ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCENCE, SCHOOL OF MEDICINE, DEPARTMENT OF PSYCHIATRY

CONCEPTUALIZATION AND EXPERIENCE OF EXPRESSED EMOTION AMONG PEOPLE WITH SCHIZOPHRENIA AND THEIR CAREGIVERS; QUALITATIVE STUDY

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March 2024 G.C

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

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MARCH, 2024 G.C

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A THESIS SUBMITTED TO DEPARTMENT OF PSYCHIATRY, SCHOOL OF MEDICINE, COLLEGE OF HEALTH SCIENCE, ADDIS ABABA UNIVERSITY FOR PARTIAL FULFILLMENT OF SPECIALTY CERTIFICATE IN PSYCHIATRY.

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ACRONYMS AND ABBREVATION

AAU- Addis Ababa University

AMSH- Amanuel mental specialized Hospital

AT- Code for caregiver

CFI- Camberwell family interview

EOI- Emotional overinvolvement

EE – Expressed emotion

FMSS- Five-Minute Speech Sample

HEE- High Expressed Emotion

LEE- Low Expressed Emotion

PT- code for people with SMHC

SCFI- Standardized Clinical Family Interview

SMHC- Severe Mental health condition

SMI- Severe mental illness

ACKNOWLEDGMENT

I would like to thank almighty God for his blessing.

I would like to thank specially my primary Advisor Dr. Wubalem Fekadu (Ph.D) for his unconditional support and also co-advisor Dr. Getahun Belay (Assistant professor of psychiatry).

I would like to thank AAU for giving me this chance and funding the research. In addition, my gratitude goes to Sitota center for psychiatry care and rehabilitation and Amanuel mental specialized Hospital for allowing me to conduct the research.

I would like to thank participants who participated in this study for giving me their consent and their precious time.

I would like to thank my beloved wife for her support while doing my research.

Thank you all who helped me in every aspect of the research.

TABLE OF CONTENTS

ACRONYMS AND ABBREVATION iv
ACKNOWLEDGMENT v
LIST OF TABLES vii
LIST OF FIGURES vii
ABSTRACT 1
1. INTRODUCTION 2
1.1. BACKGROUND 2
1.2. STATEMENT OF THE PROBLEM 4
1.3. JUSTIFICATION AND SIGNIFICANCE OF THE STUDY 5
1.4. LITERATURE REVIEW 6
2. RESEARCH QUESTION 12
3. OBJECTIVES 13
3.1. GENERAL OBJECTIVE 13
3.2. SPECIFIC OBJECTIVES 13
4. METHODS AND MATERIALS 14
4.1. STUDY DESIGN, SETTING AND PERIOD 14
4.2. PARTICIPANTS 14
4.3. INCLUSION AND EXCLUSION CRITERIA INCLUSION CRITERIA 16
4.3.1. INCLUSION CRITERIA 16
4.4. SAMPLE SIZE 16
4.5. DATA COLLECTION 16
4.6. DATA ANALYSIS 17
5. DATA QUALITY ASSURANCE AND RIGORS 18
6. ETHICAL CONSIDERATION 19
CONSENT FOR PUBLICATION 19
DISSEMINATION AND UTILIZATION OF RESULTS 19
7. RESULT 20
7.1. PARTICIPANTS CHARACTERISTICS 20
7.2. THEMATIC ANALYSIS 22
7.2.1. QUALITY OF RELATIONSHIP 22
PERSPECTIVE OF PEOPLE WITH SMHC 22

7.2.2. CRITICISM 25
7.2.3. HOSTILITY 28
7.2.4. OVERINVOLVMENT 30
7.2.5. WARMTH AND POSITIVE REGARD 34
7.2.6. COPING STRATEGIES 35
8. DISCUSSION 36
9. CONCLUSION- 40
10. STRENGTH AND LIMITATIONS 41
11. RECOMMENDATIONS 41
12. REFERENCES 42
APPENDICES 44

LIST OF TABLES

TABLE 1-SOCIODEMOGRAPHIC CHARACTERSTICS OF PARTICIPANTS 20

LIST OF FIGURES

FIGURE 2-PARTICIPANTS SELECTION PROCEDURE 15

ABSTRACT

BACKGROUND- Schizophrenia and schizoaffective disorder are psychotic disorders and severe mental illnesses manifested by positive and negative symptoms. High expressed emotion, which comprised of criticism, emotional oveinvolvement and hostility of care givers towards people with those mental illnesses has been implicated as a reason for frequent relapse.

OBJECTIVE- to explore conceptualization and Experience of expressed emotion among people with severe mental health condition and their caregivers at Amanuel mental specialized hospital Sitota center for mental health care and rehabilitation and.

METHOD- qualitative study was conducted among 16 participants; eight were from Amanuel Mental Specialized Hospital and others from Sitota center for mental health care and rehabilitation. Half of them were people with severe mental health condition and the remaining eight were caregivers. After in-depth interview conducted and audiotaped the primary author repeatedly listened the interviews and made the transcription and translation. As the conceptualization was mainly related with the well-established conceptualization of expressed emotion, the analysis was guided by established frameworks specially related to expressed emotion and while still being open to any new themes that emerged.

RESULT- Six themes were identified; Quality of relationship, hostility; criticism; overinvolvement; warmth and positive regards and coping strategies. Caregivers consider people with SMHC they are caring for are lazy, dependent, lack confidence, and they lack motivation. They also show their criticism and hostility in different circumstances. Participants reported overinvolvement is beyond EOI, and they have justifications for that. People with SMHC also reported different coping strategies, like keeping quiet, decrease level of contact and so on

CONCLUSION- the way people conceptualize expressed emotion matches what previous research has shown. Caregiver's experience of high expressed emotion correlates with the way they understand the symptoms, their understanding of the illness in general. With this, it will be important to raise awareness about the negative impact of high expressed emotion and develop and evaluate interventions to address these issues as the care givers did not understand the impact of their action possibly by incorporating family psychoeducation plan as a part management.

1. INTRODUCTION

1.1. BACKGROUND

Schizophrenia spectrum and other psychotic disorders is a group of mental illness which include schizophrenia, schizoaffective disorder, schizotypal personality disorder and other psychotic disorders, ant those illnesses are characterized by sign and symptoms like delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (which includes catatonia), and negative symptoms. (1)

Expressed emotion is a concept to refer the emotional climate, attitude, feeling, or behavior relies on the response of care givers and subsequent feedback towards family members who has illness. In the 1960s by George Brown and his team developed the concepts and measurements, initially in schizophrenia and later on used for a number of physical and psychiatric conditions. The team explained critical comments, hostility, emotional over involvement, positive remarks, and warmth as components of expressed emotion. (2, 3)

Critical comments are one of the high expressed emotions which is generally to mean the negative assessment of the patient's behavior. Almost seventy percent of critical comments focus on misunderstanding of negative symptoms of schizophrenia as laziness and being selfish and greedy. Their way of expressing criticism encompasses talking by an high tone of voice, tempo, and volume of voice that the ill family member frustrates them, accusing that they are deliberately causing problems to them, living with them as difficult and addressing them as being burden to family, and also criticizing how the patient is ignoring their advices (2)

Hostility is based on a negative conception and attitude to the those who are ill as a person and has manifestation by caregivers mentioning how those who are ill are causing problems and telling their wishes the patient to go away, embarking at them, easily getting angry and getting irritable, showing rejection, and having statement that they can better control themselves and so on (2).

Emotional over-involvement is the other form of high expressed emotion which has characteristics of like desperation, devotion, self-sacrifice, and excessive protection of those

who are ill or excessive emotional response to the person's illness to the level of giving up personal needs. Caregivers may blame themselves as if everything as their fault; feeling pity, remorse, may not allow the patient to carry out his day-to-day activities. These lead them to initiate compensatory efforts to make situation better for the child and extend to overprotectiveness and bypassing the freedom of the person with SMHC. This may discourage the person's skills and self-reliance, hence hampers the person's recovery in the long run and also causes to the person with SMHC to be dependent on their caregivers. It is told to be shown mostly by parents, especially mothers (2, 4).

The other two form of expressed emotion are warmth and positive regard. Those are characteristic of having the low expressed emotion. In case of warmth, caregivers mention that person with SMHC is trying his best to socialize with everyone, makes a lot of sense, they are easy going, and it is glad to have them, their behavior can be understandable and can be due to the illness by giving due understanding to pre-morbid self and so on. Positive regard is the other low expressed emotion which is characterized by statements which express appreciation or support for the behavior of person with an illness and caregivers reinforcing people with an illness both verbally and nonverbally, feeling close to the person with SMHC they are caring for, they appreciate efforts and their initiation in their daily functioning, stating how they enjoy by being with them (2, 3).

High EE are all depends on overt behaviors which involves direct interactions between people suffering from schizophrenia or other mental illness and their caregivers. As an example, caregivers criticism is often characterized by aversive words and disapproving actions directed toward the patients. It has been point of controversy that potential impact of non-verbal expressions and other subtle behaviors of caregivers have largely been neglected (5).

There are various types of measurement and assessment tools of expressed emotion which includes Camberwell Family Interview (CFI), the Five-Minute Speech Sample (FMSS), Standardized Clinical Family Interview (SCFI), perceived criticism (2).

