other drugs in this context refer to any stimulant or sedative substance used for pleasure other than those mentioned above (alcohol, cigarette and khat) which remained relatively low

and stable throughout the study period (ranging 1.4% at baseline to 1.1% at ninth month follow-up).

Three common non-invasive cardiometabolic health indicators (blood pressure (BP), body mass index (BMI) and waist-to-hip ratio (WTHR) were assessed at all three rounds of measurements. The prevalence of hypertension showed continuous increases during the follow-up period; from baseline (20.7%) to the third month (21.6%) and to the ninth month (23.5%). The prevalence of overweight and obesity (as measured by BMI) were 15.6% and 2.3% respectively which showed minor increase after nine months 16.2% were overweight and 2.7% were obese. Among 251 participants, 109 (42.2%) were found to be centrally obese based on their waist-to-hip circumferences ratio at baseline measurements which persisted almost the same through the follow-up period (42.4% at third month and 42.5% at ninth month) with categorizations adopted from the WHO (World Health Organization, 2013). Details of substance use and physical health characteristics of the participants at three round measurements are presented in Table 4.2.

Table 4-2: Substance use and physical health at three time-points measurements

Variable		Baseline *n(%)*	Second round *n(%)*	Third round *n(%)*
Cigarette smoking		14 (5.3)	9(4.5)	8(4.2)
Alcohol drinking		26 (9.9)	8(4.2)	9(4.7)
Khat chewing		23 (8.7) (N=262)	13(6.5)	19(10.0)
Other drugs using		4 (1.4)	3(1.5)	2 (1.1)
Blood pressure	*Normal*	186(75.6)	137(74.1)	125(72.5)
	Pre-Hypertensive	9(3.7)	8(4.3)	7(4.0)
	Hypertensive	51(20.7)	40(21.6)	44(23.5)
BMI (Weight to height)	*Underweight*	45(17.4)	22(11.9)	22(12.7)
	Normal weight	166 (64.3)	129(69.7)	116(67.1)
	Overweight	41(15.6)	28(15.1)	28(16.2)
	Obese	6 (2.3)	6(3.2)	7(2.7)
Centrally Obese		109 (42.2)	78(42.4)	74(42.5)

4.2.3. Subjective recovery, functional, psychosocial and clinical characteristics

Participants' level of subjective recovery, disability, and psychosocial and clinical characteristics were assessed at three time-points over the nine months. The findings of these measurements are presented in Table 4.3. The mean score of 263 participants' subjective recovery while assessed by Questionnaire about the Process of Recovery (QPR) was found to be 44.17 (SD = 5.76) at baseline ranging from 15 to 60. The scores remained high throughout the nine months follow-up with no significant difference over the study period ($P = 0.925$), which were 44.65 at third month and 44.62 at ninth month assessments.

The participants' level of hopelessness at three time-points was assessed with Beck's Hopelessness Scale (BHS) with a possible score of 0 to 20. At each follow-up measurement, wide-ranging hopelessness scores (0 to 18 at baseline and second round

and 0-19 at third round measurements) were found. Presented in Table 4.3 below, significantly continuous increasing levels of hopelessness were recorded (*P=0.001*) at each round measurement; mean BHS 3.25 (SD = 3.88), 3.59 (SD = 4.15) and 4.56 (SD = 4.70) were found at baseline, third and ninth-month's follow-up assessments respectively.

The level of internalized stigma that participants had felt due to their mental illness was assessed by the Internalized Stigma of Mental illness (ISMI) with a possible mean score of 1 to 4. At the baseline assessment participants had a moderate mean internalized stigma score of 2.12 (SD = 0.44). It remained at moderate level throughout the nine months study period; 1.99 at third month and 1.95 at ninth month follow-up assessments (*P = 0.05*). Levels of disability assessed with the WHODAS 2.0 (possible score of 12 to 60) were moderate and was no difference (*P = 0.199*) across the three measurements, 20.25 (SD = 9.3), 18.03 (SD = 8.10) and 19. 47 (SD = 8.70) at baseline, third- and ninth-month's assessment points respectively.

Table 4.3 below also presents the psychotic symptom levels of individuals with recent-onset psychosis as rated by the Positive and Negative Syndrome Scale (PANSS) with three subscales, positive, negative, and general psychopathology. The overall mean psychotic symptom level was found to be low i.e. 37.6 (SD = 8.5) at baseline and almost the same score was found at third month assessment (mean PANSS (SD) = 37.36(8.99)); while a slight increase was observed at the ninth month measurement (mean PANSS (SD) = 39.48 (11.55)). The three subscales scores of each measurement time are also presented in the table. Study participants were assessed to have higher negative symptoms (ranging from 9.13 to 9.60) than positive symptoms (ranging from

8.20 to 8.90). It appeared that only the positive and general psychopathology subscale of the PANSS had significant increases over the study period ($P < 0.05$).

Participants' social support and their satisfaction with the support was assessed with the Social Support Questionnaire (SSQ6). The scale has two subscales (domains), number of supporters and satisfaction with the support. Nearly equivalent mean scores (ranging from 41.04 at ninth month to 42.85 third month) of the overall scale (SSQ6) were found. For the satisfaction with the social support subscale high mean scores (30.98 (SD= 7.49), 31.92(3.60) and 31.09 (3.62) were found at baseline, third- and ninth-month assessments respectively from a possible highest score of 36. However, the number of reported social supporters was found to be low (mean number of supporters range from 9.95 (SD = 5.9) to 11.71 (7.26) at ninth month).

The quality of life of the participants was assessed by the World Health Organization Quality of Life (WHOQOL-BREF). The self-reported quality of life of the study participants was found to be high and sustained throughout nine months with the overall mean score of 3.24 (SD = 0.52) at baseline assessment and 3.16 (SD = 0.4) at third and ninth-month's measurement when scored from five. Among the four domains of the scale, the highest quality of life (QoL) mean score was recorded for the physical domain (3.51, SD = 0.5) at third month follow-up, while the least score was found for the social domain (2.76, SD = 0.54) at third month follow-up assessment. The overall scale and its environmental and social subscales of quality of life showed significant decreases over the study period $(P \leq 0.001)$. The ANOVA test results of the repeated measurements are presented in Table 4-3 below.

Table 4-3: Subjective, functional, psychosocial and clinical recovery characteristics and their progresses over nine months

Variable (Possible score range)		Baseline Mean (SD)	Second round Mean (SD)	Third round Mean (SD)	Repeated ANOVA test within subject (df, error) = F, *P* *
QPR (0 - 60)		44.17 (5.76) (N = 163)	44.65 (5.47 (N = 201)	44.62 (7.17) (N = 190)	(1.73,295.77)=0.06, *0.925*
ISMI (1 - 4)		2.12(0.45) (N = 262)	1.99(0.39) (N = 201)	1.95(0.57) (N = 189)	(1.92,325.09)=3.69, *0.05*
BHS (0 –20)		3.25(3.88) (N = 260)	3.59(4.15) (N = 201)	4.56(4.70) (N = 190)	(1.91,324.90)=10.84, *0.001*
WHODAS (12 – 60)		20.25(9.33) (N = 261)	18.03(8.10) (N = 201)	19.47(8.70) (N = 190)	(1.87,314.88)=1.63, *0.199*
WHOQOL-BREF	Overall scale (1-5)	3.24(0.52) (N = 261)	3.16(0.41) (N = 200)	3.16(0.40) (N = 190)	(1.77,297.03)=7.31, *0.001*
	Physical (1-5)	3.47 (0.64) (N = 261)	3.51(0.499) (N = 200)	3.47(0.46) (N = 190)	(1.95,326.69)=1.17, *0.311*
	Psychological (1-5)	3.35(0.57) (N = 261)	3.38(0.43) (N = 200)	3.32(0.46) (N = 190)	(1.61,267.86)=0.281, *0.705*
	Environmental (1-5)	3.02(0.59) (N = 261)	2.90(0.48) (N = 200)	2.89(0.54) (N = 190)	(1.78,298.91)=14.17, *0.001*
	Social (1-5)	3.05(0.71) (N = 261)	2.76(0.54) (N = 200)	2.82(0.53) (N = 190)	(1.88,316.29)=20.22, *<0.001*
PANSS	Overall scale (30 – 210)	37.61(8.50) (N = 261)	37.36(8.99) (N = 198)	39.48(11.55) (N = 190)	(1.89,314.05)=2.27, *0.162*
	Positive (7 – 49)	8.90(2.71) (N = 261)	8.20(1.93) (N = 198)	8.44(2.34) (N = 190)	(1.84,305.53)=8.99, *0.001*
	Negative (7 – 49)	9.42(3.30) (N = 261)	9.13(2.72) (N = 198)	9.60(3.63) (N = 190)	(1.79,298.45)=2.89, *0.062*
	General psychopathology (16 – 112)	19.28(4.08) (N = 261)	19.34(4.06) (N = 198)	20.01(4.95) (N = 190)	(1.97,327.04)=3.71, *0.011*
SSQ-6	Overall Scale (6 – 90)	42.56(11.55) (N = 261)	42.85(8.9) (N = 200)	41.04(8.05) (N = 188)	(1.71,287.04)=0.74, *0.199*
	Number (0 – 54)	11.71(7.26) (N = 261)	10.94(7.04) (N = 200)	9.95(5.90) (N = 188)	(1.86,312.31)=1.19, *0.303*
	Satisfaction (6-36)	30.98(7.49) (N = 261)	31.92(3.60) (N = 200)	31.09(3.62) (N = 188)	(1.36,222.47)=1.77, *0.183*

QPR: Questionnaire about the Process of Recovery, PANSS: Positive and Negative Syndrome Scale, BHS: Beck's Hopelessness Scale, SSQ6: Social Support Questionnaire with six items, ISMI: Internalized Stigma of Mental Illness, WHODAS: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life.

* Greenhouse-Geiser results were used since the assumption of sphericity was violated

4.2.4. Predictors of subjective recovery from psychosis

The variables that predicted subjective recovery were identified with four hierarchical multiple regression tests. A separate regression test was computed for each measurement time points. Finally, to identify the predictor variable/s of the subjective recovery score during the ninth month, another multiple regression test was computed. This was done by inserting variables that predicted subjective recovery in any of the previous regression tests into the three regression hierarchies according to their assessment time points, i.e., baseline measurements inserted into the first model, second round measurements inserted into the second regression model and finally third round measurements were inserted into the last regression model. Details of the analysis procedures were presented in the methods chapter.

4.2.4.1. Predictors of subjective recovery at baseline measurement

Results of hierarchical regression test for the baseline measurements, presented in Table 4.4, indicated that the test was significant at F (17, 207) = 12.13, $P < 0.001$) in the final regression model with adjusted $R^2 = 0.458$. Hence, 45.8% of participants' level of subjective recovery was predicted by the variables in the model. However, the tests were not significant for the first model ($P = 0.31$) for the three independent variables (gender, cigarette, alcohol and khat) and the second model tests ($P = 0.46$) while three more physical health variables (waist-to-hip ratio, blood pressure and BMI) were added to the regression model. Indeed, these variables also explained a very low variance (less than 1.0%) of the dependent variable (subjective recovery) presented in Table 4.4 (A).

In the final regression model for the baseline measurements (model 3), three variables (quality of life, hopelessness and waist-to-hip ratio) significantly predicted subjective

recovery. These three significant predictors: quality of life (unstandardized *B* coefficient = 4.15 (95% CI = 2.51, 5.64), *P* < 0001), hopelessness (unstandardized *B* coefficient = -0.34 (95% CI = -0.51, -0.14), *P* = 0.001) and waist-to-hip ratio (unstandardized *B* coefficient= –1.53 (95% CI = -2.75, -0.31), *P* = 0.014) alone explained 41.1% of the dependent variable (QPR). Subjective recovery is most predicted by participants' quality of life (standardized β coefficient = 0.40) while hopelessness and central obesity (standardized β coefficient = -0.25 and -0.16, respectively) negatively predicted subjective recovery.

A manuscript was produced from this baseline data and published in a scientific journal in the field of psychiatry (Temesgen, Chien, & Bressington, 2019b).

Table 4-4: Baseline data multiple linear regression test (A: Model Summary, B: ANOVA, C: Coefficients)

A. Model Summary[a]

Model	R	*R* Square	Adjusted *R* Square	Std. Error of the Estimate
1	0.146[b]	0.021	0.004	4.843
2	0.174[c]	0.030	-0.001	4.855
3	0.706[d]	0.499	0.458	3.573

B. ANOVA[a]

Model		Sum of Squares	df	Mean Square	*F*	Sig.
1	Regression	112.920	4	28.230	1.203	0.310[b]
	Residual	5161.720	220	23.462		
	Total	5274.640	224			
2	Regression	158.804	7	22.686	0.962	0.460[c]
	Residual	5115.836	217	23.575		
	Total	5274.640	224			
3	Regression	2631.496	17	154.794	12.123	0.000[d]
	Residual	2643.144	207	12.769		
	Total	5274.640	224			

a. Dependent variable: QPR (subjective recovery);

b. Predictors: (Constant), Gender, Khat, Alcohol, Cigarette;

c. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, BP, Waist to Hip ratio;

d. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, BP, Waist to Hip ratio, DUP, SSQ6-number, SSQ6-satisfaction, PANSS-N, WHODAS, ISMI, PANSS-Positive, BHS, PANSS-General Psychology, WHOQOL

Table 4.4: Continued (C: Coefficients)

C. Coefficients[a]						
Model		Unstandardized Coefficients		Standardized Coefficients	*t*	Sig.
		B	Std. Error	Beta		
1	(Constant)	44.854	0.455		98.50	0.000
	Gender	-0.805	0.650	-0.083	-1.239	0.217
	Cigarette	-2.065	1.879	-0.099	-1.099	0.273
	Alcohol	-1.007	1.253	-0.062	-0.804	0.423
	Khat	1.223	1.409	0.072	0.868	0.386
2	(Constant)	44.635	0.874		51.08	0.000
	Gender	-0.824	0.790	-0.085	-1.044	0.298
	Cigarette	-1.987	1.894	-0.096	-1.049	0.295
	Alcohol	-1.017	1.256	-0.062	-0.809	0.419
	Khat	1.349	1.417	0.079	0.952	0.342
	Waist-to-hip ratio	-0.116	0.810	-0.012	-0.143	0.886
	Blood pressure	1.021	0.817	0.085	1.249	0.213
	BMI	0.353	0.837	0.029	0.422	0.674
3	(Constant)	33.885	3.869		8.758	0.000
	Gender	-0.410	0.619	-0.042	-0.662	0.509
	Cigarette	-2.424	1.434	-0.117	-1.690	0.093
	Alcohol	-0.844	0.942	-0.052	-0.896	0.371
	Khat	0.817	1.090	0.048	0.750	0.454
	WTHR	-1.530	0.620	-0.156	-2.467	0.014*
	BP	0.559	0.615	0.047	0.909	0.365
	BMI	-0.403	0.653	-0.033	-0.618	0.537
	BHS	-0.326	0.094	-0.246	-3.483	0.001*
	WHOQOL	4.093	0.784	0.396	5.220	<0.001*
	WHODAS	-0.051	0.036	-0.096	-1.435	0.153
	SSQ6-Satisfaction	0.049	0.037	0.076	1.321	0.188
	SSQ6-Number	-0.024	0.038	-0.034	-0.620	0.536
	PANSS-P	0.023	0.114	0.013	0.201	0.841
	PANSS-N	-0.136	0.097	-0.093	-1.394	0.165
	PANSS-G	0.087	0.089	0.074	0.979	0.329
	DUP	-0.033	0.021	-0.081	-1.558	0.121
	ISMI	-0.560	0.723	-0.049	-0.774	0.440

a. Dependent variable: QPR (subjective recovery)

** significant predictor*

QPR: Questionnaire about the Process of Recovery, PANSS: Positive and Negative Syndrome Scale, BHS: Beck's Hopelessness Scale, SSQ6: Social Support Questionnaire with six items, ISMI: Internalized Stigma for Mental Illness, WHODAS: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life, DUP: Duration of Untreated Psychosis, BMI: Body Mass Index.

4.2.4.2. Predictors of subjective recovery at third month follow-up measurement

The multiple linear regression test results for the data from the third month (second round) measurements are presented in Table 4.5 below. Similar to the baseline data, the test was significant in the final (third) regression model at F (17, 161) = 5.24, $P <$ 0.001); but not for the variables in the first (P = 0.12) and second (P = 0.339) regression models. The percentage of variances explained by the variables in the first models (gender, alcohol, cigarette and khat) was only 2.0% (adjusted R squared = 0.02) and the addition of the physical health variables (waist-to-hip ratio, blood pressure and BMI) in the second model did not add any more variance (adjusted R squared = 0.02). However, while psychosocial, functioning and clinical variables were added to the model the level of variance explained was increased to 29.0%. This again indicated that subjective recovery was mostly explained by psychosocial, functioning and clinical characteristics.

Table 4.5 (C) presents the results of the regression test computed to identify individual variables independently predicted subjective recovery at the third month follow-up measurement time-points. In this round of assessment quality of life again became the first significant predictor of subjective recovery (unstandardized B coefficient = 2.43 P = 0.002). The other two significant predictors were internalized stigma (ISMI) (unstandardized B coefficient = -1.83 (P = 0.006) and satisfaction domain of the social support (SSQ6-satisfaction) (unstandardized B coefficient = 0.12 (P = 0.04). The level of subjective recovery was most predicted by the participants' quality of life (standardized β coefficient = 0.27) followed by ISMI and SSQ6-satisfaction domain (standardized β coefficient = -0.21 and -0.14, respectively).

Table 4-5: Second round data multiple linear regression test (A: Model Summary, B: ANOVA, C: Coefficients)

A. Model Summary[d]				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	0.20b	0.04	0.02	2.98
2	0.21c	0.06	0.02	2.94
3	0.59d	0.36	0.29	2.54

B. ANOVA[a]						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	66.07	4	16.51	1.85	0.121[b]
	Residual	1551.59	174	8.92		
	Total	1617.67	178			
2	Regression	72.25	7	10.32	1.14	0.339[c]
	Residual	1545.41	171	9.04		
	Total	1617.66	178			
3	Regression	576.44	17	33.91	5.24	<0.001[d]
	Residual	1041.22	161	6.46		
	Total	1617.67	178			

a. Dependent variable: QPR (subjective recovery)

b. Predictors: (Constant), Gender, Khat, Alcohol, Cigarette;

c. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, BP, Waist to Hip ratio;

d. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, BP, WTHR, DUP, SSQ6-number, SSQ6-satisfaction, PANSS-P, PANSS-N, BHS, PANSS-G, WHOQOL, WHODAS, ISMI

Table 4.5: Continued (C: Coefficients)

C. Coefficients[a]						
	Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	45.77	0.31		148.42	0.000
	Gender	-0.82	0.47	-0.13	-1.76	0.080
	Cigarette	0.75	2.01	0.04	0.37	0.712
	Alcohol	-2.92	1.51	-0.16	-1.942	0.054
	Kahat	-0.061	1.17	-0.01	-1.053	0.958
2	(Constant)	45.85	0.48		95.13	0.000
	Gender	-0.66	0.51	-0.11	-1.28	0.201
	Cigarette	0.67	2.04	0.03	0.33	0.744
	Alcohol	-2.81	1.52	-0.15	-1.85	0.067
	Kahat	-0.06	1.21	-0.01	-0.05	0.963
	BP	-0.02	0.51	0.00	-0.04	0.967
	WTHR	-0.41	0.52	-0.07	-0.80	0.427
	BMI	0.25	0.61	0.03	0.42	0.677
3	(Constant)	37.02	3.45		10.73	0.000
	Gender	-0.70	0.46	-0.12	-1.52	0.129
	Cigarette	1.39	1.85	0.07	0.75	0.453
	Alcohol	-1.15	1.38	-0.06	-0.84	0.405
	Kahat	-1.25	1.09	-0.10	-1.15	0.253
	Blood pressure	-0.42	0.49	-0.06	-0.85	0.395
	Waist-to-hip ratio	0.13	0.47	0.02	0.28	0.779
	BMI	0.31	0.53	0.04	0.59	0.556
	DUP	0.01	0.02	0.01	0.15	0.885
	WHOQOL-BREF	2.43	0.77	0.27	3.18	0.002*
	BHS	-0.13	0.07	-0.16	-1.90	0.059
	ISMI	-1.83	0.66	-0.21	-2.79	0.006*
	SSQ6-Number	0.01	0.03	0.02	0.29	0.77
	SSQ6-Satisfaction	0.12	0.06	0.15	2.07	0.04*
	WHODAS	-0.07	0.04	-0.14	-1.77	0.079
	PANSS-P	-0.02	0.13	-0.01	-0.15	0.883
	PANSS-N	-0.15	0.12	-0.14	-1.22	0.225
	PANSS-G	0.17	0.09	0.13	1.92	0.053

a. Dependent variable: QPR (subjective recovery)
** significant predictor*

QPR: Questionnaire about the Process of Recovery, PANSS: Positive and Negative Syndrome Scale, BHS: Beck's Hopelessness Scale, SSQ6: Social Support Questionnaire with six items, ISMI: Internalized Stigma for Mental Illness, WHODAS 2.0: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life, DUP: Duration of Untreated Psychosis, BMI: Body Mass Index.

4.2.4.3. Predictors of subjective recovery at ninth month follow-up measurement

Multiple regression test results of the final round measurement data are presented in Table 4.6. From the Table 4.6 (A) and (B), it is observable that variables in the first model (gender, cigarette, alcohol and khat) explained only 5.0% of subjective recovery (adjusted R squared = 0.05) but was significant (P = 0.001). The variance explained increased to 12.0% while physical health variables (waist-to-hip ratio, blood pressure and BMI) were introduced into the model which again was significant at P < 0.001. The level of variance explained further increased to 45.0% while psychosocial, functional and clinical variables were included in the last regression model. Table 4.6 (B), indicated that the final model test was also significant at F (17, 160) = 9.54, P < 0.001).

The quality of life (unstandardized B coefficient = 5.60 P > 0.001), level of disability (WHODAS) (unstandardized B coefficient = -0.17 P = 0.03) and ISMI (unstandardized B coefficient = -1.99 (P = 0.036) were found to be the significant predictors of subjective recovery (QPR) at third month follow-up measurement. Similar to the previous two follow-up measurements (baseline and second round) subjective recovery was most predicted by participants' quality of life (standardized β coefficient = 0.42). The other variable that negatively and significantly predicted subjective recovery following quality of life was the level of disability (WHODAS) (standardized β coefficient = -0.23). Internalized stigma due to mental illness (ISMI) was a negative predictor of subjective recovery at second round follow-up assessment which kept its negative prediction to subjective recovery at third round measurement

(six months after second round measurement) (standardized β coefficient = -0.20, respectively).

