ADDIS ABABA UNIVERSITY COLLEGE OF HEALTH SCIENCES, SCHOOL OF MEDICENE, DEPARTMENT OF PSYCHIATRY

EXPLORING THE CARE- RECEIVING EXPERIENCES OF PEOPLE WITH SEVERE MENTAL ILLNESS, AMANUEL MENTAL SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA: A QUALITATIVE STUDY.

BY: GIZACHEW LEGESSE (MD, 3RD YEAR PSYCHIATRY RESIDENT)

A RESEARCH PAPER SUBMITTED TO DEPARTMENT OF PSYCHIATRY, COLLEGE OF HEALTH SCIENCES ADDIS ABABA UNIVERSITY.

ADDIS ABABA

ETHIOPIA

JANAUARY, 2022

EXPLORING THE CARE-RECEIVING EXPERIENCES OF PEOPLE WITH SEVERE MENTAL ILLNES, AMANUEL MENTAL SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA: A QUALITATIVE STUDY

BY: GIZACHEW LEGESSE (MD, 3rd year psychiatry resident)

ADVISORS:

SELAM ABERA (MD, Assistant professor of Psychiatry)

ENGIDA GIRMA (MD, Assistant professor of Psychiatry)

BENIAM WORKU (MD, Assistant professor of Psychiatry)

A RESEARCH PAPER SUBMITTED TO DEPARTMENT OF PSYCHIATRY, COLLEGE OF HEALTH SCIENCES ADDIS ABABA UNIVERSITY FOR PARTIAL FULFILLMENT OF SPECIAL CERTIFICATE IN PSYCHIATRY.

ADDIS ABABA

ETHIOPIA

JANAUARY, 2022

EXPLORING THE CARE-RECEIVING EXPERIENCES OF PEOPLE WITH SEVERE MENTAL ILLNES, AMANUEL MENTAL SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA: A QUALITATIVE STUDY

BY: GIZACHEW LEGESSE (MD, 3rd year psychiatry resident)

Mobile number: +251924443548

Email: gizishl@yahoo.com/ gizishlegesse@gmail.com

APPROVED BY:

EXAMINERS: signature date

Professor ATALAY ALEM ________________ __________

IKRAM AHMED (CP) ________________ ___________

ADVISORS:

Dr. ENGIDA GIRMA _________________ ____________

Dr. BENIAM WORKU __________________ _____________

ACKNOWLEDGEMENT

First of all I would like to thank our GOD for his guidance, support and protection.

I would like to express my deepest gratitude to psychiatry department who assigned advisors to make our research fruitful.

I also like to thank Dr. Selam Abera, Dr. Engida Girma and Dr. Beniam Worku for their invaluable comments and help for the development of this research paper.

I offer my special appreciation and gratitude to Dr. Barkot Milkiyas who has been great help in my ups and downs while doing this research work.

I would also like to thank AMSH for permission and cooperation in doing this study.

I am also grateful to Ato Tesfaye Mekonnen for his tireless help in facilitating patient selection and arranging a private interview room.

Last but no least I like to thank all the study participants for their cooperation to be involved in the study and share their personal experiences.

TABLE OF CONTENTS PAGE

ACRONYM

AAU: - Addis Ababa University

AMSH: - Amanuel Mental Specialized Hospital

HICs: - High income countries

LMICs: - low and middle income countries

MDD: - Major depressive disorder

PI: - principal investigator

SMI: -Severe mental illness

List of tables:-

Abstract

Background: - An understanding of the experience of individuals living with severe mental illness cared by mental health professionals and caregivers promote better understanding of the patient. This may in turn promote enhancement of the therapeutic relationship, engagement of people living with severe mental illness in their care and finally improvement of clinical outcomes.

Objective: - To explore the care-receiving experience of people with severe mental illness receiving care at Ammanuel Mental Specialized Hospital.

Method: - a qualitative study design was used. Nine in-depth interviews were conducted using semi-structured questions. The in-depth interviews were audio recorded, transcribed and translated into English. Data was coded by using open code 4.03 software package and thematic analysis was used to identify key themes.

Results: - There appear five overarching themes with underlying subthemes: firstly, the meaning to illness and care received. Most participants mentioned that it is very difficult to accept mental illness and they tend to accept it gradually and mentioned the care received was lifesaving and mean a lot for their survival. Secondly, Positive experiences of care received, most had positive experiences regarding the care they received. They mentioned variety of positive expectations and hopes about what the care they received would lead to in terms of improvement in their current and future situations. Thirdly, negative experiences of care received, their negative care receiving experiences emanated from different problems they encountered and stigma they faced while receiving care. Fourthly, relationships with care provider in which most experienced good relationships while few experienced bad relationships and finally coping mechanisms.

Conclusion: - The study revealed the positive and negative experiences of people with severe mental illness regarding the care received. It is paramount importance to continue positive aspect of the care provided and to devise ways to tackle negative aspect of care voiced by care receivers to improve care provisions that enhance patients' recovery.

INTRODUCTION

Severe mental illness (SMI) affects 5.1% of people around the world (1) and includes depression, bipolar disorder, and schizophrenia when symptoms result in marked impairment in social or occupational functioning (2).

Mental illness is considered a silent epidemic throughout most parts of Africa. Owing to structural and systemic barriers such as inadequate health care infrastructure, insufficient number of mental health specialists, and little opportunity to all levels of care, It has been characterized as a neglected and highly burdensome problem affecting all parts of the population throughout Africa (3).

In Ethiopia, mental illness is the leading non-communicable disorder in terms of burden.(4) Indeed, in a predominantly rural area of Ethiopia; mental illness comprised 11% of the total burden of disease, with schizophrenia and depression included in the top ten most burdensome conditions, out-ranking HIV/AIDS. These startling statistics show that mental illnesses have been overlooked as a major health priority in Ethiopia and other LMICs (4).

In early 2018, The Beryl Institute set out on an exploration of what really matters to consumers of healthcare regarding their experience. The intent of this inquiry was to understand to what extent experience matters to consumers of healthcare, how they define it, what priorities they have in identifying a positive experience and the impact that experience has overall. The results discovered, while perhaps not surprising, represent some of the first data that reinforces the importance of a focus on patient experience from the perspectives of those who use the healthcare system themselves (5).

In this time of patient-centered care, the previously considered measures of quality of care such as; advances in diagnosis and treatment and decrease in mortality rate etc…are not enough. The issue of patient satisfaction has increasingly become an important component and indispensable measure of care quality (6, 7 and 8).

As patients are the primary customers of the care provider, the information from them with regard to the service is priceless since they are not just passive participants in a care transaction or simply recipients of care, rather they are partners in a care conversation, who must be acknowledged and cared for as people in a healthcare experience. These voices, what matters to them and the expertise they bring, regardless of the side of the care equation they sit, must now be part of the overall solution and their satisfaction assessment is a valuable input for care quality evaluation (9).

STATEMENT OF THE PROBLEM

Over 90% of people with severe mental illness (SMI; referring to psychotic and affective disorders associated with recurrent or enduring disability) never receiving evidence-based care in most low-income countries (10). Even when locally available, people with SMI may experience specific barriers to accessing care, due to lack of autonomy, stigma, impoverishment, discrimination and disempowerment related to long-term illness.

Patients' views of services are increasingly recognized as central to improving service design and delivery (11). This is particularly important in mental healthcare where patients and providers often have different perspectives on what constitutes good care and where patients experience poorer health and healthcare than the general population and are subject to significant stigma, even from within the medical profession (12).

