DEPARTMENT OF PSYCHIATRY,

SCHOOL OF MEDICINE, COLLEGE OF HEALTH SCIENCES,

ADDIS ABABA UNIVERSITY

LIVED EXPERIENCE OF CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA AT AMANUEL MENTAL SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA: A QUALITATIVE STUDY

A final research report submitted to the Department of Psychiatry in partial fulfillment of the requirements for the specialty certificate in psychiatry.

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ACRONYMS

AMSH	AMANUEL SPECIALIZED MENTAL HOSPITAL
SMD/I	SEVERE MENTAL DISORDER/ILLNESS
QOL	QUALITY OF LIFE
CBR	COMMUNITY BASED REHABILITATION

Abstract

Background- Schizophrenia can be one of the most disabling of all mental health conditions, due to the effects of psychotic symptoms, associated cognitive impairment and substantial disturbance to psychosocial functioning. Schizophrenia not only impacts the life of the affected person but also those around them, especially the caregivers. Describing the impact of caring for a relative with schizophrenia in terms of social leisure, family relations, work and financial difficulty of care givers is important. In addition to this, exploring their coping mechanisms is also important to develop or improve intervention programs that could improve patient and family outcomes.

Objective: To explore the lived experience of care givers of people with schizophrenia and their priorities and preferences for intervention

Methods- The study was done at Amanuel Mental Specialized hospital. A qualitative study design was used. Purposive sampling was carried out. Data was collected by in depth interview from caregivers of people with schizophrenia who were admitted to the wards and who visited the hospital for follow up during the study period. The interview was directly transcribed into Amharic, then translated into English. The data were coded using Open code software 4.03. Thematic analysis was used to identify key themes.

Results- The subjective experiences of 13 caregivers of people with schizophrenia were summarized in to four major themes with subordinate subthemes**.** The four major themes are:-

Challenges of caregivers; this includes problems related to work and finance, social relation, health, personal life and goals.

Responsibilities of caregivers; this includes care giving responsibility, non-care giving responsibility and additional distress.

Coping, support and good experience; religious activity, getting help from other relatives, seeing the improvement of their relative as a rewarding experience.

Preferences for intervention: help from other relatives, mental health education, experience sharing

Conclusion- Multiple areas of challenges and multiple areas of responsibility of caregivers were identified. Although there are multiple areas of challenges for caregivers of people with schizophrenia, there are also positive experiences associated with caregiving. Caregivers were also able to provide direction on intervention to reduce the difficulties they faced.

1. INTRODUCTION

1.1 BACKGROUND

Schizophrenia is arguably one of the most puzzling yet disabling of all mental health conditions, which can present with severe and persistent psychotic manifestations accompanied by variable cognitive dysfunction and profound psychosocial impairment.

Antipsychotic medications often reduce positive symptoms of psychosis, but they have limited impact on negative symptoms, cognitive impairment, and psychosocial functioning. For the great majority of patients, medications do not restore premorbid levels of functioning and do not produce normative role performance.(1)

People with schizophrenia need comprehensive treatment that extends beyond antipsychotic medication to include psychosocial treatments, behavioral therapies, family training and support, and community involvement (1)

Schizophrenia not only impact the lives of the affected person but also those around them, especially the caregivers. Chronic schizophrenia causes functional decline that impairs social functioning, disrupts family communication patterns, creates challenges at work, and places a strain on the family. Care load, dread and embarrassment over illness signs and symptoms, uncertainty about the course of the disease, lack of social support, and stigma are some of the reactions of the family to having a family member with schizophrenia.(2)

In Ethiopia, over a million people are estimated to suffer from schizophrenia and affective disorders and millions of their family members struggle to cope with its social consequences. (3)

In most developing countries, including Ethiopia, there are insufficient services that could help patients with schizophrenia to rehabilitate. Thus, the responsibility of taking care of the patient falls on the family. (4) The caregivers are obliged to deal with the patients' symptoms, covering the cost of their treatment and basic needs, and provide support for their physical and emotional needs in their daily activities.

In cases where schizophrenia is chronic or relapsing, there can be persistent impairments in information processing, social and occupational functioning which have long-term impacts on the caregivers.(5)

In addition to the emotional psychological, physical and economic impact the concept of ‘burden of care’ involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame.(6)

Stigmatization and its detrimental effects on people with mental illnesses and their families have been studied in the developed world. No other illness in the Western world causes the patients and their families to face such social rejection. The public frequently overemphasizes social impairments in those with mental illnesses, which makes them even more socially isolated and distressed. The public's perception of serious mental diseases has not been addressed until recently, despite widespread beliefs in Ethiopia that they are caused by demon possession, bewitchment by bad spirits, ancestors' spirits, or the evil eye.

While understanding the magnitude of the family burden and coping strategies is important to plan family intervention programs, very little is known about the extent of caregiving-related distress in Ethiopia. Describing the impact of caring for a relative with schizophrenia in terms of social leisure, family relations, work and financial difficulty of caregivers is important. In addition to this, exploring their coping mechanisms is also important to develop or improve intervention programs that could improve patient and family outcomes.(4)

1.2 STATEMENT OF THE PROBLEM

Until recently, St. Amanuel Mental Specialized Hospital has been the only mental hospital for many years in Ethiopia where people with schizophrenia and other mental illnesses get inpatient care. The treatment of people with schizophrenia mostly gives emphasis to medication. There is insufficient service that works on their rehabilitation. It is a common practice to give psychoeducation to the patients' caregivers about the illness of their family member, about medication adherence and side effects and common symptoms of relapse. When patients have completed their stay in the hospital, even though there is nothing to describe what exactly their care would look like, it is a common observation that they would be sent home and it would be their families’ responsibility to look after them. There are not much of practice that addresses the multiple aspects of the caregivers difficulty while looking after people with schizophrenia. A study done at AMSH in 2013 suggested that caregivers should undergo mental distress screens and emotional health evaluations for the diagnosis of probable mental distress rather than just patients, and that doing so would likely have a large positive impact on lowering caregivers' mental suffering.(7)

1.3 RATIONALE OF THE STUDY

The multidimensional impact of SMD on the person with the illness, the family, and the community was found to be profound in a study done in rural Ethiopia. (21)

Even though people with schizophrenia come to get treatment to AMSH from all over the country, the challenges and needs of caregivers have not been getting proper attention. Understanding the magnitude of family burden and coping strategies in the Ethiopian context with its peculiarities is also important to plan family intervention programs. This research tried to explore the main challenging aspects of the daily life of caregivers of people with schizophrenia and tried to identify their priorities and preferences for intervention. (4)