Table 4-6: Third round data multiple linear regression test (A: Model Summary, B: ANOVA, C: Coefficients)

A. Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	0.270[b]	0.07	0.05	5.23
2	0.393[c]	0.15	0.12	5.04
3	0.709[d]	0.50	0.45	3.98

B. ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	372.36	4.00	93.09	3.40	0.010[b]
	Residual	4730.70	173.00	27.35		
	Total	5103.06	177.00			
2	Regression	787.33	7.00	112.48	4.43	<0.001[c]
	Residual	4315.72	170.00	25.39		
	Total	5103.06	177.00			
3	Regression	2568.09	17.00	151.06	9.54	0.000[d]
	Residual	2534.97	160.00	15.84		
	Total	5103.06	177.00			

a. Dependent variable: QPR (subjective recovery)
b. Predictors: (Constant), Gender, Khat, Alcohol, Cigarette;
c. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, Blood pressure, Waist-to-hip ratio;
d. Predictors: (Constant), Khat, Gender, Alcohol, Cigarette, BMI, BP, WTR, DUP, SSQ6 Number, SSQ6 Satisfaction, PANSS-P, PANSS-N, BHS, PANSS-G, WHOQOL, WHODAS, ISMI

Table 4.6: Continued (C: Coefficients)

Coefficients[a]						
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	46.09	0.56		82.82	0.000
	Gender	0.16	0.82	0.01	0.19	0.849
	Cigarette	-3.48	2.56	-0.13	-1.36	0.175
	Alcohol	-1.07	2.07	-0.04	-0.52	0.606
	Khat	-3.00	1.85	-0.15	-1.62	0.107
2	(Constant)	42.80	1.10		38.81	0.000
	Gender	0.89	0.88	0.08	1.01	0.315
	Cigarette	-2.87	2.49	-0.10	-1.15	0.251
	Alcohol	-1.18	2.03	-0.05	-0.58	0.561
	Khat	-3.64	1.81	-0.18	-2.01	0.046
	Waist-to-hip ratio	1.91	0.95	0.16	2.01	0.046
	Blood pressure	2.85	0.84	0.24	3.38	0.001
	BMI	-0.23	1.03	-0.02	-0.23	0.822
3	(Constant)	30.98	6.34		4.89	0.000
	Gender	-0.06	0.72	-0.01	-0.08	0.934
	Cigarette	-3.11	2.03	-0.11	-1.53	0.129
	Alcohol	1.51	1.64	0.06	0.92	0.359
	Khat	-1.68	1.52	-0.08	-1.10	0.273
	WTHR	0.39	0.79	0.03	0.49	0.624
	BP	0.01	0.85	0.00	0.01	0.993
	BMI	0.01	0.85	0.00	0.01	0.993
	DUP	0.03	0.03	0.07	1.12	0.266
	WHOQOL	5.60	1.37	0.42	4.09	<0.001*
	BHS	0.11	0.12	0.09	0.94	0.351
	SSQ6-Number	-0.01	0.06	-0.01	-0.09	0.927
	SSQ6-Satisfaction	0.11	0.10	0.07	1.15	0.254
	WHODAS	-0.17	0.08	-0.23	-2.19	0.03*
	PANSS_P	0.01	0.18	0.00	0.03	0.973
	PANSS-N	0.10	0.19	0.07	0.51	0.609
	PANSS-G	-0.03	0.13	-0.03	-0.26	0.797
	ISMI	-1.99	0.94	-0.20	-2.11	0.036*
	DUP	0.03	0.03	0.07	1.12	0.266

** significant predictor*

QPR: Questionnaire about the Process of Recovery, PANSS: Positive and Negative Syndrome Scale, BHS: Beck's Hopelessness Scale, SSQ6: Social Support Questionnaire with six items, ISMI: Internalized Stigma for Mental Illness, WHODAS 2.0: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life, DUP: Duration of Untreated Psychosis, BMI: Body Mass Index.

4.2.4.4. Predictors of subjective recovery at three time-points measurements at the nine months follow-up

In the final regression tests, variables predicted subjective recovery at either of the three time-points measurements were selected and inserted into the regression models. Variables were inserted in three hierarchical models sequenced according to the time of measurement. Accordingly, presented in Table 4.7 (A), the amount of variance that explained subjective recovery at the ninth month (QPR third) were constantly increased from baseline (2.7%) to the second round (10.0%) to the final (62 .4%) regression models. Table 4.7 (B) presents the significance level of the tests at each model. The test was significant for the third (final) regression model at F (20, 242) = 20.67, $P < 0.001$) with adjusted $R^2 = 0.624$. The test was also significant for the second ($P < 0.001$) but not at the first ($P = 0.051$) model tests.

Table 4.7 (C) presents the regression test results computed to identify independent predictors of subjective recovery at ninth month follow-up measurement. The first model, that data from the baseline measurement only were inserted, indicated that only baseline internalized stigma score (ISMI baseline) were found to be a predictor of subjective recovery at ninth month ($P = 0.014$). In the second regression model while data from the second round (third month measurements) were added to the model showed that only hopelessness at third month (BHS second) significantly predicted QPR third ($P = 0.041$). However, none of these variables (ISMI baseline and BHS second) could maintain their significant relation to the ninth month QPR while the ninth month follow-up measurement data were added into the model.

In the final regression model, it was found that four variables (one from the third month and three from the ninth month measurements) significantly predicted

subjective recovery ninth month. As to the previous regression tests of each time point measurement (first, second third round regression tests Table 4.4, Table 4.5 and Table 4.6), quality of life score at ninth month was found to be the most significant predictor of subjective recovery; third round WHOQOL unstandardized *B* coefficient = 5.24 *P* < 0.001 with standardized β coefficient = 0.36. Internalized stigma for mental illness at ninth month measurement (ISMI third) was also found to be a significant negative predictor to subjective recovery at this regression test again (unstandardized *B* coefficient = -1.92 (*P* = 0.022) with standardized β = -0.15.

The level of disability due to ill health condition as measured by the WHODAS at the third month and ninth month was negatively predicted with the subjective recovery at ninth month. Level of disability at the third month of follow-up (WHODAS second) has negatively predicted subjective recovery after six months (the ninth month follow-up) with unstandardized *B* coefficient = -0.11 (*P* = 0.025) with standardized β = -0.13. The level of prediction of disability has strengthened (which became the second most negative predictor) at the ninth month measurement (WHODAS third); unstandardized *B* coefficient = -0.31 (*P* < 0.001) with standardized β = -0.35.

Although the other variables contributed in explaining majority (62.4%) of the variance of subjective recovery at ninth month, none could predict subjective recovery at the ninth month. Even the score of subjective recovery at baseline (QPR baseline) and third month (second round) (QPR second) could not show a significant prediction for the subjective recovery at the ninth month (QPR third).

Table 4-7: All round data multiple linear regression test (A: Model Summary, B: ANOVA, C: Coefficients)

A. Model Summary[a]				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	0.230[b]	0.053	0.027	6.01
2	0.385[c]	0.148	0.1	5.78
3	.0808[d]	0.653	0.624	3.73

B. ANOVA[a]						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	514.75	7	73.54	2.04	.051[b]
	Residual	9205.97	255	36.10		
	Total	9720.72	262			
2	Regression	1437.83	14	102.70	3.08	<0.001[c]
	Residual	8282.89	248	33.40		
	Total	9720.72	262			
3	Regression	6344.24	20	317.21	22.74	<0.001[d]
	Residual	3376.47	242	13.95		
	Total	9720.72	262			

a. Dependent variable: QPR third round (subjective recovery)

b. QPR baseline, WHOQOL baseline, BHS baseline, WTHR baseline, ISMI Baseline, SSQ6-satisfaction baseline, WHODAS baseline

c. QPR baseline, WHOQOL baseline, BHS baseline, WTHR baseline, ISMI baseline, SSQ6-satisfaction baseline, WHODAS baseline, QPR second, WHOQOL second, ISMI second, WHODAS second, SSQ6-satisfaction second, BHS second and WTHR second

d. QPR baseline, WHOQOL baseline, BHS baseline, WTHR baseline, ISMI baseline, SSQ6-satisfaction baseline, WHODAS baseline, QPR second, WHOQOL second, ISMI second, WHODAS second, SSQ6-satisfaction second, BHS second, WHTR second, ISMI third, WTHR third, BHS third, WHODAS third, WHOQOL third and SSQ6-satisfaction third

Table 4.7: Continued (C: Coefficients)

C. Coefficients[a]						
	Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	49.94	5.91		8.45	0.00
	QPR baseline	0.078	0.09	0.074	0.872	0.384
	WHOQOL baseline	-0.688	1.141	-0.059	-0.603	0.547
	BHS baseline	-0.005	0.131	-0.003	-0.041	0.967
	Waist-to-hip ratio baseline	0.399	0.784	0.032	0.509	0.611
	ISMI baseline	-2.542	1.027	-0.185	-2.475	0.014*
	SSQ6-satisfaction baseline	-0.027	0.064	-0.029	-0.43	0.667
	WHODAS baseline	-0.043	0.051	-0.066	-0.833	0.406
2	(Constant)	56.77	8.09		7.02	0.000
	QPR baseline	0.06	0.09	0.06	0.72	0.473
	WHOQOL baseline	-0.75	1.17	-0.06	-0.64	0.522
	BHS baseline	0.13	0.13	0.08	0.98	0.331
	Waist-to-hip ratio baseline	0.42	0.85	0.03	0.50	0.621
	ISMI baseline	-1.96	1.02	-0.14	-1.92	0.056
	SSQ6-satisfaction baseline	-0.03	0.06	-0.04	-0.54	0.593
	WHODAS baseline	-0.04	0.05	-0.06	-0.77	0.440
	QPR second	0.02	0.10	0.02	0.21	0.837
	WHOQOL second	0.65	1.52	0.04	0.43	0.668
	ISMI second	-1.93	1.39	-0.11	-1.39	0.166
	WHODAS second	-0.10	0.07	-0.12	-1.44	0.151
	SSQ6-satisfaction second	-0.13	0.12	-0.07	-1.06	0.292
	BHS second	-0.26	0.13	-0.15	-2.05	0.041*
	Waist-to-hip ratio second	0.01	0.49	0.00	0.02	0.986
3	(Constant)	32.72	6.53		5.01	0.000
	QPR baseline	0.01	0.06	0.01	0.16	0.876
	WHOQOL baseline	-0.42	0.77	-0.04	-0.54	0.587
	BHS baseline	0.00	0.09	0.00	-0.02	0.984
	Waist-to-hip ratio baseline	-0.17	0.56	-0.01	-0.30	0.765
	ISMI baseline	0.41	0.68	0.03	0.60	0.549
	SSQ6-satisfaction baseline	-0.04	0.04	-0.04	-0.95	0.342
	WHODAS baseline	-0.05	0.03	-0.08	-1.51	0.132
	QPR second	0.05	0.07	0.04	0.82	0.410
	WHOQOL second	0.87	1.01	0.05	0.86	0.389
	ISMI second	-0.99	0.91	-0.06	-1.09	0.275
	WHODAS second	-0.11	0.05	-0.13	2.25	0.025*
	SSQ6-satisfaction second	0.02	0.08	0.01	0.28	0.782
	BHS second	0.05	0.09	0.03	0.56	0.578
	Waist-to-hip ratio second	0.28	0.37	0.04	0.75	0.453
	ISMI third	-1.92	0.83	-0.15	-2.31	0.022*
	Waist-to-hip ratio third	-0.29	0.79	-0.02	-0.37	0.712
	BHS third	-0.04	0.09	-0.03	-0.43	0.669
	WHODAS third	-0.31	0.06	-0.35	-4.80	<0.001*
	WHOQOL third	5.24	1.05	0.36	4.99	<0.001*
	SSQ6-Satisfaction third	0.06	0.08	0.03	0.73	0.468

** significant predictor*

QPR: Questionnaire about the Process of Recovery, BHS: Beck's Hopelessness Scale, SSQ6: Social Support Questionnaire, ISMI: Internalized Stigma for Mental Illness, WHODAS 2.0: World Health Organizations Disability Assessment Schedule, WHOQOL: World Health Organization Quality of Life, WTR: Waist-to-Hip Ratio

In summary, nearly three-quarters (72.24%) of service users with recent-onset psychosis who involved at baseline measurement completed all the three time-point measurements. The mean subjective recovery score (QPR) was relatively consistent ranging from 44.17 to 44.65 over the study period. Participants' quality of life was found to be the most significant predictor through all three time-points measurements. Internalized stigma negatively was negatively associated with the subjective recovery both at third and ninth-month measurements. Hopelessness and waist-to-hip ratio (central obesity) was negatively associated with the level of subjective recovery at baseline measurement. Participants' satisfaction with their social support was the other predictor of subjective recovery at the third month follow-up measurement. At the ninth month measurement level of disability due to illness was another factor negatively predicted with subjective recovery.

4.3. Qualitative Results

A total of nineteen individuals with recent-onset psychosis were interviewed to share their conceptualizations of recovery from recent-onset psychosis and perceived challenges and opportunities relating to the recovery. The majority of the participants were male (63.16%) and diagnosed with schizophrenia (52.6%) which is similar to the larger cohort that these qualitative participants were sampled from. Mean age (29.9) (SD =9.6)) and QPR (45.2) (SD = 5.31) are also similar with the population that they were sampled from (mean age = 29.6 (SD = 9.11) years, and mean QPR = 44.2 (SD = 5.76) at baseline measurement). The sociodemographic, recovery and clinical characteristics of the qualitative participants are presented in Table 4.8 below.

Table 4-8: Descriptions of qualitative study participants

	Category	Number (N = 19) 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)
	Mean (SD)	Range
Age in years	29.9(9.6)	18-55
DUP in months	9.3 (14.54)	1-48
Duration with illness in months	15.37 (14.03)	3-48
QPR	45.21 (5.31)	37-60
PANSS total	38.47 (11.28)	30-70

4.3.1. Conceptualization of recovery by service users with recent onset-psychosis

Transcripts from nineteen interviews were analysed with inductive thematic analysis method. This qualitative part of the study was conducted for the objectives: to identify the conceptualizations of subjective recovery and perceived challenges and opportunities related to subjective recovery. Therefore, inductive thematic analysis was conducted separately for these objectives. Participants' conceptualizations of subjective recovery were summarized into four main themes, "*domination over the disturbance of psychosis", "complete antipsychotic treatment course and stay normal", "staying active in life with optimal functioning",* and *"reconcile and rebuild*" while each theme has their own subthemes.

4.3.1.1. Domination over the disturbance of psychosis

Ethiopian service users with recent-onset psychosis described that they perceived themselves as recovered if they dominated the disturbances of the symptoms they

had/were having. Some participants perceived that recovery was not only being free from the illness rather it was gaining ability to live a life which was not devastated by the illness. Three subthemes, *"free from symptoms", "control over symptoms"* and "re*gain awareness into self, situation, and illness"* were also identified under this main theme and are presented in Table 4.9 below.

Free from symptoms: Most service users vividly mentioned that being free from symptoms would be a clear indicator of their recovery. Though participants could have multiple psychotic symptoms, most of them mentioned only one or two that they were most concerned about (i.e. being disturbed with) which they need to get relief in order to define their recovery. Indeed, not all participants expected a complete disappearance of all the symptoms they had, rather they wanted a relief (maybe temporary) from the symptoms and symptomatically respond to the treatment they were having. A female participant placed more 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 day time, like any other people.*"[G5]

She actually had other complaints, but she defined her recovery in terms of her sleep quality. Another male participant emphasised how his interaction with others was affected by his illness and he considered overcoming this illness symptom 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 his expression 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.

Control over symptoms: Service users also mentioned that it was not only being free from symptoms which could be considered as recovery, rather they considered as recovered if they had the capability to have control over the illness/symptoms and were able to live a life in a self-directed way. They stated that recovery is when they regain their ability to suppress their aggressions and confusions which made them do something they perceived as being "wrong". A 38 years 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 quitted my work … I wish the treatment could help me to overcome this feeling …" F2*.

This subtheme is not about whether the symptom level is reduced or not, rather it is about service users' own strength to suppress the symptoms that affected their behaviour and life. Another participant mentioned the difficulties he had to stay focused and hence he defined his recovery as "*... recovery is when I am able to focus/concentrate …*"F4 Indeed, this subtheme could be supplemented by other subthemes, participants also clearly acknowledged that gaining insight/awareness into symptoms, behaviour and self was a central component of recovery.

Regain awareness into self, situation, and illness: Interviewees stated that they considered themselves as recovered when they became aware of the problematic behaviours (illness) they had and therefore they could strive to suppress these behaviours. Service users acknowledged that their misperceptions, such as delusions and hallucinations, were the main challenges they had during their illness period. A 26 years old male stated he would know he was recovered when "… *I am aware of*

myself; I am recognizing the behaviours I have; I am aware of the words I am speaking" [F1]. Regaining awareness/orientations either with the help of medicine or not was perceived as recovery. Another 24 years old female stated that

> *"…I will say I recovered if the pills helped me and 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 my words and actions*."[D4]

Regaining awareness is not limited to the behaviour, for some regaining orientation to the place they reside or went was another important component of recovery under this subtheme.

Generally, under this theme "*dominate over the disturbance of psychosis*", participants' conceptualization of the subjective recovery was categorized into three subthemes being *"free from symptoms*", "*dominate over symptoms*" and "*regaining awareness to self, situation and illness*". These subthemes could, perhaps, be understood as participants' priority in conceptualizing recovery; i.e., for most their prior need/expectation to say they were recovered was to be fully "*free from the symptoms"* they had. However, for some to staying in control of themselves by suppressing/dominating the illness symptoms would be enough to define their recovery. Even some others needed to stay aware (gain awareness) of themselves, their environment and illness so that they could say they were recovered. Certainly, interviewees defined their recovery not only from the experiences of illness perspective but also from the medical treatments they were having.

4.3.1.2. Complete antipsychotic treatment course and stay normal

Interviewees acknowledged the benefits of medicine for embarking onto the journey of recovery as discussed later in the next section 4.4. However, some participants stated that they should be able to live free from medicine (antipsychotics) to say they have recovered. To consider themselves as "recovered" they need to stay in control of themselves or to be free from symptoms independently from 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 for their life, like any other person without a psychotic illness in their community.

Free from medicine and symptoms: In this subtheme, it seems that interviewees perceived the problem they had was like any other acute illness, which could be cured by a specific period of treatment. A thirty years old male service user stated recovery is "*... complete everything (treatments) and being normal*" [F4]. This perception to the illness/psychosis and treatment for it could affect perceived recovery, also one of the themes related to factors affecting subjective recovery as discussed later. In this case, it seems that participants understood/conceptualize "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 years old male make it clear that

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

Another female participant also emphasised that her recovery should be defined for staying free from both the pills and symptoms. She also perceived recovery was

equivalent with cure "… *when I stop taking the pills, that is recovery/cure for me*". [G6] Perhaps, the concern might not be only being free from medicine but also being free from the side effects of these antipsychotic medicines which gave another subtheme under the same main theme.

Free from side effects of the antipsychotics: Participants clearly recognized multifaceted impacts (side effects) of the antipsychotics medicines they were taking. Physical complaints like getting easily fatigued when engaging in routine activities, weight gain, sleepiness and even sexual dysfunctions were mentioned as the impacts of the medicine, which affects their social and economic states. 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 to stay on bed I always feel tired, but I could not fall asleep… I know the pills are helping me to stay stable, I have been also told that the pills should not be interrupted … but I would be happy if I could live without these pills*" [G4].

Interviewees perceived that even though their psychotic symptoms were controlled with the medicine they were taking, the side-effects of the medicines were making their life difficult in the other ways. For example, another female participant stated that:

> "*… the pills helped me to get well … but in the morning it/the medicine drowns me I always have difficulties to wake up on time and keep up with others since I started it/medicines*" [D1].

Hence, to consider themselves as "recovered" they also expected to be free from the negative impacts of the medicines they were taking.

Regaining premorbid wellness: This subtheme could be defined from different perspectives. Participants conceptualized recovery not only from symptoms, treatment and impacts of medicine perspectives, but also from a very broad perspective such as returning to premorbid wellness. A 26 years 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".*
> When he was saying "*…I get them back …" F6*

He was referring for 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 also in terms of functioning.

4.3.1.3. Staying active in life with optimal functioning

Interviewees stated that being able to function and lead an active life was one of the pillars needed to be considered for recovery. Under this main theme, four subthemes were identified. Service users disclosed that having a work/job to keep themselves active "*have a job/study appropriate to the health condition*" was an important component/indicator of getting recovered from the mental health problems they had. Other participants would consider themselves as recovered if they "*resume premorbid job*". "*Regaining independence*" in self-care, economic, treatment preference and

decision in general was also vividly stated. Being "*able to perform roles and meet social expectations"* was stated as another important component of the theme and recovery as a whole.

Have a job/study appropriate to the health condition: Most participants recognized that directly due to their illness they risked losing their job or interrupting 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. In this subtheme it became apparent that most service users clearly recognized their health state had been altered and hence having something to stay active, whether could generate income or not, would be acceptable to consider themselves as recovered. A 30 years old man who worked in the merchant navy recognized that his current health state would not permit him to remain working on the ships for a prolonged period. However, remaining inactive was making his mental health worse; and hence he started helping his mother in the kitchen and planned to work with his father. He said:

> "*I used to* work *on the 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 (described earlier) 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 "… *I will consider myself as recovered if I am able to help my family in work …*"[D3] others 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].

Resume premorbid job: Some participants made it clear that their recovery would be defined by resuming their premorbid occupation. A 26 years old male participant stated that resuming the job that he used to do was his wish so that one of his criteria to define 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 …" [F1].*

From his statement, it is also possible to depict that recovery is a progress to the optimum level of functioning.

Regain independence: 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 a criterion to define their recovery. A 22 years old male student stated that:

> "*I used to rely on others in everything, I even was not able to feed myself … but now thanks to God I am independent … after that (attending treatment) I become responsible for my treatment and now I am coming here (the hospital that he was having his follow-up) by myself and taking the pills with no need of the reminder … I am living by myself" [G7].*

The need for independence was not actually limited to comfort for the self but also to ease the caring burden of the families. A 23 years old female was worrying about her parents:

> "*… my concern is … 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].

Here the concept of independence is not limited to self-care but could also extend to economic issues.

Able to perform role and meet social expectations: Participants mentioned that they were expected to perform different roles, such as a parent, husband, employee or student and identified that being able to perform their role should be among the indicators of their recovery. A 42 years old husband mentioned he would define his recovery as "*I wish I could help my wife in generating income for the family*" [F3]. Another interviewee, a student, emphasized that meeting others' expectations in his academic performance could be considered as part of recovery "*... my community expected me to score a good grade" [G7].* Role and social expectation may vary with age and gender a 32 years old divorced female clearly pointed 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, the theme "*staying active in life with optimal functioning*" is designated for a broad concept ranging from a simple concept of "*able to work*" to a more complicated one "*meet social expectations*". The purpose of being functional was not limited to having a paid job rather it was having anything to do that helped them to stay active in life. Being active in life and society would help service users to recognize

their situation/surroundings, which in turn could help them to reconcile with the realities they were having.

4.3.1.4. Reconcile and rebuild

Life is full of ever-changing phenomena. The realities of the participants' lives were clearly altered following the development of psychosis. Participants recognized this change and decided to move on to the next level. Some participants defined their recovery as accepting the new reality (i.e., the change in their health state) and working to build new lives, giving the theme "*reconcile and rebuild*". This theme has been constructed with two subthemes "*reconciliation with the new reality*" and "*rebuild hope and life*".

Reconciliation with the new reality: Certainly, facing psychosis changes core elements of one's life. Recovery from psychosis demands a critical readjustment of these vital components of life; it needs to reconcile with the new reality (health condition and situation) that alters almost everything. Service users clearly identified their recovery should be defined in terms of their acceptance/reconciliation to their new identity, family, society and situations in general. An interviewee stated that

> "*…I am aware of my condition … now I am peaceful, I get my internal peace*" [F1].

A 24 years 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 these two participants, 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.

Rebuild hope and life: Psychosis is a devastating illness that destroys core elements of life such as identity, relationship, role, and occupation that were built before the onset of the illness/psychosis. A 22 years old high school student who stated that he had close interaction and intimacy with the psychotherapist in the hospital explained that:

> "*… when I came here (hospital) for the first time I saw other patients, I was much more critical than anyone else here, I used to hate others and myself … that time was really tough time … I was not willing to be admitted or for any treatment … but through time I started to change my attitude …. I started to believe it is okay to get sick, the point is able to challenge/face it, hope to the future … I am in 12th grade this year I hope I will join university next year … I never imagined I would have such good health … now I believe I am equal with anyone else*" [G7].

Participants recognized that recovery requires developing (gaining) hope and having courage, stamina and strength to rebuild the life. A 26 years old male stated the indicators of his recovery as *"… now I have courage and plan to resume work …*" [F1]. Another female aged 18 hoped to resume the education that she withdrew due to her illness "*… in God's will, I am going to start my education again, have a job and live my life*" [F7]. Indeed, it also became clear that the life to be reconstructed did not require

to be the same as the life before the onset of illness, rather a life which gives meaning and motivation to live for, to hope for better future was given emphasis.