The ultimate principle of care in the realm of mental health is the development of therapeutic relationship between health professionals and people living with mental health problems, including those living with severe mental illness (SMI) (13,14). This in turn requires a holistic understanding of perceptions and needs of people living with SMI (15). However, research shows that comprehension of the problems faced by people living with SMI is difficult for health professionals to achieve, as they hold strong stereotypes regarding mental illness, in line with the wider society. Examples of such stereotypes are that people living with mental illness are unable to communicate their needs, or that their needs are very simple, thus very easy to be understood (16-18). As a result, people living with SMI do not show confidence in healthcare professionals and provided services (19). Therefore, an in-depth understanding of the experience of individuals living with mental illness cared by mental health professionals might promote better empathic understanding of the patient (20-27). This may in turn promote enhancement of the therapeutic relationship, engagement of people living with mental illness in the therapeutic process and finally improvement of clinical outcomes (21, 28-33).

SIGNIFICANCE OF STUDY

To my knowledge, currently there are researches done in Ethiopia about lived experiences of caregivers of persons with SMI, but there are no such studies about lived experiences of persons with SMI about care receiving. Therefore, this study aims to explore lived experiences of persons with SMI about care receiving and also aimed to show understanding their experiences will inform policy maker to devise a system that improve clients care, encourage care receiver to be involved in shared- decision making on their care, other caregiver to provide sustained support and health professionals to provide sound and client centered health care.

LITERATURE REVIEW

Literature review was conducted by search on Pub Med and Google Scholar databases for studies published in English describing lived experience of persons with severe mental illness using search terms “lived experiences”, “severe mental illness”, “phenomenology and SMI”, “lived experience of persons and SMI”, “SMI and care receiving”, lived experience of persons with SMI and care receiving, service utilization and perception of people with SMI…

Although much of the lived experience literature related to mental illness describes the lived experience of caregivers, some research was found that considered a particular mental illness from the perspective of the person diagnosed with it. Chafetz (34), for example, conducted life-history interviews of 43 people with chronic severe mental illness. Participants were recruited from outpatient clinics, treatment programs, and skilled nursing facilities. Their diagnoses were with schizophrenic illnesses, bipolar disorder, or recurrent depression. The participants described individual learning and personal choices that influenced the course of mental illness overtime. Hayne and Yonge (35) used a hermeneutical approach to analyze the published written narratives of 40 people living chronic mental illness. One dominant theme centered on the turmoil between self and one's mind; another theme was that receiving a mental health diagnosis was akin to hearing a death sentence. Mourning for lost dreams for the future also emerged as a theme. Fredriksson and Lindstrom (36) used a method they term hermeneutic phenomenology to interpret the 20 "caring conversations" between eight patients with mental health disorders and three psychiatric nurses over a period of two years. The findings indicated these hospitalized psychiatric patients first concealed suffering, but if allowed to narrate freely, they were able to confront suffering and shame in a way that opened up the potential for sustaining relationships with others.

Diaz-Caneja and Johnson (37) conducted semi-structured interviews of women with schizophrenia, bipolar affective disorder, or severe depression with psychotic symptoms. Participants in this study reported feeling unable to openly discuss their problems due to experiences of being shunned or isolated by family and friends. The mothers among the participants reported that their children also encountered the effects of stigma associated with mental illness. Mothers of neighborhood children, for example, often viewed the children of the participants as undesirable playmates for their own children. Despite experiencing stigmatization and the periodic negative impact of parenting on their own mental illness, participants described motherhood as rewarding and sustaining.

Thompson et al (38) conducted a photo-voice study of seven adult people living with various forms of chronic mental illness. Participants were asked to photograph objects that symbolized their lives with mental illness and then write a narrative explaining the photo. Participants selected a variety of objects. For example, one person photographed a collage of items that had been used to physically abuse her; another participant took a picture of the computer he had used to connect with others. Four major themes emerged in this investigation: (1) feeling misunderstood and invisible in the world; (2) attempting to gain control and be safe through various actions and activities; (3) making an ongoing effort to repair injured self-esteem; and (4) using various coping skills. Participants reported they enjoyed the process and believed they were able to capture meaningful images that effectively communicated their experience of living with a mental illness.

Roe and Lachman (39) warned against oversimplification of mental illness and reducing it to symptoms and pathology, in essence treating individuals as "entirely ill". They concluded that it is not possible to study disorders as separate from the individuals experiencing them, and that more attention needs to be paid to the personal meanings individuals attribute to their illnesses, within their unique contexts.

Similarly, Davidson and colleagues (40) noted that professional inquiries should focus on the person, rather than the illness, in order to find out how people recover. They believe that researchers and practitioners should be opened to the complexity of each individual's unique experiences, capacities and talents because it is these factors that will help the individual recover. Both arguments point towards experiential and contextual factors, whether in the form of personal strengths or meaning making processes, rather than the clinical ones. It should be not so much what professionals do to the person to treat the disorder but what persons with the illness do to get better. Failure to acknowledge the crucial role of these factors and processes could result in failure to understand, promote and foster recovery.

Overall, reviews of first-person accounts and qualitative, experiential explorations indicate that studies tend to fall into four general categories: (1) subjective experience of illness, which includes responses and attitudes towards illness, the impact of illness on people's life, studies on insight/awareness and the role of trauma; (2) the person's experience of self; (3) subjective experience as influenced by social contexts, focusing on the person's desire for normalcy and life in the community; and (4) the experience of care and treatment (39, 41). It would seem that far from being passive recipients of treatment, many individuals experiencing mental illness, even those hospitalized for severe psychiatric problems, make active attempts to try to understand their illness and its role in their lives; strive to build interpersonal relationships with others, including family/friends, peers and providers; and look for strategies that could help them improve. (42)

OBJECTIVE AND REASERCH QUESTION

GENERAL OBJECTIVE

- To explore the care receiving experiences of people with SMI receiving care at AMSH.

Specific objectives

- To explore the meaning people with SMI give to their care-receiving.
- To explore the relationship people with SMI have with their mental health care providers and other caregivers.
- To explore the challenges they face in receiving care.
- To understand the different coping methods they use to overcome their challenges.

Research question

- How is the care receiving experience of people with SMI at AMSH?

Methodology

Study design

Qualitative study was conducted to explore and describe the care- receiving experiences of people with severe mental illness receiving care at Amanuel mental specialized hospital, Addis Ababa, Ethiopia.

Study setting

Study setting was conducted at Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia. According to AMSH communication directorate's report; the hospital was established by Italian invaders in 1930E.C to serve as a medical set up for the native population. It has been serving as the only public specialized psychiatric hospital since 1948E.C. under Ministry of Health. The service was initially given by foreign psychiatrists from Russia, Bulgaria, Cuba and Yugoslavia until it was taken over by Ethiopian psychiatrists and other psychiatry professionals. Its premise has over 15660.6 m2 of land and has 2 new and 15 old building blocks for administrative and clinical purposes. It has 264 clinical and356 nonclinical/administrative employees. The Hospital has 235 beds inside in 14 wards and, 2 emergency rooms for inpatient services such as general adult psychiatry, addiction, forensic and clozapine treatment services. It has 24 outpatient clinics which also include Medical, Maternal and Child, ART clinics and child psychiatry. It has a 24 hour service.

Study population

Study participants were Patients with SMI receiving care both as an outpatient and inpatient at AMSH.

Inclusion criteria

1. Patients with SMI (schizophrenia, bipolar disorders, schizoaffective disorder and MDD with psychotic features) both inpatients and outpatients.
2. Patients above the age of 18 years
3. Able to speak language of the interview
4. Those who were stable, willing to participate and had capacity to give consent.