2. LITERATURE REVIEW

People with schizophrenia mostly depend on their relatives for physical, emotional and economic support. As a result, caregivers face a great challenge in being long term care giver of their relatives who experience long-term functional impairment and deterioration.(5)

Research published on multidimensional impacts of severe mental disorders in rural districts in 2021, showed that the presence of severe mental disorder (SMD; schizophrenia and bipolar disorder) in a household is a risk factor for multidimensional poverty and higher mortality. It also showed that there is an association between food insecurity, lower family satisfaction, and the presence of SMD. (8)

Multidimensional poverty was significantly higher in the households of a person with SMD (schizophrenia and bipolar disorder), 74.44%, than the comparison group, 38.35%. The research reported that the mean family satisfaction scale score was lower in households that have a person with SMD compared to the controls, and indicated that the results of lesser family satisfaction were also reported in high income countries, and the contributing factors might be general concern about the illness, the role of each family members in the care process, and treatment cost.(8)

On a study done in Benin City, Nigeria, on the burden of caregiving for people with severe mental illnesses, it was found that the strain of caregiving was moderate to severe for about 37.6% of the caregivers. The length of time spent providing care was inversely correlated with the burden of care. When other factors were taken into account, the duration of caregiving and poor social support continued to have a statistically significant, independent relationship with the burden of caregiving, accounting for about 16% of the variance. The authors stated the necessity for social assistance for those who care for those with mental illnesses is evident. The burden can be lessened by hospital and medication cost reduction.(9)

Research done in Spain in 2017 on quality of life in family caregivers of schizophrenia: caregiver characteristics, caregiving burden, family functioning, and social and professional support the results showed that the primary carers for patients with schizophrenia had an average age of 60.1 years old, and 62% of them were the patients' mothers. The majority (62%) of caregivers did not work 26% of participants stated they had quit their jobs to take care of their family member and 79% lived with the patient. Regarding the amount of time they spent on care, almost 90% spent most of their day

caring for their family members. only 39 participants stated that they received help in their caregiving duties from other family members. The factors that most effectively predicted QoL were social support and burden perception. The social contact and affective support for caregivers are a factor that predicted improved QoL in the psychological, social, and environmental domains. Finally, a greater QoL in the environmental domain was significantly predicted by appropriate professional help.(10)

A review paper done in USA 2019, indicated that individuals with schizophrenia get direct care from caregivers, aid with daily living activities, and emotional, social, and financial support. The strain on caregivers is increased by longer sickness and care periods, severe or ongoing symptoms of schizophrenia, criticism of the care receiver, financial hardship, and patient impairment.

Caregivers frequently experience depression and anxiety, and they require more physical healthcare resources than healthy controls. Enhancing caregivers' stress management and coping mechanisms, institutional support programs, and unofficial social networks all help to lessen the load of caregiving.(11)

A qualitative study was done on exploring the experience of relatives living with individuals diagnosed with schizophrenia in Oman 2021: Parents, spouses and siblings were confronted with a burden-specific question about the demands of different life situations, and their needs differ accordingly. The research developed four main themes from the data and these are burden, stigma, violence and family need.(12)

2.1 BURDEN AND POSITIVE EXPERIENCES OF CAREGIVING

Magnitude of the family burden based on the research done on Schizophrenia illness impact on family members in a traditional society – rural Ethiopia, 2003, care givers of schizophrenia were most commonly impacted by financial issues connected to providing care for sick family members, followed by illness-related social issues, employment challenges, and family-related issues.(4)

The qualitative research done in Oman 2021, the interviews produced three subthemes based on the experience of family load, and these are (1) objective burden; the effect of caregiving on the house hold caused by tangible caregiving- related disruptions to their life. (2) Subjective burden; caregiver experience extreme negative emotions, such as feeling overwhelmed, stressed, worried, nervous, sad, disappointed, annoyed, ashamed, lost, terrified, and even crying at times, were a defining feature of the experiences of the relatives. (12)

A review paper done in USA in 2019, on caregivers of individuals with schizophrenia: who are they and what are their challenges? it is found that a significant emotional cost is taken

by caregivers as a result of their caregiving responsibilities. When patients have persecutory delusions or show positive symptoms but don't improve after taking antipsychotic medication, the emotional cost of providing care increases. As a result of their severe and unrelenting symptoms, people with treatment-resistant schizophrenia have less time to devote to themselves as care takers, less hope for a cure, and greater reason to worry for their safety. These people's caregivers frequently experience overwork, stress, exhaustion, and frustration.(11)

Positive feelings; mostly siblings reported that the positive experience of caring as enhancing their personal development and being more considerate and have a stronger sibling bond. Compassion and love for the ailing family member are the emotions that are most frequently expressed.(12)

Caregivers of patients with schizophrenia do enjoy positive aspects of caregiving while taking care of their ill relatives. In these caregivers, the positive aspects of caregiving were associated with better quality of life.(13)

In a cross-cultural study done in India 2010, compared to 34% of Malaysian caregivers, 90% of Indian caregivers felt that their relationship with their spouse was rewarding despite their partner's illness.(2)

On a review paper World J Psychiatry 2012, nearly 70% of the caregivers said they had been more understanding of people with disabilities. More than 50% of respondents said that taking care of their relative greatly aided them in determining their priorities in life and increased their sense of inner strength.(14)

2.2 STIGMA

On the study done in Butajira

on the perception of stigma among family members of individuals with schizophrenia and major affective disorders. The results showed that a higher proportion of family members are concerned about stigma. The study was a community-based survey done using the Family Interview Schedule, and about 75% of the respondents perceived that they were stigmatized or had experienced some sort of stigma due to the presence of mental illness in the family, 42% were worried about being treated differently and 37% wanted to conceal the fact that a relative was ill.