Table 4-9: Conceptualizations of subjective recovery by service users with recent-onset psychosis

Themes	Sub-themes
Dominate over the disturbance of psychosis	Free from symptoms Control over symptoms Regain awareness to self, situation, and illness
Complete antipsychotic treatment course and stay normal	Free from medicine and symptoms Free from side effects of the medicine Regain to premorbid wellness
Staying active in life with optimal functioning	Have a job/study appropriate the health condition Resume premorbid job Regain independence Able to perform role and meet social expectations
Reconcile and rebuild	Reconciliation with the new reality Rebuild hope and life

4.3.2. Journey to health care setting for mental illness treatment

Participants were asked to share their journey to treatment for their mental illness and the findings are presented in the figure below, Figure 3.1. The majority of the participants mentioned that their first attempt to manage their illness was attending either spiritual or traditional healing sites. A 42 years old male participant stated that

> "*I have been visiting traditional healers, they gave me some medicines to smoke and drink, but none of it has worked that is why I came here*."[F3]

A thirty years old male also said that

> "*… they (his parents) took me to different places for prayer and traditional healing, they gave me things to smell, smoke and tie on my neck … trying all these for about a year, I did not get any betterment … and then they brought me here…*"[F5]

Many participants who received traditional healing eventually came to hospital for treatment. This is because there was only temporary improvement in their symptoms, or they experienced no benefit at all. A 24 years old male who lived with his parents stated that

> "*… they (family members) first took me to the holy water site and I stayed there for about a month. But there was no improvement there".* [G2]

Some were even referred to the hospital by the traditional healing practitioners for their particular symptoms. For example, a 27 years old male who seemed to have addictions to substances (khat, cigarette and alcohol) mentioned that

> "*the traditional healer said that I am cursed with … and have mental distress … he gave me a traditional medicine for the curse, but for the mental distress he said I have to be treated in hospital for six months … and taking his advice I came here to the hospital*" [G3].

However, few reported that their first visited treatment sites were health care settings. A female participant stated that "*I came here on the first day I get sick, they (psychiatric care providers in the hospital) gave me pills*". [G9]

Participants reported that after having treatment in the health care settings, they had improvements in their symptoms and then some discontinued the treatment. A 32 years old participant said that

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

The reasons for treatment interruption were different for different participants (discussed under the themes "*collective understanding and social process to psychosis management"* and "*medical treatment and its side effects*").

Participants who interrupted treatment again went back to the spiritual healing sites (holy water). But the symptoms emerged and therefore they came back to the hospital. A participant who reported she visited the hospital on her first day of illness said that

> "*...after few days of treatment ... I refused to take them (the pills) ...they (parents) took me to the holy water ... but after a few months I get sick again ... and came back here*" [G9].

Another participant also stated that

> "*… after taking the pills for a month, I again went back to holy water for about three months discontinuing the pills ...*" [G7]

An important point here is that, these participants are those who engaged with the treatment, and it is worth noting that many others might stay longer or even forever interrupting or even without initiating treatment for their mental illness.

At the time of the interview, the majority of participants were attending both the spiritual and modern/western treatment modalities. A participant who interrupted his treatment after getting improved with treatment for a couple of months said that

> "*… I again come back here ... at this time I am taking the pills and also attending holy water".* [G7]

Majority of the participants were waiting for their "doctors" (psychiatric care providers) to decide in their treatment dose reduction and completions. A female interviewee stated that

> "*I am having too many pills … for how long I should keep taking the pills, it has been three years since I started taking it.*"[G5]

Another male participant also said "*the doctor also told me if … she will reduce the doses of the pills*" [F4]. Another participant also reported that he was waiting to complete the treatment "*I wish to complete my treatment as soon as possible and …" [F1].* This might be an issue of insight into the nature of illness and treatment which potentially affects hope, motivation and recovery. Generally, presenting the participants' journey to the health care sites and their experiences during their illness period could, perhaps, articulate how they understood their illness, treatment and recovery; and it also illustrates the perceived factors that are embedded in their journey and experiences of treatment.

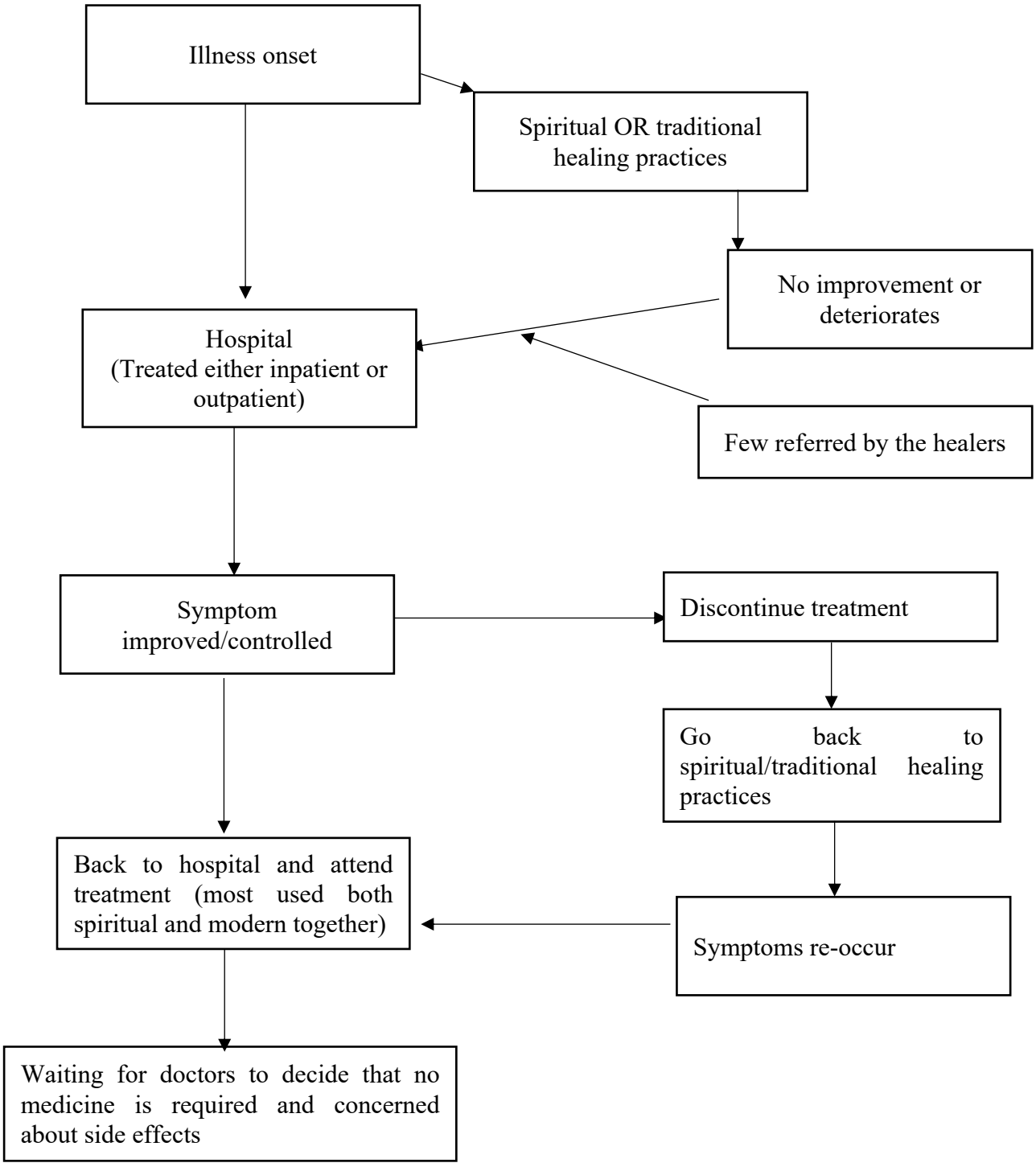


Figure 4-1. The journey to treatment for psychotic disorder

4.3.3. Service users' perceived challenges and opportunities related to their recovery

Participants' perceived factors related to their recovery from recent-onset psychosis were categorized into four main themes. These factors either enhance or hinder the recovery process. As presented below in Table 4.10, "*altered health, psychiatric treatment and side effects of antipsychotics*", "*collective understanding and social process to psychosis management*", "*opportunities and challenges of working*" and "*faith, hope and determination*" are the main themes identified as factors related with recovery from psychosis as perceived by service users with recent-onset psychosis.

4.3.3.1. Altered health, psychiatric treatment and side effects of antipsychotics

Participants stated that their altered health state and side effects of the antipsychotic medications were the main challenges they faced when recovering. Participants stated that they fatigue easily and were unable to perform daily activities. They also complained of gaining weight that they considered might be due to the side effects of the antipsychotics or reduced activity due to the fatigue. Most of the participants complained about the poor quality of sleep. Some participants reported they had problems related to digestive system (eating too much or too less, urge to toilet, pain on stomach and food preference which might not be affordable). These factors relating to recovery were categorized into three subthemes, "*physical wellness*", "*disabling symptoms of psychosis*", "*psychiatric treatment and the side effects of the antipsychotics*".

Physical wellness: Having physically illnesses made the participants' journey of recovery more challenging. Physical health problems ranged from minor infections to

a more complicated non-communicable diseases, such as weight gain and cardio-metabolic disorders. These problems affected their recovery and were often overlooked by the health care providers. A 30 years old man stated that:

> "*… I also have abdominal pain … I am gaining weight … I feel tired every time, I could not focus, and the problem in my abdomen also would not allow me to stay away from toilet for a long time … I could not go out, I could not work, I could not sit with others for a long time … I have been assessed for it but they (health professionals) said there is no problem, so I give up on it*" [F4].

Another participant also reported problems related to his stomach that his families did not even recognized, and the health care providers did not attempt to treat it:

> "*I am having a discomfort on my abdomen, have nausea, vomiting … I should not be forced to eat the food which is not comfortable for me … it is the food causing for problems … I reported to the health care professionals, but they only focus on my mind*" [G1].

Most participants who complained physical health problems stated that their complaints about their physical health problems are usually undermined, most felt high level of weakness/fatigue which they even could not tolerate to stay active in their daily activity.

Disabling symptoms of psychosis: Participants were critical about the specific symptoms making their "recovery" problematic. Many participants stated that some of their symptoms sometimes flare-up and destroy the things they constructed, like social relationships, occupation and trust with others. Some of participants stated that,

the illnesses/symptoms they had prohibited them to achieve important things in their daily activities. Some lost their marriage, others could not get married due to their illness, some lost their jobs, and some found it challenging to continue the study/job they had. Few participants sometimes lost their awareness without any warning signs. A 26 years old male stated that:

> " *... when I go somewhere I have a problem/difficulty to recognize it, I accidentally (unexpectedly/without any warning) get confused and I sometimes get lost ... for the first three or four months I used to be accompanied to come here, but after that I able to come by myself. But today again, I get confused, when I come here everything is new, I went to toilet and in a moment, I lost where I was. I was ashamed to ask others to tell me where I was. How could I ask my address while I was inside the restrooms?"* G1

Another participant stated the problems he was having as:

> *"... at the night it concurs my body, ... I feel it coming to me, I hear it marching to me like a herd of ... that is the time my body is dodged/evaded and gets out of my control".* F3

His symptom is not only affecting him but also his caring wife:

> "*… when I sleep with my wife another scary dark woman sometimes come and horrified me at that time, I scream ... I may sometimes slap my wife sleeping next to me ... and my wife wakes me u*p *… after that I could not sleep*". F3

A 30 years old male also shared one of his typical problems facing in his recovery journey:

> "*…for example, if I need to have a cup and I go to the kitchen, but when I get into the kitchen I accidentally forget why I am there and leave the kitchen without it… and return to the kitchen … and leave … it is really annoying and embarrassing …*" [F4]

From the interviews it became apparent that the symptoms they had affected their recovery, relationship and life in general. These kinds of symptoms, that appear and disappear, destroy their confidence; and sometimes participants queried if it was the effect of the antipsychotic medicine/s they were taking.

Psychiatric treatment and the side effects of the antipsychotics: Participants' narratives highlighted that they had gone through a long journey to receive the psychiatric treatment for their mental illness. However, after starting the treatment, almost all participants recognized substantial improvements in their mental health state. A participant shared how the monthly injections were helping him in getting better:

> "*… after that … I came here and they (health professionals) gave me an injection, and it (the injection) stabilizes all my turmoil …. After that, I am having an injection every month and have no problem. As I get a close follow-up to the treatment, I get much improved"* [F1].

He also recognized that some interruptions in treatment dosage made the problems emerge again.

> *"I once missed my injection and the problem reoccurred. After that, I am very strict on my schedule and get much better*" [F1].

Figure 4.1 above could also demonstrate the challenges/journey that participants had gone through to initiate and adhere to the psychiatric treatment. Although this subtheme is about the importance of medication treatment, the figure above (Figure 4.1) and the next theme "*collective understanding and social process to psychosis management*", would demonstrate how difficult it was to initiate and sustain treatment in health care facilities.

Antipsychotic medications were recognized to stabilize psychotic symptoms. However, their side effects have also a distinct negative impact on recovery. The boldly recognizable benefits and side effects of the antipsychotics make it a "double edged sword" while one edge manages/treats psychotic symptoms, its' other edge causes a tremendous damage. A 32 years old employed women mentioned that:

> "*I am gaining a lot of weight; my blood pressure is also raising. Those people measuring my blood pressure told me it is due to the stress and the pills I am taking. I do not know what is good, whether to keep taking the pills and get these problems or stop taking it and facing the other problem, I really do not know.*" G6

It was not only the individuals with psychosis who were concerned about the side effects, but family members were also advising to discontinue treatment to be free from the side effects. A 55 years old divorced man stated that:

> "*…you know, to get married to another woman here, the medicine has killed my sexual feeling ... to get married and live with a wife, the medicine has effects, it (medicine) does not make you be married. My ex-wife is also telling me to stop taking the pills, but my sister is opposing that".* G4

Complaints about the side effects of the medicines were also related to altered functioning; a college student stated that:

> "*… the medicine is unexpectedly affecting my orientation; I am losing my balance … I might get faint there (working field) even on the dangerous machines. I have to stop either the medicine or the study I am attending*" [G1].

Service users were concerned not only after they experienced the side effects but also comments from others about it (negative effects of antipsychotics) were too bold to ignore. A 27 years old male living with his mother and financially supported by his sisters said that:

> "*… some people, like my aunt, she is a nurse in the USA, and she said I better stop taking the drug (antipsychotics) … she said it has side effects, it will cause me a trouble if I adapts to the drugs.*"[G3]

This kind of comment is common for others too. From these, it seems that the participants and their families have developed a collective understanding about psychosis and its management. This understanding seems to have a strong influence on treatment preference/adherence and eventually affect recovery.

4.3.3.2. Collective understanding and social process to psychosis management

Individuals with psychosis and their family members share the understanding of the illness that constructed by the community they reside in. This understanding affects the way they attempt to manage the illness, which further affects recovery. Certainly, the treatment preference is not something that is decided by the patient alone or by the family, directly or indirectly it is a community's decision, it is the tradition that the

community has built for a long time. Hence, shared understanding and social process to manage psychosis was identified as a main theme related to recovery, while four subthemes were identified within it.

Understanding of the illness and its treatment: Participants discussed different perceptions into psychosis and its treatment. Most participants viewed that psychosis was just like any other acute illnesses, which needs to be treated for a limited period before it was cured. This understanding could certainly affect recovery. The participants in this study had less than five years duration of illness and most of them were treated for a short time before they experienced a substantial improvement in their psychotic symptoms. Those with much improved symptoms and functioning might perceive that they have been cured or recovered from their illness. Maybe that is why the majority of the interviewees mentioned that they were "waiting for their doctors to decide no more medicine is required" during interviews as presented in Figure 4.1. A female student, 18 years old, and who have been on treatment for about 3 years stated that:

> "*…thanks to God I am well now … but I am having too many pills. I am also concerned for how long I should keep taking the pills*" [G5].

Another recently married male also acknowledged a considerable improvement in his symptoms after he started the treatment, and he aspired to complete his treatment and resume his premorbid job.

> "*… things have changed now … I even get married … now a days nothing is disturbing me … I want to complete my treatment as soon as possible … and resume my job free from disturbance and any medicines.*" [F1]

From the interviews, it seemed that most participants had not yet recognized that they might need lifelong treatment for their psychosis.

Social process to illness management: The social process to the management of psychosis arises from a collective understanding of the illness. Individuals' understanding of the illness seems to be learned from the society they reside in and from their experiences of illness and treatment. The society commonly relates mental illness to something supernatural and believe it should be managed with traditional/spiritual mechanisms. Almost all participants reported that they have visited either traditional or spiritual healing sites before visiting health care facilities. This is a clear reflection of communities' perception to the illness (psychosis or mental illness in general). As presented in the Figure 4.1 above, participants were attempting to manage their illness from the two care settings (spiritual/traditional healing sites and modern health care settings) either simultaneously or switching in between. A male participant stated that:

> "*When I got sick my mother used to take me to the traditional healers and holy waters. Even if they (traditional and spiritual healers) knew I was not sick, they said I was sick, and they decided for me*" [G4].

That is how the individuals with psychosis were made to think or believe before and after getting the illness. Perhaps, it even does not matter for most of the participants, it is not their decision where to get the care, but their family's decision especially during acute illness phase. An interviewee mentioned that:

> "… *they (her father and the priest/religious father of the family) took me to the holy water for four months. I suffered a lot there, I had parasitic infestations … I had no improvement there and so they brought me here*". [G1]

Treatment initiation, choice and continuation decisions were commonly made by the family, which was not be solely due to the inability of the patient to make the decision, rather it was also due to a high level of interdependency among family members.

Close interdependence within the family: In the study, it was clearly depicted that there was a close interaction within the family which could contribute to the recovery. Most participants were living with their parents and some others with their spouses. Among the participants, no one reported living alone. Most of them perceived that it was their families' responsibility to care for them during their illness. Almost all participants expressed their illness and treatment experiences passively. A 27 years old male expressed his living and treatment conditions as "*my mother brought me here ... my mother took me to ... she gives me any amount I asked ...*" [G3] which was also common for the majority of other interviewees. A 30 years old male who quitted his job dues his illness was totally relying on his elderly parents. He stated that:

> "*… they (his parents) support me, they feed me, and they let me live free I have no job/responsibility to worry about. I do not consider them in this (as supporting) because they are family*". [F4]

The close interdependence was seen positively by all participants, although some complained they had lost their freedom to make decisions. For example, a 24 years old college student stated that:

> *"... you know, it is my life ... it should be my decision to attend classes or not ... it should be my preference to select a profession for myself ... but ... it is only my brother who understands and also respects my preference*".[G1]

From the field notes I wrote, I understood that some of the participants came to the interview room with their family members (mostly parents), stayed there while interviewees gave consent. The family members told me if they could help during the interviews, and they were commonly waiting outside the interview room until the interview had finished.

Role/social behavioural expectations: Due to their illness or the side effects of the treatment participants found it challenging to fulfil the roles and responsibilities they had within the family and society more broadly. Participants stated that they found it stressful to demonstrate acceptable behaviours all the time, this affected their recovery process. A 24 years old male college student participant stated that:

> "*...I believe my survival should be the primary concern ... I started to study in a college, but I could not continue. My friends are asking me if I am still in study and I am saying "yes I am studying" but I need to live first, first I have to know myself".* [G1]

Another participant also found it difficult to maintain good relationships with his friends as they all were working and having income but not him:

> "*I have some friends, but they all have completed their education and have jobs and income, I am trying to act like their friend, but you know it is not easy ... I can feel there is some improvement in our relationship, but it cannot be "normal" I rather prefer to stay in my home reading books or watching TV".* G8

This kind of feeling of incompetency and inability to meet others' expectations made participants to isolate/stigmatize themselves, which certainly affects their recovery.

4.3.3.3. Opportunities and challenges of working

Most of the participants acknowledged that staying active in life with any kind of activity/work was helpful for their recovery. As described earlier, having an occupation was also seen as an indication that they had "recovered". A 30 years old male who lost his job due to his illness mentioned that:

> "*… I also saw the change (improvement) in myself, when I did some small activities at home and now, I am thinking if I started work more, I hope I will get much better*" [F4].

Starting to function was not helping him only to stay active but also it triggered his hope for resuming a more challenging occupation in future. *"It will be just the beginning ... to get back to my earlier job*" [F4].

Another government employed male aged 55 stated that:

> "*... staying at home which again causes depression. Nobody is there (home) to stay with, I will spend the whole day closed at home just watching the TV, spending days at home is not good, staying at work is better*" [G4].

The advantages of having something to work on is not limited to staying active in life, for some generating income for themselves and family was also the concern. A single mother of three children shared the challenges she was having for not being able to do her work. She was the only one taking care of her family but after she developed psychosis, she quitted her private work and faced difficulties even to pay for her treatment.

> "*I used to have a small shop, but I quitted because of the problem, I have no income now, I applied for free treatment, but it is taking time, nowadays I even could not cover for the pills".* [F2]

In her description it became apparent that she was in a stressful situation which certainly affects her recovery. Nonetheless, for most of the participants generating income was not the primary concern, rather the main emphasis was engaging in something to keep them busy and active.

However, having a job or being in study was not helpful for all, some participants mentioned that their premorbid occupation or the occupation they were having during the interview was not appropriate to their health condition. Some of them found it difficult to maintain competency in their job particularly their premorbid occupation. Perhaps this could be the reason almost all of them had quit the jobs they had before the onset of their illness. A college student stated the problems he was facing:

> "*I cannot continue my study … it demands some work in outdoor and on machineries … it demands labour work for longer time … I could not tolerate that … I do not have that much energy; in addition, the drugs have an effect of losing balance".* [G1]

The challenge is not only from the work and working environment but also the colleagues in work or school. A female student mentioned that the challenges she was facing from other students in the school.

> "*… students are not good for me, for example, last semester they even snatched and torn my school bag … they asked me to give them money, but I had none … I do not know why … maybe I talk to no one there, I am quit and alone, I*

was also new for the school maybe that is why … I also changed the school it was too far from my home" [F5].

In general, participants commonly stated that staying active in daily life had a significant contribution to their recovery, it did not matter greatly if the work they did generated income, but it should be appropriate to their health conditions, otherwise it could cause stress and suppress their recovery.

4.3.3.4. Faith, hope and determination

Ethiopians usually relate psychosis with spirituality. Individuals with psychosis face tremendous devastations in almost every dimension of their life, such as occupation, social roles and relationships. The participants' narratives highlighted that they need to have strong faith, hope and determination to recover. An individual who has these important components would recovery better and faster. Three subthemes were embedded under this main theme, "*hope versus despair*" "*spirituality and its integration with modern treatment*" and "*Commitment to get better*".

Hope versus despair: As described earlier, participants of this study conceptualized recovery as "*rebuilding new life*" which indeed was built with hope or demolished by despair. A divorced man hoped reuniting with his family was the solution for most of the problems he had, but the reality he was facing was despairing for him.

"*… the only solution was to live with my wife and children. But they do not need me; even my own children do not want to see me … my sister is telling me to forget them … I was hoping my wife would get strong to take me back, but she is the same … I do not know how to live … I do not know … I am thinking if God takes me to him soon (kills me).*" [G4]

Another single 30 years old man described that he had no plan for any relationship.

> "*I do not have such (get a girlfriend or married) plan. I even cannot manage myself, second, I cannot communicate with others. I even could not create some simple jokes/discuss*ions. *I am not thinking about the future anymore, I stop thinking, I gave-up. You know, spending nearly five years in such (illness) condition is despairing … five years … is too long … I am not even looking for vacancies anymore*." F4

Though this man mentioned he gave-up in returning to his premorbid occupation and important social relations, he was hoping to recover in the other way.

> "*… I hope my health will be improved, this is what the doctor told me … if I started to work, she (his psychiatric care provider) told me she will reduce the doses of the pills*". F4

Some interviewees mentioned their illness had destroyed their hope and made them desperate about the future. A mother who lost her job and marriage stated that:

> "*It (the illness) is affecting my whole life, it destroys my morale, it makes me inferior … I hate to live*." F2

Nevertheless, not all have been traumatized by the illness some have revived from it and even taken it as a good opportunity. A 22 years old high school student stated that:

> "*This year I am in 12th grade I hope I will score good grade, join University, be a good citizen for my country and be doctors like you people here. I believe my sickness has no negative impact on me; even to the reverse it gave me good opportunities. If I was not sick, I would not have a chance to talk to the*

psychologists here, visit monasteries (holy water sites) which all gave me a lot of lessons … I think what all happened to me was for good". [G7]

In general, hope and despair appeared in this study as two mutually exclusive factors affecting recovery. While hope enhances recovery, despair damages it and even destroys an interest to sustain life. These two important factors are indeed not solely related to the severity of symptoms and the life difficulties service users had, it is also related to something to have faith, to believe in and rely on.

Spirituality and its integration with modern treatment: In a traditional community, like Ethiopia, it is very common that health and illness are closely related to spiritual things, particularly if the illness is a mental illness. Indeed, the majority of participants' first experience of treatment was at spiritual healing sites and many of them repeatedly switched between the spiritual healing practices and modern/western treatment throughout their recovery journey. These activities have been prolonging the time of treatment initiation and profoundly affected treatment adherence, which certainly affect recovery. An 18 years old female described that:

"*…after few days with pills (antipsychotics) … I stop taking them (the pills) … my mother took me to the holy water*".