1.2. STATEMENT OF THE PROBLEM

The concept of expressed emotion told to be introduced in 1960s by George Brown and his teams after observing patients who were treated by chlorpromazine and discharged improved. They noticed those patient readmitted soon due to relapse which they started considering the possibility of adverse influence prolonged contact of patients with their family members in the degree of disability, functioning and relapse rate. Brown and colleagues researched relapse rates of people who have from differing living setups and their research showed relapse rates of around 17% for those live by themselves or with siblings, around 32% for those who live with their parents and 50% for those who lives with spouses. (6, 7)

There are various studies which found high expressed emotion as relapsing and maintaining factor of the illness and suggesting psychosocial interventions along with the pharmacotherapy would provide better outcome and help in the person with SMHC as well as the caregivers (7).

Numerous studies were conducted after Brown's study in this regard. Among those, Vaughn and Leff researched 43 people with schizophrenia and 32 people with depressive neurosis, and followed 37 and 30 patients respectively in the two groups. 50% relapse rate was recorded for the patients from families that showed high expressed emotions compared to 12% for those who were from families with low expressed emotion (8).

There is previous quantitative study done on expressed emotion and factors associated with it at Dilla and Jimm, Ethiopia. In this study, The proportion of high expressed emotion (EE) ranges from 43.6% to 50.5%, and one study reported that female caregiver was 1.2 times more likely to have high expressed emotion, those who give care for 6–8 years were 3.5 times more likely to have high expressed emotion than those who give care < 2 years and those with illness duration of more than 6 years were 1.6 times more prone to expressed emotion. This study is quantitative and may not give detailed lived experience about EE of caregivers or people with SMHC. So we found it will be relevant conducting this qualitative research. (3, 10)

1.3. JUSTIFICATION AND SIGNIFICANCE OF THE STUDY

Starting from Brown and colleagues research in 1960s, there have been different evidences that High expressed emotion leads to relapse and acts as a maintaining factor, which usually influences the clinical outcome and majority of the studies have indicated different solution that psychosocial interventions along with the pharmacotherapy would provide better outcome.

Based on the research finding, different family based psychosocial interventions can be applies targeting the high expressed emotion so as to reduce the rate of relapse.

Though there are quantitative studies on high expressed emotion and factors associated with it, I did not found any qualitative study conducted in this regard in Ethiopia and this study will try to explore how those patients with schizophrenia and schizoaffective disorder and their care givers conceptualize and experience expressed emotion and can be used as future directive for further studies in this line.

1.4. LITERATURE REVIEW

HOW WAS THE CONSTRUCT OF EE INTRODUCED?

The concept of expressed emotion told to be introduced in 1960s by George Brown and his teams following those patients who were treated by chlorpromazine and discharged improved. They observed those patient readmitted soon due to relapse which they started considering the possible adverse influence of having prolonged contact of people with mental illness with their family members in influencing the degree of disability, functioning and relapse rate. Then they come up with five constructs of expressed emotion which incorporates critical comments, hostility, emotional over involvement, positive remarks, and warmth. (6, 7)

George Brown and his teams conducted a research with 229 people with mental illness who were discharged from psychiatric hospitals, and 156 of them had diagnosis of schizophrenia. The study showed those who resides with their parents or wives after their discharge were more likely to get relapsed than those who reside in lodging or with their siblings. This study has implicated the possible adverse outcome of prolonged contact of person having schizophrenia with their caregivers and family members in determining the degree of disability and level of functioning. Another study by Vaughn and Leff also emphasized that high expressed emotion as single best predictor of a symptomatic relapse after they were discharged from the hospital. Both of those studies suggested eight times more relapse risk in patients living with high than low EE families (2, 6).

IMPACT OF EXPRESSED EMOTION ON PEOPLE WITH SMHC

While having high EE was told to increase relapse in people with SMHC, there are studies which found the protective nature of having low expressed emotion (warmth and positive regard) and also there is decreased relapse in such contexts. (19)

It has been suggested that high expressed emotion may be higher among parents than spouses. In one Australian study, expressed emotion better predicted relapse in single-parent households than in two-parent homes. In addition, Mothers tend to manifest with EOI than other family members (2).

STUDY IN ETHIOPIA

There were cross sectional studies done at Dilla and Jimma, Ethiopia, which showed the proportion of high EE ranges from 43- 50 %. The study reported that female caregiver was 1.2 times more likely to have high expressed emotion, those who give care for 6–8 years were 3.5 times more likely to have high expressed emotion was reported among those who were giving care to patients for 6-8 years compared to who give care < 2 years. It was also shown, for those with illness duration of more than 6 years was 1.6 times likely to have expressed emotion (3, 10).

STUDY IN AFRICA

There was study done in Lagos with Nigerian family members of 19 people with schizophrenia. The research found that 63% of them showed high expressed emotions. The research also implicated that the proportion of high EE families increased progressively with the number of previous hospitalization (9).

There was a study done in Egypt, around 55% of caregivers of person with schizophrenia presented with high expressed emotion. It was also reported in study that Egyptian people with schizophrenia will tolerate increased levels of criticism before they relapse than western studies. Another study presented criticism as normative component of relationship in Egyptian culture and shown as an component of care as well (15).

STUDY IN OTHER PARTS OF THE WORLD

A research done in United Kingdom following people with schizophrenia and depression over the period of two-year, the relapse rate in high EE was fifty percent compared with twelve for those lives with families who has low EE. This study was also replicated in California, assured that the score of families expressed emotion are predictive of relapses over periods of time and the amount of face-to-face contact with the caregiver after hospital discharge is identified as important determinant. Similar findings were also replicated in Australia which discovered that fifty nine percent relapse in the high expressed emotion group and 36% in the low EE group (8, 11, 12).

According to different studies done in different part of the world also replicated those findings, showing higher relapse rates among high expressed emotion groups. There is a meta-analysis of

twenty six studies which confirmed twice higher recurrence rate than base line in regard to symptoms if people with schizophrenia lives in environments with high EE. According to different researches, female gender and increased number of previous episodes told to be correlated with high EE (2, 13).

A research done in China showed seventy one percent of caregivers of people with schizophrenia have high EE, Criticism being the main form of high EE, with the rate of 34.78%. The study has shown elevated rate of re-hospitalization with those caregivers of high EE than those with low EE, mainly among those with high criticism, but no significant difference was identified in the which is be due to high EOI (14).

In a study done in Brazil studied 89 dyads, 31% of people with mental illness in the research were presented with relapses and among those, 68% of the relatives presented with high EE. (16)

In a study done in Japan, 48% of Japanese caregivers were identified as they are showing high EE. Criticism was most common one, 39% of households forwarded six or more critical comments which are contrary to the consideration to Japanese culture to have low EE hence they usually not to display their emotions readily (16).

WHO has done the study of first-onset schizophrenia at Chandigarh London and Aarhus. Chandigarh is one of the 3 centers of the WHO study where hundred and four relatives were interviewed. Among the other centers, the Chandigarh study reported the lowest ratings on the following parameters: mean number of critical comments; proportion of families showing hostility; positive remarks; the mean score on warmth; and level of parental overinvolvement. In this Chandigarh study, it was only 23% of relatives who are classed as having high expressed emotion which was relatively lower that other centers of the WHO study. Which showed proportion of high EE is around fifty four percent. Twenty nine percent of the Chandigarh sample showed hostility but low criticism. The other fascinating finding was, among families of people with mental illness living in Chandigarh; it is common to express both high criticism and high warmth simultaneously. (17, 18)

CULTURAL ASPECT OF EXPRESSED EMOTION

In western culture, which has predominantly egocentric in its characteristics, emotional over involvement usually seen as something abnormal hence it bypasses personal boundaries. On the other hand, in most of sociocentric societies, emotional over involvement is acceptable because the individual is considered as member of the larger kinship group. Taking Indian context as an example, mothers are over-involved with their children and this cannot be described as necessarily problematic and rather is not showing emotional over involvement considered as not giving appropriate care. To look at Jewish culture, critical comments and over involvement of the mother is considered as culturally appropriate and mentioned it should not be taken as something bad. There are also cultures which follows the sentiment that failure to express one's anger as a form of weakness. Considering all cultural viabilities, different studies suggests expressed emotion ratings must be adjusted in context to the normative levels of overt expression of emotions. (15,20,21).

The correlation between high EOI and adverse outcome to patient health is not consistent across cultures. There are also findings which implicated the construct and measurement of EOI itself are culture-specific and effect of high EOI may be moderated by some dimension of warmth and mutual interdependence in close relationships. Ultimately, EOI is about bypassing and crossing of interpersonal boundaries, balance between proximity and autonomy should be delineated. There are ongoing thoughts that, even in cultures with a collectivistic conceptualization of self, there should be an interpersonal boundary and crossing this boundary may lead to the disrupt ability of the individual for self-reliance and protection (4, 22).

DETERMINANTS AND FACTORS ASSOCIATED WITH EXPRESSED EMOTION

There are various care giver factors are related with expressed emotion which comprises; caregiver’s personality factors meaning who have decreased satisfaction of their person’s activities, low optimism about their future, and decreased self-efficacy and those low empathy, rigidity, and intolerance are told to be associated to have high EE. Those attendants with internally based locus of control are told to have high critical comments, by attributing the causes

that are controllable and personal to the patient. Having guilt feeling is antecedent of EOI (2, 14).