Exclusion criteria

1. Those who were unable to communicate in the language of the interview.
2. Those who were acutely disturbed, incoherent, distressed, or confused.
3. Those who would not give consent to participate in the study.

Sampling technique and Sample size

Non- probability, heterogeneous purposive sampling technique was used to select participants from patients receiving care at AMSH during the study period. The researcher selected patient participants from inpatients and outpatient psychiatry clinic of AMSH. A total of nine participants (5 males and 4 females) were involved in the study from which four outpatients and five inpatients.

Data collection tool

An in-depth interview was conducted to collect information pertaining to care- receiving experiences of people with severe mental illness using a topic guide. The guide was prepared by the research team for in-depth interviews which was based on literature and experts' opinion. The in-depth interview was following a semi-structured format, using open-ended questions, in a face to face conversational style. It covered the key topics which were explored with the respondents. The topic guide was flexible in nature but some direction would be given by using probes whenever necessary so that focus was not lost.

Data collection procedure

There was an assistant at the Hospital for medical record provision and scheduling interview time with participants. Before the audio recorded interview started basic socio-demographic data were obtained from the patients on the structured data collection sheet, which were supplemented from the participants' charts for the remaining part of information, diagnosis and related information. Semi structured in depth interviews were conducted using topic guide which was prepared in advance. All interviews were conducted by the PI in complete privacy in the Hospital. All of the approached patients who met the selection criteria volunteered to participate and said they could be interviewed any time so were interviewed on the day they were recruited. All the volunteered participants completed the interviews and the interviews were conducted in a single session of 45 minutes to 90 minutes. Interview was recorded after securing permission from the participants using smart phone application.

Data management and analysis

The audio interviews were deleted from the recorder once transferred to a personal computer. The audio, transcription and translation files were stored in an anonymous folder.

Analysis began in a month after data collection. Nine participants were interviewed and data from those included in results until theoretical saturation was reached.

The audio recorded in-depth interviews were transcribed in Amharic and translated into English. Selected translations were compared with the original Amharic text by a colleague who is fluent in both Amharic and English languages and there was no significant difference identified. A total of 70 pages of translated material resulted from the in-depth face to face interviews.

Using Open code version 4.03 system package the translated interview was coded line by line, by the principal investigator. As being a beginner researcher PI coded data using in vivo coding methods. Thematic analysis was done using the main concepts in the interview as themes. As the analysis progressed the original themes were modified and revised as new and finer themes emerged.

Ethical approval

Before data collection ethical clearance was obtained from Department of Psychiatry College of Health Sciences, Addis Ababa University and Amanuel mental Specialized Hospital ethics committee. The purpose of the study and the nature of the study, confidentiality, the freedom to opt-out of the study at any stage were explained to all participants. The rights of the participants were respected.

For those who opted to take part in the study, capacity assessment was done to check the participant’s ability to form informed consent. Once this was achieved informed consent was obtained. The interviews were conducted in a private setting. Confidentiality was maintained at all times, no personal or identifiable information was recorded or printed in the study. Participants were addressed by a letter and numerical representation in the research. There were no participants psychologically distressed during the interview.

RESULTS

9 participants were interviewed until theoretical saturation was reached. The detailed characteristics of the participants were presented in the Tables right below.

Table. 1. Participants' demographic profile, diagnosis and related data

Coded id	P1	P2	P3	P4	P5	P6	P7	P8	P9
Age	43	50	32	34	21	30	50	25	48
Sex	M	M	M	F	F	M	F	F	M
Education status	Bsc degree	Grade 11	Grade5	BA degree	Grade7	MA	Grade 12	Grade 7	Grade 10
Marital status	Married	married	single	divorced	single	married	single	married	single
employment	employed	employed	unemployed	employed	unemployed	employed	unemployed	unemployed	unemployed
religion	orthodox	orthodox	Muslim	Muslim	protestant	orthodox	orthodox	Muslim	protestant
address	AA	AA	Oromia region	AA	AA	SNNPRS	AA	AA	AA
diagnosis	schizophrenia	Bipolar I d/o	schizophrenia	MDD with psychotic features	MDD with psychotic features	Bipolar I d/o	MDD with psychotic feature	Bipolar I d/o	Schizophrenia
treatment	chlorpromazine	Valproate , risperiddone	modecate	Valproate and risperidone	Olanzapine and fluoxetine	risperidone	Amitriptyline, haloperidol	Risperidone, valproate	modecate
Duration of illness	22 years	30 years	10 years	3 years	1 year	5 years	22 years	3 years	12 years
#of hospitalization	None	10x	2x	1x	1x	None	1x	2x	4x
Duration of current admission	Not admitted	4weeks	5weeks	4 weeks	3 weeks	Not admitted	Not admitted	3 weeks	Not admitted

Themes identified

Participants of this qualitative study have revealed their care receiving experiences in different manner. From those participants' data, there were 5 overarching themes, 10 subthemes and 110 codes emerged.

The themes emerged were:-

1. Meaning to illness and care received
2. Positive experiences of care received
3. Negative experiences of care received
4. Relationships
5. Coping mechanisms

Table. 2. Summary of themes and subthemes.

Themes	Subthemes
Meaning to illness and care received	Meaning to illness
	Meaning to care received
Positive experiences	Expectation of care
	Outcome of care
Negative experiences	Problems encountered
	Stigma
relationships	Good relationships
	Bad relationships
Coping mechanisms	Coping mechanisms of difficulties
	Solutions to problems encountered

1. Meaning to illness and care received

This theme has two subthemes, meaning to illness and meaning to care received.

1.1. Meaning to illness

In this subtheme most participants mentioned that initially they were unaware of their illness and how they are impacted by it. Most of them gave different reason why they became ill. It's noticed that accepting illness was difficult and it took long time and through reading, getting information from care providers and observing similar condition in their vicinity helped them to accept their illness. They also mentioned living with such condition is very hard and difficult that makes them to depend on others for their day to day activities.

Most participants had different experiences ranging from difficulty to accept illness to gradually accepting it.

> “….*But at first I did not understand it. That is, I could not understand how the illness affected my mind. I was so sad and crying when I thought a mentally ill person would be discarded. It was very difficult for me to accept the illness. However, while I was taking your medication, I was still able to sleep, calm, but it took me a long time to accept the illness itself; I prayed, I cried, I thought God was punishing me for what I had done, but I did not accept it as illness. It has long been difficult to accept. After that I saw the sick, I read when they were sick, I came to receive illness over time. I accept that I am sick, that I can be treated like any other person.”* (P1, 43M B.Sc. psy nurse from OPD).

Some of participants shared their experiences that living with mental illness is very difficult and makes their life limited.

> One participant said “*I had a very boring time living with that disease. That means it's very difficult. Am limited socially, ‘living in isolation means living on your own island’. And that is very difficult. As you are being human, to live in isolation from human, is very difficult. Uh, that's what it showed me. Feeling lonely around people, just thinking I'm lonely.”* (P4,34F, BA degree, from inpatients).

The other participants said it is just like disability and requires support from others.

> “*I see myself as a person with a disability, something is missing; For example, one who has lost one hand is forced to work with one hand, one who has lost other leg is forced to walk with one foot, and I feel like I am lame; I can't work as hard as I can, I can't learn as hard as I can, I can't run as hard as I can, I'm all caught up, that's very hard; It is not possible without human support*.” (P1, 43M B.Sc. psy nurse OPD).

Some of participants discussed their different explanatory model of their illness.

One participant said” *initially I thought my illness was due to punishment of God since I gave up my spiritual rituals after I got to Saudi Arabia, but now I know its mental illness after psychiatrist told me about it*.” (P5, 21 F, grade7, from inpatients).