The paper indicated that the finding is consistent with the findings of other studies, which reported the presence of clear signs of stigma among family members of patients with severe mental disorders but the ways in which the family members experience stigma is different the differences in the culture, setting and other factors. This study implies that

stigma is a major obstacle to recovery and can limit job opportunities and social functioning of patients and family members. (3)

In India, 36% of caregivers, compared to 30% of caregivers in Malaysia, believed that their relative's disease made it difficult for them to have fulfilling relationships with friends. This could be due to the stigma around mental illness, for example. Mental health policy places a high premium on minimizing the effects of stigma, particularly for schizophrenia.(2)

In Oman relatives of people with schizophrenia tried to avoid society's negative reaction by not disclosing the diagnosis because if people knew “instead of helping you, they would make things worse’’.(12)

2.3 VIOLENCE

In a qualitative study done on physical restraint of people with schizophrenia in community settings in Ethiopia 2017, almost all caregivers and individuals with schizophrenia described their own personal experiences with restraint. The research identified three specific reasons for restraint. The first reason is to protect the person with schizophrenia, it is because of the perceived threat that People with schizophrenia are at risk to run away, get hurt or hit by a car, be attacked by hyenas, get washed away in a flood, and engage in physical fights with others. The second reason is to protect people and property, The threat of physical violence from people with schizophrenia towards others was frequently cited. For some caregivers, this was in the context of the arguments and household conflict, particularly with their spouse. The third reason is to access medical care and the implication was that it would not have been physically feasible to travel without restraint.(15)

The potential of violence, according to relatives, made caring for a person who has schizophrenia even more stressful. They claimed that physical violence, which can vary from yelling and threatening behavior to breaking property or assaulting individuals was frequently directed at family members. According to relatives, these instances typically occurred before diagnosis, during a relapse, or when individuals did not take their medicine as prescribed. Family members described feeling trapped in a potentially dangerous position and sharing their concern of the unpredictable violent outbursts caused by mood swings.(12)

2.4 OCCUPATIONAL AND FINANCIAL IMPACT

The prevalence of job loss among patients with schizophrenia was 37.3%. factors including severe positive symptoms, severe general psychopathology, and poor level of social and occupational functioning were significantly associated with job loss among schizophrenia people.(16)

A study done in Butajera on the Schizophrenia illness impact on family members in a traditional society in rural Ethiopia

showed the magnitude of the impact on social, family occupational and financial aspects.

For carers, financial stress is more difficult to deal with than other family stressors, including its effects on mental and physical health. Even in developing nations, schizophrenia treatment is costly. Due to costs associated with hospitalization, treatment, and rehabilitation as well as lost productivity, lost income for family members

Caregiving obligations may have an impact on the professional life of those who care for people with treatment-resistant schizophrenia, causing them to decline promotions, take time off work, or take on less-responsible professional tasks. Occupational difficulty is more significant in female relatives, they experienced a higher work burden in terms of difficulty in going to work or stopping work to care for a relative with schizophrenia illness as compared to male relatives, and spouses of the cases showed significant association with work burden. The fact that 65% of these spouses were female also shows that female caregivers have difficulty going to work because of the need to care for the ill relative.(8)(11)

2.5 SOCIAL IMPACT

The social impact of schizophrenia on caregivers is found to be significant in those who are separated, divorced and widowed. There was a significant association between being a parent and carrying a social burden. Being a son/daughter of a person with schizophrenia was shown to have a significant association and family-related impact.(4)

2.6 COPING MECHANISMS AND FAMILY NEEDS FOR INTERVENTION

In the study done on the impact of schizophrenia on family members in rural Ethiopia, the result on coping mechanisms showed that the majority of the family members were more likely to turn to prayer (71.4%) than to their coping techniques, such as talking to someone about their issues and taking satisfaction in modest victories. It appears that compared to

other relation and residence categories, parents of schizophrenia cases and relatives who reside in towns practice much more prayer.(4)

On community-based rehabilitation for people with schizophrenia in Ethiopia results of a 12-month cluster-randomized controlled trial,2022, the investigators found that CBR was successful in lowering disability (especially with regard to participation, social interactions, and cognition), symptom severity, caregiver stress, and worry; and in boosting antipsychotic medication adherence and attendance to facility-based care among schizophrenia patients.

However, they reported that they could not find any proof that CBR had an effect on physical constraint, discrimination, employment or work, or aspects of disability relating to home and self-care. Only after the study had been running for a year were the advantages of CBR clear.(17)

In a study done in Nigeria on the Burden of caregiving among caregivers of patients with severe mental illnesses in 2022, to significantly lessen the burden of care givers of people with severe mental illness and to enhance the achievement of the goals of treatment in the patients, the investigators recommend that:

1) The emphasis in therapy and rehabilitation in psychiatry should not just be on the patients, as has been done in the past, but also on the patients' carers.

2) The development of community mental health services will be essential in assisting caregivers and patients in the community. Using community health services reduces the burden on caregivers as patients' health functions significantly improve.

3) There is a need for the establishment of psychoeducational and counseling services in mental health settings, in which psychoeducational programs are important for enhancing the knowledge and skills required to assume the responsibility of caregiving.(9)

3. OBJECTIVE OF THE STUDY

3.1 GENERAL OBJECTIVE

- ✓ To explore the lived experience of caregivers of people with schizophrenia and priorities and preferences for intervention

3.2 SPECIFIC OBJECTIVES

- ✓ Describe the day-to-day experience of caregiving.
- ✓ Explore the challenges and unmet needs of caregivers.
- ✓ Explore caregivers coping strategies and supports.
- ✓ Identify priorities and preferences for interventions.

4. RESEARCH QUESTION

What is the lived experience of caregivers of people with schizophrenia, and what are their priorities and preferences for intervention?

5. METHODS

5.1 STUDY DESIGN

The study is qualitative and based on phenomenological theory, examining the lived experience of care givers of people with schizophrenia who are admitted to AMSH and those visiting the hospital for follow up during the study period.

5.2 STUDY SETTING

The study was conducted at Amanuel Mental Specialized Hospital in Addis Ababa. AMSH is one of Addis Ababa's public hospitals and the only specialized hospital providing mental health care in Ethiopia. The hospital has 236 beds for inpatient care and around 610 patients are seen at the outpatient setting daily. A total of 384 health care professionals and 460 support staff are currently working in the hospital.

5.3 STUDY PERIOD

The study period was from September 10 to November 10, 2023.

5.4 STUDY POPULATION

The source population was caregivers of people with schizophrenia who were admitted to AMSH and who were visiting the hospital for follow up from September 10 to November 10,2023

5.5 SAMPLING

A total of 13 caregivers of patients with schizophrenia who were admitted to AMSH and visiting the hospital for follow up during the study period were selected through purposive sampling with the eligibility criteria below to include maximum variation e.g. by gender, educational level and urban/rural residence. Sampling continued until no new major themes emerged.

The participants were selected based on the eligibility criteria below. Potential participants were identified via the treating physician and were informed through the principal investigator about the ongoing study. Those willing to participate were interviewed after signing an informed consent form.

5.6 **INCLUSION AND EXCLUSION CRITERIA**

Inclusion criteria

- Primary caregivers of patients with schizophrenia who are admitted to AMSH and visiting the hospital for follow up during the study period; and
    - are informal caregivers (nonprofessional)
    - have been care givers for at least 6 months
    - who live in the same house with the relative with schizophrenia and most of their time is invested in taking care of the relative on a daily basis
    - are 18 years old and above.
    - who can speak in Amharic
    - who are willing to participate in the study.