There are different models used to describe the correlation between high EE and relapse. Stress-vulnerability model is one of them; which tries to incorporate biological factors and cycles of mutual influence between symptomatic behavior, life events, and EE. Social interaction model of schizophrenia is a model used to mediate issues that EE represents an attempt to blame families for schizophrenic relapse. Uncompassionate behaviors in people with mental illness and their families are seen as considerable reactions to stress and social perceptions and coping skills are mentioned as moderating factors (23).

There are different factors up on which the feature of expressed emotion depends on. This includes cultural meanings of relations, interpretations of the characteristics of the behaviors across different cultures, identification of cultural rule violations, how they name emotions, difference in personality traits, nature of the psychopathology, and dynamics of family interaction, intentions to control socially deviant relative and availability and quality of social supports. This factors in addition to validity problems in measurement instruments can explain the difference of high EE among different part of the world (24, 25).

Vaughn came up with redefined four factors that differentiate relatives with low versus high expressed emotion which have their basis on respect for patients relationship needs. These factors include; attitudes toward the legitimacy of the illness, level of expectations for patients functioning and emotional reactions to the patient's illness. This construct has variability across different cultures. As an example, respecting patient's interpersonal distance, considering the illness as outside of their control, having few expectation for normal functioning, and showing a concern in combination by being easy going and by maintaining flexibility are some of characteristics which British families may be rated low in expressed emotion (22)(26).

Different studies showed more than 35 hours per week of Face-to-face contact with a relative with a high EE score increased the risk of relapse. On the opposite in the setting with a low expressed emotion score, high levels of contact found to be protective. Among explanations for this relation includes those patients with schizophrenia may not be allowed to strive for daily

activities by their own and subsequently will depend on their caregivers and there is high chance that they may tend to evaluate their life as being filled with interruptions. (9, 11)

RECOMMENDED INTERVENTIONS

Family-focused psychosocial interventions is a therapy model focusing on reducing the levels of EE of caregivers by working on their knowledge about the illness is one of mostly examined and suggested modality of intervention. There are also other family interventions which include illness education and associated coping skills training, crisis intervention, and emotional support which will help with to overcome distress and also has good impact on treatment adherence which may last up to six to nine months for patients who have ongoing contact with their families. Those therapeutic interventions can have an outcome of reducing in hospitalizations or relapses over two year period to the extent of twenty five to fifty percent. There are also researches in United Kingdom implicated that the combination of routine antipsychotic medication and decreasing contact with those relatives who are highly critical or overinvolved would decrease the rate of relapse (1, 2, 11).

2. RESEARCH QUESTION

- How is your relationship between People with SMHC and their care givers
- How do people with SMHC and their caregivers conceptualize expressed emotion
- How is the experience of expressed emotion among people with SMHC and their caregivers?
- How does people with SMHC cope with high EE

3. OBJECTIVES

3.1. GENERAL OBJECTIVE

- To explore the conceptualization and experience of expressed emotion among people with severe mental health condition and their caregivers at Amanuel Mental Specialized hospital and Sitota center for mental health care, from June to August 2023.

3.2. SPECIFIC OBJECTIVES

- To explore the conceptualization of EE among people with SMHC and their caregivers
- To explore the lived experience of expressed emotion among people with schizophrenia and their care givers
- To explore the perceived effect of EE on the patient
- How does people with SMHC cope with expressed emotion they experienced

4. METHODS AND MATERIALS

4.1. STUDY DESIGN, SETTING AND PERIOD

It was a qualitative study using mainly a phenomenological approach aiming to explore the lived experience of people with schizophrenia and their care givers.

Study was conducted at Amanuel mental specialized hospital and Sitota center for mental health care during the time frame given for data collection.

Amanuel mental specialized hospital is the only mental specialized hospital in Ethiopia Situated in the capital city Addis Ababa. It is the only specialized mental hospital in the country serving psychiatric patients all over the country. The hospital has 236 beds for inpatient care and around 610 patients are seen at the outpatient setting daily. More than 384 health care professionals and 460 support staff are currently working in the hospital.

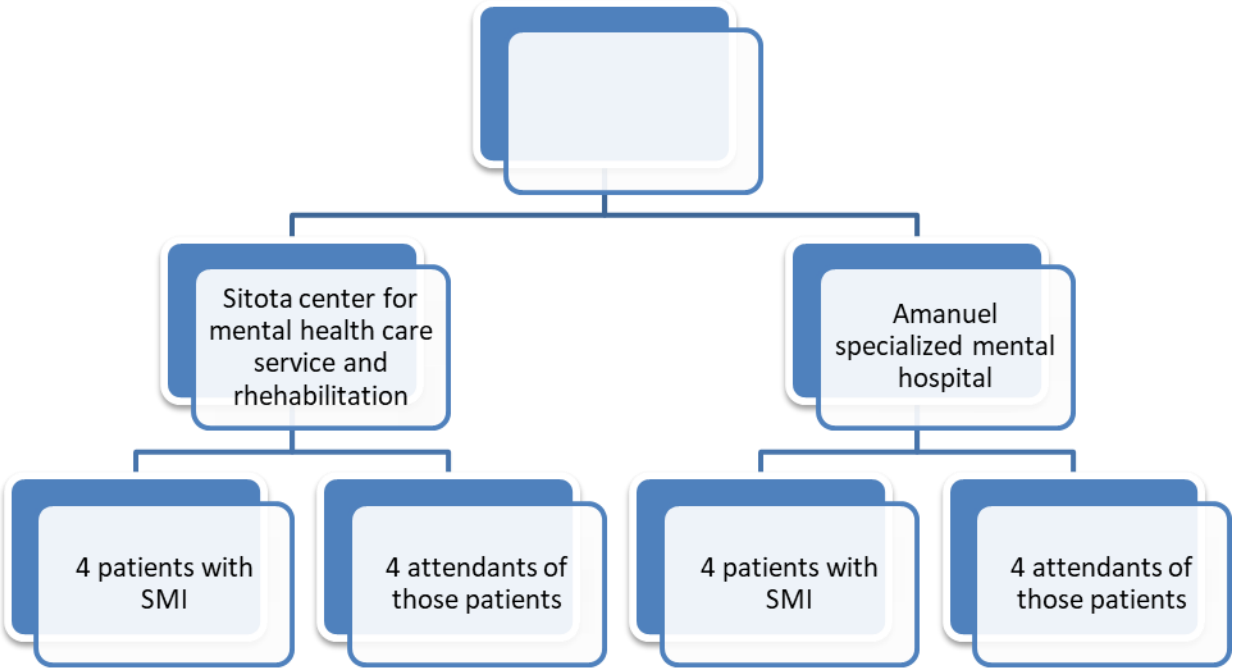
Sitota center for mental health care is the private center situated in Addis Ababa, the capital city of Ethiopia. It has services like general psychiatric, psychologic, child psychiatry, emergency psychiatry, addiction psychiatry service as outpatient and inpatient.

4.2. PARTICIPANTS

Purposive sampling technique was used and participants were those people diagnosed with schizophrenia/schizoaffective disorder and their family care givers attending them on specific period.

Patients diagnosed with schizophrenia/schizoaffective disorder that were on treatment at those centers, caregivers who are attending schizophrenia patients

Sampling was continued till theoretical saturation was maintained when neither new information nor new themes emerged in two consecutive interviews.



The purpose considers

- Sex of the person with the illness
- Age
- Living place
- Educational status
- Illness progress

So that we managed to include the possible variations in impact

FIGURE 1-PARTICIPANTS SELECTION PROCEDURE

4.3. INCLUSION AND EXCLUSION CRITERIA INCLUSION CRITERIA

4.3.1. INCLUSION CRITERIA

Age of participants is 15 and above with diagnosis of schizophrenia and schizoaffective disorder. Semi structured interview was conducted to asses mental state and capacity to consent or assent to involvement. Informed consent was applied for people with SMHC who are >18 years of age and assent for was also prepared for those less than 18 years of age. Caregivers age more than 18years who can give consent and are willing to participate are included to the study.

4.4. SAMPLE SIZE

The sample was determined by theoretical information saturation. At the end I interviewed total of eight patients and eight attendants assuming theoretical saturation has achieved.

4.5. DATA COLLECTION

Rapport was created between the interviewer and the participants. Data was collected by the principal investigator of this project using in-depth interviews face to face, at the Addis Ababa staff office, in AMSH and at offices in Sitota center for mental health care.

Basic information about socio-demographic characteristics was collected as reported by the participants. This was done using a structured form designed for this purpose which will include age, educational level, marital status, occupation and living situation.

Topic guides was translated to Amharic, which was the language to be used for the interview.

Notes were taken in addition to audio recording during the interview. The records will only be used for this research every effort will be made by the researcher to preserve your confidentiality by assigning code names/numbers that will be used on all research notes and documents.

4.6. DATA ANALYSIS

After in-depth interview conducted and audiotaped the primary author repeatedly listened to the interviews and familiarized with the data, then the transcription and translation was made. Then initial codes were generated, subsequently searching for sub-theme and theme, reviewing sub-themes and themes, defining and naming themes, and finally producing the report of thematic data analysis. As the conceptualization was mainly related with the well-established conceptualization of expressed emotion, the analysis was guided by established frameworks specially related to expressed emotion and while still being open to any new themes that emerged.

Open code 4.0.3.0 software was used to manage the gathered data.