Another participant said *“...this happened after the death of my father. He died suddenly without visiting him a single day since then my mind got disturbed. Another reason for my illness was displacement from my work place*.” (P2, 50M, grade11 drop out, from inpatients).

1.2. Meaning to care received

Participants discussed the care received in this hospital as extraordinary which gave them second chance to begin life. They mentioned that without care living is unthinkable and their life would have been destroyed.

Most of participants believed that the care they received is life saving and meant a lot to their survival.

One participant said" *if Ammanuel Hospital had not treated me and given me medicine, I could have lived on the road or street, or I was dead. It saved my life, which means I don't deny it. Without this treatment, I would not have survived."* (P6,30M, MA in governance, lecturer, from OPD).

Also another participant said "*I have been treated in many places but this hospital is the reason for my health. It was at Ammanuel Hospital that I was helped to get myself*." (P8, 25F, grade 7, from inpatients)

Another respondent stated that "*It is because of this hospital that we have been able to live our lives. Otherwise, without this hospital, we would all be insane. As long as Ammanuel hospital is there, it will change my life. It is a very important life-changing experience. Otherwise, my life would be ruined*." (P2, 50M, grade11 drop out, from inpatients).

2. Positive experiences of care received

Most participants perceived care-receiving positively. They mentioned their positive experiences emanated from having positive expectation and hope regarding care provided. They also stated they got good results from care received claiming they discovered their former health, able to lead life and overall satisfied with the care received.

2.1 expectations of care

The participants revealed a variety of positive expectations and hopes about what treatment at AMSH would lead to in terms of improvement in their current and future situations.

Most of the respondents mentioned that they expect complete cure from their illness, but they said that improvement evolves gradually.

Expressing his hope, one respondent stated that "….*The result I want is complete cure. I want to give up the medicine and go back to where i was before. But the illness and the anxiety are not completely gone. Treatment is long-term, requires patience, and requires family and personal support.'' (P1, 43 M B.Sc. psy nurses, from OPD).*

One of the respondent stated that she expects perfect health as usual and said *''……I just want to get out of the hospital with a perfect health. I want to go back to being as healthy as I used to be. I just want to be 100 per cent. So the sum of their care is that it makes me come out healthy here and I expect it to come out completely healthy now as before." (P4,34F, BA degree, from inpatients).*

The other respondent also mentioned that the results he hopes and what he achieve are going hand in hand (parallel).

> ” *The result I want is that my health can be improved and I can be completely healed. I expect such results and I found it in that way, because the drugs I take are helping me, I am doing my job, I am running a family, I am participating in various socio-economic, political, religious and cultural* things*.”* (P6,30M, MA in governance, lecturer, from OPD).

2.2. Outcome of care

In this subtheme participants discuss about their overall view of their satisfaction in the service provided in the Hospital. Most participants said that they are overall happy about the service they got from the Hospital and about their stay. Some of them said the following:-

“*My overall stay is excellent. I am very, very satisfied with the care. I am very grateful to the doctors and nurses.”* (P8,25F, grade7, from inpatients)

“*I'm just happy that the problems have been solved*.” (P7, 50F, complete grade12, from OPD)

“*I am very satisfied with the treatment, it is a satisfaction to sit down and talk to you now. Without my peace of mind, you and I would not be able to sit down and talk now.” (P2, 50M, grade11 drop out, from inpatients).*

Some of the participants also mentioned that they discover their previous health after care. Some of them said as mentioned below:-

“*My health, happiness, and peace returned to where I was.”* (P8,25F, grade7, from inpatients)

“…..Yes, it has helped me to restore my former health. I believe it has helped me get back to my old health in just a month and a week.” (P4,34F, BA degree, from inpatients).

3. Negative experiences of care received

As mentioned above many of the participants expressed they had positive experiences, but they also mentioned negative experiences they faced on receiving care for their illnesses. They mentioned many problems they encountered and stigma while receiving care.

3.1. Problems encountered/ challenges faced

Participants reported they faced different challenges ranging from personal to facility level. Management problem they reported was that they didn’t focus on patients and didn’t assign professionals and didn't handle them in professional manner. They also reported they lack regular follower of their care which frustrate and hamper continuity of their care.

Participants' perspective of some of the challenges they faced mentioned below:-

Some of the respondents discussed about management problems.

> *"The service at Ammanuel Hospital is good; but the management is not suitable for the mentally ill. Administrative content is not conducive to caring for mentally ill patients. It's not something that makes professionals work; this is because the people in charge are not focusing on medical care, they are engaged in other administrative activities and they are not paying attention to the needs of the patients. Specialists do not want to work at Ammanuel Hospital; they are hired, they leave because the system is not valid, it is not recipient."* (P1, 43M B.Sc. psy nurse from OPD).

Almost all of the respondents mentioned that they lack regular follower of their care with whom they confide their problem.

> "*Doctors are not always available, they change frequently. When they change, on one hand you will get better one on other hand you will get the confused one. If the doctor who knows you and knows all about your problems well, he will always treat you well. When our doctors changed, we were all frustrated; I saw a lot of people here like me. It would be nice if someone could see us regularly*" (P7, 50F, complete grade12, from OPD)
>
> *"Care provider change from time to time. When they change, you may be told to repeat your history, or you may be prescribed another medicine and in that regard it is not possible to follow progress and side effects of drugs." (P6,30M, MA in governance, lecturer, from OPD).*

Some participants found side effects of drugs where troublesome. One participant said *" ....drug side effects like I was unable to speak properly and my hand shakes trouble me."* (P3, 32M, grade5, from inpatients)

Another participant said "*…Another is side effect of drug is very difficult. I used to take risperidone and olanzapine but it made me overweight, put blood pressure on me, and generally things like this make treatment difficult."* (P1, 43M B.Sc. psy nurse from OPD).

Some respondent mentioned that there is no place to pass time or no entertainment to refresh them. "*It would be nice if there were things like TV, things like chess, 'dama' things that would make you have funny. The absence of these things makes it boring for the patient and these things make staying hard."* (P4,34F, BA degree, from inpatients)

All of the respondents from inpatients mentioned that they encounter problem regarding quality of food. They put their ideas as follows:-

"*There is a food shortage. The ox used to be slaughtered on Thursday. The sick are saying that we are dying for meat. It is said that there is a budget but it is not known where it will go*." (P2, 50M, grade11 drop out, from inpatients).

"*There is the problem regarding food. All patients including me have compliant regarding food. Always they make 'shiro', in the last time I was admitted, there were eggs and meats, but now because the eggs and meats become expensive they provide us only 'shiro'. I think if they improve food service, it is crucial for patients because if you eat shiro the whole week, you lost your appetite*."(P3, 32M, grade5, from inpatients)

"*They make 'misir wot' at lunch and dinner. And we are very tired of the repetition. It's just that* it *repeats itself. Uh, that makes it a little boring."* (P4,34F, BA degree, from inpatients).

3.2. Stigma

Some of participants mentioned they experience stigma from care provider.

> One participant stated*" … When a lot of people come here, they hide themselves because there is discrimination in our country.do you know what happened for me 2 months back, I came for my follow up and the physician ordered me the drug I took, then I went to buy from the pharmacy. The pharmacist gave me wrong medicine and then I said, 'What are you doing? This is not a medicine for me. I can read, this is not right medication and I know the drug I took, I know how many doses I was given, then he threw prescription over my face saying something that hurts me. Then I went to talk pharmacist head and he said that before to talk to me, are you in good state? I know what he is inferring he is stigmatizing me….*" (P6,30M, MA in governance, lecturer, from OPD).