She and other interviewees agreed that they got some benefits in the holy water sites.

"*The holy water was good for me I got improved there*". [G9]

Another interviewee mentioned what he benefited at the holy water site:

> "*The water (holy water) there is cold, my mother was always there with me, the compound is relatively quiet, and I also get rest when I went there, all these were helping*". [G4]

In contrast, for most of the participants attending holy water was much more a spiritual obligation. A man who has been exhausted with the spiritual practices stated that:

> "*I got no much help from it (holy water). I tried hard on it for a long time but gave up now, it is not helping. But I am a Christian I keep praying and being baptized in the holy water".* [F4]

The above mentioned 18 years old female added that:

> "*… after few months improvement with holy water I get sick again, at that time I came here … after that, I am taking the pills and holy water together … this is holy water we (she and her mother who is waiting outside) brought from St Gabriel. We just came from there*". [G9]

This statement informs that the two care segments (modern/western and traditional/spiritual) are being used together, which many others had the same experience. Another 22 years old Christian also mentioned

> "*I could say it (holy water) helped me. Whether I am here (hospital) or there (spiritual healing sites) it is God's will that helps me. It is which way God wants to cure … for me, both are God's way of helping people. So, I should say both (medicine and holy water) helped me to recover*". [G7]

This could conclude that spiritual cares were helpful, but interruption/discontinuation of hospital treatments for the spiritual care could prolong the time of recovery and

hence the integration of the two care modalities could augment each other for better recovery.

Commitment to get better: Considering the fact that subjective recovery is individualistic in its nature, personal efforts to overcome the illness were identified among important subthemes affecting recovery. The efforts could vary between individuals based on their illness conditions and needs. For some initiating treatment was not easy and hence, demanded them efforts to visit health institutions. A 42 years old male mentioned that:

> "*I myself initiated the treatment, I am adhering to the treatment, I am not missing the pills it is my commitment and of course the pills I am taking are helping me to get better*" [F3].

For some others, it was not easy to adhere to treatment due to side effects, financial shortage or others influence. A short sentence from 26 years old male could strengthen this statement:

> "*… after that (the time that he missed his monthly injection and get sick) I am very strict on my schedule and get much better*" [F1].

Some interviewees also recognized that their physical health and self-esteem (self-confidence) were among the important components of their recovery and hence they were working and committed to building these. Few others were also struggling to overcome their substance addictions such as Khat which they believed was hindering their recovery. Indeed, the kind of effort and extent of commitment required are different among service users. However, participants acknowledged that as more

effort they put and committed towards their goal (recovery) they would enjoy better recovery level.

Table 4-10: Perceived challenges and opportunities related to subjective recovery from recent-onset psychosis

Themes	Sub-themes
Altered health, psychiatric treatment and side effects of antipsychotics	Physical wellness
	Disabling symptoms of psychosis
	Psychiatric treatment and the side effects of the antipsychotics
Collective understanding and social process to psychosis management	Understanding of the illness and its treatment
	Social process to illness management
	Close interdependence within the family
	Role/social behavioural expectations
Opportunities and challenges of working	
Faith, hope and determination	Hope versus despair
	Spirituality and its integration with modern treatment
	Commitment to get better

4.4. Integration of the Findings from Both Study Approaches

The findings from the two approaches were analysed for their commonalities and differences. The integrations of the findings from the quantitative and qualitative study approaches are described below.

4.4.1. Recovery levels

Consistently high mean subjective recovery scores were found across the nine months. This could be explained with the results from the qualitative data, which was conducted following the longitudinal quantitative measurements. In the qualitative part, participants reported that their disturbances were stabilized with the treatments they had. This was illustrated by the themes of "*dominate over the disturbance of psychosis*" and "*altered health, psychiatric treatment and side effects of antipsychotics*". Under these themes, it clearly emerged that participants gained a substantial improvement in their health that eventually gave them hope for a better future. Though they sensed the devastating side effects of the antipsychotics, they undeniably enjoyed the relief from the turmoil they had. The participants in this study were those with short duration of illness and treatment, therefore their understanding of the enduring nature of the illness and maybe the need for life-long treatment for it, was not recognized, which again did not yet impact their perceived recovery. Coupled with their own understanding, the community's interpretations to the illness, that did not label them as chronic patients, rather the community perceived such illness as any other acute illness. This is depicted in the theme "*collective understanding and social process to the management of mental illness*" which might help them to perceive as they were going to have a cure. In addition, "close interdependence within the family" could have also boosted their recovery by affording them high social support. Most of the decisions were made by the family members this might have also positively contributed to the recovery by reducing stresses related to responsibility for major living issues, such as shelter, food, safety and treatment related expenses.

4.4.2. Predictors of recovery and perceived related factors

From the cohort study six variables (quality of life, hopelessness, central obesity, functional disability, internalized stigma and satisfaction with social support) were found to significantly predict subjective recovery. The qualitative part of the study also supports and provides some potential explanations for these findings.

4.4.2.1. Quality of life and recovery

The most significant predictor for subjective recovery was found to be the self-reported quality of life. Quality of life is indeed a multifaceted variable that touches most major components of life. The findings of the qualitative part of the study could directly relate to individuals' quality of life. For example, the first theme identified in conceptualizing subjective recovery was "*dominate over the disturbance of psychosis*". Psychosis affects psychological wellbeing, which certainly affects other life components, such as social interactions and physical health. The majority of the participants complained about physical health problems, difficulties of performing daily activities and maintaining social interactions. Some participants found the working environment and the job they had were not appropriate for their health conditions. Many participants felt incompetent within their social environment, had low self-esteem, had poor sleep quality and being ignored for their physical health complaints. Indeed, all these could relate to the quality of life that eventually affects perceived recovery level.

4.4.2.2. Hope and recovery

Hopelessness was the other variable that negatively predicted subjective recovery in the quantitative part of the study. This result was also strengthened in the qualitative

part of the study. "*Faith, hope and determination*" was one of the themes identified that related to recovery. As the participants in this study had a short duration of illness and treatment, but with substantial improvement in their symptoms, the majority of the participants were found to have optimistic hope and believed they had positive prospects in their future. This positive prospect and hope could perhaps also due to a high level of reliance and integration with the spiritual healings as depicted in a sub-theme "*spirituality and its integration with modern treatment*". From the qualitative results, it became clear that most participants were hopeful for their health and future life that could certainly contribute to their recovery. However, there were some participants who were exhausted with their illness and treatment for it and gave-up on things which could hinder their recovery. In general, from both study approaches it was found that hope or hopelessness has relationship with recovery.

4.4.2.3. Physical health problems and functional disability

The other predictors of recovery were central obesity and functional disability. These two variables could perhaps relate to each other and be explained by the qualitative results. The qualitative participants clearly stated that either the illness or the treatment for it (side effects of antipsychotics) made them disorientated to themselves and their environment as presented in the subtheme "*regain awareness to self, situation and illness*" that caused difficulties to stay active in the working environment. Almost all participants boldly stated that they had high fatigue to perform daily activities and therefore they spent most of their time laying on bed or sitting as presented in the themes "*stay active in life with optimal functioning*" and "*opportunities and challenges of working*". Participants also made it clear that coupled with the "*side effects of the antipsychotics*" their sedentary lifestyle caused them to gain weight

which could result in central obesity and other metabolic health problems. Generally, both the illness and the treatment for it caused them to be inactive in performing daily activities and gain weight; therefore, these both negatively predicted subjective recovery in the quantitative results.

4.4.2.4. Internalized stigma

Low level of functioning, central obesity, unaddressed physical health needs, disabling symptoms and unable to meet "role/social behavioural expectations" could certainly cause internalized stigma as manifested by self-isolation and feeling of incompetent with friends. Stigma or internalized stigma did not emerge as a theme or subtheme, but other themes and subthemes could indirectly illustrate that participants were facing challenges similar to internalized stigma. For example, under the subtheme named "*role/social behavioural expectations*", much information which relates to internalized stigma are entrenched in. Participants clearly mentioned that they felt incompetent to behave as they were expected in the society and hence, they isolated themselves. The stressful expected behaviours, inability to be productive within the family, being obese, being ignored for physical health complaints that caused them to have low self-esteem and internalized stigma which could ultimately affected their recovery.

4.4.2.5. Satisfaction with the social support

Strong social interactions between the participants and their families were reported from the qualitative participants. These interactions were more of paternalistic support to the participants. As clearly presented under the subthemes called "*social process to*

illness management" and "*close interdependence within the family*", the treatment decisions for most participants were made by family members, mainly parents. Not only the treatment, for some the occupation, the study programme and even the food to eat were decided by other people. Indeed, in such traditional societies in low-income countries where psychiatric and rehabilitation services are limited the family is the only institution to rely on in such chaotic conditions. In the country, there is no institution that covers expenses for the treatment, shelter and food. Some participants were thankful that their family were feeding, sheltering and taking care of them. The main point here is how the participants perceived the support they had. Therefore, participants who perceived their support positively and satisfied with the support, they had better level of recovery as recorded in the regression tests in the quantitative data.

Some variables, such as levels of psychotic symptoms and substance use did not show statistically significant prediction to subjective recovery. This could be because, most participants had similar experiences in these variables; i.e., all participants were in treatment who were enjoying the benefits of the treatment and facing the challenges caused by the side effects the antipsychotics. Hence there might be low variability in these variables among quantitative cohort participants to be detected in the statistical tests. However, "*disabling symptoms of psychosis*" was one of the subthemes identified in the qualitative analysis. Variations in the qualitative and quantitative findings are because findings from the qualitative data were inclusive to the experiences before initiating treatment (qualitative findings could have reports of retrospective experiences), however, findings in quantitative part were only about current experiences (after initiating treatment).

In general, higher subjective recovery scores could be explained by the qualitative findings of stabilized psychotic symptom levels within short treatment period, understandings to the illness and its treatment, having positive prospect and close interdependence within the family. Factors predicting subjective recovery in the quantitative approach are also explained with the findings from the qualitative approach.

CHAPTER 5. DISCUSSION

5.1. Introduction

This chapter discusses the overall findings of the PhD study. In the first section (section 5.2) the levels and progress of subjective recovery over nine months, conceptualizations of recovery and other important variables are discussed. In the second section (section 5.3) factors related to subjective recovery identified from the quantitative and qualitative data are discussed. Finally, the strengths and limitations of the study are presented.

5.2. Levels, Progress and Conceptualizations of Subjective Recovery

5.2.1. Levels and progress of subjective recovery over nine-month

The recovery level of Ethiopian psychiatric outpatient service users was found to be high and remained stable over the study period with no significant change over the nine months. The level was also recorded to be higher than those reported in studies conducted in Western countries where all previous studies in the topic were conducted. However, recovery levels might not be directly comparable between high-income Western countries and a low-income African country due to great variations in culture, perceptions of illness, expectations of treatment outcomes and health care systems (Balaji et al., 2012).

In the current study, the levels of subjective recovery scores at all time-points (mean values of QPR range from 44.17 to 44.65, possible range 0 - 60) were greater than that reported in the UK studies in which their adjusted mean scores were 32.47 (Law et al., 2016), 35.13 (Law et al., 2014) and 28.76 (Morrison et al., 2014) according to the original QPR scoring method (Neil et al., 2009). Several reasons could be given for better recovery scores for the participants in this study. In addition to the fact that,

symptomatic and functional recovery from severe mental illness may be better in low-income countries (Isaac et al., 2007; Iyer, Mangala, Thara, & Malla, 2010; Jaaskelainen et al., 2013; Menezes et al., 2006), there are other potential reasons for this consistently high subjective recovery levels, such as perceptions of the illness and its treatment, low hopelessness, tight social bonds, utilization of more than one care modalities, (Abbo, 2011; Iyer et al., 2010; Ofori-Atta et al., 2018) and variations in study participants.

Participants in the qualitative part of the current study perceived that the illness they were facing was something to be permanently free from after completing a limited course of treatment indicating they were expecting a cure from treatment, which is inline with another study in Ethiopia conducted among individuals with SMI (Hailemariam, Fekadu, Prince, & Hanlon, 2017). They reported that they experienced a substantial improvement in their distress after engaging in a short duration of psychiatric treatment, which could have boosted their hope and their perceived recovery level; and might cause treatment discontinuation (Hailemariam et al. 2017; Kreyenbuhl, Nossel, & Dixon, 2009). This supposition could also be supported by the low reported hopelessness score and low psychotic symptom levels.

The participants in the UK's subjective recovery studies were also more hopeless (mean BHS = 8.49) in Law et al. (2016); and 9.17 in Law et al. (2014) than the Ethiopian service users in the current study; mean hopelessness (BHS) score at baseline = 3.23 (although this increased to 3.59 at the third month and 4.56 at the ninth month). The high level of hope and subsequent elevated level of subjective recovery might be related to the participants' optimistic understanding of their illness and treatment for it. Several studies reported that insight into the nature of illness was a

determinant factor for different treatment outcomes such as quality of life and hope (Carroll et al., 1999; Sim, Mahendran, Siris, Heckers, & Chong, 2004; Smith et al., 2004). When service users become aware that their illness may become enduring or realize that the illness can have a progressive deteriorating course (Andreasen et al., 2005; Davidson et al., 2008; Romano, 2009) this may lead to decreased subjective recovery levels (Carroll et al., 1999; Temesgen et al., 2019a). This indicates that the currently achieved level of subjective recovery may not be sustained (Sim et al., 2004).

The levels of psychotic symptoms of participants in this study were also low and static as compared to those in previous studies conducted in Ethiopia and Europe. In this study, the overall PANSS mean scores ranged from 37.61 to 39.48, which were almost half of the reported symptom scores from Ethiopians with schizophrenia spectrum disorder (mean = 78) in Shibre et al. (2010) and from Norwegians with first-episode psychosis (mean = 70) in Larsen et al. (2004). The overall scale and subscales PANSS scores in this study were lower than PANSS scores of individuals with psychosis recruited from different settings of the North-west of England; e.g., the PANSS – 'Positive Symptoms' was 13.64 in the UK (Law et al., 2016), while it was 8.9 in this study. This substantial reduction of symptoms in short period of treatment might have boosted their hope and recovery.

The majority of participants (78.4%) were engaged in a regular job or study; staying active in life with optimal functioning and the high rate of employment could have also contributed to higher level perceived recovery. Having a meaningful occupation was identified as a common contributing factor for recovery in a systematic review (Shanks et al., 2013) and individual studies conducted among individuals with SMI in the UK (Shepherd et al., 2008; Slade, 2009) and individuals with early psychosis in

Canada (Bourdeau, Masse, & Lecomte, 2012). However, the meanings of having work or being employed might be different in participants from high-income countries when compared to those participants in the current study. Participants in this study reported that they had a "job" if they had anything to work on each day, for example, assisting their family in cooking, farming, and taking care of children, which might not be considered as a job in other societies in high-income countries. However, the important point here is that the participants' perceived that they were having something to be engaged within daily life that seems to positively impact upon their subjective recovery.

Participants in the current study reported a high level of satisfaction with the social support they had (mean SSQ6-Satisfaction ranged from 30.98 to 31.92, from a maximum possible score of 36). Social support to individuals with psychosis was identified as a major contributor for positive outcomes from SMI, such as reductions in symptom levels and relapse in a hospital-based study in Ethiopia (Fikreyesus, Soboka, & Feyissa, 2016), better quality of life and functioning in studies conducted in the USA (Breitborde, Woolverton, Frost, & Kiewel, 2014), Brazil (Eisenstadt et al., 2012) and in a systematic review (Gayer-Anderson & Morgan, 2013), and for better subjective recovery level in Hong Kong (Lam et al., 2011). Participants in the qualitative part of this study boldly stated that they had strong support from their family, although some claimed that they were being over-controlled. Hence, this perceived high level of social support could have contributed towards the higher recovery level in this study when compared with the previous studies.

Higher subjective recovery levels recorded in this study as compared to the previous studies could be partly justified with the above-mentioned reasons. However, direct

comparisons between these studies are complicated due to variations in recruitment strategies, inclusion criteria, and scoring systems. Participants in this study were only those individuals with psychosis who had stable psychotic symptoms and were engaged in treatment. Therefore, participants having higher levels of symptoms but who were still engaging with treatment were admitted as inpatients, whereas those with inadequate symptom control might have disengaged from the hospital-based treatment and sought traditional/spiritual healing. Indeed, over 90.0 % of people with mental illness in Ethiopia are reported not to receive treatment from the Western-style health care system, only those individuals with better socio-economic status would stay engaged in hospital followup care in Ethiopia (Ayano, 2016), while most tend to seek traditional treatment (Alem et al., 2009; Ayano, 2016; Fekadu & Thornicroft, 2014) due to several reasons including financial constraints (Hanlon et al., 2019).

Besides, the study inclusion criteria resulted in recruiting participants that were different from the previous studies and hence comparisons might be problematic. For example, Morrison et al. (2014) included individuals with psychosis who withdrew from taking antipsychotics by themselves for at least six months but were still experiencing psychotic symptoms. Whereas, participants in Law et al. (2016) and Law et al. (2014) studies were recruited from different settings and not limited to the diagnosis of recent-onset psychosis. Participants in the study by Shibre et al. (2010) in Ethiopia had a long duration of illness (mean = 13 years) as compared with the current study (mean duration of illness = 22.4 months). These variations could have an impact on recovery levels and therefore comparisons should be treated with caution.

Perhaps, lower symptom severity, lower hopelessness and higher subjective recovery levels might suggest better recovery levels in low-income countries, as reported in some earlier systematic reviews (Isaac et al., 2007; Jaaskelainen et al., 2013; Menezes et al., 2006). This may be related to the contextual and social issues such as potential benefits from traditional and religious healing practices (Abbo, 2011; Ofori-Atta et al., 2018), and having less competitive/stressful lives, tighter social bonds and a lower degree of urbanization in low-income countries than in high-income countries (Harrison et al., 2001; Iyer, Mangala, Anitha, Thara, & Malla, 2011; Myers, 2010; Purgato et al., 2012).

An earlier study in the Ethiopian population with psychosis outpatient service users found that visiting spiritual healing sites was a significant protector from illness relapse (Fikreyesus et al., 2016) which might have also predicted recovery level if it was assessed. A prayer camp based randomized experimental study in Ghana also found that individuals receiving care from both modalities (spiritual and antipsychotics) have more favourable outcomes than their counterparts (Ofori-Atta et al., 2018).

The results from the current study may provide some supporting evidence for the previous reports that people with psychosis in low-income countries have better clinical, psychosocial and subjective recovery levels; however, treatment coverage for people with mental illness in the country is very low (Ayano, 2016; Fekadu & Thornicroft, 2014); indicating that the majority of individuals with psychosis are not represented in this study. This gap needs to be addressed with more comparative and inclusive studies incorporating individuals who do not engage in treatment.

The other important point to be considered is that the type of recovery assessed and discussed in this study was subjective recovery. As the term suggests, what has been assessed was the perceived level of recovery self-reported by the service users themselves, which might be perceived differently by other socio-cultural groups and across individuals. This suggested that the subjective recovery scores recorded in the current study and other studies in western countries might not have exactly the same meaning. Although maximum efforts were made to assess the level of subjective recovery in the longitudinal quantitative study, the subjective nature of recovery should be acknowledged. Hence, in order to gain a deeper and contextual understanding of subjective recovery among Ethiopian service users with recent-onset psychosis qualitative individual interviews were conducted to explore the conceptualizations of their own recovery.

5.2.2. Conceptualizations of subjective recovery

Participants in the qualitative part of the study conceptualized their recovery as "*dominate over the disturbance of psychosis*", "*complete antipsychotic treatment course and stay normal*", "*stay active in life with optimal functioning*", and "*reconcile and rebuild the new life*". Indeed, recovery from mental illness is multifaceted, incorporating the symptomatic, functional and psychosocial components. Previous studies also documented that people with SMI often understood recovery from mental illness differently, ranging from cure from the illness (Noiseux et al., 2009) to having a meaningful life (Shepherd et al., 2008). In a systematic review conducted prior to this study, it was found that subjective recovery was conceptualized as an outcome to achieve, a process towards a targeted outcome or endeavours of overcoming illness-related disabilities (Temesgen et al., 2019a). The conceptualizations of recovery from recent-onset psychosis by service users in the current study could be embedded under

these broad ranges of recovery definitions with some more themes and contextual meaning variations.

Domination over disturbance of psychosis: As presented in section 4.3, participants in the qualitative part of the study conceptualized their recovery as being able to dominate the disturbances of their illness. Several previous studies also found similar conceptualizations. For example, Shepherd et al. (2008) and Noiseux et al. (2009) defined recovery in mental illness is 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, reconciling the meaning of the illness experience, regaining control over the experience, and negotiation and acceptance of treatment (Windell et al., 2015). However, some interviewees 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 their awareness about the nature of the illness and optimistic treatment expectations. Service users with a psychotic illness in Hong Kong also defined their recovery as being free from medications and have steady health (Ng et al., 2008). Other studies also found that participants defined their recovery as being able to live without the medicines (Norman et al., 2013; Windell & Norman, 2013). But for the current study participants, it was not only about being free from the antipsychotics, but it was also "*finishing the course of treatment*" which might indicate lack of insight about the nature of treatment for psychotic disorders.

Indeed, there are contradicting reports about the importance of maintaining antipsychotics after achieving symptomatic remission for short- and long-term

recovery outcomes. A recent review reported that antipsychotic drug discontinuation was the main cause of illness relapse (Suvisaari et al., 2018). Despite this widely accepted viewpoint, a randomized trial in the Netherlands found that higher proportions (40.4%) of individuals with psychosis achieved symptomatic and functional recovery with reduced doses or by discontinuing the antipsychotic after six months of treatment than in individuals who maintained treatment (17.6%) (Wunderink et al., 2013).

There is no limited "course of treatment" to be completed for psychotic disorders as perceived in the current study participants, both dose reduction and discontinuation depend on the illness prognosis, patients' preferences and clinicians' decisions (Harrow et al., 2012), some authors even strongly recommended maintenance of the treatment irrespective of symptomatic remission (Gaebel, Weinmann, Sartorius, Rutz, & McIntyre, 2005). Nevertheless, participants in the current study seemed that they perceived their illness was something to be cured with a limited course of treatment which might have caused higher perceived levels of recovery by giving unrealistic hope.

Stay active in life with optimal functioning: Severe mental illnesses, such as psychosis, affect most dimensions of functioning (Sumskis, 2013; Valencia et al., 2014; Whiteford et al., 2013). Individuals with psychosis do not only have an impaired functioning, but they also 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 may not be unexpected 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 perceived (subjective) recovery (Connell et al., 2015; Eisenstadt et al., 2012; Wilken, 2007) which helps to regain self-reliance, confidence and independence (Habtamu, Alem, Medhin, Fekadu, & Hanlon, 2018; Menezes et al., 2009; Romano, 2009).

The potential difference between previous studies in Western countries and in the current study could be 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 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 emphasised 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, no matter whether it directly generates income or not. The other important point to highlight in this regard is that participants in the current study need to stay well and active in daily functioning not only for the sake of themselves but also for important others, to reduce or share burden from the family which might reflect the collective nature of the society. This could also be among the reasons for the higher perceived recovery level in the current study. This could have also helped them to properly readjust with the changed reality.

Reconcile and rebuild: The other main point that participants defined their recovery was reconciling with the changed reality and rebuilding a new identity, job and life. Seminal authors in the field of recovery from SMI also emphasized that recovery is a

journey of self-discovery to personal growth (Anthony, 1993; Deegan, 1996; Slade, Amering, & Oades, 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.

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). Researchers agreed that recovery is an ever-changing journey of goal readjustment, developing new meaning and purpose in life and self-optimization (Anthony, 1993, 2000; Davidson et al., 2008; Deegan, 1996). From this concept of recovery, it is possible to articulate that psychotic illness alters several aspects of life, and recovery from it demands continuous readjustment with the changing realities by reconciling with it and rebuilding the new hope and life based on the new platforms. Generally, the holistic view of recovery is emphasized in the service users' conceptualizations of recovery in the current study.