Exclusion criteria

- Care givers who are not willing to participate
- Caregivers who can't speak Amharic
- Caregivers who are younger than 18 years of age

5.7 **DATA COLLECTION**

The data collection was held privately in the afternoon at AMSH child OPD (since it is free in the afternoon and convenient for privacy) & AAU department office at AMSH. Demographic data of the participants were taken excluding their names to ensure confidentiality.

In depth interview was done by the principal investigator and the average duration of the interview was 40 minutes. The interview was audio recorded and additional notes were taken.

5.8 DATA ANALYSIS

Data analysis took place concurrently during the data collection period. The audio recording of the interview (Amharic) was first transcribed and then translated into English. Then coding was started using Open code software 4.03. Then patterns were looked for and codes were sorted into potential themes. Important themes were generated by inductive thematic analysis.

The thematic analysis was done: first familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and finally producing the report of thematic data analysis.

6.ETHICAL CONSIDERATIONS

Ethical permission was obtained from the Department of Psychiatry, College of Health Sciences, Addis Ababa University and St. Amanuel Mental Specialized Hospital.

Written informed consent was taken from the participants in the research, 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. The participants were informed that their participation in the study will not have an impact on the care that their family member receives from the hospital. Participants were paid 200-birr reimbursement for their transportation and time. They were assured of their information confidentiality by removing personal identifications and the information only be handled by the primary investigator.

For participants who needed clinical attention, they were linked to the OPD at Amanuel mental specialized hospital, information was given about other places where they could get mental health services. The options of taking a break or discontinuing the interview were provided if they felt disturbed.

7.Results

Table 1: Characteristics of participants

Caregiver (participant)	Age	Gender	Relationship to the patient	Educational level	Source of income/job
P1	55	Female	Mother	No formal education	Daily labor
P2	37	Female	Mother	No formal education	House wife
P3	22	Female	Daughter	Highschool	Merchant
P4	60	Male	Husband	Reading and writing	Private company
P5	56	Female	Mother	No formal education	Daily labor
P6	70	Female	Mother	No formal education	Other children
P7	32	Male	Brother	Degree	Government employee
P8	32	Male	Brother	Highschool	Builder
P9	40	Female	Mother	Primary education	Janitor (private school)
P10	30	Male	Brother	Highschool	Works in private company
P11	38	Male	Brother	Highschool	Security guard
P12	60	Female	Aunt	Masters' degree	Accountant
P13	57	Male	Father	Degree	Government employee

Participants' characteristics

Data was taken from thirteen participants through in depth interviews. Five of them were mothers, 4 of them were brothers, one daughter, one husband, one father and one aunt.

Seven of the participants were female and 6 were male. The age of the participants ranges from 22 to 70. Four of the participants didn't receive formal education. Nine participants had full-time jobs, and the others were either at home or worked as daily laborers.

THEMES

4 main themes were developed from the data.

1. Challenges of caregivers

2. Responsibilities of caregivers

3. Coping mechanisms, support and positive experience

4. Preference and priorities for intervention

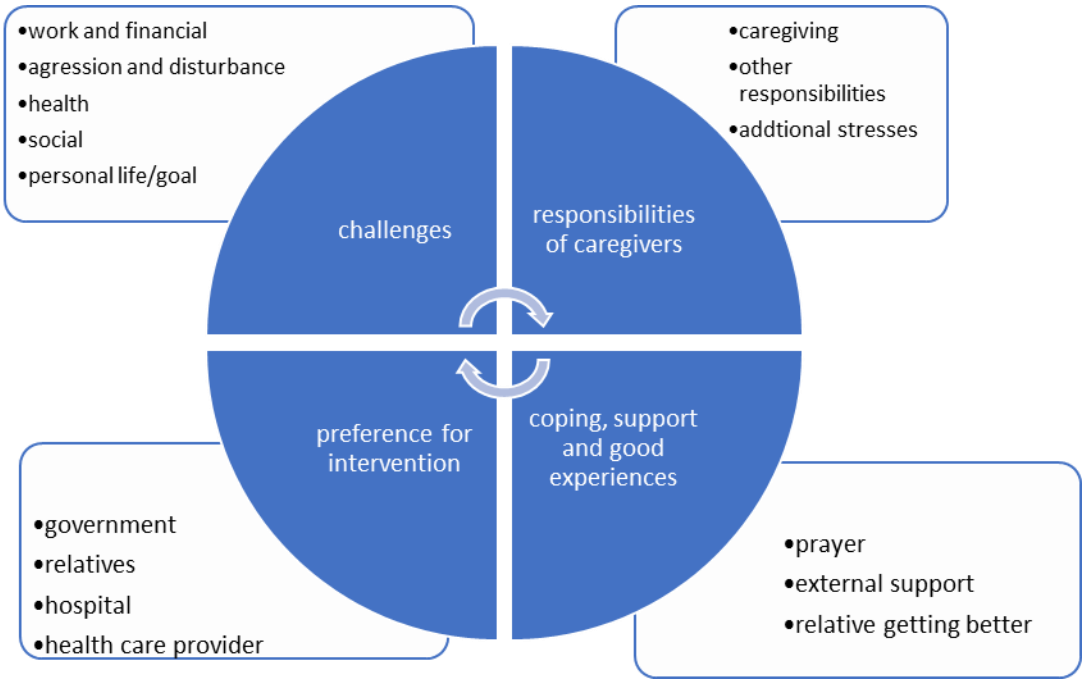

Figure 1: Overview of themes

1. Challenges of caregivers.

The challenges of caregivers included work and financial problems, aggression and disturbance, health problems (physical and psychological), social problems, problems with personal life /goals.

1.1 Work and financial problems.

The majority of participants reported that they had faced great challenges regarding work and managing their finances.

'' My salary was cut down, sometimes I leave work, I will be absent, ……. It had an impact on my work. They tried to fire me from work."

"I took him to traditional places and he didn't get improved. I rented a car and even took him to Amhara region. I paid around 85000 birr. No change. Still there are expenses, cigarettes, khat, to fulfill his desire." P#7, a brother

Another participant who is a mother stated, "……. I don't have any one to support me, I have nothing, because of that I beg…. When people see me as a beggar? God knows, look, just like this" (covering her face). P#1, a mother

1.2 Aggression and disturbance

Several participants expressed their concern about aggressive and disturbing behavior of their relatives. Participants reported that they had been disturbed with shouting, being hit, threats to be killed. And they also reported that that this had interfered with their social relationship.