5. DATA QUALITY ASSURANCE AND RIGORS

The purposive sampling tries to incorporate various socio-demographic factors to insure the rigor of the study. Participants were from one governmental and one private setup so as to grasp different perspectives of all the possible perspectives and experiences. We tried to incorporate both inpatient and outpatient setups. Interview was conducted in one to one in-depth interview of people with severe mental health condition and their respective caregivers.

There was frequent meeting with advisor about the progress, and evaluating whether the research questions address the objective.

6. ETHICAL CONSIDERATION

Ethical clearance was obtained from Department of Psychiatry, College of Health Sciences, Addis Ababa University. Then the letter was submitted to ethical board of Amanuel Mental Specialized Hospital and Sitota center for mental health care service and permission was granted.

In this study, all participants were above the age of 18 years. Written informed consent was taken from the participants in the research after they were provided with the information regarding the objective, procedure, potential risks and benefits of participating in the study and the right to withdraw from the study at any time throughout the interview and confidentiality.

They were provided an information sheet for the person to read. Some of them asked the information sheet to be read by the interviewer and done accordingly. All participants had capacity to participate which was assessed semi-structured capacity assessment tool. They provided informed consent through a signature.

Transcripts were anonymized to ensure people could not be identified by reference to individuals/places and we have given codes.

All the ethical procedures were followed in accordance with the Helsinki declaration.

CONSENT FOR PUBLICATION

Not applicable as we have anonymized all individual data

DISSEMINATION AND UTILIZATION OF RESULTS

The results of this study will be disseminated to the Department of Psychiatry, Addis Ababa University and AMSH and Sitota center for mental health care and rehabilitation.

The final thesis will be available in both soft and hard copies at the library of College of Health Sciences, Addis Ababa University. This will be open for the staff and future publishing.

7. RESULT

7.1. PARTICIPANTS CHARACTERISTICS

The Age of respondents of people with SMI ranges from 20- 45 years with mean age of 33 years. While the age of respondents from caregivers range from 32-65 years with mean age of 45.6 years. Among participants from people with SMHC, six of them are male and two are females and six are from Addis Ababa and all have formal education.

TABLE 1-SOCIODEMOGRAPHIC CHARACTERSTICS OF PARTICIPANTS

Parameters	**People with severe mental health condition (8)**	**Caregivers(8)**
Diagnosis	• Schizophrenia (7) • Schizoaffective disorder(1)	• NA
Sex (male/female)	• Male (6) • Female(2)	• Male- 3 • Female- 5
Mean age (years)	• Mean= 33 • SD=8.44	• Mean age- 45.6 years
Education	• No formal education- • Only up to Primary school • Only up to Secondary school (5) • College and above (3)	• No formal education • Primary school (3) • Only up to Secondary school and above (3) • College and above- (2)
Religion	• Muslim (4) • Orthodox (1) • Protestant (2) • Jehovah witness(1)	• Muslim (4) • Orthodox (1) • Protestant (2) • Jehovah witness(1)
Residence	• Addis Ababa(6) • Jimma(1) • Zeway(1)	• Addis Ababa(6) • Jimma(1) • Zeway(1)

Relationship patient	•	• Parents (4); - AT-001(Mother); AT-004(Mother); AT-006(Mother) and AT-005(mother) • Siblings (2) - AT-007(sister): AT-003(brother) • Spouses (1)- AT-002(Husband) • Other family (1)
Marital status	Single- 6 Married- 1 Divorced- 1 Widowed- 0	Single- 0 Married- 3 Divorced- 3 Widowed- 2
Duration of illness	1-5 year; 1 6-10 years- 7	NA
Disposition	Inpatient- 6 Outpatient- 2	
Number of Admission	Median Interquartile ratio= 5	
Place of followup	- AMSH- 4 - Sitota center for mental health care and rehabilitation service- 4	
Lives with	▪ With Mother- 2 ▪ Mother and siblings- 2 ▪ With mother and grandmother- 1 ▪ With mother and spouse- 1 ▪ With grandmother- 1 ▪ With siblings and other families- 1	

7.2. THEMATIC ANALYSIS

In thematic analysis we developed six themes, those themes are

- Quality of relationship
- Critical comments,
- Hostility,
- Overinvolvment,
- Warmth/positive regard and
- Coping techniques

7.2.1. QUALITY OF RELATIONSHIP

PERSPECTIVE OF PEOPLE WITH SMHC

Most participants from people with SMHC reported they have good relation with their family members. Some stated there is no family of preference while others mentioned someone who they are close with. Most spend their time at home with families. Some mentioned specific member of their family as supportive while others either critical or harsh to them. In general they prefer spending time with those who has supportive outlook towards them. They talk to those supportive family members for their concerns and get helped. Among those who lived together with their mother, they addressed them as good and comforting while some mentioned them harsh and critical.

"..Still it is my grandmother who is supportive enough. I talk to her, she read me bible and comfort me when I get distressed" PT-001

My mother has unpredictable behavior. I feel she don't like my wellness- PT-001

Participants from people with SMHC who reported there are some of their families who have bad outlook and aggressiveness towards them mentioned that this spans from showing bad face up to hitting them for different reason. They feel abused by their caregivers. This abuse may be

directly imposed by the primary caregiver or they may call for someone like their uncle or some other threatening figure to punish them claiming they are aggressive and disturbing people.

"I spend my time with my husband, his sister and maid. My husband is caring person. But I have no good relation with her mother…. She does not want my wellness. PT- 002

"Though my mother doesn't hit me, she will call my uncles and they will hit me saying how aggressive and disturbing I am." PT-006

There are also people with SMHC who reported they don't interact much with family and prefers to be alone. They rather prefer listening to themselves and stay at their room. .

"I prefer staying at my room than interacting with families. I have same outlook to his family members. PT-007

There are others who also reported there is times which they feel misunderstood by their caregivers. They were even critical of their illness saying after everything is fulfilled, how a person can get depressed. Those people with SMI blame their caregiver for their current condition. They were mentioning the restricted life imposed on them and early misunderstandings by the family predisposed them to the current condition.

"On initial period of his illness, my families don't understand what I have been through. They even said how come you depressed after all things fulfilled….I blame my mother for the current condition because she was abiding me from expressing his feeling. PT-001

CAREGIVERS PERSPECTIVE

Regarding their attitude towards people with SMHC and their behavior, and also their general relationship quality, Caregivers reported that they feel pity for those people with SMHC they are caring for. They feel patient is not fine and desperately need their assistance. Considering them talking alone and showing behavioral symptoms warrant their presence. They may regret if they leave the patient alone and fears something bad will happen to them**.**

"I will never let her alone, how dare I leave her who talks alone? What if something bad happen to her? If so I can't cope with the regret I may have." AT-004

Caregivers think the person with SMHC they are caring for is dependent and lost confidence. They used to be active before the illness, but progressively getting more dependent, losing his confidence and requires their assistance in their day to day activity and lack motivation. Some are not sure whether they are doing this on purpose or it is the manifestation of the illness. Both caregivers and patients reported this issue is main reason of argument between them.

"He used to be active prior to illness, but now he is dependent on us even to dress up, to iron his cloth he doesn't want to wash his body. He is losing his motivation and am not sure whether it is intentional behavior or due to illness" AT-001

Field note- This care giver (AT-001) who is mother of the person with SMHC, she was tearful while talking talking about how dependent he is getting through out time.

"He is getting more dependent. He can't even take a shower by himself. He has lost his motivation"AT-008

Caregivers also reported that it is really difficult to care people with mental health condition. They were telling how the illness also impacted them. The effect is beyond the health of the person with the illness, but has also has social stereotypy, people gossiping that child is mentally ill, and it restricts their social activity. Also reported it is painful as a mother seeing all this suffering on their child.

"You will lose your patience while taking care of him. You will lose your peace, your happiness, economic stability...People gossip my child is mentally ill. They feel sympathy for me..I feel sick of the stigma in my neighborhood. My social life is so restricted due to this." AT- 001

Field note- AT-001who is the mother of PT-001; she was seems distressed and overwhelmed and tearful when talking about this impact.

Caregivers also mentioned though there is genuine illness, patient is feigning some their symptoms intentionally. They seem acting the sick role to be cared and exempted from work. Also seeing the discrepancy of symptoms at home and hospital asserts he is acting in a way intentionally.

"Though he has illness, he is using those symptoms as an excuse to be exempted from work and to get our attention and help…He told to my wife one time that acting sick is easy way to live.."- AT-003

Caregiver also think person with people with SMHC they are caring for want to be treated as a kid. They usually try to act as kid in front of their mother. Though people with mental health condition wanted this, caregivers think it is not appropriate thing to do. They even tell those who treat them as kid to stop it hence they are spoiling them.

"He wants to be seen as someone special …Our mother is over caring for him and that is why he is such delinquent by now. I don't treat him as a kid though" AT-003

Caregivers think person with SMHC they are caring for has difficult behavior. Some caregivers will react to this difficult behavior aggressively, while other tries to be as patient as possible because they can't cope with the aggressiveness of the patient.

"She will destruct household things. She doesn't listen to me. She may appear calm and quite now, but she is aggressive enough at home. " AT-004

Caregivers also reported that the patient is selfish only concentrated to their needs. They attribute some odd behaviors a form of greediness.

"He is selfish.. Always stands for his needs; he does not care for his families or others. That is why he pees inside the house."AT-003

Field note- AT-003 is younger brother of PT-003; he was irritable while talking about those behaviors of the person he is caring for.