The other respondent said "the guards has no positive attitude towards the mentally ill, just when we appear, just tells us to go in, I think we should be treated in a 'secret' place and I don't understand why they have a negative attitude towards us." (P4, 34F, BA degree, from inpatients)

Other participants discussed that they perceived internalized stigma due to their illness but said they didn't experience any stigma while receiving care in this hospital.

One of respondent said "*I used to think I would be discriminated due to my illness, but there is no such thing I experienced in this hospital. Doctors don't use anything and doesn't stigmatize any patient instead they just give the profession right*." (P2, 50M, grade11 drop out, from inpatients).

Other participants also shared the same and said "*I have never been stigmatized because many colleagues do not even know I am sick. At first I thought the nurses would refuse to greet me when they heard I was sick, but nothing, as we know each other before, there is no exclusion*." (P1, 43M, B.Sc. psy nurse from OPD).

4. Relationships between care provider and receiver.

Majority of Participants mentioned that they had sound relationships which help them to meet their needs and facilitate participation in their care. Some of also discussed they experienced bad relationships that posed difficulties and barriers in facilitating this process.

4.1. Good relationships

4.1.1. good relationships with mental health care providers

Most of participants mentioned that they have positive relationships with their care providers. They stated the care providers treat them politely, in respectful manner and they had warm well coming attitude towards their patients.

One participant said" *I have a beautiful relationship. The nurses are very welcoming, for example, when you ask them to charge your cell phone, they respond respectfully. They answer our questions. They all respond well, no one annoy us*." (P2, 50M, grade11 drop out, from inpatients).

Some participant believed trusting care provider and care they provide is crucial for their recovery process.

In this regard one of the respondent said" *The important thing is to trust the doctor first; when I go to the doctor, I have to believe that I will get treatment and the treatment will help me*." (P1, 43M, B.Sc. psy nurse from OPD).

The same participant also said he was cared with love. ", I have never had anything bad on the service other than love and greetings."

One participant mentioned that her care provider cares her with in polite and respectful manner.

She said" *…they follow us very politely. In fact, I say that God created them, and God has kept them for us. So I always say that I am very happy that they were created for us*." (P7, 50F, complete grade12, from OPD)

One respondent stated that he actively involved in his care.

> He said" *I fill out the form provided by Psychotherapist. I take an active part in such things. I play these roles in terms of asking my doctor about the side effects of the*

> *medicine, in terms of reading about my illness. And I'm contributing to my health by doing what doctors asked me to do*." (P6,30 M, MA in governance, lecturer, from OPD).

4.1.2. Good relationships with other care givers

Most of the participants mentioned that they have sound relationships with their care givers.

> One of the respondent said" *I have a good relationship with my family, my father, my mother, my brothers and my sisters. They also have good love for me. They were terrified when I was sick, they were very sad at the time, they did not expect that. They expect me to go to university and become a doctor or an engineer or a lawyer. When I experienced this, they were very sad. They are very hurt. And after that I was being treated and they were very happy to see my life getting better. And they take good care of me. Even now that I am a nurse, the most amazing thing is that I can't wash my clothes. Also, after I got married, my wife took good care of me when she was aware of my problem."* (P1, 43 M B.Sc. psy nurse from OPD).

The other participants also said "*my relationship with other caregivers is beautiful especially with my wife. She brings me food; she brings me everything I need. It was my wife who brought me here. I would not have a life without her. I really appreciate my wife at this time. " (P2, 50 M, grade11 drop out, from inpatients).*

Another participant also mentioned that she had good relationships with other care providers. She said" *I have a good relationship with everyone. I have never had a fight with a patient, a ward coordinator, a family caregiver, a doctor, or a nurse."* (P4, 34 F, BA degree, from inpatients)

4.2. Bad relationships

Some of participants mentioned that they experienced bad relationships with care providers and care givers. They mentioned that some of care giver use coercion, had bad attitude towards patients and don't provide information regarding their illness, treatments and paternalistic way of handling things.

One respondent stated that the guards use forces:

He said" *I think the problem at this point is that the security guards beat the mentally ill with a stick that has no awareness. Instead of taking care of us, they push hard, force, and beat us with a stick. They come to this ward and bleed patients. There is no discipline with guard; there is a serious problem with guard."* (P2, 50M, grade11 drop out, from inpatients).

The other participant mentioned that some of caregiver had bad attitude: "*In Pharmacy there was an abusive boy. He was annoying boy. He had problem not only with me but three times I saw him arguing with other."* (P7, 50F, complete grade12, from OPD).

Another respondent mentioned that care provider don’t share information regarding his illness and about his treatment. He said” *They ask me, my wife, my son, but I am not told what the disease is, and we are not told why the amount of medicine was increased or decreased*.” (P2, 50M, grade11 drop out, from inpatients).

One participant discussed that she is not involved on decision making regarding the treatment she took. She said” *They know the medicine they give me, they say we give it to her this, they decide for themselves and then I accept it from the profession*.” (P4,34F, BA degree, from inpatients)

One participant mentioned she has no care provider apart from mental health care provider. She said” *I'm lonely. I have a sister. She doesn't take care of me. I am taking care of myself with the money I have with God. I have no other caregiver*.” (P7, 50F, complete grade12, from OPD).

5. Coping mechanisms

Under this theme there emerged two subthemes: coping mechanism for difficulties and solutions to problems encountered during care receiving.

The participants devised several ways to tackle the difficulties they faced and recommended things to be done to facilitate and maximize their care.

5.1.Coping mechanism for difficulties faced during care receiving

Participants used different coping mechanisms when they faced difficulties receiving care.

One respondent stated that she utter certain words and try to be calm when providers care annoys her.

She said “*I say, God, reassure me. I will try to answer in the affirmative.”* (P7, 50F, complete grade12, from OPD).

One participant mentioned that she engaged herself in activities that will help to refresh her. She said “*We bring books from home and read them. We just read books and enjoy ourselves.”* (P4,34F, BA degree, from inpatients).

5.2. Solutions to the problems encountered

One participant mentioned his recommendation as follows: he said” *the management should be professional, allocate budget for patients, and use all resources for treatment. It would be better to fix the other rooms, clean the rooms, fix the showers, make the hospital more attractive to the patients, fix the food, make the clothes more comfortable, give the shoes to the patients, make the nurses room better, fix the doctors' dormitory. From a professional point of view, if you have a place for a specialist, I mean, if you have a psychiatrist in place, it would be better if all patients* *get treated by a professional. It is not appropriate to hire an unskilled person in a specialist hospital*.” (P1, 43 M B.Sc. psy nurse from OPD).

One of participants stated getting health insurance solved his financial problem.

He said”*... And I'm experiencing a lack of money. In this regard, thanks to the government, there is a system called Health Insurance, without it, it would have been very difficult for me. This is what I think is the solution to this problem*.” (P6,30M, MA in governance, lecturer, from OPD).

One of participant discussed the importance of provision of training and awareness creation for care providers.

She said “…*if those supporting staff and the ward coordinators are given awareness or training. If the food situation improves and there are no recurring foods, then I believe that the Hospital will become a world-class hospital in the future*.” (P4, 34F, BA degree, from inpatients).

One participant indicated reporting the challenges they faced to concerning body is another way of solving problems.

He said “… As I told you before I was stigmatized by one of the pharmacists and I reported that to grievance office.” (P6,30M, MA in governance, lecturer, from OPD).

Discussion

This qualitative study explored the care-receiving experiences of people living with severe mental illness receiving care at Ammanuel mental specialized hospital using phenomenological methods and summarized the findings into five themes: meaning to illness and care received, positive experiences of care received, negative experiences of care received, relationships and ways of improvement of care.