5.3. Predictors of Subjective Recovery from Recent-Onset Psychosis

The second aim of the study was to identify factors related to subjective recovery from recent-onset psychosis among service users in the outpatient psychiatry clinics. Findings from both the quantitative and qualitative study approaches are discussed together in comparison with previous research. For the longitudinal quantitative data, hierarchical regression test results showed that the demographic, substance use and most physical health variables did not significantly predict subjective recovery at any of the measurement time-points. These variables also explained little variance (R^2

ranged from 3.0% at baseline to 15.0% at third round measurements) in subjective recovery scores. This indicated that subjective recovery is mostly explained by psychosocial variables such as quality of life, internalized stigma, satisfaction with social support, hope, and functional disability.

5.3.1. Quality of life

Quality of life was found to be the strongest predictor of subjective recovery in all three time-point measurements over nine months, (unstandardized coefficient *B* ranges from 2.43 at second round to 5.60 at third round measurements, while the *P* values were less than 0.001 in all-time point data regression tests). The construct of quality of life has very broad concepts touching almost every dimension of human life. It is perhaps logical that someone with a poor quality of life would have also a low subjective recovery level. Although not limited to individuals with recent-onset psychosis, studies by Kukla, Lysaker, and Roe (2014) and Chiu, Lo, and Yiu (2010) also found a direct relationship between subjective recovery and quality of life in people with SMIs.

Previous studies conducted among individuals with psychosis, although only qualitative in their study design, also documented that meaning of life and satisfaction with life (Lam et al., 2011; Romano, 2009), role perception, involvement in their society and personal capacity (Connell et al., 2015; Eisenstadt et al., 2012; Windell et al., 2012) were among the important factors influenced subjective recovery from recent-onset psychosis which could be explained as parts of quality of life. Some researchers have attempted to define and measure subjective recovery from the subjective quality of life perspective (Gardsjord et al., 2016; Roe, Mashiach-Eizenberg, & Lysaker, 2011). Nevertheless, these measurement tools have different

constructs and hence have different targets of measurement. Quality of life is very broad concept that measures the physical, social, environmental, psychological wellbeing for any individual whether with mental illness or not (World Health Organization, 1996), while subjective recovery measures how individuals with severe mental illness particularly psychosis feel in overcoming the illness he/she had/is having; and hence to evaluate the progresses of perceived recovery (Neil et al., 2009). Therefore, subjective recovery and quality of life are assessing two different constructs, though might have some shared points.

The prediction of quality of life to subjective recovery in the quantitative part of this study has also been supported by the findings in the qualitative part. From the participants' narratives, it was found that they defined their recovery as overcoming disabling psychotic symptoms, the side effects of the antipsychotics and the related physical, psychological, social and functional impairments. Participants also defined their recovery in terms of reconciling with the new reality and rebuilding new hope and life. They also perceived that making readjustment and reconciliation with the new self and aspiring to build new life were among the helpful components for their recovery.

The concept of reconciliation in this study perspective represents making peace and harmony with the realities surrounding the participants. The one who had peace and harmony with his/her environment would most likely be satisfied in his/her life and feel that he/she had a good quality of life. From the participants' narratives the defining and perceived challenges and opportunities related to recovery could be the elucidation of quality of life as its wide range coverage of life components (World Health Organization, 1996). This is in line with several previous studies conducted

around the world. The first priority of service users from the UK in defining their recovery was having an acceptable self-defined quality of life (Law & Morrison, 2014). The ultimate goal of living whether ill or well is to have a better quality of life. It perhaps is not unexpected if the participants' conceptualized their recovery as improving their quality of life; after all that is the dream of every human being, although the level and type of desire may vary between individuals.

Connell et al. (2015) also found that in the early stages of psychosis self-consolidation and reconciliation were important for personal growth and recovery. A previous study in the Ireland found that individuals with psychosis had experienced a disturbed world and self, and absence of understandings to their situations (Brew, Shannon, Storey, Boyd, & Mulholland, 2017). Conceivably, it would be expected if the participants in this study perceived their recovery as regaining awareness to self, situation, and illness; and reconcile with the new reality and rebuild the new hope and life. A study in Hong Kong among people with schizophrenia who were living in the community also reported similar concepts of recovery such as, acceptance of ones' own condition, developing new meaning and purpose of life, and developing a new social role (Law, 2017). All these points could be considered as the defining components of perceived quality of life.

However, few researchers speculated that improved levels of recovery in people with psychosis could also lead to a reduced quality of life due to distress resulting from having more insight into the illness and a greater awareness of the challenges of living with the illness in their future (Buck et al., 2013; Hasson-Ohayon, Kravetz, Meir, & Rozencwaig, 2009). This could be argued in a different way as found in the qualitative part of this study. In the current study, one of the main themes found to define

participants' perceived recovery was "*collective understanding and social process to psychosis management*". One of the subthemes under this main theme was "understanding of illness and its treatment" which embraces participants' insight into the illness and treatment they were having. Different understandings were identified ranging from "the illness they had was acute to be cured in a course of treatment" to "something spiritual to be managed in a spiritual way". In both understandings, it was possible to assume that participants had not yet gained proper insight about the possibility of relapse, enduring illness and that they might require long-term treatment.

The somewhat unrealistic understanding of the illness and treatment could have contributed towards a high degree of hope which is based on fragile realities. Interestingly, although the concept of recovery is very hope orientated, the recovery model itself has been criticized by some authors for overlooking the potential for a long-term battle with illness and hence offering false hope (Bellack, 2006; Silverstein & Bellack, 2008). Strengthening this assumption, a 10-year community-based cohort study among Ethiopians with schizophrenia found that individuals with shorter duration of illness had better recovery outcomes as assessed in social and physical self-reported functioning (Kebede et al., 2019). As recorded by Hasson-Ohayon et al. (2009), Carroll et al. (1999) and Romano (2009) when some individuals with psychosis start to recognize the enduring nature of the illness they have, several desired outcomes such as quality of life and hope would be negatively affected which subsequently impact their recovery.

5.3.2. Hopelessness

Although that the variance explained was small (Unstandardized Coefficients R = -0.326), hopelessness was found to be a significant negative predictor of subjective

recovery at the baseline measurement. This finding concurs with earlier studies conducted in Western countries showing that inner strength and hope for future prospects were related to better levels of subjective recovery (Anthony, 2000; Eisenstadt et al., 2012; Slade & Longden, 2015; Vass et al., 2015). Law et al. (2016) also found that hopelessness was among the significant negative predictors of subjective recovery among the UK psychiatric service users.

Findings from the qualitative part of this study also supported a possible relationship between hope and subjective recovery. *Faith, hope and determination* was one of the main themes identified that interviewees perceived as a contributing factor to their recovery from the illness. Participants were found to have a positive faith and strong reliance on spiritual healing, particularly in their early periods of illness. Later on, they also gained trust in the modern treatment; and at the time of the interviews, the majority of them were using both treatment modalities as depicted in the subtheme "*spirituality and its integration with modern treatment*". This indicated that service users in the study area have multiple sources of hope including close interdependence within the family which is embedded within the main theme named "*collective understanding and social process to psychosis management*". The importance of hope in the recovery journey has been articulated in several studies and personal narratives. Hope was one of the five CHIME (Connectedness, Hope, Identity, Meaning in Life, and Empowerment) components that defined subjective recovery by Slade et al. (2012). Hope is not only important for recovery (Scottish Recovery Network, 2009; Shepherd et al., 2008; Valencia et al., 2014) but also a mandatory to sustain life (Deegan, 1996) as it was also recorded in this study that a few participants were fed up with the chaos they had and despaired even to live. However, participants also pointed out several sources of hope such as spirituality and healing services from

religious and traditional sites, close social interdependence within the family, having a job appropriate to their health condition and treatment from the hospital.

5.3.3. Satisfaction with social support

The current study identified that individuals who had better satisfaction with social support were found to have higher level of subjective recovery (Unstandardized coefficient $B = 0.12$, $P = 0.04$ at second round measurement). The qualitative interviews also revealed that familes were identified as the main source of social support high interdependence within the family was was reported. This finding, the relationship between social support and recovery, is in line with many previous studies conducted in Western countries (Corrigan & Phelan, 2004; Law, 2017; Roe et al., 2011). Having suitable social support was among the factors contributed to better subjective recovery level from mental illness that was identified in some earlier studies (Albert et al., 2011; Fikreyesus et al., 2016; Kebede et al., 2006). Isaac et al. (2007); Myers (2010) and Harrison et al. (2001) articulated that a high level of social support could be one of the potential reasons for better recovery outcomes in low-income countries. This assumption could be strengthened by the findings of the current study.

One of the participants' perceived factors (themes) affecting progress of recovery was "*collective understanding and social process to psychosis management".* This theme encompasses the participants' understanding about the nature of the illness and its management which is believed to reflect the community's perceptions as well. Different communities in Asia and Africa relate mental illness to supernatural causes which directly impacts treatment seeking and preference behaviours (Hailemariam, 2015; Ham et al., 2011; Zafar. et al., 2008). This shared understanding at the community level about psychosis, its treatment and even to individuals with mental

illness could influence recovery (Tse & Ng, 2014). In the current study, it was found that individuals with psychosis initially sought care from spiritual and traditional healing sites that were often decided by others, which is in line with other reports in Ethiopia (Fekadu & Thornicroft, 2014; World Health Organization, 2011). The treatment decisions being made by others might not be necessarily due to the incompetency of participants' but due to the collective perceptions towards individuals with the illness. Besides, the support to individuals with psychosis was found to be mostly paternalistic, as also found in another study in Ethiopia (Souraya, Hanlon, & Asher, 2018). This kind of support eases distress from patients and was mainly viewed positively by the majority of the participants, however, some felt that they were being over-controlled.

Getting support from spiritual healing sites was found to have a considerable contribution to several positive outcomes of psychosis in other studies (Fikreyesus et al., 2016; Hutchinson & Haasen, 2004), including recovery by providing hope and broadening social support (Cornah, 2006; Mitchell, 2010). Previous studies also found that if social support is delivered in accordance with the needs of the person with SMI, it enhances recovery but might also hinder recovery if it is controlling and judging the patient (Gayer-Anderson & Morgan, 2013; Ng et al., 2008; Souraya et al., 2018).

Variations in the interpretations of the social support that service users have could be the reason that their satisfaction with the social support predicted level of recovery in the quantitative part but not the number of individuals involved in providing the social support. In other words, when participants were not satisfied with the support they had, their recovery might be hindered; even if they had a large social network. It appeared clear that social interactions should be in a constructive and supportive way

rather than being controlling. It was found that not all social interactions/support were positive, some interactions with the family and community in their living and working environments were consisted of critiquing, negative and paternalistic attitudes towards the patients, which could cause self-isolation and internalized stigma.

5.3.4. Internalized stigma

Internalized stigma was found to be the other significant negative predictor of subjective recovery both at second and third round measurements. Previous studies found that mentally ill individuals were highly stigmatized (Guner, 2014; Wood & Irons, 2016; Woodside et al., 2007) even at the symptom-free periods (Hopper et al., 2007). When stigma is internalized it critically affects recovery through physical inactivity, weight gain, poor self-care, and poor social interactions (Habtamu et al., 2016; Robson & Gray, 2007). In developing countries like Ethiopia, individuals with psychosis are often viewed as being possessed with evil spirits, which might worsen stigmatisation (Assefa et al., 2012; Teferra et al., 2013). In fact, mentally ill individuals are often stigmatized by family members, health professionals and spiritual healing practitioners (Chien, Chan, et al., 2015; Parle, 2012; Robson & Gray, 2007). Family members of individuals with mental illness are also victims of stigma (Harison, 2008). Previous studies have reported that mentally ill individuals experiencing stigma had poor recovery (Chien, Lam, et al., 2015; Guner, 2014; Habtamu et al., 2016; Livingston & Boyd, 2010; Vass et al., 2015).

Internalized stigma could hinder recovery via several mechanisms, such as individuals with mental illness might deny symptoms they have due to fear of stigma (Smith et al., 2004), social withdrawal (Assefa et al., 2012; Girma et al., 2013), delayed treatment initiation and poor treatment adherence (Chien & Leung, 2013), depression,

negative feelings about self, alcohol and drugs use, dissatisfaction in life and poor quality of life (van Zelst, 2009; Vass et al., 2015). A study among Australian individuals with psychosis also found a negative impact of internalized stigma on subjective recovery (Thomas et al., 2016). A community-based study among individuals with SMI in Ethiopia, although it did not measure the relation with subjective recovery, found that internalized stigma significantly influenced functioning (Habtamu et al., 2018).

Narratives from the qualitative part of the current study also explained the impact of internalized stigma on perceived recovery level. Participants pointed out that they were having difficulties to meet social expectations of their family, friends, community and colleagues in the working environment. They found it challenging to behave and perform as they were expected to. They felt incompetent to maintain positive and parallel interactions with friends, to have important relations such as marriage and to perform roles, and hence isolated themselves from important social interactions. Being isolated due to internalized stigma did not only hinder their recovery but also it caused them to become incompetent to perform roles and had limitations in functioning in multifaceted ways.

5.3.5. Functional disability

The level of disability (functional difficulties due to an ill-health condition) was found to be moderate throughout the follow-up period, which negatively predicted subjective recovery at the third-round assessment; although the power of prediction was low (unstandardized coefficient B = -0.17, P = 0.03). Level of disability at second round measurement was also the only variable that predicted subjective recovery after six months (Unstandardized Coefficient B = -0.11, P = 0.025), indicating its' prolonged

impact on subjective recovery compared to other variables studied. Despite many scholars have studied the impact of disability on functional and clinical recovery and quality of life, no study was found that tested the direct relation of disability and subjective recovery. Indeed, psychosis is a known illness that affects several aspects of functioning which impacts recovery (Habtamu, 2016; Habtamu et al., 2018; Nowak, Sabariego, Switaj, & Anczewska, 2016). Improvement in functioning (reduced disability level) was among the pillars in defining the overall recovery identified in an influential recovery definition (Liberman et al., 2002).

From the qualitative data, one of the themes identified was "*opportunities and challenges of working*". Participants found it benefiting to be engaged in any kind of activity, however, if the job was not appropriate to their health condition it created distress and left them vulnerable to other health problems which hindered their recovery. Having limitations in functioning affects recovery in a multifaceted way. A recent study in Ethiopia found that individuals with SMI have low employment rates and less income to cover for proper nutrition and treatment expenses (Hanlon et al., 2019). The economic problem was not limited to individuals with SMI, coupled with individuals' functional disability, treatment expenditure was found to affect their families in a recent study in Ethiopia (Hailemichael et al., 2019). Although the majority of participants in the current study emphasized the benefits of functioning to keep them active and engaged in life, some also pointed out that they spent all their resources for their treatment and were facing constraints to buy their antipsychotic medication.

Having a job was not helpful for all, some found it challenging to perform their roles and a few were afraid of the dangers in their working environment, some also had

challenges to have positive relations with colleagues in the working/school environment. From both the quantitative and qualitative data it is possible to conclude that functional disability has a close relationship with recovery. Having a job which is appropriate to individuals' specific health conditions would enhance recovery by keeping them engaged in life, generating income for their treatment and basic needs, and also make them physically active and healthy.

5.3.6. Central obesity

Central-obesity was found to be one of the significant negative predictors of subjective recovery at the baseline measurement (Unstandardized Coefficient B = -1.53, P = 0.014). This is an important and novel finding because, although some qualitative studies have reported that good physical health was an important treatment goal for people with first-episode psychosis (Ramsay et al., 2011), no other studies yet identified this statistically significant association with quantitative data. Sedentary lifestyles, iatrogenic effects of medications, poor nutritional practice and genetic factors of individuals with SMI place individuals with mental illness at a higher risk of physical health problems that eventually result in not only poor recovery but also a reduced life expectancy (Bradshaw & Mairs, 2014; Bressington et al., 2016). Individuals with SMI taking multiple and higher doses of psychiatric medications were found to have both poorer quality of life and poor physical health (Bressington et al., 2016; Kolotkin et al., 2008).

The impact of central obesity on subjective recovery level may be explained by the fact that being obese results in less social engagement, perpetuates stigma and damages self-esteem, all of which can negatively impact upon levels of subjective recovery (Oh, Song, & Shin, 2017). Indeed, these physical health problems not only

affected subjective recovery, but they also constitute some of the main causes of early deaths for people with SMI (Bressington & White, 2015; Das-Munshi et al., 2016; Yasamy et al., 2014). Physical health problems like infectious diseases were found to be the main reasons for early death in people with SMI in Ethiopia (Teferra et al. 2011). The current study also documented that 11.9 % to 17.4% of study participants were underweight for their BMI indicating they were either undernourished and/or had physical health problems which could cause for early death as also found in an earlier study in Ethiopia (Fekadu et al. 2015). The most concerning thing in this regard is that despite their potentially devastating consequences, the physical health concerns of the people with mental illnesses are not given due emphasis (Coyne & Schwenk, 1997; World Health Organization, 2008) as also conveyed in the qualitative part of this study. Some previous studies have also reported that improvements in physical activity and health are associated with reduced psychotic symptoms, enhanced psychosocial functioning and quality of life (Bressington et al., 2018; Firth et al., 2018; Kolotkin et al., 2008).

Physical health concerns such as weight gain/central obesity is also reflected in one of the themes identified from the participants' narratives i.e., *altered health, psychiatric treatment and side effects of antipsychotic.* Participants clearly recognized that not only their mental health, but their physical health also was altered. As indicated in the previous studies, this study also found that the physical health concerns of the service users were not given due emphasis by health service providers despite them having several and continuous complaints (Ramsay et al., 2011; World Health Organization, 2008; Yasamy et al., 2014).

The benefit of antipsychotics was well acknowledged in controlling the devastating psychotic symptoms; however, the side effects were also prominently hindering their recovery through several mechanisms including causing weight gain. There is plenty of evidence on the undesired effects of antipsychotics on recovery and some studies report better functional and symptomatic outcomes for patients who were not on antipsychotics (Eisenstadt et al., 2012; Harrow et al., 2009; Harrow & Jobe, 2007; Harrow et al., 2012; Lam et al., 2011; Woodside et al., 2007). A hospital-based study in Ethiopia also found that the presence of antipsychotic side effects predicted psychotic relapse (Fikreyesus et al., 2016), which might also indicate that side effects are likely to impact subjective recovery.

From the extant literature and findings of the current study, it is possible to conclude that service users with recent-onset psychosis who are on antipsychotic treatment have high levels of physical health problems that affect their recovery. These physical health problems might arise from low physical activity, social isolation, feelings of incompetence, stigma, sedation and metabolic effects of the antipsychotics. However, their physical health concerns/complaints were not recognized by both family and health care providers. Findings from both study approaches and literature in the area thus suggest that, by improving physical health and helping service users to have active lifestyle, it may be possible to enhance subjective recovery.

5.4. Strengths and Limitations of the Study

Considering the individualistic and non-linear nature of recovery from psychosis, this study adopted a longitudinal observational sequential explanatory mixed-methods design. Most of the strengths and limitations of the study arise from the study design.

In terms of the strengths, the study employed a mixed-methods study design that enables to attest the quantitative findings with the qualitative findings, and hence the individualistic nature of subjective recovery from recent-onset psychosis was addressed properly. By employing repeated assessments in the quantitative measurements, the non-linear nature of subjective recovery and the variability of its related factors was addressed. Findings from the qualitative interviews were helpful to understand the local health services, culture and habits that influence health care seeking behaviour and the overall progress of recovery.

The study was conducted in three hospitals using a sufficiently-powered large sample size with reasonable retention rate. Appropriate analysis and interpretation techniques for both quantitative and qualitative results, and combined interpretations were employed that make the study valid, reliable and rigorous. Furthermore, the validity and reliability of the study instruments were also tested prior to the main study.

The critical evidence gap about recovery from psychosis in low-income countries could not be addressed by this study alone. As to my knowledge, this study is the first study measuring subjective recovery from recent-onset psychosis in a developing country, particularly Sub-Saharan Africa. Thus, the findings of this study make a significant contribution to the knowledge in the field. Besides, this study pioneered in identifying some new and culture-specific influencing variables such as central obesity and the community's shared understanding of the illness and its treatment.

In relation to limitations, the study is a naturalistic observational study; hence, it could not demonstrate cause and effect relationships in related variables. The majority of individuals with SMIs in Ethiopia are not getting treatment from hospitals and the participants in this study were those symptomatically stabilized individuals sampled

only from outpatient departments of the three study hospitals. Hence, the findings of the study only represented those stable outpatients engaged in treatment. Those who disengaged from the study may have a different progress and level of recovery. These disengaged individuals were not also represented in the qualitative interviews, they could possibly have different experiences and conceptualizations of recovery and hence had different challenges.

The study mostly relies on self-report data gathered by psychiatric nurses working at the study hospitals. Therefore, there might be some reporting biases; for example, participants might over report levels of recovery, underreport substance use and level of disability or vice-versa based on their perceived desire, or through trying to present an overly positive picture of their progress to clinical staff.

Only the most prominent potentially related variables identified from the systematic review were surveyed in the quantitative part of the study (Temesgen et al., 2019a) and thus other potentially important influences were not captured quantitatively. Nevertheless, many additional issues explored in the succeeding qualitative interviews which could perhaps be taken as a strength of the overall study. For example, visiting to spiritual and traditional healing sites were reported as influencing factor in the qualitative interviews; however, in the quantitative part this variable was not assessed and therefore the influence of spirituality and use of spiritual and traditional healing practices on recovery was not statistically tested.

CHAPTER 6. IMPLICATIONS AND CONCLUSIONS

6.1. Introduction

This final chapter presents the study's unique contribution to knowledge in the field. The implications of the study for psychiatric care, health services policy and future research are also discussed. Finally, the overall conclusions are presented.

6.2. Study Contribution to Knowledge

This study is the first to explore subjective recovery and to involve a large number of service users with recent-onset psychosis in a longitudinal mixed-methods design, resulting in the generation of robust evidence. Compared to previous studies conducted in high-income Western countries, the level of subjective recovery appeared to be better among Ethiopians with recent-onset psychosis. This observation seems to concur with and perhaps strengthen previous reports indicating that better rates of recovery existed in low-income countries. The findings also suggest that improving quality of life, boosting hope, reducing internalized stigma, providing needs-based social support, engaging in daily life and activity and maintaining a healthy physical health state might enhance subjective recovery.

Service users with recent-onset psychosis affirmed that their recovery should be defined not only in terms of improved psychotic symptoms and functional impairments they had, but also being able to live without antipsychotics, reconciling with the altered reality and building new life and hope. Another important contribution to the knowledge in the field is that the community's collective understanding of the illness and related social process to psychosis management is a new culture-specific concept which impacts psychiatric treatment initiation, engagement and recovery in

Ethiopia. Almost all previous studies documented that having a job enhances recovery, and this is also supported by the findings of this study. However, this study found that the job/work and roles of individuals with mental illness in Ethiopia are usually assigned by others (mainly family members), and these can cause distress and even life-threatening dangers which might also hinder recovery. These findings may help to inform the development of recovery focused psychiatric services for people with recent-onset psychosis in Ethiopia and possibly to the wider Sub-Saharan African region.

6.3. Implications for Practice and Policy

Participants were found to have an optimistic view of their future health, but this might not be based on the true understanding of the realities about the illness and its treatment requirements. They might experience a drastic reduction of hope if they continue to experience symptoms/relapsing illness or even if they continue taking medication for longer than their expected timeframe. Nurses and other clinical staff might be perpetuating this idea by not providing realistic information and advice about the illness and its treatment, and these ideas are also likely to be reinforced by the local society's understanding of mental illness. It is important that service users have optimistic but realistic views about the illness prognosis. Their illness might need long term treatment with possibility of symptomatic relapse contradicting service users' expectation of being cured in a specific period of treatment. Thus, it is important to maintain realistic hope to support subjective recovery and sustain the achieved recovery level. This could be achieved by introducing a culturally appropriate and empowering psychoeducational component to their treatment, which would involve

training nurses how to exchange realistic information with service users in an appropriate and positive way.

In this study, it was found that individuals with recent-onset psychosis who were attending outpatient psychiatric treatment had consistently high levels of subjective recovery. From the literature, it was also learned that the majority of individuals with psychosis in low-income countries are not getting treatment for their illness. The majority of the study participants were also visiting spiritual healing sites, most by discontinuing their psychiatric treatment. In addition, some service users believed they could stop their antipsychotics once their symptoms had resolved. This perception could be shared within the family members who have important role in service users' treatment decision. Thus, service users and their family need to be informed that any dose reduction or treatment discontinuation should be discussed and decided together with psychiatric care providers.