7.2.2. CRITICISM

EXPERIENCE OF CRITICISM

Caregivers reported that they blame the people with SMHC living with them when they get irritable of their behaviors. They will be irritable for their aggressive behavior, for not motivated

enough and doing their activities, being a burden to them and killing their time by being guardian of them and patient being selfish. Though caregivers mentioned those reasons, patients said they are getting inappropriate criticism from their care givers. They also said their words are so harsh and inappropriate.

"I tell him 'You are creating problem to us..why don't you let things go. I said to him how he killed our time and our life. We have been stressed by your actions all the time. We never rest. Why don't you give us peace?" AT-003

"For no appropriate reason, my mother insults me 'insane/mad- yeleyelesh' and also "you scandal" which really disappointed me". PT-002

There are caregivers also reported that there are times that person with SMHC they are caring for to demise and wish they were not born when they get irritable and burn out. They said it is overwhelming caring of patients. It is when the overwhelm exceeds their control, they will make those remarks.

"When I get angry, I tell him that am tired of him, he makes me suffer and wish he is not born" AT-001

There are also caregivers who give harsh comment and remark toward the person with SMHC they are caring for by mentioning his laziness, performing and living below his colleagues, not working as expected, drifting back to childish behavior. They will also reflect on person as selfish behavior.

"Sometimes we say to him Look at you. Why don't you be just as your peers?" AT-008

CONCEPTUALIZATION OF CRITICISM

Regarding possible reaction of people with SMHC and changes anticipated after having critical comments, some caregivers reported that the patient may react back for the feedback given and get more disturbed and irritable, will have silent treatment and defiant look to caregivers, and may get counteroffensive back to caregivers and subsequent negative impact to the patient. They may say how dare to complement like that, I am grown person. Some may stop their comments when they see these changes, while others will be harsher after hearing the counteroffensive acts

from patients to make them calm and disciplined. Some of caregivers conceptualize symptoms of the person with SMHC as laziness, intentional amotivation and so on which possibly be negative symptoms of schizophrenia. This misunderstanding seems to be main reason for the critical comments the caregivers are having. They also pointed out that their critical comment is making things worse than showing a better outcome to their behavior.

"When we threaten him, the patient becomes irritable and there will be change in behaviour."AT-007

There is also report that the critical comment given to patient has deleterious outcome to the extent of attempting suicide, and perceived reason being hopeless and getting sad after harsh words forwarded. There is also person with SMHC who stated they were in disagreement recently. The caregiver, who is his mother occasionally blames and criticizes him for not being just likes his colleagues and as if he is a kid. He reported these critics made to hate him and lose his confidence, get depressed anxious and he even said his hearing of voice had come and subsequently attempted suicide. Now days when she tries to criticize him, he is thinking of leaving the house.

"He will cry and sad for days. It was due to my harsh words he attempted suicide by overdosing medication…" AT-OO1

Caregivers also described criticism will have an implication behavior and illness of the person with SMHC they are caring for. They associated some of their symptoms can be a direct effect of arguments and criticism they experiencing. They also developed sense of hatred towards family member who is critical of them. Caregivers also reported that because of the critical environment the patient is in, the frequency of admission is increasing. Patient also reported the harsh criticism creates disappointment and sad mood.

"In the past couple of years she was admitted frequently. It may be due to the quarrel she is in with her mother" AT-002

On the other side, there are also caregivers who reported the positive side of criticism. They mentioned being harsh on patients make them more active has a better impact on person's behavior. Caregivers being aggressive forces the person with SMHC to ask for an apology for

their mischievous behavior. They also blame some family members for being lame and easy towards patients and also for not allowing them to be harsh which in turn really spoils the patient. Caregivers believe there need to be someone to criticize and shape the patient otherwise they will derail in their behaviors. On other hand, people with SMHC stated their families are abusive for no reason and even insisted to tell them to stop.

"Our mother spoils him by over caring. I tell to the patient 'look at you.. You are just a burden on our mother. You need to be independent.' I am being harsh on him to make him more active" AT-003

"He needs someone to criticize him when he did something wrong. I don't think giving critical comments and feedback to patients will have that negative impact. Those comments are making him more disciplined- AT-008

"My families are abusing me. They even hit me. Can you tell them to stop?"PT-008

7.2.3. HOSTILITY

EXPERIENCE OF HOSTILITY

Caregivers manifest their hostility towards people with SMHC in different forms. Some of them include chaining them, sending out of home, hitting (caregivers themselves or by calling someone to punish them) , using force to make the patient to do something they required.

"My uncles approach me by holding stick to hit him. It is my mother calling them…They claim I am acting aggressive but I am not. They are abusing him verbally and physically" " PT-006

Caregivers' chain people with SMHC they are caring, when the behavior is beyond their control. Among the reason mentioned, they chain the patient when they impose physical threats to family members or someone and impose injury to the caregivers; when they resist coming to the hospital willingly as a way of bringing them forcefully. Some reported, other than chaining, they try to not to hit patients claiming it may worsen their condition. But patients claim they are not merely chained, but also bitten aggressively, even by big sticks. Though the caregiver claims

they are trying to make the patient disciplined, patients reported that their caregivers hit them claiming that they are aggressive by misunderstanding them. They defend themselves they are not bad person as caregivers claim

"When he is aggressive threaten our mother, I may chain him. He usually unchains himself. I was also about hitting him. I used to hit him previously, but now I am stopping it thinking it may precipitate the illness." AT-003

Caregiver also reported there are times they sent patient out of home when they get irritable. They think there are some behaviors patient do intentionally and this makes them so irritable to the extent of sending patient out of home in the middle of the night.

" I can't help it when he repeated inappropriate things. I finally sent him out of home shouting on him. It was the middle of the night. There were hyenas barking and he returned back soon. I let him in" AT-003

Attendant use force to enforce the patient to do things they required. There are times patients lack motivation or interest in doing things. During those times care givers said they will use force so as the patient do things and event they will shout at them and make verbal threats which really helps them in a way and give temporary relief. They also threaten them so as to take them to follow-up.

"If he refuses to take shower after they told him, we will splash water and wash him forcefully .then he will continue washing his body' AT-008

There is a patient who reported he used to be chained and even bitten during his admission. Health professional there in the hospital used to hit him whenever they think he was aggressive and will get in to confrontation with other patients. They also did that so as to give him medication.

COCEPTUALIZATION OF HOSTILITY

Caregivers mentioned there are times they have difficulty of containing their irritability and they will be harsh towards the person they are caring for assuming that they are acting this was

intentionally, they are being burden to them, they are disrupting families life and disrespecting them and even wish they were not born. Showing this hostility, caregivers reported that if they hit the patient too much, it may cause physical injury and also may precipitate the patient condition and illness. Claiming they are trying to avoid it as much as possible.

"Though I may be harsh on him, I try not to hit him thinking it may precipitate the illness." AT-003

There are also some caregivers who mentioned it is better harsh on the patient. There are times patient approach families with disrespectful manner. During such times it is caregivers being harsh which is really helping the patient making them disciplined. They even reported being lame and too soft to the patient is spoiling and can create problem.

"I observed he don't like an act of kindness. When you become lame on him, he becomes insultive and intimidating and disobedient. It is better to be harsh on him and this makes him to act appropriate.." AT-003

Field note- AT-003, brother and caregiver of PT-003 had anger and irritability in his face while talking about this.

7.2.4. OVERINVOLVMENT

EXPERIENCE OF OVERINVOLVMENT

Caregivers mentioned that there are many things which they do for the person with SMHC they are caring for. This includes, washing patient cloth, preparing their meal and serving them, showering them, always giving medication themselves, washing their care, waking them up from sleep. One caregiver, who is the mother the of person with SMHC also mentioned in total duration of 19 years of illness, the patient never went to followup without her accompany. She stated she is can't let her go alone because she may lost. Patient also reported she can't go alone because she fears she may be lost.

"I prepare his cloth, wake him up, and wash his car….."AT-001

"My mother, my grandmother and the maid do almost most of my things. They wash my cloth and iron it, wash my car, make my bed, clean my room, wake me up from bed and force me to go to work…though I earn money working, they don't ask me for that. I am getting more dependent on them" PT- 001

There are also caregivers who quitted their job and stay at home to take care of the person they are taking care of. The reason mentioned for quitting a job was, may not find someone who can really take care of their child just they do also want to give everything they can to their beloved child.

"I quitted my work long ago to take care of him" AT-001

Caregivers reported that the person with SMHC they are caring for are getting more dependent on their daily activity and they obliged to do most of patient's activity. Patients are losing their motivation and their illness is also incapacitating them not to be active as usual. There are also others mentioned they need to be always with the patient claiming protecting them from possible danger they will have. Some reported they are not letting the patient to take medication all by themself because they suspect she may spit it out.

"I fear she may harm herself if I leave her alone. I feel with all this symptoms of talking alone and disorganization, leaving her alone is not fair. I may regret it if I did so. I feel pity for the patient for not being functional. I wish she is capable of doing that by her own, but I doubt" AT-OO4

There are also care givers mentioning they wish attendant is self-reliant and do things by their own. Caregivers said they overcare for them because they lack motivation to work. They mentioned will be happy if he able to do his things by his own.