One participant reported that '……. she will hit suddenly, people tell me to tie her, they say she will kill a kid and I might get into bad blood. She slaps me too……" P #1, a mother

Another participant reported that "What can I tell you (crying) …… you know I get confused, I don't have a house I live by rent, when I get into rental house the owners tell me to leave and take him away. I suffered he shouts, shouts standing near window, they say we do not need money we need peace." P#5, a mother

1.3 Health problems

1.3.1 Physical

Two participants reported that they became hypertensive after their relative developed mental illness. They attributed the cause to the stress experienced in taking care of their relative. One participant reported that he would get stomach ache whenever he got angry.

Others reported experiencing temporary physical disability because of being hit by their relative.

"……..he kicked me here (showed his leg), last time when I brought him, I was what do you call it (showed limping action)" P#7

1.3.2 Psychological

Regarding the psychological impact of care giving, participants had reported that they felt irritable or angry, lacked sleep, experienced regret (wasted time), fear of developing mental illness themselves, and general feeling of unwellness. (n=12)

"…….. I worry, that is why I am like this, my elder brother didn't have grey hair, but I have. It is anger." P#8, a brother

Most reported that they are continuously worried that their relative might put themselves in danger. They worry that their relative might get lost, run over by car or get sexually assaulted.

"I worry about what would happen to her, what if she got run over by a car, or she got raped, did something happen to her? Or did she go to someplace else? I worry until she returns when she is gone out. There is nothing I enjoy." P#9, a mother

Some also reported that what they are mostly worried about is the fate of their relative after they die.

"If I die, I go to dirt and he would go out to the street, no one will tolerate his manners." P#5, a mother

1.4 Social problems

Almost all of the participants reported that being a primary care giver to their relative had an impact on fulfilling their social obligations. The majority of them stated that they would not go at all to funerals, weddings, visiting a sick person and they had decreased hanging out with their friends. Some stated that they would go if only it is nearby and others said they would go and return shortly when the relative is asleep.

“I couldn’t go to a funeral, a funeral of my friend when his wife died. I was his best man when he got married, but I couldn’t go to the funeral, because of my sister’s illness.” P#11, a brother

One participant reported that being primary caregiver had disconnected her from her social support.

“…. I have no social life, even if I get sick myself nobody will visit me, no one get into my house, I have no edir. Why? Because he is not in good terms with people, if I stand and talk with people, he would say are you talking about me……” P#5, a mother

One participant who is taking care of her mother reported that she is obliged to go to social events that she doesn’t want to, because her mother would be expected to go.

“…. It is me who goes, even if I don’t want to, it is must so I go, I fear going to weddings but it is my obligation, so it is me who goes. It was her before who goes to such things.” P#3, a daughter

One participant (father) reported that care giving to his son had imposed difficulty on his marriage.

“Our marriage is disturbed; we blame each other saying this is your fault. we will get a break when he is admitted here…… We cannot communicate with each other, while talking about other issues our mind will be with him, and if she mentions him, I would say I don’t want to hear, but my mind is with him as hers.” #P13, a father

Only two of the participants had reported that being care giver didn’t affect their social life, they said they will arrange whatever is necessary for their relative and they can go where ever they wish to.

1.5 Personal life and /goals

The majority of participants reported that being the primary caregiver had affected their life. Most them had reported being unable to achieve their personal goals like owning a house, going abroad, buying necessary things for their other family members or getting married.

“I can’t go anywhere …… I mean I can’t leave her, I can’t even think about my own life, if she was okay, you know I am a girl, marriage would have been for certain. I had that plan, but I don’t, now.” P#3, a daughter

A few participants reported that taking care of their relative has become their life goal. While some regarded it positively, others acknowledged it as a cause for loss of purpose.

“He is my sister’s child, I raised him from the beginning. As my child. There is nothing I lost in taking care of him. He is my goal” P#12, an aunt

“There is nothing, no goal in my life, it is like something floating on water you know. My life is like that. even though I wouldn’t complain on God. I thank him and accept what he has given me…” P#9, a mother

2. Responsibilities

The responsibilities of caregivers for their relatives were extensive. Most primary caregivers reported that they had additional responsibilities to taking care of their relatives. Some reported that they have additional stresses too in addition to this responsibility.

2.1 Caregiving responsibilities

This includes preparing food and feeding the relative, keeping their hygiene, giving them medication, protecting them from danger, and intervening when they become aggressive /disturbing.

"What I do is keep him from disturbing……If I go to work there will be a phone call and sometimes, I even return from the road, they tell me he is disturbing then…., if he knows that I am around he will keep quiet, he doesn’t disturb… I scold him if is too much, we start to fight, I win and he is afraid of me, …he is not afraid of anyone.” P#7, a brother.

Almost all reported that the first thing they do in the morning is preparing things that would be necessary for their relative. They said they make breakfast, make the relative wash up, go out, bring holy water or do some other thing.

“I wake at 6 am, then I make breakfast, make him go to the toilet. I make him pray salat. Now he has stopped …… Immediately after I wake up, I make breakfast and give him medication. Then I go to work by telling people to look after him. It is the same when I return, I will make dinner then give him his medication. Change his clothes, and wash. I am the one who keeps his hygiene, bathing him.” P#10, a brother

Some caregivers who have jobs also said they would call from work place to check up on their relative.

“……but it does affect my work. I can’t carry out my work appropriately, my mind will be with him all the time.” P#13, a father

2.2 Other responsibilities and additional distresses

The participants reported that in addition to the caregiving roles, they also had to carry responsibilities to generate income, raise kids and take care of the household.

“It is me who does every necessary work in the house. Washing clothes, doing the dishes, everything, there is no one to help me. The kid (her younger brother) is young, and since he is a boy, he goes outside and play, he doesn’t do anything. The responsibility of the house is on me.” P#3 a daughter

“I had a son, he made friends with bad guys and he is arrested at Worabie now, there is no one at home, no one…….. It has been a while, I work a daily labor, 90 birr a day, I spend that on doctor, I also ran out of food (crop), for her and for my son also, who is in Worabie (prison)”

“I fear my daughter might die so I come here, I go to Worabie, here and there, yeah, I wouldn’t add a child by giving birth, who do I have?..... is she going to die too? I lost a young son, she might die like him, he died suddenly he went somewhere as a stranger and he died, she might die too, without me getting passed his death….” P#1, a mother

One mother said there is also another sick child in the house who is her grandson and taking care of him is also her responsibility in addition to doing the house chores.