Although only a few have disclosed, service users also interrupted their treatment due to financial constraints, and hence the government should make the service affordable to these people whom most have no income through either community-based health insurance which is being exercised in the country in recent years or community-based interventions (Asher et al., 2018; Hanlon et al., 2019). The policy should devise mechanisms to broaden the health service coverage not only in treatment initiation but also to reduce the disengagement rate since the illness often requires long term treatment.

Almost all participants received healing services from spiritual or traditional healing practices before having the western psychiatric treatment and/or engaged in spiritual and traditional healing practices concurrently, indicating a very strong conviction

towards spiritual and traditional healing in the community. If these people are forced to choose between the western and spiritual/traditional approaches they may be likely to disengage with western treatments. Engaging in traditional healing may help or hinder subjective recovery, but the effect is currently undocumented. It may be also wise if the main stakeholders work to integrate the two sectors (spiritual healing sites and Western treatment modalities) that the community is mostly visiting. Individuals may benefit if they could have access to antipsychotic medications while they are attending their spiritual healing care (Ofori-Atta et al., 2018). The health care system should also assure that the psychiatric care they provide is culturally and contextually appropriate to the population and hence increase service users' engagement rate (Dixon, Holoshitz, & Nossel, 2016; Leamy et al., 2011).

The results of this study highlighted that the life experiences of Ethiopians with psychosis are heavily influenced by society's understanding and attitude towards the illness. Mental health literacy programmes for the public need to inform the community that mental illness could be treated, and those who receive treatment can benefit greatly, as evidenced by high levels of recovery in this study. Service users with psychosis were also found to have high physical health problems which impacted their recovery coupled to internalized stigma and functional disabilities. These components could be addressed by improving the overall health literacy of service users (Zheng et al., 2018). Clinicians, social care providers and the community need to be aware that individuals with SMI require health care beyond their mental illness and hence to reduce early deaths in this population group (Cabassa, Ezell, & Lewis-Fernández, 2010; Vancampfort et al., 2019).

The other important finding of this study is that individuals who have better satisfaction with social support were found to have better subjective recovery levels. Besides, strong familial interdependence was also reported that some felt being controlled. These prominent findings suggest that interventions such as psychoeducation should involve family members. Previous individual studies and systematic reviews found that psychoeducation interventions involving family members have several favourable impacts not only to the family members but also the clinical, functional and subjective recovery outcomes of the service users with SMI (Pekkala & Merinder, 2002; Pharoah, Mari, Rathbone, Wong, & Pharoah, 2006). In this study it was also found that roles and responsibilities assigned to service users were distressing for some, and hence family members need to be informed about it and employers should be considerate for their employee's health states. The government and other stakeholders might also consider supported employment as part of recovery-oriented psychiatry service (Modini et al., 2016). Although the effectiveness of mental health service in the country is constrained by overcrowding, busy psychiatric care providers in daily routines, and limited expertise and resources, the health care system could consider group interventions. There are several effective group and family inclusive interventions conducted in high income countries (Pekkala & Merinder, 2002); however, none of them are yet adopted to the Ethiopian context and tested for their feasibility and efficacy in terms of subjective recovery. Therefore, future research should target to fill the gap as suggested below.

6.4. Implications for Research

Evidence in the field of recovery from SMI is scant from low and middle-income countries particularly Sub-Saharan African countries. Given that the health care

seeking and engagement rate for mental illnesses is low in Ethiopia future research needs to explore the overall treatment seeking, preferences and practices of the community. Particular attention should be given to identifying the reason/s for a low rate of treatment coverage. Most importantly, future research should target on the short- and long-term illness prognosis and recovery outcomes of individuals with SMI who are not receiving or engaging to their psychiatric treatment in health institutions but are receiving healing services from spiritual and/or traditional sites. Besides low treatment coverage, there is also conflicting evidence if continuous antipsychotic treatment is helpful for long term recovery outcomes, particularly for subjective and functional recovery outcomes. Future research should also involve participants from different settings such as communities without psychiatric treatment available, different health service provision sectors, traditional and spiritual healing sites. The study recruited individuals with recent-onset psychosis irrespective of the duration of treatment, and hence it failed to detect significant changes in majority of the study variables such as subjective recovery, psychotic symptoms and functioning. Future research can have a better chance to detect the progress in these variables if it recruits participants with first treatment contact. Maximum attempts should be made to trace those individuals who have discontinued their treatment and explore their prognosis and reason/s for disengagement. As emphasized throughout the thesis the individualistic nature of subjective recovery could be addressed by utilizing different study approaches and therefore future studies could consider complementing both interventional and observational studies with qualitative methods.

This nine-month naturalistic observational study has made a significant contribution to the evidence base, however, as to the enduring nature of the illness and treatment, follow-up studies for a longer duration considering several other potentially related

variables are suggested. By doing so, it may be possible to make more conclusive generalizations about the recovery levels and its related factors in low-income countries particularly in an Ethiopian context.

Learned from the findings of this study, future studies may focus on developing or adapting interventions targeting the improvement of the quality of life and need-based social supports. Studies may also target culture and context-specific interventions on reducing internalized stigma, disability, physical illness and hopelessness. Future studies may devise or adopt possible interventions to increase early initiation and adherence of psychiatric treatment, such as Adherence Therapy (Gray et al., 2016). Researchers should put efforts to develop possible strategies to integrate the two commonly used sectors i.e., spiritual/traditional healing and Western psychiatric treatment modalities and test its effectiveness with appropriate study designs.

6.5. Conclusion

Subjective recovery is an important and seminal component of the overall recovery from psychosis that service users and family members are hoping for. A nine months longitudinal sequential explanatory mixed-methods study was conducted to assess the levels, progress and conceptualizations of subjective recovery from recent-onset psychosis and determine related factors among service users in three hospitals of North-western Ethiopia. The level of subjective recovery from recent-onset psychosis was found to be high and the mean value was consistent over nine months. However, continuous decline in significantly associated variables such as hope and quality of life would indicate the currently achieved recovery scores might decline over time. Participants in the qualitative interviews conceptualized their recovery in-terms of reduced and controlled psychotic symptoms, antipsychotic treatment and its side

effects, functioning, and altered perception, relationship, role and identity. Although most shared major defining components of recovery, individual differences in conceptualizing recovery were witnessed in this study.

Both the quantitative and qualitative approaches identified factors related to subjective recovery and these two sources of data were found to complement and explain each other. Quality of life was found to be the most significant predictor of subjective recovery throughout the follow-up period. Internalized stigma, hopelessness, functional disability, satisfaction with social support and central obesity were significantly related with subjective recovery in the quantitative measurements. These variables were also explained by findings from the qualitative interviews such as altered physical and mental health, antipsychotics side effects, strong familial interdependence, strong faith and reliance on spirituality, impaired functioning, challenges in working environment and related economic constraints. While most of the related factors are in line with the previous studies conducted in western countries, some new findings such as the relationship between central obesity and subjective recovery and culture-specific components such as collective understanding and social process to psychosis management were identified. Delayed treatment initiation and profound treatment disengagement for different reasons such as preference for traditional and spiritual practices, misunderstanding about psychosis and its treatment, treatment side effects and even economic constraints are among the other important findings of this study.

APPENDICES

Appendix 1. Consent to Participate in Research

1.1. Amharic Version

ከአእምሮ ሕመም የማገገም ሂደትና ተያያዥነት ያላቸው ጉዳዮች: ጥምር የጥናት ዘዴ

እኔ _____ በዚህ ጥናት; በፕሮፌሰር ቺን ዋይ ቶንግ እና ዶ/ር ብረሲንግተን ዳንኤል (ረዳት ፕሮፌሰር) ተቆጣጣሪነት በወርቁ አንማው ተመስገን (የፒኤችዲ ተማሪ) በሚደረግ ጥናት ላይ ለመሳተፍ ተስማምቻለሁ።
እኔ ከዚህ ምርምር የተገኙ መረጃዎች ወደፊት ጥናት ውስጥ ጥቅም ላይ ሊታተሙ እንደሚችል እረዳለሁ. ሆኖም ግን, ማለትም, የግል መረጃዎቼ/ዝርዝሮቼ አይገለጡም።
በተሰጠው የመረጃ ወረቀት ውስጥ የተቀመጠው አሰራር ሙሉ በሙሉ ተብራርቶልኛል፤ የተካተቱትን ጥቅሞች እና አደጋዎች ተረድቻለሁ። በፕሮጀክቱ ውስጥ ያለኝ ተሳትፎ በፈቃደኝነት ነው።
ማንኛውንም የአሰራር ሂደቱን የመጠየቅ መብት እንዳለኝ ተርጋግጦልኝል እናም በማንኛውም ጊዜ በማንኛውም መልኩ ማቋረጥ እችላለሁ።

ተሳታፊው ስም:
ተሳታፊው ፊርማ፡

ተመራማሪው ስም፡ <u>ወርቁ አንማው ተመስገን</u>
ፊርማ፡

1.2. English Version

Progress of recovery and its associated factors in patients with early onset psychosis: A mixed-methods study

I _____ hereby consent to participate in the captioned research supervised by *Chien Wai Tong (Prof)* and *Bressington Daniel Thomas (Asst Prof*) and conducted by *Worku Animaw Temesgen (PhD Student*).

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefits and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant:

Signature of participant

Name of researcher Worku Animaw Temesgen

Signature of researcher

Date

Appendix 2. Information Sheet

2.1. Amharic Version

ከአእምሮ ሕመም የማገገም ሂደትና ተያያዥነት ያላቸው ጉዳዮች: ጥምር የጥናት ዘዴ

በፕሮፌሰር ቺን ዋይ ቶንግ እና ዶ/ር በረሲንግተን ዳንኤል (ረዳት ፕሮፌሰር) ተቆጣጣሪነት በወርቁ አንማው ተመስገን (ፒኤንዲ ተማሪ) በሆንግ ኮንግ ፖልቲክኒክ ዩኒቨርሲቲ ነርሲንግ ትምህርት ቤት ተማሪ በሚደረግው ምርምር ውስጥ እንዲሳተፉ ተጋብዘዋል።

አላማ፡- ይህ ጥናት በቅርቡ የእንእምሮ ህመም ያጋጠማቸውን ሰዎች የመሻሻል/ማገገም መጠን በሦስት ግዜ ምርመራዎች ለማወቅ እና በግዜ ሂደት ውስጥ ያለውን የመሻሻል ሄድትና ተዛማጅ ጉዳዮችን ለማወቅ ነው።

ስልት-ይህ ተከታታይ ጥምር የጥናት ዘዴ በቅርብ ጊዜ ውስጥ የአእምሮ ጤና ችግር ካጋጥማችው ግለሰቦች መካከል በኢትዮጵያ ሆስፒታሎች ውስጥ ህክምናቸውን በተምላላሽነት የሚከታተሉት ላይ ይካሄዳል። የመጀመሪያው ክፍል የጥናት ክትትል በ 9-ወራት የመከታተያ ጥናት (የመጀመሪያ, 3 ኛ እና 9 ኛ ወር) ቃለ-መጠይቅ እና ሌሎች አካላዊ ጤና መለኪያዎች ናቸው። ሁሉም አስፈላጊ መረጃዎች በቃለመጠይቅ እና አካላዊ ጤና ምርመራዎች ይገመገማሉ። ሁለት መቶ ሰባ ግለሰቦች የተፈረመውን ስምምነት ከተፈረሙ በኋላ ከሶስት ሆስፒታሎች በአጋጣሚ ይመረጣሉ. በጥናቱ ሁለተኛ ክፍል የሕመምተኞችን ግንዛቤ እና ልምዶች በተሻለ ሁኔታ ለመረዳት, ከላይ በተጠቀሰው ተመሳሳይ ሁኔታ ከ 15 ከተስማሙ ተሳታፊዎች በጥራት ቃለ-መጠይቅ ይደረጋል.
ለጥናት ጥያቄዎች ምላሽ ለመስጠት ከሚወስደው ግዜ በስተቀር በዚህ ጥናት ውስጥ መሳተፍ ምንም አደጋ የለውም።
ጥናቱ ክመጀመሩ በፊት ወይም በሂደቱ ወቅት ምንም አይነት ቅጣት ስያኖረው የማቆም መብት አለዎት። እርስዎን የሚመለከቱ መረጃዎች ሁሉ በሚስጢር ይጠበቃሉ፤ ለተመራማሪው ብቻ በሚታወቁ ኮዶች ሊለዩ ይችላሉ.
በዚህ የምርምር ጥናት አሰራር ላይ ማንኛውም ቅሬታ ካለዎት, ለሆንግ ኮንግ ፖሊቴክኒክ ዩኒቨርሲቲ የሰብዓዊ ስነ ምግባራዊ ንኡስ ኮሚቴ ፀሀፊ ወ/ሪት ቸሪ ሞክ, በአካል ወይም በፅሁፍ ለማነጋገር አያመንቱ.

ይህንን ጥናት በተመለከተ ተጨማሪ መረጃ ከፈለጉ በስልክ ቁጥር + 251-91227 **ወይም ሀላፊውን ፕሮፌሰር ቺን በ**(852) 2766 **ደውለው ማነጋገር ይችላሉ።**
በዚህ ጥናት ውስጥ ለመሳተፍ ፍላጎት ስላሳዩ እናመሰግናለን.
ዋና ተመራማሪ: ወርቁ አንማው ተመስገን

2.2. English Version

Progress of recovery and its associated factors in patients with early onset psychosis: A mixed-methods study

You are invited to participate in a study supervised by *Chien Wai Tong (Prof)* and *Bressington Daniel Thomas (Asst Prof*) and conducted by *Worku Animaw Temesgen (PhD Student*) who is student in the School of Nursing at The Hong Kong Polytechnic University.

Aim: This study is being conducted to investigating the levels of recovery at three measurements, thus examining the progress of recovery over time, and identify the predictive factors of recovery in recent onset psychosis patients in Ethiopia.

Method: This is a sequential mixed method (quantitative followed by qualitative) study. It will be conducted in hospitals of Ethiopia among individuals with mental health problem happened recently and having follow-up for their mental health improvement in outpatient clinics. The first part the study is nine-month observational follow-up study with three-time point (first, 3rd month and 9th month) interview and other physical health measurements. All required data will be assessed by interview and non-invasive physical health measurements. Two hundred and seventy individuals will be randomly selected from three hospitals after getting their signed consent. In the second part of the study, to get better insight to patients' understanding and experiences, qualitative interview will be conducted from 15 consented participants with the same condition mentioned above.

There is no risk in participating with this study, except spending time to respond for the study questions.

You have every right to withdraw from the study before or during the measurement without penalty of any kind. All information related to you will remain confidential and will be identifiable by codes known only to the researcher.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Miss Cherrie Mok, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Research Office of the University), stating clearly the person and department responsible for this study.

If you would like more information about this study, please contact Worku Animaw at telephone number +251-91227 or their supervisor Prof Chien at telephone number (852) 2766

Thank you for your interest in participating in this study.

Principal Investigator: *Worku Animaw Temesgen*

Appendix 3. Data collection checklist from medical record

Sr N.	Variable (Item)	
1	Chart number	
2	Patient Name	
3	Sex/gender	
4	Age	
5	Address	
6	Date of first contact/diagnosis	
7	Duration of illness before contact	
8	Duration with current diagnosis in month	____month
9	Medical diagnosis	
10	Medical treatment given	
11	Any history of admission for mental illness reason	
12	If “yes” how many times	

Appendix 4. General information of participants

Socio-demography			
S.N	Question	Response	
1	Identification of interviewee (Patient Chart Number)		
2	Date of interview	DD / MM / YY ____/_____/_____	
3	Residence	1. Urban 2. Rural	
4	Marital Status	1. Single/never married 2. Married/cohabitant 3. Separated/ Divorced 4. Widowed 5. Other	
5	Education Status	1. Unable to read and write 2. Read and write only 3. Primary School 4. Secondary School 5. College diploma and above	
6	Religion	1. Orthodox 2. Muslim 3. Protestant 4. Catholic 5. Other	
7	Occupation	1. Have no job 2. Student/Employed/Merchant/Private work 3. Farmer 4. House wife 5. Other	
8	Number of family size?	____	
9	Current living status	1. Alone 2. With Parents 3. With spouse 4. Other	
10	Average Family monthly income from any source	_____Birr/month	
Substance Use: Now I am going to ask you some questions about various substance use behaviours; like smoking, drinking alcohol, eating fruits and vegetables and physical activity.			
Cigarette: Let's start with tobacco			
1.	In your life, have you ever smoked cigarettes, or tobacco?	1. Yes 2. No	
2.	Are you currently smoking?	1. Yes 2. No	
Alcohol: The next questions ask about the consumption of alcohol			
1.	Do you consume alcoholic drink such as beer, draft, wine, Arekie, Tej, Tella etc..	1. Yes 2. No	
2.	During the past 30 days, on how many occasions did you have at least one alcoholic drink?	1. __occasions 2. Not sure	

Khat Consumption: The next questions ask about khat consumption.			
1.	Do you chew Khat?	1. Yes 2. No	
2.	Have you used any other drugs?	3.	
Medication Adherence			
1.	Do you ever forget to take your medicine?	1. Yes 2. No	
2.	Are you careless at times about taking your medicine?	1. Yes 2. No	
3.	When you feel better do you sometimes stop taking your medicine?	1. Yes 2. No	
4.	Sometimes if you feel worse when you take the medicine, do you stop taking it?	1. Yes 2. No	
Physical health measurements			
1.	Weight (kg)	___/___/.__/__/	
2.	Height (cm)	___/___/.__/__/	
3.	Waist circum. (cm)	___/___/.__/__/	
4.	Hip circum. (cm)	___/___/.__/__/	
5.	Calculated BMI	___/___/.__/__/	
6.	WHR	___:___	
Blood Pressure			
1.	Systolic pressure in mmHg	_____ mmHg	
2.	Diastolic pressure mmHg	_____mmHg	
3.	Pulse (beats per minute)	_____bt/min	

Appendix 5. Positive and Negative Syndrome Scale (PANSS)

1=Absent, 2=Minimal, 3=Mild, 4=Moderate, 5= Moderate severe, 6= Severe,7=Extreme		
	Positive Scale (P)	Score
P1	Delusions	
P2	Conceptual disorganization	
P3	Hallucinatory behaviour	
P4	Excitement	
P5	Grandiosity	
P6	Suspiciousness/persecution	
P7	Hostility	
	Negative Scale (N)	Score
N1	Blunted affect	
N2	Emotional withdrawal:	
N3	Poor rapport	
N4	Passive/apathetic social withdrawal:	
N5	Difficulty in abstract thinking	
N6	Lack of spontaneity and flow of conversation	
N7	Stereotyped thinking	
	General Psychopathology Scale (G)	Score
G1	Somatic concern	
G2	Anxiety:	
G3	Guilt feelings:	
G4	Tension:	
G5	Mannerisms and posturing:	
G6	Depression: F	
G7	Motor retardation:	
G8	Uncooperativeness	
G9	Unusual thought content	
G10	Disorientation:	
G11	Poor attention:	
G12	Lack of judgment and insight:	
G13	Disturbance of volition:	
G14	Poor impulse control:	
G15	Preoccupation:	
G16	Active social avoidance:	

Appendix 6. Internalized Stigma of Mental Illness (ISMI-9)

6.1. Amharic Version

ቀጥሎ ባሉት ጥያቄዎች ውስጥ ‘‘የአዕምሮ ህመም’’ ሚለውን ሀርግ እንጠቀማልን፥ ይህ ሀረግ ማይመችዎት ከሆነ ለርስዎ ትክክል የሚምስለዎትን ማንኛውም ቃል ማሰብ ይችላሉ።

ለእንዳንዱ ጥያቄ 4 የመልስ አማራጮች አሉት፡ እነሱም 1) በጣም አልስማም፥ 2) አልስማም፥ 3) እስማማለሁ፥ 4) በጣም እስማማለሁ ናቸው።

ተ.ቁ	ጥያቄ	በጣም አልስማም	አልስማም	እስማማለሁ	በጣም እስማማለሁ
1	ማህበረሰቡ በአዕምሮ ህሙማን ላይ ያለው የተሳሳቱ ድምዳሜዎች በእኔም ላይ ይደርሳሉ	1	2	3	4
2	ባጠቃላይ መኖር የምፈልገውን አይነት ኑሮ እየኖርኩ ነው።	1	2	3	4
3	ስለአእምሮ ህመም በማህበረሰቡ ዘንድ ያሉ የተሳሳቱ ግንዛቤዎች/ድምዳሜዎች ከተለመደው የአኗኗር ሁኔታ እራሴን እንዳገል አድርጎኛል	1	2	3	4
4	የአዕምሮ ህመምተኛ ስለሆንኩ በዚህ አለም ላይ ቦታ የሌለኝና የተገለልኩ እንደሆነ ይሰማኛል	1	2	3	4
5	የአዕምሮ ህመምተኛ ካልሆኑ ሰዎች ጋር ስሆን ብቁ እንዳልሆንኩና ያለቦታየ እንደተገኘሁ ስሜት ይሰማኛል	1	2	3	4
6	የአዕምሮ ህመምተኛ ያልሆኑ ሰዎች እኔን ሊረዱኝ/ሊገነዘቡኝ አይችሉም	1	2	3	4
7	የአዕምሮ ህመምተኛ በመሆኔ ማንም ሰው ከእኔ ጋር የቀረበ ግንኙነት እንዲኖረው አይፈልግም	1	2	3	4
8	የአዕምሮ ህመምተኛ ስለሆንኩ ለማህበረሰቡ ምንም ማበርከት አልችልም	1	2	3	4
9	የአዕምሮ ህመምተኛ ብሆንም እንኳ መልካም የሚባል፥ የተሟላ ኑሮ መኖር እችላለሁ።	1	2	3	4

6.2. English Version

We are going to use the term “mental illness” in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it.

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

SR No	QSn	Strongly disagree	Disagree	Agree	Strongly disagree
1	Stereotypes about the mentally ill apply to me.	1	2	3	4
2	In general, I am able to live life the way I want to.	1	2	3	4
3	Negative stereotypes about mental illness keep me isolated from the ‘normal’ world.	1	2	3	4
4	I feel out of place in the world because I have a mental illness.	1	2	3	4
5	Being around people who don’t have a mental illness makes me feel out of place or inadequate.	1	2	3	4
6	People without illness could not possible understand me	1	2	3	4
7	Nobody would be interested in getting close to me because I have a mental illness.	1	2	3	4
8	I can’t contribute anything to society because I have a mental illness.	1	2	3	4
9	I can have a good, fulfilling life, despite my mental illness.	1	2	3	4

Appendix 7. Social Support Questionnaire - Short Version (SSQ6)

7.1. Amharic Version

መመሪያ

ቀጥሎ ያሉት ጥያቄዎች ባካባቢዎ ካሉ ሰዎች (ቤተሰብ/ጓደኛ) እነማን እንደሚርዱዎ/እንደግዙዎ የሚጥይቁ ናቸው። እያንዳንዱ ጥያቄ ሁለት ክፍል አለው።
የመጀመሪያው ክፍል እነማን እደሚያግዙዎ ስማቸውንና ዝምድናቸው/ከርስዎ ጋር ያላቸውን ግንኙነት እንዲዘረዝሩልን ሲሆን ሁልትኛው ክፍል ደግሞ ለመጀመሪያው ክፍል ለተገለጠው ድጋፍ ምን ያክል እንደረኩ የርካታ መጠንዎን ሚጠይቅ ነው።
ለመጀመሪያው ክፍል ጥያቄ መልስዎ "ማንም" ሚለው ቢሆንም እንኳን የርካታ መጥንዎን ግን ይገልፁልናል::

እባክዎ ሁሉንም ጥያቄዎች በሚችሉት መጠን ይመልሱ። የሚሰጡን መልስ ሚስጥርነቱ የትጠበቀ ነው።

ለምሳሌ : **እጅግ ሲብሳጩ ሊያፅናናዎትና ሊያረጋጋዎት ሚችል ሰው ማን ነው**?

ማንም( )	2) **አ.በ(ጓደኛ)**	4) **አ.ን(አባት)**	6)	8)
1) **ሀ.አ(ወንድም)**	3) **ረ.ግ(ጓደኛ)**	5)	7)	9)

አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል?