"I wish he can do things by his own. But has no motivation to that. He needs my assistance after all" AT- 001

Caregivers also mentioned that by over vigilant and scarified they making sure no relapse again. By fulfilling the need of the person and caring as much as possible, they are trying to reduce the relapse. They also mentioned the family misunderstood the patient at early times which they really regret about. Also mentioned they deserve their attention considering patient being the only child.

"I must be vigilant so as to make sure his initial symptoms not to come back"AT-001

Field note- AT-001 is PT-001 mother and she was felling regret for her son's illness and tearful most of the time.

CONCEPTUALIZATION OF OVERINVOLVMENT

Caregivers has involvement in different aspects of life of person with SMHC they are caring for mentioning different reasons. Considering the possible pros and cons of the overinvolvment they have, there are caregivers who reported there will be a problem by overly involved. They conceptualize the problem as it making them more dependent, making them lazy and may lose their motivation. The other attendant said if we are always involved on the patient decision and activities, the patient may feel neglected.

"When I serve everything of him, he got more dependent on me" AT- 001

Caregiver reported their mother overcare for the patient and the patient seems happy with that, caregiver understood she is spoiling the patient to be disobedient and making him lazy. The patient mentioned he has special feeling to his mother and praises her as his guardian and loves her more than anyone and can't live without her. He mentioned he is more comfortable with his mother than with his brother who is harsh on him.

"My mom washes my cloth. She is my financial support. My mother is my guardian and I need her desperately…". "PT-003

"When he was at prison, people there were sympathy for him and overcared which might have contributed for his laziness"AT-003

Caregivers who mentioned their though they think care must be provided to the patient, they are about knowing it need to be balanced. There are also caregivers who claim it is appropriate involving people with SMHC in their decision unless they will feel neglected. They also mentioned while discussing with other care givers at the ward, they were complemented the care they are providing to the patient seems excess and it may not be good to the patient. They even complemented to the caregiver that she needs to be harsher and it is what people with mental illness need. Though she argues both over caring and being harsh has their own consequences mentioning our care should be just like what we do with other illnesses.

"I think it is good to balance the level of involvement and I was also complemented by other caregivers at the ward" AT-001

"When we care for the patient and involved, we need involve the patient in the decision we made, otherwise he may feel neglected" AT-006

There are also caregivers who mentioned there is no problem to overcare for people with mental illness. Caregiver think psychiatric patients need special treatment because their brain which is the part of body to execute everything is ill and they need more support than other patients.

"It is their brain which is affected and I believe they need more support and assistance" AT-008

In relation to the response from people with SMHC to the over care they are getting, caregivers reported different opinions. Some said they are enjoying it while others mentioned opposite. The other caregivers said all the family treats the patient as a kid and patient enjoyed it.

"All her brothers treat her as a kid..I am always with her in every activity. She is 36 and don't even have her own ID saying yours is enough, and never heard of complaining about it"AT-004

"I never came for followup alone. I fear I may be lost if my mom is not along with me. I don't consider this involvement as problematic." PT-004

There are also other participants from people with SMHC who stated them rather to have their freedom and negative outlook to the care they were given. Caregiver reported despite their

sacrifices, they may discount it all. The person with SMHC also second that though his mother scarified for him, it is his freedom he needs. There is report that they feel annihilated by excess involvement from the mother. Caregiver also mentioned person with SMHC may not want to be a center of attention all the time hence it may create a sense of being unable to do things by their own. There are also caregiver who reported patient may interpret the over care given as way of frauding them and trying to possess their property. Some has ambivalence towards the care they are getting from caregivers and even mention it is excess and taking away their freedom.

"He sometimes doesn't understand my effort. Despite all this sacrifices....,..he says you are making me more dependent and depressed. I need my fredom"AT-001

"Though I appreciate her care and sacrifices, it is making me lose my confidence, feeling dependent at work place. I think Ovecare will have significant impact on patient's self-confidence and reliance if it is not balanced." PT-001

7.2.5. WARMTH AND POSITIVE REGARD

WARMTH

There are people with SMI who reported some of their family members are really caring and show them love. This makes them to calm down when they fell distressed. Caregiver also mentioned the good relationship of the person with SMHC they are caring for and they show their love and warmth to them in different ways and they try to be as supportive as possible.

"My grandmother gives him advice based on her background and past. She strengthens him spiritually. I am grateful for having a person to talk and calm me when he feels irritable." PT-001

"I am always by the patient side in her up and downs. I share her concerns and try to give solutions. It is me attending her at hospital every time she gets admitted. I don't want her get distressed and worried. I try to comfort her when she gets irritable" AT- 002

There are caregivers reported it is good to treat patients with love and warmth and they are better with that. They mentioned there are times they treated them by being harsh and by being gentle

and respectful. And they claim their behavior is better with the second one. Patients seem to prefer those who are calming them with respectful manner. They observed patients want to be listened.

"I believe it is better to treat them with love and respect than force" AT-006

"His grandmother calms him by telling him stories and God's word. He will be better after that" AT-001

POSITIVE REGARD

Attendant reported that they say to the patient they are capable to work and have their normal life. They even try to arrange and enforce them to work and be functional as much as possible.

"I say to him I know you can work, raise family, raise children and live normal life. All you need is have followup and take your medications" AT-002

"I arranged him to work as ride driver so as him not stay at home for long and get depressed. " AT-001

7.2.6. COPING STRATEGIES

People with SMHC reported that they try to be as patient as possible and leave the critics behind.

"I keep quiet and tried not to confront people" PT-003

There are people with SMHC who reported that they don't know how to cope with the hostility they are experiencing and it is making him them mad. They mentioned they even consider leaving the house to live alone.

"I don't know how to cope.. They are making me mad. I want to work and live normal life, but they are making me admitted against my will and hitting me with no reason. They are killing my time" PT-006

Those who reported their care givers over care and overinvolved, mentioned that there are times they thing of going out of their house they are living and have their freedom.

"I sometime think to leave the house to have my freedom..." PT-001

There are also those who reported they will not allow anyone to pass against their right from the outset and also reported they will not tolerate the critical comment.

8. DISCUSSION

Although there are quantitative studies on EE in Ethiopia, there were no exploratory studies on the lived experience and conceptualization as far as we know. We conducted the research on how is the experience and conceptualization of expressed emotion among people with severe mental health condition and their caregivers as well as how are people with SMHC cope with the high Expressed emotion they are experiencing.

The construct of EE comprises of the following factors/behavioral patterns: Criticism, hostility, and emotional overinvolvement (EOI) (2, 8). Like many other environmental stressors, they can cause relapse of psychiatric symptoms among people with a vulnerability to stress. We tried to frame our themes based on underlying theoretical framework.

We conducted the research at one governmental hospital (Amanuel mental specialized Hospital) and one private setup (Sitota center for mental health care and rehabilitation). In both studies, participants' report of the conceptualization and experience of expressed emotion does not appear to have much difference reported almost similar experience and conceptualization of expressed emotion.

Most of attendants have different understanding towards the behavior of person with SMHC they are caring for. It seems their emotional reaction will be depending on their attitude towards the patient behaviors. this attitudes like thinking people with SMHC they are caring are lazy, dependent, has no confidence, can't do things by themselves and their understanding towards the symptoms and to the illness in general seems to have implication towards their interactions. This has been shown in other researches as well. This misinterpretation of negative symptoms as laziness and intentional amotivation led them to have criticism and hostility to patients in general. (2)

There are caregivers in this study who reported they feel burdened by caring people with SMHC. There are studies implicated that high-EE relatives reported more subjective burden of care in disturbed behaviors and adverse effects areas which highly depend on caregivers appraisal of the patient condition than on patients' actual deficits. Studies has shown that High EE relatives display less effective coping responses, and may adversely affect the patient by creating an

unpredictable environment. This feeling of burdened by the person they are caring can further led caregivers to show high expressed emotion.(27, 28)

In context of this research, care givers overinvolvement has manifested in terms of self-sacrifices to the level of quitting their job and being overprotective for the patient claiming they need their accompany considering their illness condition. This is also implicated in other researches in which overinvolvement takes into account on the basis of reported behavior such as caregivers blaming themselves, sacrificing things, being overprotective of patients, excessively being concerned for patients, neglecting personal needs of self (i.e., caregiver's), and similar others. (2) And also cultural construct of caring for patients should be taken to account. Our culture seems to endorse mothers to take care of their child and it as a form of kin relationship, unless they will be labeled as negligent. But, emotional over-involvement does more harm to the relative as it increases stress and the burden of care. (2, 21) .