Another participant (brother) reported that they lost their mother recently, and he is giving care for his brother while he himself is in grief.

3. Coping, support and good experiences

Participants reported their different ways coping with their daily challenges. The majority of the participants reported they cope by praying and having faith in God.

“I pray to God; say to him you know everything. There is nothing else. No one consoles me.” P#9, a mother

Other participants reported that they cope by seeing the experience from a religious point view.

“But if Allah brought everything, I say this test is for good, that is why I tolerate and stay still. It is a test from Allah, Allah test those he loves, it is for good, that is how I see it.” P#3, a daughter

“This is God’s work, she is sick and he made me the caregiver, it is God’s work. If it was me who is sick, she would have taken care of me.” P#4, a husband

Others reported that being a blood relative and their close relationship gives them strength.

“He is my son; it is our attachment. What choice do I have if I don’t cope, it is my obligation. I care for him like a mother." #13, a father.

About half of them reported that they get help from other relatives and neighbors and this gives them hope.

Others reported that they see the caregiving as an opportunity to return the favor the relative done while they were well, and they said this gives them strength.

Most of them had reported that seeing their relative improve is a good experience for them and they see it as a reward.

“She got improved one time, that time I thanked God. She got improved that time. Many people said to me, if you weren’t here, she would have become crazy and she would be wondering on the streets. They praised me.” P#8, a brother

4. Preference for intervention

Participants suggested their different preferences for intervention in taking care of their relatives. The most important form of intervention they preferred was to get help from relatives or neighbors.

One participant reported that, “It is better if family helps me. If they support me with money, there are expenses. I left the house and came, I left my work, it would have been better if they help me at least some days.” P#8, a brother

Almost all of the participants emphasized the benefit of giving education about mental illness and sharing experiences with other caregivers. Getting information about the causes of mental illness, on how to reduce worry and how to take care of their relatives are considered to be the benefits of education.

Regarding sharing experiences from other caregivers, they mentioned they would learn from others and they will also share what they learned in their own experience. Some also reported it would make them happy and lessen their worries.

One participant reported that, “…… it will be a lesson, what others had faced in their life, when they tell you that, and when you share your experience, it will be a lesson. When I talk about myself, and then when others tell me what they faced, worse than mine, it makes me calm that there is worse than mine. In the ward when I see those worse than me, I say Alhamdulillah’s there is also such thing. So, what you see from others is a lesson, discussing and sharing is good.” P#3, a daughter

A few suggested it would help them if the government identify those caregivers and help them. One participant said she would prefer if her daughter got sponsor permanently to be taken care of and she said she even thought about taking her to media.

Others reported their preference for intervention regarding food and a place to rest in the hospital setting while their relatives are admitted.

“When I come here and go back 100 birr is not enough, and after I came here where would I get money for food? We could have brought what we have, one injera from home, relatives also could do the same, I would be happy if I ask you that. One mother also talked to me about this today, all of us need to gather around and speak about this. Buying one injera with 55 birr?.....” P#2, a mother

Most reported what they want the most is for their relative to get better. “Treat them and return them to us” P#4, a husband

One participant suggested that the health care providers work on changing Amanuel Hospital's reputation.

“It would be good if the name Amanuel gets a better perception, when you hear the name Amanuel, including me, it is like a very scary place. Even in the countryside, if somebody got admitted to Amanuel they think that person is a killer, hit with stone, that is how it is perceived. Change how it is viewed…. it is as good as any hospital. Make that known.” P#13, a father

8. DISCUSSION

In this qualitative study, we have explored the subjective experiences of 13 primary caregivers for people with schizophrenia. The findings are summarized into four themes. The discussion is going to be presented under the identified themes. The themes are the challenges of primary caregivers, the responsibilities of the care givers, coping, external support and good experiences and priorities and preferences for intervention.

Primary caregivers of people with schizophrenia had expressed their multiple aspects of challenges in taking care of their relative. The areas of challenges include, financial and work related, dealing with aggression and disturbance, health problems (both physical and psychological), social problems and problems with personal life/goal. Primary caregivers reported that they had faced financial problems in the form of housing, food and treatment cost. They also reported that they take time off from work, had frequent absentees or leave work when there is an issue at home with their relatives.

Caregiving obligations may have an impact on the professional life of those who care for people with treatment-resistant schizophrenia, causing them to decline promotions, take time off work, or take on less-responsible professional tasks. (4) Although it appears that the work and financial related seem to affect almost all of the caregivers, we found that to be more significant on mothers who are giving care by themselves without external support. We also found them to have no jobs, they are housewife or work as daily laborers. These finding also has similarities with another research. Women caregivers, predominantly spouses and mothers, reported significantly more financial problems or were more often forced to devote the scarce resources they had to care for their ill relatives than male caregivers. They experienced a higher work burden in terms of difficulty in going to work or stopping work to care for a relative with schizophrenia illness as compared to male relatives, and spouses of the cases showed significant association with work burden. (1) (4)(8) Treatment costs for care recipients, providing financial support, and lost productivity and revenue are some of the financial effects of providing care.

Regarding their social and personal life, most participants had reported facing difficulties. They reported that they are mostly unable to fulfill their social obligations like going to funeral, they also reported to have marital problems. Regarding their personal life they also faced difficulty in achieving their own personal goals and some reported feeling regret

about wasted time. Participants also reported facing health challenges, both physical and psychological health problems. Physical health problems like hypertension stomach upset and sustaining some injuries from their relative they are giving care to. Psychological stresses include excessive worrying, sleep problem, anger and loss of peace of mind. Our finding has similarity to a review paper done in USA 2019, which stated caregivers of people with persistent symptoms frequently experience overburden, stress, exhaustion, frustration, or anger. Caregivers frequently experience depression and anxiety, and they require more physical healthcare resources than healthy controls. By enhancing caregivers' stress management and coping mechanisms, institutional support programs, and unofficial social networks all help to lessen the load of caregiving. (11)

The responsibility of caregivers includes taking care of their relatives, carrying out additional house hold activities and dealing with additional distresses like taking care of additional sick family members, and this is mostly seen in mothers. These together with the financial problem, we found it to have a significant impact on them. The absence of external support also imposes significant challenges.