This study revealed that people with severe mental illness had different experiences regarding the meaning of illness and care received. Most participants mentioned that it is very difficult to accept mental illness and they tend to accept it gradually. Also living with it is troublesome and requires personal support. Similar study in HICs showed that living with mental illness is a gradual learning journey and Acceptance might have been preceded by denial or by having to face one's own preconceived ideas of mental illness but was eventually associated with a sense of relief (42). Another study showed accepting mental illness means hearing death sentences (35). Regarding to the meaning to care received; this study showed that most participants mentioned that it was lifesaving and mean a lot their survival. Hospital admissions could in fact represent a life-changing moment when the person realized he/she was no longer "normal" (42).

Most of participants in this study revealed they had positive experiences regarding the care they received. They mentioned variety of positive expectations and hopes about what the care they received would lead to in terms of improvement in their current and future situations. They expected complete cure, perfect health and the results they achieved were going in parallel to care they received. This study also showed most of participant overall satisfied with the care they received and happy about the service they got from the Hospital and about their stay.

Participants high expectation (complete cure and perfect health) on one hand implies that they had low understanding about care and on the other hand high satisfaction from care they received indicate their low expectation about care. Similar positive experiences reported from HICs and LMICs. In describing positive experience, the themes most reported were caring, helpful, and friendly, professional, excellent and efficient and compassionate, comfortable and reassuring (5,8).

In a similar light, the study also showed some of participants had negative experiences regarding the care they received. Their negative care receiving experiences emanated from different problems they encountered during care receiving. The problems reported were the management issue in which doesn't give due attention to patient care rather focus on other issues, lack of regular follower of their care for whom they confide their problem, repetitive and low quality of food served, lack of place to pass time or absence of entertainment to refresh them and troublesome drug side effects all affect their care negatively.

The study also found that patients face stigma while receiving care. Some participants reported that they experienced different coercive behaviors such as being abused, annoyed, insulted, pushed or even hit on occasions. This is reported to happen usually in interaction with the guards but also the rest of medical and non-medical staff. This has significant negative impact on care received. Stigma has been reported to be fairly common experience in psychiatric outpatient and inpatient settings and had negative impact on care received in a number of studies (16-18).

Most of participants had good relationship with care providers. This was reported to be result of many factors such as being cared with love, care providers polite and respectful provision of care, trust they have towards care giver and their active participation on their care. Good relationship with care providers have been reported to be a determinant factor in better outcome and have been frequently reported to be generally very good in psychiatric care (28).

The findings revealed that some of participants had bad relationships with their care provider. The factors responsible for bad relation was the use of forces by guards, care giver bad attitude, lack of information provision regarding their illness and their care, lack of involvement to make decision on their care. The study showed an overall dissatisfaction with information provided and the opportunity to participate in decision making (18, 29, 30).

The study found that care receivers devise different remedies to tackle challenges they faced and recommended different ways that will improve their care in future. The study revealed participants use some form of coping mechanisms which included getting pieces of advice from family and friends, try to be calm uttering certain words and reading books. The participants also suggest that hospital to use wisely every budget for patient care, improve food problem and provision of training and awareness creation to care providers especially guards and janitors how to handle patients with mental illness.

STRENGTH AND LIMITATION

Unlike previous study which tried to explore the satisfaction of inpatients , this study tried to include both inpatients as well as outpatients at approximately in equal proportion of male and female to explore care- receiving experiences of people with SMI.

However this study being qualitative in nature has issue of generalizability, which is it is not possible to generalize from 9 participants experience to those who attend the hospital. The other limitation is the recruitment methods that were purposive which is the weaker methods than other sampling method like random sampling. There could have been a social desirability response bias because the primary investigator is physician and the interview was conducted in the hospital.

Conclusion and recommendations

An understanding of the experience of individuals living with severe mental illness cared by mental health professionals might promote better empathic understanding of the patient. This may in turn promote enhancement of the therapeutic relationship, engagement of people living with severe mental illness in the therapeutic process and finally improvement of clinical outcomes.

In this study we found that most of the patients had positive experiences and some of them also had negative experiences regarding the care they received. The study showed there have been multiple factors responsible for those who experience the care positively. These factors are good relationship with care providers which enhances their involvement in care process and that realize their expectation about care and help them to achieve good outcome from care they received. In similar manner the study also revealed those who experience care negatively. The reason for it is the different challenges the patient faced and the stigma they encountered while receiving care. Those challenges revealed by study were bad relationship with care provider, management problem, lack of regular care giver, stigma, bad attitude of care provider, and absence of information provision, facility problem such as lack of quality food, entertainment issue and facing physical trauma by guards.

Therefore, we generally recommend the continuity of positive aspect of the care provided and to devise the ways to tackle negative aspect of care voiced by care receivers to improve care provision that enhance patient recovery.

Particularly we recommend: - provision of training and awareness creation to care providers how to handle patients with SMI and meet to their needs, provide information about their illness, treatment, and involve patients in their treatment decision, facilitate patient participation on their care and devise ways to improve food problems.

REFERENCE

1. Charlson, F., van Ommeren, M., Flaxman, A., Cornett, J., Whiteford, H., & Saxena, S. (2019). New WHO prevalence estimates of mental disorders in conflict settings: a systematic review and meta-analysis. *The Lancet*, *394*(10194), 240-248.

2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Association AP, editor. Washington: American Psychiatric Association; 2013. .

3. Faustin Armel, Etindele Sosso; African Burden of Mental Health: Rethinking Primary Care in Mental Health.Department of Biological Sciences, University of Montreal, Quebec, Canada,Received September 09, 2017

4. Ministry of Health. National Mental Health Strategy 2012/13 - 2015/16: The Ministry of Health, Addis Ababa, Ethiopia (2012).

5. Consumer perspectives on patient experience 2018 Jason a. wolf, Ph.D., cpxp, president

6. Wong et al. Item generation in the development of an in-patient expérience questionnaire: a qualitative Study. BMC Health Services Research. 2013; 13:265.

7. Elisabetta Miglietta, Clara Belessiotis-Richards, Mirella Ruggeri, Stefan Priebe. Scales for assessing patient satisfaction with mental health care: A systematic review; Journal of Psychiatric Research. 2018: (02)014

8. Shan L et al. Patient Satisfaction with Hospital Inpatient Care: Effects of Trust, Medical Insurance and Perceived Quality of Care. PLoS ONE. 2016; 11(10).

9. Stallard P. The role and use of consumer surveys in mental health services. J Mental Health 1996; 5(4): 333-348.

10.. Shidhaye R, Lund C, Chisholm D. Closing the treatment gap for mental, neurological and substance use disorders by strengthening existing health care platforms: strategies for delivery and integration of evidencebased interventions. Int J Ment Health Syst. 2015;9:40

11. Shield T, Campbell S, Rogers a et al. Quality indicators for primary care mental health services. Quality and Safety in Health Care 2003;12(2):100-6. .

12. Brown J, Weich S, Downes-Grainger E, Goldberg D. Attitudes of inner city GPs to shared care for psychiatric patients in the community. Br J Gen Pract. 1999; 49: 643-44.

13. Stockman C. A literature review of the progress of the psychiatric nurse-patient relationship as described by Peplau. Issues Ment Health Nurs. 2005;26:911–9.

14. Nursing WJ. Human science and human care. A theory of nursing. NLN Publ. 1988;15:1–104.

15. Rogers C. A theory of therapy, personality, and interpersonal relationships: as developed in the client-centered framework. Koch S, editor. New York: McGraw-Hill; 1959.