Different studies framed overinvolvement as to the extreme of self-sacrifices and abandoning one's personal need taking care of the patient. In this study there were attendants who quitted their job altogether and fully taking care of the patient. Two of mothers interviewed reported that they involve in every activity of their child. Considering the sociocenteric nature of the country, it is expected to have some level of overinvolvement to the people with SMHC. In other researches, it is mothers who are told to have more level of overinvolvement that other family members.(2) This is also rationalized as they will have some form of regret for their child's illness and that will contribute to their overprotectiveness and involvement. In this study, mother's has reported that they fear their child may have a relapse if they leave them alone because they may not get maximum care they deserve. This can be emanated from their self-criticism for the past and wish of compensation by avoiding any possible mistakes here after. (20)

The conceptualization varies among caregivers, some says it is good and some said it has bad outcome to people with SMHC. There are some described overinvolvement spoil patients, while others emphasized the need of over care for people with SMI claiming it is their brain which is affected and they will have difficulty of conducting activities with full autonomy. People with SMHC in this study have different perspectives regarding the care they are getting. Some said they are fine with it even idealizing their caregivers, and others are ambivalent about it and even

emphasizing how the overinvolvement made them dependent and loss their confidence, which can show the negative effect of overinvolvement to them. Though the relationship between high EOI and poor outcome is inconsistent across culture, still EOI is ultimately about the transgression of interpersonal boundaries, the balance between proximity and autonomy. With this there are arguments that even in cultures with a collectivistic sense of self, there must be an interpersonal boundary and breach of this boundary leads to the breakdown of an individual's capacity for self-protection which can be too close for comfort. Subsequently this high level EOI beyond that cultural norm can be detrimental to the patient's well-being. (4, 22)

In this study, the level of involvement is not only to emotional level, rather also in other aspects of person's life. So we tend to use the term Overinvolvement than sticking to the widely used 'emotional overinvolvement'. There is congruent study with same report of extending the involvement beyond emotional overivolvement. (29)

The quantification of critical comments and hostility is greatly reliant on the way in which the respondent uses their tone of voice to convey their feelings (anger, rejection, irritability, ignorance, blaming, negligence, etc). Caregiver's hostility was manifested in term of chaining, sending the patient out of home with potential dangerous consequences, hitting, and hostile threats and so on. It has been shown Hostility relates to a negative conception of the patient as a person; manifested as caregivers state that patient causing problems for them, wishing to live away from the patient, shouting at the patient, easily getting angry and getting irritation, patient can control himself, he is acting (2). There are caregivers in this research reported they think patient is simulating symptoms so as to have sick roll and they are angry and irritable of that to the extent of sending them out of home in the middle of the night. There are also times caregivers wished for patient death and get rid of them. This report goes in line with previous studies and conceptualizations. There are also similar pattern of manifesting hostility in other researches. (2)

Caregivers also manifested their criticism on different circumstances. Some of mentioned reasons include not performing in equivalence to their peers, for having laziness and poor motivation for work. In one article, it was stated that Almost 70% of critical comments were found to focus on these negative symptoms of schizophrenia rather than on the florid symptoms of delusions and hallucinations because they understand those negative symptoms as laziness and

being selfish. It seems caregiver's misunderstanding of negative symptoms as laziness, being selfish and intentional act of amotivation led them to the critical comment they reflect to the people with SMHC. (2)

Patients have different reactions to the critical comment and hostility forwarded. Some reported patient has relapsed; others reported patient started disliking their caregiver, argumentative. There are also reports patient become disciplined and started acting as required after the critical comment given. With this caregivers were praising criticism and some level of hostility towards people with SMHC which deviated what has been known in different researches. There are caregivers mentioning being harsh to the extent of criticism and hostility works for the Person with SMHC they are caring for, mentioning some evidences, though people with SMHC who experienced hostility pointed out those incidents affected them negatively. They mentioned the hostility as an abuse and even they are making them mad. In different researches it has been shown people with SMHC living with caregivers of High EE tend to have frequent relapse and bad outcome to the illness.(3, 10, 12, 23)

There are also respondents who reported they do show warmth to the people with SMHC they are taking care of. The usual manifestation as encouraging them, showing concern, giving motivational comments and so on which is congruent with previous conceptualizations which mentioned its characteristics as showing sympathy, concern, positive comments, interest in other as a person, and expressed enjoyment in mutual activities (2, 22). High ratings of warmth often accompanied ratings of high EOI which is also found in this study. (4)

With all this finding, most caregivers seem to have high expressed emotion, and all the three constructs of high EE was identified. So it is better addressing such issues with assessment during routine clinical activity and implementation of different psychosocial interventions will have a great implication to the outcome of patients. One of the recommended modality is family psychoeducation about the effect of high expresses emotion on the behavioral and illness outcome of the patient.(1, 2). These Interventions have been successful in reducing relapse, and do so by increasing the tolerance and coping skills of the relatives, and by establishing more realistic expectations. There are also some studies endorsing the protective nature of low expressed emotion, i.e Warmth and positive regard. (19). With this it would also be

recommended to work on advocating having low expressed emotion will have a good out come to people with SMHC.

9. CONCLUSION-

The way people conceptualization and experience expressed emotion matches what previous research has shown and goes with the previous construct of expressed emotion. In this research, the overinvolvement of caregivers spans more than emotional overinvolvement and they tend to involve in most of person's activity they are caring for.

The experience of high expressed emotion correlates with the way caregivers understand the symptoms of the person with SMHC they are caring for and negative evaluation of the person and also their understanding of the illness in general which has been shown in previous studies as well.

Most caregivers appraised that having level of criticism, hostility can have a negative impact to the person with SMHC while some others were mentioning it will be good to be harsh to the person with SMHC so as to shape their deviant and inappropriate behavior and also there are those who appraised overinvolvmment is appropriate thing for those who have mental illness. this shows there seems to be a gap in level of understanding of the possible impact of caregivers high EE towards people with SMHC.

10. STRENGTH AND LIMITATIONS

STRENGTH- it will be an eye opening qualitative research which can pave the way for further explorations about the concept of expressed emotion.

LIMITATION- hence it is qualitative research done with purposive sampling, it may not represent the vast majority and generalizability is not applicable.

It would have been good if the interview included at least one father caregiver to grasp different perspectives and ensuring the rigor of the research.

11. RECOMMENDATIONS

We recommend having further studies, like ethnographic qualitative study so as to have a better understanding of cultural construct of expressed emotion and also cohort studies about on this area.

We also recommend further qualitative study on the how people with SMHC coping with the high expressed emotion they are experiencing.

Creating awareness about possible impact of caregivers high EE towards people with SMHC is recommended. This can be done by incorporating it in routine evaluation for high expressed emotion and integrating of family psychoeducation therapy to the psychosocial intervention.

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APPENDICES

Annex I

Information sheet

My name is Dr. Estifanos Endalamaw, I am final year psychiatry resident at Addis Ababa university- college of health science. My primary advisor is Dr. Wubalem Fekadu and co-advisor Dr. Getahun Belay. I am conducting research on "Conceptualization and experience of expressed emotion among people with schizophrenia and their caregivers".

By participating in the study, you will be contributing to the development of research with potential contribution for betterment of patient care.

The interview may take around 1 hour with a break in between as needed, in a secure private office. Notes will be taken in addition to audio recording during the interview so that I don't miss anything. The records will only be used for this research every effort will be made by the researcher to preserve your confidentiality by assigning code names/numbers that will be used on all research notes and documents. Your participation in this study is voluntary.

If you decide to take part in this study, you will be asked about your understanding of the study and once that is checked you will be asked to sign a consent form. Even after signing the consent form, you are still free to withdraw anytime during the interview.

Whether or not you decide to participate will have no effect on your care. There will not be any direct benefit for you due to your participation in this study. After completing the interview, at the end you will be paid 200-birr reimbursement for your time and transportation. If you feel distressed during the interview you can stop or withdraw from the interview anytime.

If you have questions or complaints at any time about this study, you can contact the researcher, or the department of Psychiatry at Addis Ababa University or the Ethical Review Board at of the health facility through the contact information provided in this information sheet.

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Phone- (+251)112137971

Email- amsh_reg@amsh.gov.et

BRIEF ASSESSMENT OF CAPACITY TO CONSENT

I will now ask you some questions to check your understanding regarding the research study.

(For the interviewer: For each of the following questions and tick yes if the patient answers the questions correctly and tick no if the patient did not answer correctly after the information sheet is read to them)

What's the purpose of the study?

Yes ☐ No ☐

What are the risks and benefits of the study?

Yes ☐ No ☐

Is this a research or medical care?

Yes ☐ No ☐

Will withdrawing from the study impact your care at the hospital?

Yes ☐ No ☐

The patient has the capacity to consent for this research study (Tick yes and proceed to fill the consent form if the patient answered all the above questions correctly.)

Yes ☐ No ☐

ፈቃድ የመስጠት አቅም አጭር ግምገማ

ጥናቱን በተመለከተ ያለዎትን ግንዛቤ ለመፈተሽ አሁን አንዳንድ ጥያቄዎችን እጠይቅዎታለሁ።

(ለጠያቂው፡ የመረጃ ቅጹ ከተነበበላቸው በኋላ ለሚከተሉት እያንዳንዱ ጥያቄዎች ታካሚዋ ጥያቄዎቹ በትክክል ከመለሱ አዎ የሚለውን ምልክት ያድርጉ: ጥያቄዎቹ በትክክል ካልመለሱ አይ የሚለውን ምልክት ያድርጉ።)

የጥናቱ ዓላማ ምንድን ነው?

አዎ ☐ አይ ☐

የጥናቱ አደጋዎች እና ጥቅሞች ምንድን ናቸው?

አዎ ☐ አይ ☐

ይህ ጥናት ነው ወይስ የሕክምና እገልግሎት?

አዎ ☐ አይ ☐

ከጥናቱ መውጣት በሆስፒታል ውስጥ ያለዎት ክትትል ላይ ተጽእኖ ይኖረዋል?

አዎ ☐ አይ ☐

(ለጠያቂው ብቻ) ታካሚዋ ለዚህ የምርምር ጥናት ፈቃድ የመስጠት አቅም አላቸው ?