6. **በጣም ረክቻለሁ**	5. **በመጠኑ ረክቻለሁ**	4. **ትንሽ ረክቼያለሁ**	3. **ትንሽ አልረካሁም**	2. **በመጠኑ አልረካሁም**	1. **በጣም አልረካሁም**

Section II

ተ.ቁ	**ጥያቄ**	**መልስ**					
1	**በጭንቀት ሲዋጡ ከጭንቀትዎ እንዲወጡ ሊያደርጉዎት የሚችሉ እነማንን ሊጠቅሱልኝ ይችላሉ**?	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1
2	**ጭንቀት ወይም ውጥረት ሲያጋጥምዎ የበለጠ ዘና የሚል ስሜት እንዲሰማዎ ሊያደርግ የሚችል ሰው ሊጠቅሱልኝ ይችላሉ?**	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1

3	**ያንተን ደካማም ጠንካራም ማንነትህን ሙሉ በሙሉ ማን ይቀበልሃል**?	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1
4	**ምንም ነገር ቢሆኑ/ቢያጋጥምዎ ይንከባከበኛል/አብሮኝ ይሆናል/ያስታምመኛል የሚሉትን ሰው ሊጠቅሱልኝ ይችላሉ?**	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1
5	**በአጠቃላይ እጅግ አስቸጋሪ (ጭልም ያለ) ስሜት ሲሰማዎት ይደርሱልኛል፥ የተሻለ ስሜት እንዲሰማኝ ያደርጋሉ ሚሏቸውን ሰዎች ቢጥቅሱልኝ**?	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1
6	**እጅግ ሲናድዱ ሊያፅናናዎት ሊያረጋጋዎት ሚችል ሰው ማን ነው**?	**ማንም** ( ) 1) 4) 7) 2) 5) 8) 3) 6) 9)					
	አጠቃላይ በነዚህ ሰዎችና ድጋፍ ድጋፍ ምን ያህል ረክተዋል	6	5	4	3	2	1

6. በጣም ረክቻለሁ	**5. በመጠኑ ረክቻለሁ**	**4. በትንሹ ረክቼያለሁ**	**3. በትንሹ አልረካሁም**	**2. በመጠኑ አልረካሁም**	**1. በጣም አልረካሁም**

7.2. English Version

Instructions
The following questions ask about people (family/friends) in your environment who provide you with help or support. Each question has two parts.

For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see the example). Do not list more than 1 person for each of the numbers beneath the question. Do not list more than nine persons per question.

For the second part, circle how satisfied you are with the overall support you have.

If the best answer for a particular question is no one, put a tick in the bracket next to "No one", but still rate your level of satisfaction.

Please answer all questions as best you can. All your responses will be kept confidential.

Example: Who can you count on to console you when you are very upset ?

No one( )	2) L.M. (friend)	4) T.N (father)	6)	8)
1) T.N. (brother)	3) R.S. (friend)	5)	7)	9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

---

Section II

1. Who can you count on to distract you from your worries when you feel under stress?

No one( )	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

---

2. Who can you really count on to help you feel more relaxed when you are under pressure or tense ?

No one( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

3. Who accepts you totally, including both your worst and your best points?

No one( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

---

4. Who can you really count on to care about you, regardless of what is happening to you?

No one( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

---

5. Who can you really count on to help you feel better when you are feeling generally down-in-the-dumps ?

No one( ) 1) 4) 7)
2) 5) 8)
3) 6) 9)

How satisfied overall?

6- very satisfied 5- fairly satisfied 4- a little satisfied 3- a little dissatisfied 2- fairly dissatisfied 1- very dissatisfied

6. Who can you count on to console you when you are very upset?

No one( )	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

How satisfied overall?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

Appendix 8. WHOQOL-BREF English Version

8.1. Amharic Version

መመሪያ

ይህ መጠይቅ ስለህይዎትዎ ጥራት/የንሮ ሁኔታ፤ ጤንነትዎና ተዛማጅ ሁኔታዎች ነው። እባክዎ ሁሉንም ጥያቄዎች ለርስዎ ትክክል የሆነውን መልስ ይመልሱ። ለጥያቄዎቹ ሲመልሱ ባለፈው ሁለት ሳምንት ውስጥ ያለዎትን የንሮ ሁኔታ፥ ተስፋ፥ ደስታና ስጋት እያሰቡ ይሁን። ለእያንዳንዱ የምጠይቅወት ጥያቄ 5 የመልስ አማራጮች አሉት። እንደየጥያቄው አግባብነት ሊስተካከል ቢችልም በዋናነት መልሶቹ፥

1. **የለም**
2. **በትንሽ**
3. **መካከልኛ**
4. **በጣም ከፍትኛ**
5. **እጅግ በጣም ከፍትኛ የሚሉ ናቸው።**

		በጣም ዝቅተኛ	ዝቅተኛ	ከፍተኛም ዝቅተኛም አደልም	ከፍተኛ	በጣም ከፍተኛ
1	የህይወትዎን ጥራት ደረጃ እንዴት ይገመግሙታል?	1	2	3	4	5

		በጣም የማያረካ	የማያረካ	መካከለኛ	የሚያረካ	በጣም የሚያረካ
2	በጤናዎ ምን ያህል ረክተዋል?	1	2	3	4	5

ቀጥሎ ላሉት ጥያቄዎች ባለፈው ሁለት ሳምንት ውስጥ ምን ያክል እንዳጋጠመው ይነግሩኛል

		የለም	በትንሽ	መካከለኛ	በጣም ብዙ	እጅግ በጣም ብዙ
3	የአካል ህመም ምክንያት ማድረግ ካለብዎት ነገር ምን ያህል እንዳስትጓጎልዎት ይሰማዎታል?	1	2	3	4	5
4	ይዕለት ተለት እንቅስቃሴዎን ለመከወን ምን ያክል የህክምና እርዳታ ያስፈልግዎታል?	1	2	3	4	5
5	በህይወትዎ ምን ያክል ይደሰታሉ?	1	2	3	4	5
6	ህይወትዎ ምን ያክል ትርጉም አለው ብለው ይገምታሉ?	1	2	3	4	5

		የለም	በትንሽ	መካከለኛ	በጣም ብዙ	እጅግ በጣም ብዙ
7	አእምሮዎን ለማሰባሰብ (ትኩረት ለማድረግ) ምን ያህል አቅም አለዎት?	1	2	3	4	5
8	በእለታዊ ህይዎትዎ ምን ያህል ደህንነት ይሰማዎታል?	1	2	3	4	5
9	ምን ያክል የአካል ጤንነት ይሰማዎታል?	1	2	3	4	5

ላልፉት ሁለት ሳምንታት ቀጥሎ ያሉትን ጥያቄዎች/ነግሮች ምን ያህል በተሟላ ሁኔታ እንደሰሩ ይመልሱልኛል

		የለም	በትንሽ	መካከለኛ	በአብዛኛው	ሁሌም
10	ለዕለት ተዕለት እንቅስቃሴዎ በቂ ጉልበት አለዎት?	1	2	3	4	5
11	የአካልዎን ገፅታ በፀጋ ተቀብለዋል?	1	2	3	4	5
12	ፍላጎትዎን ለማሟላት በቂ ገንዘብ አለዎት?	1	2	3	4	5
13	በየእለቱ የሚያስፈላዎትን መረጃ ያገኛሉ	1	2	3	4	5
14	የመዝናኛ እንቅስቃሴዎችን የማግኘት አቅምዎ ምን ያክል ነው	1	2	3	4	5

		በጣም ዝቅተኛ	ዝቅተኛ	መካከለኛ	ጥሩ	በጣም ጥሩ
15	በአቅራቢያዎ ለመዘዋወር ምን ያክል አቅም አለዎት?	1	2	3	4	5

የሚከተሉት ጥያቄዎች ባለፉት ሁለት ሳምንታት ውስጥ ምን ያክል እርካታ፥ የደስታ፥ ወይም ጥሩ ስሜት እንዳደረብዎ የሚጠይቁ ናቸው

		በጣም የማያረካ	የማያረካ	መካከለኛ	የሚያረካ	በጣም የሚያረካ
16	በእንቅልፍዎ ምን ያክል ረክተዋል	1	2	3	4	5
17	ዕለታዊ የኑሮ እንቅስቃሴዎን በመምራት ምን ያክል ረክተዋል?	1	2	3	4	5
18	በስራ ችሎታዎ ምን ያክል ረክተዋል?	1	2	3	4	5
19	በራስዎ ምን ያክል ረክተዋል?	1	2	3	4	5
20	ከሰዎች ጋር ባለዎት ግንኙነት ምን ያክል ረክተዋል?	1	2	3	4	5
21	በወሲባዊ ህይዎትዎ ምን ያክል ረክተዋል?	1	2	3	4	5
22	ከጓደኞችዎ በሚያገኙት ዕርዳታ ምን ያክል ረክተዋል?	1	2	3	4	5
23	በመኖሪያ ቦታዎ ምን ያክል ረክተዋል?	1	2	3	4	5
24	ለጤና አግልግሎት አቅርቦት ያለዎት እርካታ ምን ያህል ነው?	1	2	3	4	5
25	በመጓጓዣ በኩልስ?	1	2	3	4	5

ቀጥሎ ያለው ጥያቄ ባለፍው ሁለት ሳምንት ግዜ ውስጥ ምን ያህል በተደጋጋሚ እንዳጋጠመዎ ነው

		በፍፁም አልፎ አልፎ	በተድጋጋሚ	ብዙ ግዜ	ሁልግዜ
26	አሉታዊ ስሜቶች፤ እንደመከፋት፥ ተስፋ መቁረጥ፥ ጭንቀት ወይም ድብርት ምን ያህል ተድጋግሞ ደርሶብዎታል?	1	2	3	4	5

ሌላ ሊነግሩን ሚፈልጉት ነገር አለ?.....

8.2. English Version

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

Do you get the kind of support from others that you need?	Not at all 1	Not Much 2	Moderately 3	A great deal 4	Completely 5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

Do you get the kind of support from others that you need?	Not at all 1	Not Much 2	Moderately 3	A great deal 4	Completely 5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	Extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extreme amount
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quit often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

How long did it take to fill this form out? .....

Do you have any comments about the assessment?.....
.....
.....
.....

THANK YOU FOR YOUR HELP

Appendix 9. World Health Organization Disability Assessment Schedule (WHODAS 2.0)

9.1. Amharic Version

ይህ ቃለመጠይቅ ሰዎች በጤና እክል ምክንያት ስለሚኖራቸው ችግር ይሆናል፡ ፡ የጤና እክል ስል በሽታ ወይም ህመም፤ ሌሎች ለአጭር ወይም ለረጅም ጊዜ የሚቆዩ የጤና ችግሮች፤ ጉዳቶች፤ የአዕምሮ ወይም የመንፈስ መታወክ እንዲሁም ከመጠጥ እና ከዕጽ ጋር የተገናኙ ችግሮችን ይሆናል፡ ፡ ቃለመጠይቁ ውስጥ ያሉ ጥያቄዎችን ሲመልሱ ሁሉንም የጤና ችግርዎንና ባለፈው 1 ወር ግዜ ውስጥ ያጋትጠመወን እንዲያስቡ እፈልጋለሁ፡ ፡ ጥያቄዎቹን ሲመልሱ እነዚህን አምስት የችግር ወይም የእክል ደረጃዎች ይጠቀሙ፡ ፡

1. **ምንም ችግር የለም** 2. **አነስተኛ ችግር** 3. **መካከለኛ ችግር** 4. **ከፍተኛ ችግር** 5. **በጣም ከፍተኛ ችግር ወይም ፈፅሞ መስራት አለመቻል**

	ባለፈው አንድ ወር ጊዜ ውስጥ ቀጥሎ ለምጠቅሳቸው ስራውች ለመከወን ምን ያክል ይቸገሩ ነበር?	**ምንም**	**አነስተኛ**	**መካከለኛ**	**ከፍተኛ**	**በጣም ከፍተኛ**
S1	**ረዘም ላለ ጊዜ ቆሞ መቆየት ምን ያህል ይቸግርዎት ነበር**? (**ለምሳሌ፡ ለግማሽ ሰዓት**)					
S2	**የቤትና የግቢ ውስጥ ስራዎችንና ሌሎች ኃላፊነቶችንመወጣት ምን ያህል ይቸግርዎት ነበር**?					
S3	**አዲስ ነገር ወይም ስራ ለመማር ምን ያህል ይቸግርዎት ነበር**? (**ለምሳሌ፡ የእርሻ ስራ፤ ባልትና፤ የእጅ ስራ ወዘተ...**)					
S4	**በማሕበራዊ እንቅስቃሴ ውስጥ (ለምሳሌ፡ አመት በዓል፤ ድግስ፤ ለቅሶ፤ እድር፤ ሊቃ ወዘተ...) ልክ እንደሌላው ሰው መሳተፍ ምን ያህል ይቸግርዎት ነበር**?					
S5	**በጤና ችግርዎ ወይም በሕመምዎ ምክንያት ስሜትዎ ምን ያህል ተረብሿ**?					
S6	**በሚሰሩት ስራ ላይ ለጥቂት ጊዜ (ለ**10 **ደቂቃ) ያህል ትኩረት ማድረግ ምን ያህል ይቸግርዎት ነበር**?					
S7	**የተወሰነ ርቀት መንገድ ለመጓዝ ምን ያህል ይቸግርዎት ነበር**? (**ለምሳሌ፡ የሩብ ሰዓት መንገድ ወይም አንድ ኪሎ ሜትር**)					

S8	ሰውነትዎን መታጠብ ምን ያህል ይቸግርዎት ነበር?					
S9	ልብስዎትን ለመልበስ ምን ያህል ይቸግርዎት ነበር?					
S10	ከማያውቋቸው ሰዎች ጋር ለመግባባት ምን ያህል ይቸግርዎት ነበር?					
S11	ከአንድ ሰው ጋር በጓደኝነት ለብዙ ጊዜ መቆየት ምን ያህል ይቸግርዎት ነበር?					
S12	የእለት ተዕለት ስራዎትን ወይም ትምህርትዎትን ለማከናወን ምን ያህል ይቸግርዎት ነበር?					
H1	በአጠቃላይ ባለፈው አንድ ወር ጊዜ ውስጥ እነዚህ ችግሮች ለምን ያህል ቀናት ነበሩ?	---------- ቀን				
H2	በባለፈው አንድ ወር ጊዜ ውስጥ በማንኛውም የጤና ችግር ምክንያት የተለመደ ስራዎትን ወይም እንቅስቃሴዎትን ሙሉ በሙሉ ማድረግ ያልቻሉት ለምን ያህል ቀናት ነበር?	---------- ቀን				
H3	በባለፈው አንድ ወር ጊዜ ውስጥ በማንኛውም የጤና ችግር ምክንያት (ሙሉ በሙሉ ምንም ስራ መስራት ያልቻሉበትን ሳይጨምር) የተለመደ ስራዎትን ወይም እንቅስቃሴዎትን ለመቀነስ የተገደዱባቸው ምን ያህል ቀናት ነበሩ?	---------- ቀን				

ስለተጠያቂው ተጨማሪ አስተያየት _____ ለተሳትፎዎ በጣም አመሰግናለሁ፡፡

9.2. English Version

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S1	Standing for long periods such as 30 minutes?	1	2	3	4	5
S2	Taking care of your household responsibilities?	1	2	3	4	5
S3	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
S4	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
S5	How much have you been emotionally affected by your health problems?	1	2	3	4	5
S6	Concentrating on doing something for ten minutes?	1	2	3	4	5
S7	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5
S8	Washing your whole body?	1	2	3	4	5
S9	Getting dressed?	1	2	3	4	5
S10	Dealing with people you do not know?	1	2	3	4	5
S11	Maintaining a friendship?	1	2	3	4	5
S12	Your day-to-day work/school?	1	2	3	4	5

H1	Overall, in the past 30 days, how many days were these difficulties present?	***Record number of days*** ____
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	***Record number of days*** ____
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	***Record number of days*** ____

Appendix 10. Beck's Hopelessness Scale

10.1. Amharic Version

ቀጥሎ ላሉት ጥያቄዎች፥ ጥያቄ የርስዎን ባለፈው ሳምንት ያለዎት አመለካከት የሚገልጥ ከሆነ "እውነት" ካልልሆነ ደግሞ "ሀሰት" በማለትት መልስ ይስጡኝ።

	ጥያቄ	መልስ 1. እውነት 2. ሀሰት
1	ወደፊት የሚሆነውን ሁሉ በጥሩ ተስፋና በጉጉት እጠባበቃለሁ	
2	ምንም ነገር በገዛ ራሴ መስራት፥ ማሻሻል ወይም መቀየር ስለማልችል ትቸዋልሁ	
3	አንዳንድ ጥሩ ያልሆኑ ነገሮች ሲፈጠሩ በዚህ ሁኔታ ለዘላለም እንደማይቀሩ መረዳቴ ያግዘኛል/ያፅናናኛል	
4	ከ10 አመት በሓላ ምን ሊመስል እንደሚችል ማስብ/መገመት አልችልም	
5	እጅግ ያስፈለግኝን ነገር ለማድረግ በቂ ግዜ አለኝ	
6	አሁን የሚያሳስቡኝ ነገሮች ወደፊት መልካም እንደሚሆኑ አምናለሁ	
7	መጭው ግዜየ/ህይወቴ ጨለማ ሆኖ ነው ሚታየኝ	
8	ከሌሎች የበለጠ እድለኛ ነኝ ወደፊትም መልካም ነገሮችን እጠብቃልሁ	
9	እስካሁን ምንም ፋታ አላገኘሁም ወድፊትም ተስፋ አላርግም	
10	ያለፈው ህይወቴ ቸግሮችን እንዴት መፈታት (እንዴት መኖር) እንዳለብኝ አስተምሮኛል	
11	ወድፊት የሚታየኝ/የሚጠብቅኝ ከሚያስድስተው ይልቅ የማያስደስተው ነገር ነው	
12	የምፍልገውን ነገር አገኛለሁ ብየ አልጠብቅም	
13	መጭውን ግዜ ሳስበው ካሁኑ የበለጠ/የተሻለ ደስተኛ እሆናለሁ አጠብቃለሁ	
14	ነገሮች እንደምፍልገው አይሆኑልኝም	
15	በመጭው ግዜ ፅኑ እምነት አለኝ	
16	የምፈልገውን ነገር አግኝቸ ስለማላውቅ ምንም ነገር መፈለግ/መመኘት ሞኝነት ነው	
17	ወደፊት እርካታ የማግኘቴ ነገር በጭራሽ ማይሆን ነገር ነው	
18	የወደፊቱ የኔ ሁኔታ የደበዘዘና ያልተረጋገጠ ነው	
19	ከመጥፎ ይልቅ ጥሩ ነገሮች ያጋጥሙኛል ብየ እጠብቃልሁ	
20	የምፈልገውን ስለማላገኝ ምንም ነገር መሞክሩ ከንቱ ድካም ነው	

10.2. English Version

For the following questions; please respond "true" the statement describes your attitude *for the past week, or "false"* if the statement is false for you.

	TRUE/FALSE?
1. I look forward to the future with hope and enthusiasm	
2. I might as well give up because there's nothing I can do to make things better for myself	
3. When things are going badly, I am helped by knowing that they can't stay that way for ever.	
4. I can't imagine what my life would be like in ten years.	
5. I have enough time to accomplish the things I most want to do.	
6. In the future I expect to succeed in what concerns me most.	
7. My future seems dark to me.	
8. I happen to be particularly lucky and I expect to get more of the good things in life than the average person.	
9. I just don't get the breaks, and there's no reason to believe that I will in the future.	
10. My past experiences have prepared me well for my future.	
11. All I can see ahead of me is unpleasantness rather than pleasantness.	
12. I don't expect to get what I really want.	
13. When I look ahead to the future, I expect I will be happier than I am now.	
14. Things just will not work out the way I want them to	
15. I have great faith in the future.	
16. I never get what I want, so it is foolish to want anything.	
17. It is very unlikely that I will get any real satisfaction in the future.	
18. The future seems vague and uncertain to me.	
19. I can look forward to more good times than bad times.	
20. There is no use in really trying to get something I want because I probably won't get it.	

Appendix 11. The Questionnaire about the Process of Recovery (QPR)

11.1. Amharic Version

ይህ መጠይቅ ስለአዕምሮ ጤናዎ መልሶ ማገገም ሂደት ለመረዳት ነው; በማገገም/የመሻሻል ሄደቱ ግዜ ምን ጠቃሚ/አጋዥ እና/ፈታኝ ነገሮ እንዳሉም ለመረዳት ነው። ሁሉም ሰው የተለያየ እና ለሁሉም ሰው ልዩነቶች ይኖራሉ። ይህንን መጠይቅ በመመለስ ለመሻሻል ለእርስዎ ጠቃሚ የሆኑ ነግሮችን እንድናገኝ ይረዳናል። እባክዎ በአሁን ጊዜ በተለይም በአለፉት 7 ቀኖች ከአእምሮ ጤንነትዎ እና ከማገገሚያዎ ጋር በተያያዘ ነገሮች እንዴት እንደሆኑ ጠቅለል አድርገው ያስቡና የእርስዎን ተሞክሮ በተሻለ ሁኔታ የሚገልፀውን ለምጠይቅዎት ጥያቄዎች ይመልሱልኝ።

ተቁ	ጥያቄ	በጣም አልስማማም	አልስማማም	ገለልተኛ	እስማማለሁ	በጣም እስማማለሁ
1	ስለራሴ የተሻለ/ጥሩ ስሜት ይሰማኛል	0	1	2	3	4
2	ህይወቴን መለወጥ/ማሻሻል እንደምችል ይሰማኛል	0	1	2	3	4
3	ከሌሎች ሰወች ጋር ጥሩ ግንኙነት መፍጠር እችላለሁ	0	1	2	3	4
4	ከማህበረሰቡ የተለየሁ ሳይሆን የማህበሬሰቡ አካል እንደሆንኩ ነው ሚሰማኝ	0	1	2	3	4
5	ራሴን/ማንነቴን መግለፅ እችላለሁ	0	1	2	3	4
6	ህይወቴ ትርጉም/አላማ እንዳለው ይሰማኛል	0	1	2	3	4
7	የህይወት ተሞክሮየ በጥሩ ሁኔታ ቀይሮኛል	0	1	2	3	4
8	ባለፈው ያጋጠኙኝን ነገሮች ሁሉ ተቋቁሜ ህይወቴን ማስቀጥል ችያለሁ	0	1	2	3	4
9	በጠቅላላው ጤናየን የበልጠ ለማሻሻል ቆርጬ ተነስቻለሁ	0	1	2	3	4
10	ያደረግኳቸውን መልካም ነግሮች መገንዘብ እችላለሁ	0	1	2	3	4
11	ራሴን ከማንም በላይ እርዳዋልሁ/አውቀዋልሁ	0	1	2	3	4
12	ራሴን መቻል/ማስተዳደር እችላለሁ	0	1	2	3	4
13	በሕይወቴ ውስጥ ንቁ ተሳትፎ ማድረግ እችላለሁ	0	1	2	3	4
14	የሕይወቴን ገጽታዎች መቆጣጠር እችላለሁ	0	1	2	3	4
15	የምወዳቸውን ነገሮች ለማከናወን ጊዜ ማግኘት እችላለሁ	0	1	2	3	4

11.2. English Version

This questionnaire is to understand about the process of recovery; what is helpful and what is not so helpful. Everyone is different and there will be differences for everyone. By responding this questionnaire, you will help us find out information that is important to you and your own recovery. Please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements that I am going to ask which best describes your experience.

		Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
1.	I feel better about myself	0	1	2	3	4
2.	I feel able to take chances in life	0	1	2	3	4
3.	I am able to develop positive relationships with other people	0	1	2	3	4
4.	I feel part of society rather than isolated	0	1	2	3	4
5.	I am able to assert myself	0	1	2	3	4
6.	I feel that my life has a purpose	0	1	2	3	4
7.	My experiences have changed me for the better	0	1	2	3	4
8.	I have been able to come to terms with things that have happened to me in the past and move on with my life	0	1	2	3	4
9.	I am basically strongly motivated to get better	0	1	2	3	4
10.	I can recognise the positive things I have done	0	1	2	3	4
11.	I am able to understand myself better	0	1	2	3	4
12.	I can take charge of my life	0	1	2	3	4
13.	I can actively engage with life	0	1	2	3	4
14.	I can take control of aspects of my life	0	1	2	3	4
15.	I can find the time to do the things I enjoy	0	1	2	3	4

Appendix 12. Interview Guide for Qualitative Part

12.1. English Version

Greeting

Mr/ Ms /Mrs _____ we thank you for your consent to take part in this interview. For the coming 30 minutes, I/we will ask you about the meaning and process of getting better from the mental health problems you had/have been experiencing. We will also ask you to share with us the challenges and opportunities you had/are having in the process of getting better. Are you happy for us to continue with the discussion?