16. Ben-Zeev D, Young MA, Corrigan PW. DSM-V and the stigma of mental illness. J Ment Health. 2010;19:318–27.

17. Corrigan P. Mental health stigma as social attribution: Implications for research methods and attitude change. Clin Psychol Sci Pract. 2000;7:48–67.

18. Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Soc Sci Med. 2003;56:299–312.

19. Shattell MM, McAllister S, Hogan B, Thomas SP. "She took the time to make sure she understood": mental health patients' experiences of being understood. Arch Psychiatr Nurs. 2006; 20:234–41.

20. Allen MH, Carpenter D, Sheets JL, Miccio S, Ross R. What do consumers say they want and need during a psychiatric emergency? J Psychiatr Pract. 2003;9:39–58.

21. Baker A, Procter N, Gibbons T. Dimensions of Loss from Mental Illness. J Sociol Soc Welf. 2009;36:25–194.

22. Barkham M. Common factors in psychological therapies. Psychiatry. 2002;1:5–8.

23. Davies K. Silent and censured travellers'? Patients' narratives and patients'voices: Perspectives on the history of mental illness since 1948. Soc Hist Med. 2001;14:267–92.

24. Hewitt J, Coffey M. Therapeutic working relationships with people with schizophrenia: literature review. J Adv Nurs. 2005;52:561–70.

25. Kieft RA, de Brouwer BBJM, Francke AL, Delnoij DMJ. How nurses and their work environment affect patient experiences of the quality of care: a qualitative study. BMC Health Serv Res. 2014;14:249.

26. Määttä SM. Closeness and distance in the nurse-patient relation. The relevance of Edith Stein's concept of empathy. Nurs Philos. 2006; 7:3–10.

27. Yu J, Kirk M. Measurement of empathy in nursing research: systematic review. J Adv Nurs. 2008;64:440–54.

28. Day JC, Bentall RP, Roberts C, Randall F, Rogers A, Cattell D, et al. Attitudes toward antipsychotic medication: the impact of clinical variables and relationships with health professionals. Arch Gen Psychiatry. 2005; 62:717–24.

29. Deegan PE, Drake RE. Shared decision making and medication management in the recovery process. Psychiatr Serv. 2006;57:1636–9. Kaite et al. BMC Psychiatry (2016) 16:343 Page 14 of 1719.

30. Happell B, Manias E, Roper C. Wanting to be heard: mental health consumers' experiences of information about medication. Int J Ment Health Nurs. 2004;13:242–8.

31. Kopelowicz A, Liberman RP. Integrating treatment with rehabilitation for persons with major mental illnesses. Psychiatr Serv. 2003;54:1491–8.

32. Malins G, Oades L, Viney L, Aspden S. What's in a service? Consumers' views of Australian mental health services. Psychiatr Rehabil J. 2006;29: 197–204.

33. Mueser KT, Corrigan PW, Hilton DW, Tanzman B, Schaub A, Gingerich S, et al. Illness management and recovery: a review of the research. Psychiatr Serv. 2002; 53:1272–84

34. Chafetz, L. (1996). The experience of severe mental illness: A life history approach. Archives of Psychiatric Nursing, 10(\), 24-31.

35. Hayne, Y. & Yonge O. (1997). The life world of the chronic mentally ill: Analysis of 40 written personal accounts. Archives of Psychiatric Nursing, 11(6), 314-324.

36. Fredriksson, L. & Lindstrom, U. (2002). Caring conversations—psychiatric patients' narratives about suffering. Journal of Advanced Nursing, 40(4), 396-404.

37. Diaz-Caneja, A., & Johnson, S. (January 01, 2004). The views and experiences of severely mentally ill mothers—a qualitative study. Social Psychiatry and Psychiatric Epidemiology, 39, 6,472-82.

38. Thompson, N., Hunter, E., Murray, L., Ninci, L., Rolfs, E., & Pallikkathayil, L. (2008). The experience of living with chronic mental illness: a photovoice study. Perspectives in Psychiatric Care, 44(1), 14-24.

39. Roe, D., & Lachman, M. (2005). The subjective experience of people with severe mental illness: A potentially crucial piece of the puzzle. The Israel Journal of Psychiatry and Related Sciences, 42, 223-230

40. Davidson, L., Borg, M., Marin, I., Topor, A., Mezzina, R., & Sells, D. (2005a). Process of recovery in serious mental illness: Findings from a multinational study. American Journal of Psychiatric Rehabilitation, 8, 177-201

41. Zolnierek, C. D. (2011). Exploring lived experiences of persons with severe mental illness: A review of literature. Issues in Mental Health Nursing, 32, 46-72.

42. Bartova, Z. (2014). Learning from the experts: Qualitative study of the lived experience of mental illness. https://ro.ecu.edu.au/theses/1412

APPENDICES

አባሪ-1

አማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል ፈቃድ መጠየቂያ ደብዳቤ (ለ አማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል)

የጥናቱ አላማ በአማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል ከባድ የአእምሮ ህመም ላለባቸው ሰዎች ስለ እንክብካቤ መቀበል የኖሩ ልምዶች ማጥናት ነው። ምርምሩን በሆስፒታሉ ከሚኙት እና በተመላላሽ ከምታከሙ ሰዎች ጋር ጠለቅ ያለ መጥይቅ በማድረግ ለመስራት አቅደናል። ይህ ጥናት ተሳታፊዎች ሰለ ከባድ አዕምሮ ህመም የኖሩ ልምዶችንና እንክካቤ ሰለ መቀበል ያላቸዉን አሰተሳሰብ በመመርመር ግንዛቤ በመፈጠር እነሱን ለምርዳት ለሚቀርጹ መፍትሄዎች እና ተቋሞች ግብዓት በመሆን አስተዋጽዖ ያደርጋል ተብሎ ይታሰባል። ይህንን ግንዛቤ ዉስጥ በማስገባት ተቋሙ ፈቃድ እንድዲሰጠን በትህትና እንጠይቃለን።

APPENDIX II

PARTICIPANT INFORMATION SHEET

• Hello, my name is Gizachew Legesse. I am a final year psychiatry resident at the Addis Ababa University (AAU). As part of my training, I am studying exploration of the care-receiving experiences of people with severe mental illness receiving care at Amanuel mental specialized hospital.

• Aim: The study aims to explore the care-receiving experiences of people with severe mental illness receiving care at Amanuel mental specialized hospital, Addis Ababa, Ethiopia.

• Benefits: The study may not have any direct and/ or immediate benefit to you, but your participation is very important for the outcome of the study and the positive impact it aims to create.

• Risks: You do not have to take part in this research if you do not wish to do so, and your decision to participate or not will not have any consequence. Confidentiality will be maintained at all stages of the study.

• Incentives: compensation fee in the form of mobile cards will be provided for participating in the study.

- The interview will be tape recorded and will be later transcribed into Amharic and translated into English
- The interview will take about 1 hour. You can skip questions you don’t want to answer. You can ask me to clarify the question not clear for you. You can at any time ask for break, can reschedule or withdraw from the participation with no consequences.

• If you have any questions or concerns about the study, you may contact the Principal Investigator with the following address: 0924443548

APPENDIX III

Participant consent form

I, the participant whose ID is coded, have received and do understand the information about the study and the manner of my participation in the interview verbally and in written form.

I hereby consent to participate in the interview being audio-recorded.

Participant's signature:

Date:

Interviewer’ signature:

Date:

Thank you for your cooperation!!!