Even though the caregivers reported they face challenges on daily basis we found most of them to be resilient and hopeful. Most of them reported using prayer and having faith in God giving them strength. This is similar to the study done on schizophrenia: illness impact on family members in a traditional society – rural Ethiopia, the result on coping mechanism showed that the majority of the family members were more likely to turn to prayer (71.4%). (4)

In our study some also reported that their relationship with their relatives and the support they get from other relatives or neighbors gives them hope. They found seeing their relative getting better and getting praised for that from people to be a rewarding experience and this also gave them strength. Similarly in a qualitative study done in Arab 2021, caregivers reported despite the negative feelings and high level of burden associated with living with schizophrenia, some relatives expressed many positive feelings, mostly siblings reported that the positive experience of caring enhanced their personal development and being more considerate and have a stronger sibling bond. Compassion and love for the ailing family member are the emotions that are most frequently expressed. (12)

Based on their experience, the caregivers have indicated their preference for interventions that could possibly reduce their challenges and improve their quality of life. Their preferences for intervention are getting help from relatives or neighbors, getting information about mental illness, sharing experiences with other care givers, a few suggested getting help from the government or any other organization to permanently

take care of their relative. These findings are supported by prior studies; a review paper on Family Support in India showed that participating in family self-help groups helps family members understand that they are not alone in the formidable task of caring for their loved one, besides giving them a platform to exchange helpful suggestions and coping strategies, reducing stress, isolation, and stigma. (20)

Almost all of the caregivers reported that what they desire the most is for their relative to get better; most also reported these as their good/rewarding experiences when their relative received treatment and got improved. The findings in a study done on carer burden in schizophrenia had shown similar results to this study. The severity of schizophrenia symptoms predicted a higher magnitude of burden and the reduction of these symptoms also predicted a reduction of carer-burden. (5)

9. LIMITATIONS

This study was subject to certain limitations.

First, the participants were primary caregivers of people with schizophrenia who had access to mental health care, care givers of patients who are admitted or those who came to the hospital for follow up. This excluded those who had no access to mental health care and those who may be experiencing a greater degree of challenges.

Second it also mostly excluded caregivers of people who are well and functional, because if they are well, mostly the patients themselves come to the follow up visit and the caregivers are unavailable. These might have made our findings reflect more of the negative experiences than the positive ones.

Third, the data were translated from Amharic to English, and some cultural nuances may have been lost in the translation process.

10. CONCLUSIONS

In our study, multiple areas of challenges and multiple areas of responsibilities of caregivers were identified. The majority caregivers time is occupied by fulfilling the care needs of their relative. Thus, being a primary caregiver for a person with schizophrenia had an impact on individual's work, finances, social relations, health and personal life and goals. The challenges seem more severe for those who have a low economic status and no social support.

Despite these multiple challenges caregivers of people with schizophrenia face on a daily basis, they were also able to have a positive experience associated with caregiving. Most appeared to be hopeful and resilient. They were also able to provide directions on intervention to reduce the difficulties they faced.

10. RECOMMENDATIONS

Caregivers who have poor social support and who have low economic status face the most challenges. In this study, we found these to be mostly the mothers.

We recommend

- Creating a pathway to screen these caregivers and create a support group that will enable them to share experiences and support each other.
- Giving information broadly to patients, caregivers, and also non caregiving relatives to reduce the load of caregiving on a limited number of family members.
- Increasing access to mental health care and improving the quality of care is important for reducing the burden on caregivers.

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APPENDIX I

INFORMATION SHEET

My name is Dr. Martha Gobena. I am a psychiatry resident at the Department of Psychiatry of Addis Ababa University. My advisors are Professor Charlotte Hanlon and Dr. Barkot Milkias. I am conducting a study on the lived experience of care givers of people with schizophrenia at Amanuel mental specialized hospital. The purpose of the study is to explore lived experience of care givers of people with schizophrenia and priorities and preferences for intervention. You are selected to participate in this study because you are a care giver for a relative with schizophrenia and gave a verbal consent to be contacted by a researcher on the subject. By participating in the study, you will be contributing to the development of treatment approach for people with schizophrenia that addresses the challenges of their care givers.

The interview will take about 45-60 minutes, with a break in between, 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 and I will not use your name or other identifying information to ensure 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 the care that your relative is receiving at Amanuel hospital. There will not be any direct benefit for you due to your participation in this study. After completing the interview, 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 require further support, I will link you to professionals in this hospital who can follow you. If you have questions or complaints at any time about this study, you can contact me, the Department of Psychiatry at Addis Ababa University or the Ethical Review Board at Amanuel Hospital through the contact information provided in this information sheet.

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የመረጃ ቅጽ

ዶ/ር ማርታ ጎበና እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ የአእምሮ ህክምና ትምህርት ክፍል የአዕምሮ ህክምና ስፔሻላይዝ በማድረግ ላይ የምገኝ ሀኪም(ሬዚደንት) ነኝ። የጥናት አማካሪዎቼ ፕሮፌሰር ሻርሎት ሃንሎን እና ዶ/ር ባርኮት ሚልኪያስ ናቸው። በአማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል የአእምሮ ህመም አልጋ ይዘው እና ለክትትል ወደ ሆስፒታሉ የሚመጡ ህሙማን አስታማሚዎችን የህይወት ተሞክሮ መሰረት ያደረግ ጥናት እያካሄድኩ ነው። የጥናቱ አላማ የአእምሮ ህመም ያላቸው ሰዎችን የሚንከባከቡ ሰዎች የህይወት ልምድን ለመዳሰስ ነው። በዚህ ጥናት ላይ ለመሳተፍ የተመረጡበት ምክንያት እርሶ የአዕምሮ ህመም ያለበት ሰው ተንከባካቢ ስለሆኑና በጉዳዩ ላይ ጥናት የሚያደርገው ሰው እንዲያነጋግሮት የቃል ፍቃድ ስለሰጡ ነው። በጥናቱ ላይ በመሳተፍዎ ለታካሚዎችና ተንከባካቢዎች የሚሰጡ አገልግሎቶችን ለማሻሻል አስተዋፅዖ ያደርጋሉ።

ቃለ መጠይቁ ከ45-60ደቂቃ ይወስዳል። በመካከል እረፍት መውሰድ ይቻላል። ቃለ መጠይቁ የምናደርገው ደህንነቱ በተጠበቀ የግል ቢሮ ውስጥ ነው።በቃለ መጠይቁ ወቅት ምንም መረጃ እንዳያመልጠኝ ከማስታወሻ በተጨማሪ ድምጽ እቀርፃለሁ። የድምጽ መዝገቦቹ ለዚህ ጥናት ብቻ ጥቅም ላይ ይውላሉ። በሁሉም የጥናት ማስታወሻዎች እና ሰነዶች ላይ የኮድ ስሞችን ወይም ቁጥሮችን በመመደብ ምስጢራዊነትዎን እጥብቃለሁ። የእርስዎን ስም ወይም ሌላ መለያ መረጃ አልጠቀምም።