Name: _____

Hospital Chart Number: _____

- Please tell me how you are feeling at the moment?
- When did you/your family recognise your mental well-being changed?
    - How did it happen?
    - What did you/your family do to handle it?
        - Can you elaborate each attempts in chronological (sequential with time) manner please?
            - What happened after each attempt to manage it?
- Could you please tell me a bit about what has been happening with your mental health since you have been seen by mental health team?
    - Do you think you still have different/odd thoughts/perceptions?
        - If yes how is it different?
        - How has your mental well-being affected your life and others around you?
- What does “recovery” mean for you?

  - How can it be interpreted/applied to your condition?
  - How would you know when you have fully recovered?
- What have you done or are doing to get your mental health better or controlled?
  - What and how important others are contributing for the betterment of your condition?
  - What challenges are you having?
  - What are the most helpful things you did to get better?
  - From your experiences, what components/factors do you think are most important to get better?
    - How do these factors affect your recovery journey?
- How do you feel about the future particularly your future life?
- Is there anything you wish to share with us?

  We thank you very much!

Note for interviewer: *With these triggering questions, other follow-up questions will be raised as required. Whenever you feel more elaboration is required encourage the interviewee to explain more by rephrasing questions.*

12.2. Amharic Version

ስም: _____ **ካርድ ቁጥር**: _____

ሰላም ወ/ሮ / አቶ _____ **ለመሳተፍ ፈቃደኛ ስለሆኑ አመሰግናለሁ!**

ለቀጣይ ግማሽ ሰአት ያክል ከአእምሮ ህመም መሻሻል/ማገገም ሂደት በርስዎ አረዳድ ያለውን ትርጉምና የርስዎን ተሞክሮ እንዲያካፍሉን ጥቂት ጥያቄዎችን አነሳልሁ። ለርስዎ ለአእምሮ ጤና መሻሻል ፈታኝና አጋዥ የነበሩ ነገሮችንም ያጋሩናል። ለመሳተፍ ፈቃደኛ ነዎት? እናምሰስግናለን።

- **እስኪ አሁን እንዴት እንደሚሰማህ/ሽ ንገረ/ሪኝ?**
- **ህክምናውን እንዴት ነበር የጀመርክ/ሽ?**
- **ህክምናውን ከጀመርክ ወይም ሀኪም-ቤት መታየት ከጀመርክ በሓላስ የጤናህ ሁኔታ እንዴት ነው?**
- **ከአዕምሮ ህመም ማገገም/መዳን ማለት ላንተ ምን ማለት ነው?**
    - **ከአዕምሮ ህመም ሙሉ በሙሉ ድኛለሁ ወይም ጤና አግኝቻለሁ የምትለው ምን ምን አይነት ለውጦችን ስታይ ነው?**
- **ወደ ጤናህ ለመመለስ (ከአዕምሮ ህመሙ ለማገገም/መዳን) ያጋጠሙህ ተግዳሮቶችን (ችግሮች) ምንድን ናቸው?**
- **ለጤናህ መሻሻል ያገዙህ ነገሮችስ ምንድን ናቸው?**
- **ስለወደፊቱ በተለይም ስለአንተ የወደፊት ህይወት ምን ይሰማሃል?**
- **ጥያቄዎቸን ጨርሻለሁ ሌላ ልተንግረን ምትፈልገው ነገር ካለ?**

እናመሰግናለን!

Appendix 13. Methodological Quality Score of Reviewed Studies

Table 13.1: Critical Appraisal Skills Programme (CASP) quality score of reviewed studies

Screening Questions	Eisenstadt, Monteiro, Diniz, & Chaves, 2012	Connell, Schweitzer, & King, 2015	D. Windell, Norman, & Malla, 2012	Bourdeau, Lecomte, & Lysaker, 2015)	Windell, Norman, Lal, & Malla, 2015	D. Windell & Norman, 2013	Woodside, H., Krupa, T., & Pocock, K. (2007)	(Lam et al., 2011)	Romano, D. M. (2009)	(Norman et al., 2013)
Qualitative										
Was there a clear statement of the aims of the research?	1	1	1	1	1	1	1	1	1	
Is a qualitative methodology appropriate?	1	1	1	1	1	1	1	1	1	
Was the research design appropriate to address the aims of the research?	1	1	1	2	1	1	1	1	1	
Was the recruitment strategy appropriate to the aims of the research?	1	1	1	1	1	1	1	1	1	
Was the data collected in a way that addressed the research issue?	1	1	1	3	1	1	1	1	1	
Has the relationship between researcher and participants been adequately considered?	2	2	1	1	1	1	1	1	2	
Have ethical issues been taken into consideration?	1	1	1	1	1	1	1	1	1	
Was the data analysis sufficiently rigorous?	1	1	1	3	1	1	1	1	1	
Is there a clear statement of findings?	1	1	1	1	1	1	1	1	1	
How valuable is the research?	Good	Good	Good	Good	Good	Good	Good	Good	Good	
Quantitative										
Did the study address a clearly focused issue ?				3						1
Was the cohort recruited in an acceptable way?				3						1
Was the exposure accurately measured to minimise bias?				1						1
Was the outcome accurately measured to minimise bias?				2						1
(a) Have the authors identified all important confounding factors?				2						2
(b) Have they taken account of the confounding factors in the design and/or analysis?				3						2
(a) Was the follow up of subjects complete enough?				1						2
(b) Was the follow up of subjects long enough?				2						2
What are the results of this study?				Supplement						Good
How precise are the results?				Not Sure						Good
Do you believe the results?				2						1
Can the results be applied to the local population?				1						1
Do the results of this study fit with other available evidence?				2						1
What are the implications of this study for practice?										
Key: 1 = Yes, 2 = Cannot tell, 3 = No										

Appendix 14: Results of Data Extraction for Systematic Review

Table 14.1. Results of data extraction for systematic Review

Citation and Country	Settings	Duration of illness	Design, Sample size (total/male), Sampling	Data Collection Method	Age Mean SD/(min, max)	Themes/Defining Concepts of Recovery	Contributing Factors
(Eisenstadt et al., 2012) Brazil	First Episode Program, Hospital (inpatient and outpatient	Duration with treatment (6-24 months)	Qualitative-Phenomenology, (16/12), Purposive	Semi-structured interview	23(15, 37)	Recovery is slow and gradual, It is perceived as a Decrease or absence of symptoms, Changes in social relationships, Renewed autonomy and independence Restoration of self-reliance and Trust in others.	Treatment (medication (+&-) Psychoeducation) Social support Personal effort Hope Future prospects Individual experience and characteristics
(Connell et al., 2015) Australia	Early Psychosis Services	Experienced FEP and been referred to an Early Psychosis team within the last month	Qualitative-IPA (20/14), Convenience (26 out of 30 volunteered, and 6 unable to engaged in the interview and hence excluded)	Semi-structured interview	21(19-25)	Experiences of self- estrangement Altered experience of self and world, apprehension, and experience of loss of self) and Experience of self-consolidation Strengthening close bonds, making sense of experience, and forging a stronger self). Different phases of recovery and restoration of self not all participants went through all stages	Person's resumption of social roles Ability to make meaning from their experience
(Windell et al., 2012) Canada	Early intervention service	Participants in treatment for 3-5 years	Qualitative-IPA (30/23), Consecutive	Semi-structured interview	25.9±5.3	Recovery is improvement in one or more in: Illness (not as an elimination of psychotic symptoms) Subjective control over symptom Psychological and personal	Younger age Shorter duration of illness Client-centred comprehensive and phase-specific

						Social and functional, Treatment participation (medication (opposing ideas raised) Recovery is a multidimensional, personalized and achievable goal at early stage of treatment.	treatment (medication +&-)
(Bourdeau et al., 2015) Canada	First Episode Psychosis Clinic	Individuals receiving services from a first episode clinic (a maximum of 5 years with psychotic episode)	Mixed (9 months follow-up) (47/36), Identified by clinicians using pre-set inclusion criteria (14 out of 47 completed the 3rd (9th month measurement)	Interview (semi-structured, Structured) Participants also completed form	26±5.8	Stage of recovery can be expressed in Identity and Self Vision Meaning in Life Hope and Future Responsibility Sociability Occupation Recovery is stable process	Social engagement Narrative development *(alienation, agency, social worth)*. Recently diagnosed Psychosocial functioning Years of education Negative and positive symptoms
(Windell et al., 2015) Canada	Early Intervention Program	3–5 years since onset of illness	Quali-IPA (30/23), Consecutive	Semi-structured interview	---	Symptom recovery (Improvement, relative distress); Reconciling the meaning of the illness experience (Recognizing problem, meaning); Regaining control over the experience (discovering agency, developing personal strategies) Treatment negotiation and acceptance (Engaging with provider and negotiation of treatment)	--
(Woodside et al., 2007) Canada & Australia	Early Intervention centre	First episode of psychosis within the past five years.	Grounded Theory (25/17), Purposive	Interviews and documents review	28(18-39)	Faltering Personal Capacity, Negotiating for Success Activity Performance, Social participation) Chaos Non-linear social participation.	Substance use Mental illness in the family Experiences of abuse Immigration Confused sexual orientation

						Four strategies used to ensure success and well- being in activities and socialization included: 1) Self-help strategies such as praying, reading philosophy, studying longer and focusing exclusively on work or school; 2) Strategically avoiding problematic demands to experience success. 3) Seeking specialized services to assist with managing distress. 4) Deliberately withholding information	Long-standing physical or learning problems.
(Lam et al., 2011) Hong Kong	Outpatient clinic	17-72 months	Qualitative, (6/3), Convenient (6 agreed form 35 invited)	Focus Group Interview	25(23-29)	The meaning of psychosis and psychotic experience; Meaning of recovery; stigma; and having an optimistic view of recovery. Participants' view of recovery was broader than clinicians, extending beyond symptom control and medication compliance, and positive features that the experience of illness had brought. Concerned about side effects of medication and the fear of their illness being disclosed, In the face of societal stigma.	--
(Windell et al., 2013) Canada	Specialized Early Intervention Program	Participants receiving care three to five years after first episode of psychosis	Qualitative (30/23), Consecutive	Semi-structured interview	25.87	--	Social support Medication Meaningful activities and lifestyle Stigma Substance abuse Medication side effects.
(Norman et al., 2013) Canada	First Episode Program	Mean months in treatment = 56.9 (44.3)	Cross-Sectional (84/58), Sampling method not mentioned	Questionnaire (completed by participants and rater)	28(17-48)	Neither sex nor length of time in treatment was significantly associated to any measure of subjective recovery. Analysis Done for Subscales	Social Support Negative symptoms Positive symptoms

						RAS have themes of *Confidence/empowerment* *Hope* *Help seeking* *Goals/purpose* *Support from others*	
Romano, D. M. (2009) Canada (PhD Dissertation)	Outpatient clinic	1-3 years since initial treatment	Grounded theory, 10/5, Purposive	Semi-Structured interview	23	Re-engage in life Engaging in services and support Envisioned the future Value in self Change in self Search for understanding	Stigma Fear of relapse Important insight Hope and future prospect Medication and treatment related Meaning in life

Appendix 15. Ethics Approval

15.1. Ethical approval from The Hong Kong Polytechnic University

The Hong Kong Polytechnic University
Human Subjects Research Ethics Committee

THE HONG KONG POLYTECHNIC UNIVERSITY
香港理工大學

To Chien Wai Tong (Supervisor) & Temesgen Worku, PhD Student, PI), School of Nursing

From Vaelimaeki Maritta Anneli, Chair, Departmental Research Committee

Email maritta.valimaki@ Date 21-Aug-2017

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 09-Oct-2017 to 30-Apr-2019:

Project Title:	Progress of Recovery and its Associated Factors in Recent-Onset Psychosis: A Mixed-Methods Study
Department:	School of Nursing
Principal Investigator:	Temesgen Worku & Chien Wai Tong (Supervisor)
Project Start Date:	09-Oct-2017
Reference Number:	HSEARS20170808001

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

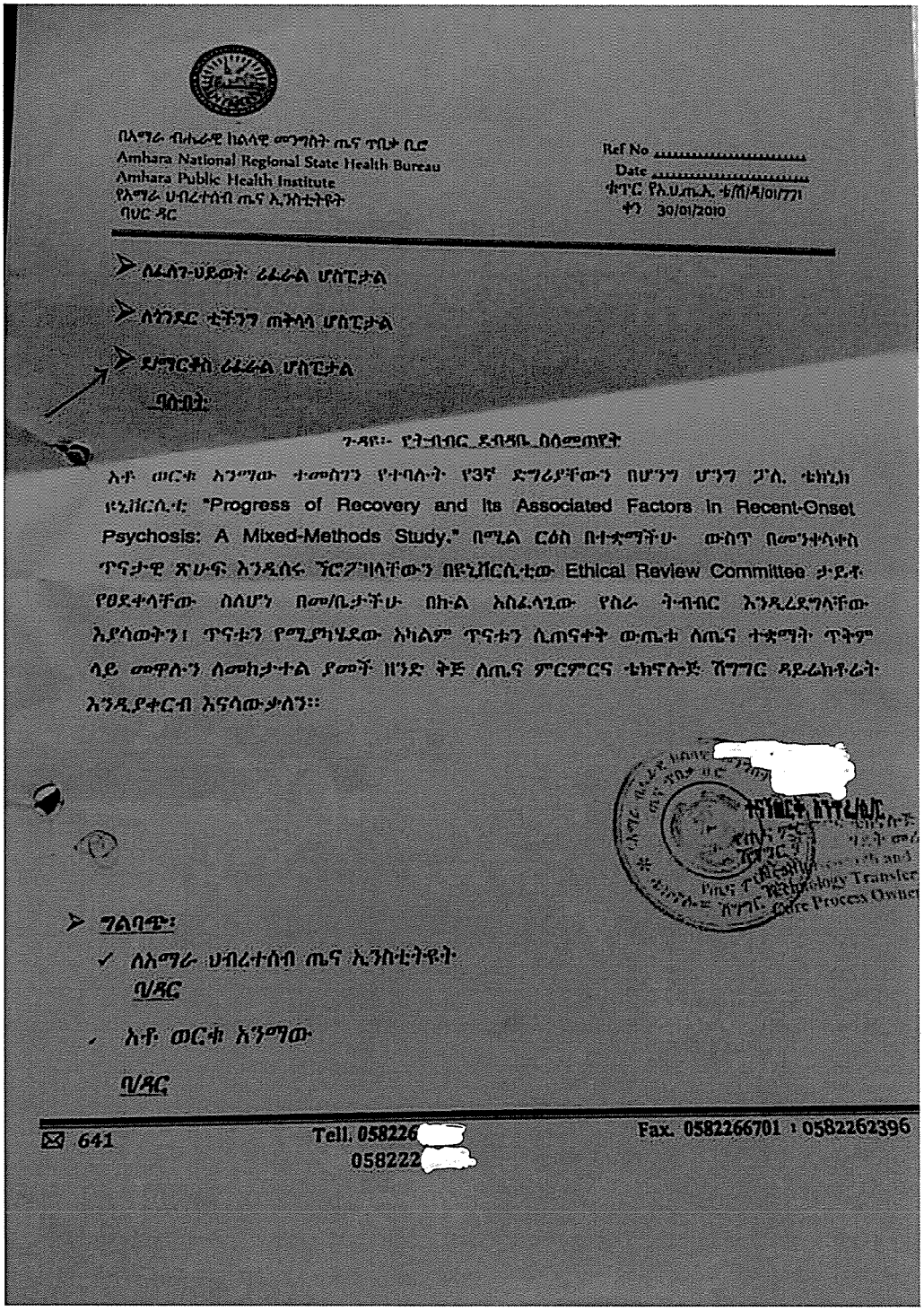
Sincerely,

Vaelimaeki Maritta Anneli

Chair

Departmental Research Committee

15.2. Letter of support from the local government office



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Amhara Public Health Institute
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አቶ ወርቁ አንማው ተመስገን የተባሉት የ3ኛ ድግሪያቸውን በሆንግ ሆንግ ፖሊ ቴክኒክ ዩኒቨርሲቲ "Progress of Recovery and Its Associated Factors In Recent-Onset Psychosis: A Mixed-Methods Study." በሚል ርዕስ በተቋማችሁ ውስጥ በመንቀሳቀስ ጥናታዊ ጽሁፍ እንዲሰሩ ኘሮፖዛላቸውን በዩኒቨርሲቲው Ethical Review Committee ታይቶ የፀደቀላቸው ስለሆነ በመ/ቤታችሁ በኩል አስፈላጊው የስራ ትብብር እንዲረደግላቸው እያሳወቅን፣ ጥናቱን የሚያካሄደው አካልም ጥናቱን ሲጠናቀቅ ውጤቱ ለጤና ተቋማት ጥቅም ላይ መዋሉን ለመከታተል ያመች ዘንድ ቅጅ ለጤና ምርምርና ቴክኖሎጅ ሽግግር ዳይሬክቶሬት እንዲያቀርብ እናሳውቃለን።

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Appendix 16. Training for data collectors

A full day training was given to 6 data collectors (2 from each of three study hospitals). The training focuses on introducing study objectives, methods of illegible participants identification and sampling, study schedule, possible ways of participant retention in the cohort survey, study variables and method of data collection, scoring the psychotic symptoms (rating PANSS), so that the team would have common understanding about the study topic.

Table 16.1. Training Schedule

Time	Activity	Responsible
8:00 – 12:00 AM	• Introduction • Over-all orientation • Introduction about the study and instruments to be used • Eligible participant identification, consent obtaining, recruitment and conducting interview	Worku (PI)
12:00-1:00 PM	Lunch	
1:00 – 6:00 PM	PANSS rating	Dr Askal (Psychiatrist)
6:00 – 6:30 PM	• Over-all study schedule introduction • Logistics concerns • Discussion and wrap-up	All team

A. Common terms and concepts to be used in the study

Psychosis is a set of symptoms like the distortion of perceptions and behaviours (America Psychological Association, 2013). Recent-onset psychosis refers to a psychosis of up to 5 years duration (Breitborde et al., 2009). **Remission**: if a person's condition for the diagnosis has improved to the point at which it would no longer meet criteria for the diagnosis (Davidson et al., 2008). Remission is at least 50% reduction

from the baseline score of eight items of PANSS and sustained for a minimum of six months (Valencia et al., 2014).

Recovery is living independently for 2 years, no psychiatric hospitalization in 5 years, full remission, normal psychosocial functioning, and taking no/low antipsychotic medication (Jaaskelainen et al., 2013).

Subjective recovery is an individualistic journey of changing one's attitudes, values, feelings, goals, skills and roles (Anthony, 2000). **It** is a way of living a satisfying, hopeful, contributing, meaningful and purposeful life as defined by the persons themselves with or without symptoms (Slade, 2009).

B. The importance of the study

- Studies showed recovery is possible and could be more enhanced.
- However, studies on the topic are very limited, particularly study from low income countries is negligible.
- Developing countries are adopting recovery-oriented service delivery system relying on evidence generated from the developed countries.
- However, conceptualizations and processes of recovery, and factors affecting recovery are different among countries with different developmental levels.
- Hence, the evidence gaps from developing countries need to be addressed.

C. **Objectives of the study**

- Investigate levels of recovery of individuals with recent onset psychosis who are being followed-up in an outpatient clinic progressing over nine-month at three-time intervals: from baseline to 3 and 9 months.
- Examine predictive factors of the recovery level and its change among these people with psychosis over 9 months.
- Explore these people's perceived meaning and state of recovery, and challenges and opportunities in the process of recovery.
- Understand the concepts about recovery from these service users' perspective and its related factors with both the above quantitative and qualitative data.

D. Ethical issues

- Ethical approval obtained from The Hong Kong Polytechnic University, and study institutions in Ethiopia.
- Written informed consent should be obtained. Consent form will be locked in cabinet for consecutive assessments
- Confidentiality should be assured.
- Questionnaires will be discarded after completion of writing up.
- If any distress happens support will be provided and if necessary referred to their clinical team.
- Participants will also be assured the right to withdraw.

E. The methods to be followed study

- A sequential mixed-methods design will be employed.

- First, quantitative data will be collected in longitudinal prospective approach and then a qualitative approach will follow.

Quantitative longitudinal study

- Service users' recovery and related variables will be measured at three time points (baseline, 3rd and 9th months) while the participants are attending their routine care.
- A participant MUST be followed/assessed only by one person/assessor.
    - NB. Please do not forget to give appointment after third and ninth months of the initial/baseline interview!

Study settings

- This study will be conducted in Ethiopia in 3 referral and teaching hospitals,
    - Felege Hiwot
    - University of Gondar
    - Debre Markos

Sampling

- Number of study participants will be proportionally distributed to the eligible attendees in each hospital
- A set of random numbers will be generated using a computer program.
    - As participants are recorded in from each hospital by you
- The total of at least 270 which we will distribute to each hospital

Inclusion and Exclusion Criteria

- Inclusion:

- Diagnosed with recent-onset psychosis disorders "*schizophrenia spectrum and other psychotic disorders*" according to the DSM-5
    - *Delusional disorder*
    - *Brief psychotic disorder*
    - *Schizophreniform disorder*
    - *Schizophrenia*
    - *Schizoaffective disorder*
    - *Substance/medication induced psychotic disorder*
    - *Catatonia*
    - *Other Specified Schizophrenia Spectrum and Other Psychotic Disorder*
    - *Unspecified Schizophrenia Spectrum and Other Psychotic Disorder*
    - *Psychotic Disorder Due to Another Medical Condition*
- Having regular follow-up
- Aged 16 years and above

- Exclusion:
    - Severe physical health problems needing emergency or acute care
    - Acute psychotic symptoms
    - Inability to comprehend questions
    - Cognitive impairments.

Measurement schedule

Variables to be measured	Validation study	Retest	Baseline	3rd Month	9th month
Socio-demographic Data	√		√		
Clinical Data	√		√	√	√
QPR	√	√	√	√	√
SSQ-6	√	√	√	√	√

Physical Health	√		√	√	√
PANSS	√		√	√	√
WHOQOL-BREF	√		√	√	√
WHODAS 0.2	√		√	√	√
ISMI-9	√	√	√	√	√
Hopelessness	√		√	√	√

Data Collection

- Methods of data collection
    - Face-to-face interview
    - From clinical records
    - Physical measurements
- The whole measurement will take about an hour, but some are to be taken from clinical records and physical measurements.
- Interview will take about 30 mins and if necessary, break may be taken during interview to have full completion.

Measuring Instruments

- The following instruments will be used
    - World Health Organization Quality of Life (WHOQOL-BREF)
    - World Health Organizations Disability Assessment Schedule (WHODAS 2.0)
    - Positive and Negative Syndrome Scale (PANSS)
    - Beck's Hopelessness Scale (BHS)
    - Questionnaire about the Process of Recovery (QPR)
    - Social Support Questionnaire (SSQ-6)
    - Internalized Stigma of Mental Illness scale (ISMI- 9)
- Three instruments will be translated and validated before use.

All of the above measurement instruments are developed either to be self or interviewer administered except the PANSS. And hence we need you only to read out these instruments to the participants. However, PANSS is unique which you need to scale for each participant after training how to scale each item. We will also provide you a copy of manual about it that you can refer anytime during the study period.

Qualitative Part

- Descriptive qualitative study will be conducted to explore and describe service users' perceived meaning and state of recovery, and the challenges and opportunities during the process of recovery.
- The qualitative data will be used to strengthen the findings of quantitative study by providing deeper, naturalistic, and contextual interpretations of service users' recovery experience.

F. Overall Study Plan

Activity	Time	Remark
Settling Official and Ethical issues at study area	October 2017	
Measurement validation	November	
Baseline study/1st measurement	Dec 2017- Jan 2019	2018
2nd follow up measurement	Mar - Apr	
3rd Measurement	Sep-Oct	

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