APPENDIX IV

1. Demographic and clinical data

Coded ID
Age
Gender
Educational status
Marital status
Employment status/source of income
Religion
Address

Diagnosis and related information

Working diagnosis
Medications
Other treatments
Duration of illness
Number of hospitalization

2. TOPIC GUIDE

1. Please describe to me your illness and how it is to live with your illness?

2. What does receiving care at AMSH mean to you (knowing its stigma)?

3. What types of care have you been receiving? For how long?

4. Who (in-terms of professional) has been providing care? What has been their role?

5. What is your role in the care-receiving/giving relationship?

6. What are your desired outcomes from the care you are receiving? In your understanding, what are the desired outcomes of the care-providers? How aligned are they with yours?

7. What's the most difficult part of receiving care at AMSH?

8. What were your expectations of the care receiving care? What have they been met? what has not been met?

9. What do you think about the health care services provided to you?

a) What is the most beneficial or positive part of care receiving?

b) What services have helped you the most?

c) What kind of help do you still need?

d) How do you want the service to be improved in the future?

9. How do you describe the relationship you have with your health care providers and other caregivers?

10. What challenges have you faced in receiving heath care for your illness?

a) How do you cope with the challenges?

አባሪ- 2

የምርምር ተሳታፊዎች መረጃ ቅጽ

- ሰላም፣ ግዛቸው ለገሰ እባላለሁ። በአዲስ አባባ ዩንቨርሲት የጤና ሳይንስ ኮሌጅ የአዕምሮ ህክምና ክፍል የመጨረሻ አመት ሰልጣኝ ሃኪም ነኝ። ከስልጠናየም ጋር በተያያዘ አማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል እንክብካበ በሚደረግላቸዉ ከባድ የአእምሮ ህመም ያለባቸዉ ሰዎች የኖሩትን ተሞክሮዎች እያጠናሁ ነዉ።

- የጥናቱ አላማ፡ ጥናቱ ከባድ የአእምሮ ህመም ያለባቸዉ ሰዎች በአማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል ዉሰጥ የኑሮ ልምዶችን ለመዳሰሰ ያለመ ነዉ

- ጥቅሞች፡ በዚህ ጥናት ለእናተ በቀጥታ የምታገኙት ባይኖርም የእናንተ መሳተፍ ምርምሩን ለማካሄድ እና ያመጣል ተብሎ የሚታሰበውን አስተዋጿ ለማሳካት ያግዛል

• አደጋ፡ በጥናቱ የሚሰራዉ በፈቃደኝነት ላይ ሲሆን፣በጥናቱ ላይም በመሳተፈ የሚመጣ ጉዳት የለም።ሚስጥር በሁሉም የጥናት ደረጃወች ይጠበቃል።

• ማካካሻ፡ በዚህ ጥናት በመሳተፍ ለሚያሳልፉት ጊዜ ክፍያ በሞባይል ካርድ መልክ ይሰጥዎታል።

•ይህ ቃለ-መጠይቅ በድምፅ ይቀዳል ቀጥሎም ወደ ፅሁፍ ተቀይሮ ወደ እንግሊዝኛ ይተረጎማል

- ቃለ-መጠይቁ እስከ 1 ሰዓት ሊፈጅ ይችላል።
- በቃለ-መጠይቁ ወቅት ያለተረዱት ጥያቄ እንዳብራራ ይጠየቁኝ። መመለስ የማይፈልጓቸው ጥያቄዎች ካጋጠሙዎት ማለፍ ይቻላል።በመሃል ማረፍ ካስፈለጎት ወይም ሌላ ቀጠሮ ቢያስፈልግ ያሳውቁኝ።
- ከተሳትፎዎት በማንኛውም ጊዜ ያለምንም ችግር አቋርጠው መውጣት ይችላሉ።
- ከጥናት ጋር በተያያዘ ለሚኖረዎት ማንኛዉም ጥያቄ አጥኚዉን ከታች በተጠቀሰዉ አድራሽ ማነጋገር ይችላሉ። 0924443548

አባሪ- 3

የተሳታፊዎች ፍቃድ መጠየቂያ ፎረም

እኔ ማንነቴ በኮድ የተገለፀው ግለሰብ ስለጥናቱ ምንነትና የተሳትፎዬ ሁኔታ በቃልና በፅሁፍ ገለፃ ተደርጎልኝ ተረድቻለሁ በዚህም በመቅረፀ-ድምፅ የሚደረግ ቃለ-መጠይቅ ለመሳተፍ ፈቃደኝነቴን በፊርማዬ አረጋግጣለሁ።

የተሳታፊ ፊርማ:-

ቀን:-

የቃለ-መጠይቅ አድራጊው ፊርማ:-

ቀን:-

ለትብብርዎ አመሰግናለው!!!

አባሪ- 4

1. የተሳታፊ ማንነት

ኮድ የተደረገ መታወቂያ
ዕድሜ
ፆታ
የትምህርት ሁኔታ
የጋብቻ ሁኔታ
የሥራ ሁኔታ / የገቢ ምንጭ
ሃይማኖት
አድራሻ

ምርመራ እና ተያያዥ መረጃዎች

የህመሙ ዐይነት
መድሃኒቶች
ሌሎች ሕክምናዎች
የሕመም ጊዜ

2. የርዕሰ መመሪያ

1 እባክዎን ህመምዎን እና ከህመምዎ ጋር አብሮ ለመኖር እንዴት እንደሆነ ይግለፁልኝ?

2. በአማንኤል አእምሯዊ ስፔሻላይዝድ ሆስፒታል ውስጥ እንክብካቤ መስጠቱ ለእርስዎ ምን ትርጉም አለው?

3. ምን ዓይነት እንክብካቤ እያገኙ ነበር? ለምን ያህል ጊዜ?

4. ማን (ከባለሙያ አንፃር) እንክብካቤ ሲሰጥ ቆይቷል? የእነሱ ሚና ምን ነበር?

5. በእንክብካቤ መቀበል / በመስጠት ግንኙነት ውስጥ የእርስዎ ሚና ምንድነው?

6. ከሚሰጡት እንክብካቤ የሚፈልጉት ውጤት ምንድነው? በእርስዎ ግንዛቤ ውስጥ የእንክብካቤ ሰጪዎቹ ተፈላጊ ውጤቶች ምንድናቸው? ከእርስዎ ጋር ምን ያህል የተጣጣሙ ናቸው?

7. በአማኑኤል የአእምሮ ልዩ ሆስፒታል እንክብካቤን ለመቀበል በጣም አስቸጋሪው ክፍል ምንድነው?

8. የእንክብካቤ መቀበል እንክብካቤ ምን ያህል ነበር? ምን ተገናኝተዋል? ምን አልተገናኘም?

9. ሲለምሰጥህ የህክምና አገልግሎት ምን አይነት ሀሳብ አለህ?

  ሀ) እንክብካቤን ለመቀበል በጣም ጠቃሚ ወይም አዎንታዊ ክፍል ምንድነው?

  ለ) የትኞቹ አገልግሎቶች ወይም ምክንያቶች በጣም የረዱዎት ናቸው?

  ሐ) አሁንም ምን ዓይነት እርዳታ ይፈልጋሉ?

  መ) ለወደፊቱ አገልግሎቱ እንድሻሻል የምፈልጉት እንደት ነዉ?

10. ከጠና እንክብካበ ሰጮች እና ከለሎች ተንከባካቢዎች ጋር ያለዎት ግንኙነት እንደት ይገልፁታል?

11. ለህመሞ የጠና እንክካበን ለመቀበል ምን ችግሮች አጋጥመውዎታል?

ሀ) ችግሮችን እንዴት ይቋቋማሉ?