አዎ ☐ አይ ☐

ታካሚው ከላይ ያሉትን ሁሉንም ጥያቄዎች በትክክል ከመለሱ የፍቃድ ቅጹን መሙላት ይቀጥሉ።

Consent Form

I have received information and understood the information provided about the research, procedure, risks, benefits and that participating in the research won't impact the treatment I receive at AMSH. I am informed that audios will be recorded and that the researchers will ensure to preserve my confidentiality. I understand the provided information and have had the opportunity to ask questions. I consent to take part in the research on 'Conceptualization of Expressed emotion among people with schizophrenia their care givers at Amanuel Mental Specialized Hospital and Sitota center for mental health care and rehabilitation".

Participant's Signature _____ Date _____

Researcher's Signature _____ Date _____

የፈቃደኝነት መጠየቅያ ቅጽ

"የታካሚና የአስታማሚ መሃከል ያለው የስሜት ልውውጥ ምን ይመስላል፤ ስላለዉ ተፅእኖስ አረዳዳቸው ምን ይመስላል" በሚል ርእስ እየተሰራ ስላለው ጥናት መረጃ ተስጥቶኛል። ስለ ጥናቱ አሰራር፣ ስጋቶች፣ ጥቅም እንዲሁም በጥናቱ መሳተፌ የማገኘውን ህክምና ላይ ተጽእኖ እንደማይኖረው ከቀረበው መረጃ ተረድቻለሁ። ድምጽ እንደሚቀረጽ እና የማንነቴን ሚስጥር እንደሚጠበቅ ተነግሮኛል። የቀረበልኝን መረጃ ተረድቼ ጥያቄዎችን ለመጠየቅ እድሉን አግኝቻለሁ። በዚህ ጥናት ለመሳተፍ ፈቃደኝነቴን በፊርማዬ አረጋግጣለሁ።

የጥናት ተሳታፊ ፊርማ _____ ቀን _____

የአጥኚ ፊርማ _____ ቀን _____

Assent form

I have been informed that my guardian have given permission for me to participate, if I want to, in a study concerning conceptualization and experience of expressed emotion among people with schizophrenia and their care givers. My participation in this project is voluntary and I have been told that I may stop my participation in this study at any time. I am informed that audios will be recorded and that the researchers will ensure to preserve my confidentiality.

Participant's Signature _____ Date _____

Researcher's Signature _____ Date _____

"የታካሚና የአስታማሚ መሃከል ያለው የስሜት ልውውጥ ምን ይመስላል፤ ስላለዉ ተፅእኖስ አረዳዳቸው ምን ይመስላል" በሚል ርእስ በሚሰራው ጥናት እሳተፍ ዘንድ ወላጆቼ/አሳዳጊዬ ተነግሯቸው እንድሳተፍ ፈቃድ ሰጠውኛል:: ተሳትፎዬም በፈቃደኝነት ላይ የተመሰረተ እንደሆነ፤ በጥናቱ ካልተስማማሁ በማንኛውም ሰአት ከጥናቱ ራሴን ማግለል እንደምችል፤ አጥኚው ግብአት እንዲሆነው ድምፄን እንደሚቀዳ፤ ተሳትፎዬ በሚስጥር እንደሚዝ ተነግሮኝ ተስማምቻለሁ::

የተሳታፊው ፊርማ_____ ቀን_____

የአጥኚው ፊርማ_____ ቀን_____

Payment Acknowledgment Form

I _____ have participated in the research study titled conceptualization of Expressed emotion among patients with schizophrenia at AMSH and Sitota center for mental health care. I acknowledge that I have received reimbursement for my time and for lunch in the amount of 200 Birr.

Signature of the participant: - _____

Date: - _____

Name of the person making the payment: - _____

Signature: - _____

Date: - _____

የክፍያ ማረጋገጫ ቅጽ

አስታማሚዎች እና ታካሚዎች ስሜቶቻቸውን በምን መልኩ ይገልፃሉ ምን ምን ይመስላል በሚል ርዕስ በተደረገው ጥናት ተሳትፌያለሁ። ለጊዜዎት እና ለምሳ እንዲሆነኝ 200 ብር ተከፍሎኛል።

የጥናት ተሳታፊ ፊርማ፡- _____

ቀን፡- _____

የከፋይ ስም፡- _____

ፊርማ፡- _____

ቀን፡- _____

Annex II

Section I- Socio demographic characteristics of participants

Thank you for agreeing to take part in the study. I will now ask you questions about yourself.

Age _____

Marital status _____

Years of Education _____

Occupation _____

Living situation _____

Duration of illness (for patient) _____

Diagnosis (for patient)_____

Place of follow-up and treatment_____

Type of relationship with the patient_____

የተሳታፊዎች ማህበራዊና ስነ-ሕዝብ አወቃቀር መረጃዎች

ዕድሜ _____

የጋብቻ ሁኔታ _____

የትምህርት ደረጃ _____

ሙያ _____

የኑሮ ሁኔታ _____

ህመሙ የቆየቦት ግዜ(ለታካሚው) _____

የህመም ዓይነት(ለታካሚው)_____

እየታከሙበት ያለው ተቋም_____

ከታካሚው ጋር ያለዎት ዝምድና_____

Topic guides

For caregivers

1. Tell me how the illness started? What are symptoms are the patient showing? How do you understand those symptoms? What do you think the cause?
2. Let's talk about your time with the before the onset of an illness
3. What changes does happen in your relation before and after the illness?
4. Can you tell me how things have been in the past months with the patient/care givers?

   Probes

   - What happened? Where did this happen? How severe was the behavior? How often would this happen? What did you do? Can you tell me more? How did/do you cope? Do you think the patient could do more to control this behavior?

2. Can you give me some idea of how the patient spends his/her day? What's a typical weekday? Can you tell me how you spend your time with the patient?

3. Irritability, criticism, hostility

- Were there times that you were irritable and critical of patient's behavior? What seems your reaction on those episodes?? What led to such episode? What do you feel about that? How did you cope with that?
- Were there arguments between you? What led you to argument? Was there verbal or physical threats?

4. What do you think the effect of criticism, over involvement, hostility, warmth to the patient?

For participants from people with severe mental health condition

1. What changes does happen in your relation before and after the illness?
2. Can you tell me how things have been in the past months with the patient/care givers?
   Probes
3. Are there times your caregives get irritable/critical/hostile of you
   probes- What happened? Where did this happen? How severe was the behavior? How often would this happen? What did you do? Can you tell me more?
4. How did/do you cope?
5. How is this criticism/hostility/overinvolvment/warmth/positive regard affecting you?
6. For person with SMHC- how are you coping those hostility/criticism/overinvolvment

መጠይቅ ለአስታማሚዎች

1. ህመሙ የጀመረበትን ጊዜ ያስታውሱታል? ምልክቶቹ ምን ምን ናቸው እነዚህን ምልክቶች እንዴት ነው የሚረዷቸው በምን ምክንያት የተከሰቱ ይመስልዎታል
2. ህመሙ ከተከሰተ በኃላ ምን ለውጦች ተከሰቱ
3. ያለፉት ወራት ለታካሚው ለእርስዎ እንዴት ነበሩ ቆይታችሁ ምን ይመስላል
4. ታካሚው/ዋ ጊዜያቸውን እንዴት ነበር የሚያሳልፈፉት
5. ታካሚዉ/ዋ ምን አይነት የህመም ምልክቶችን ያሳያሉ. ምልክቶቹን እንዴት ይረዱዋቸዋል
6. የታካሚው/ዋ ን ባህርይ እንዴት ይገልፁታል
7. ከታካሚው ጋር ስለነበረዎት የስሜት ልውውጥ ምን ይመስላል
8. በታካሚው ባህርይ ተበሳጭተው፣ ወቀሳን ሰንዝረዉ፣ በንዴት ጡፈዉና ለመማተት ቃጥቶዎት ያዉቃል፣ ምን ያህል ጊዜስ ተከስታል
9. እነዚህ የስሜት ልውውጦች ታካሚው ላይ ምን የተለየ ነገር ይፈጥራሉ

ለታካሚዎች

1. ህመሙ የጀመረበትን ጊዜ ያስታውሱታል
2. ህመሙ ከተከሰተ በኃላ ምን ለውጦች ተከሰቱ
3. ያለፉት ወራት ለታካሚው ለእርስዎ እንዴት ነበሩ ቆይታችሁ ምን ይመስላል
4. እስቲ ያለፉትን ወራት ጊዜዎትን እንዴት ነበር የሚያሳልፈፉት
5. አስታማሚዎ በባህርይዎ ተበሳጭተው፣ ወቀሳን ሰንዝረዉ፣ በንዴት ጡፈዉና ለመማተት ቃጥቶዎት ያዉቃል፣ ምን ያህል ጊዜ ተከስቶ ያውቃል
6. እነዚህ የስሜት ልውውጦች ምን የተለየ ነገር ፈጠረብዎ
7. የሚሰነዘርብዎን ወቀሳ ስድብ እና ሃይል የቀላቀለ ስሜታዊነት እንዴት እየተቋዋቋዋሙት ነው

CONCEPTUALIZATION AND EXPERIENCE OF EXPRESSED EMOTION AMONG PEOPLE WITH SCHIZOPHRENIA AND THEIR CAREGIVERS; QUALITATIVE STUDY

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