በዚህ ጥናት ውስጥ ያለዎት ተሳትፎ በፈቃደኝነት ነው። የፍቃደኝነት መጠየቅያ ቅጽ ላይም እንዲፈርሙ ይደረጋል። የፍቃደኝነት ቅጹን ከፈረሙ በኋላም ቢሆን ቃለ መጠይቁ በማንኛውም ጊዜ ማቋረጥ ያችላሉ። ለመሳተፍ መወሰን ወይም አለመወሰን ታካሚው በአማኑኤል ሆስፒታል በሚያደርጉት ክትትል ላይ ምንም ተጽእኖ አይኖረውም። በዚህ ጥናት ውስጥ በመሳተፍዎ ምንም አይነት ቀጥተኛ ጥቅም አያገኙም። ቃለ መጠይቁን ከጨረሱ በኋላ ለጊዜዎ እና ለመጓጓዣዎ ማካካሻ 200 ብር ይከፈላሉ ። በቃለ መጠይቁ ወቅት የስሜት መረበሽ ከተሰማዎት በማንኛውም ጊዜ ቃለመጠይቁን ማቆም ይችላሉ። ተጨማሪ አርዳታ ካስፈለገ በዚህ ሆስፒታል ውስጥ ካሉ ባለሙያዎች ጋር አገናኝዎታለሁ። በዚህ ጥናት ላይ በማንኛውም ጊዜ ጥያቄ ወይም ቅሬታ ካሎት የአዲስ አበባ ዩኒቨርሲቲ የአዕምሮ ህክምና ትምህርት ክፍል ወይም የአማኑኤል ሆስፒታል የጥናት ግምገማ ቦርድ ከታች በተጠቀስው አድራሻ ጥያቄአችሁን ወይም ቅሬታችሁን ማቅረብ ትችላላችሁ።

ስም - ዶ/ር ማርታ ጎበና(የአዕምሮ ህክምና ስፔሻላይዜሽን ሬዚደንት)

አማካሪዎች - ፕሮፌሰር ሻርሎት ሃንሎን

ዶ/ር ባርኮት ሚልኪያስ

የትምህርት ክፍል -የአእምሮ ህክምና ትምህርት ክፍል፣ አዲስ አበባ ዩኒቨርሲቲ

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ኢሜል- amsh_reg@amsh.gov.et

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 that my relative 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 of Lived Experience caregivers of people with schizophrenia at Amanuel Mental Specialized Hospital.

Participant's Signature _____ Date _____

Researcher's Signature _____ Date _____

የፈቃደኝነት መጠየቅያ ቅጽ

ስለ ጥናቱ መረጃ ተስጥቶኛል። ስለ ጥናቱ አሰራር፣ ስጋቶች፣ ጥቅም እንዲሁም በጥናቱ መሳተፌ በ አማኑኤል ሆስፒታል የ በተሰብ አባል የሚያገኘው ህክምና ላይ ተጽእኖ እንደማይኖረው ከቀረበው መረጃ ተረድቻለሁ። ድምጽ እንደሚቀረጽ እና የማንነቴን ሚስጥር እንደሚጠበቅ ተነግሮኛል። የቀረበልኝን መረጃ ተረድቼ ጥያቄዎችን ለመጠየቅ እድሉን አግኝቻለሁ። በአማኑኤል የአእምሮ ስፔሻላይዝድ ሆስፒታል ከባድ የአእምሮ ሕመም ያለባቸው ሰዎችን የሚንከባከቡ ሰዎች የ ህይወት ተሞክሮ ላይ መስረት ያደረገ ጥናት ላይ ለመሳተፍ ፈቃደኝነቴን በፊርማዬ አረጋግጣለሁ።

የጥናት ተሳታፊ ፊርማ _____ ቀን _____

የአጥኚ ፊርማ _____ ቀን _____

APPENDIX II

INTERVIEW GUIDE

Introduction

- The researcher introduces herself and ask if the participant had the opportunity to read the information sheet and ask if there are any questions or concerns
- Sign consent form
- Tell the participant to feel free to ask questions at any stage during the interview and if they want to take break they can
- I will be recording the interview, is that okay with you?
- The interview should take about 45-60 minutes. You are free to take break or suspend the interview whenever you want.
- Can we start now?

PARTICIPANT INFORMATION

- ✓ Age……
- ✓ Sex
- ✓ Educational status ……
- ✓ Occupation ……
- ✓ Marital status …….
- ✓ Religion……..
- ✓ Address …….
- ✓ Who are you living with currently
- ✓ Relation to the person with schizophrenia ……..

PATIENT INFORMATION

- ✓ Age …….
- ✓ Sex…….
- ✓ Educational status…….
- ✓ Occupation…….
- ✓ Marital status…….
- ✓ Religion…….
- ✓ Address ……
- ✓ Living with……
- ✓ How long has it been since started the treatment?
- ✓ Any previous admission? ……. how many……
- ✓ What is the reason for the current admission/ current visit (for medication refill or has any complaint) ……

TOPIC GUIDE QUESTIONS

- How long has it been since your relatives started to show symptoms of the illness
- How long has it been since you became primary care giver of the patient?
- How much time in a day do you spend taking care of the relative
- What does your typical day look like?
- What type of care does your relative need?
- How has being the caregiver affected your life?
- Probes:
    - Work?
    - Social life?
    - Economic status?
    - Your physical health?
    - Psychological stress?
    - Any other ways that it has affected you?
- To what extent do you think that being a caregiver affected your life goals and opportunities? Please tell me about this.
- What have you found to be any positive aspects of being a caregiver? To what extent have there been reqarding aspects of caring for your relative?
- What are the most challenges you face in taking care of your relative? How do you cope with your daily challenges? Who supports you?
- Based on your own experiences, what do you think could help caregivers like you? What do you need?
- What is the most important thing that could make a difference?
- What do you think that the role of providing an educational program for the family during admission? What kind of information should be covered?
- What do you think of the ideas of caregivers like you meeting together to share experiences? What could be the benefits? What could be the disadvantages?
- Anything else you feel has been missed and anything that is important to you that we did not cover?

የተሳታፊዎችመረጃ

እድሜ፡.....

ጾታ፡.....

የትምህርትደረጃ፡.....

ሥራ፡.....

ትዳር.....

ሃይማኖት፡.....

የመኖሪያአድራሻ፡.....

ከማን ጋር ነው የሚኖሩት?.....

ከታካሚው ጋር ያላችሁ ዝምድና ምንድ ነው?.....

የታካሚ መረጃ

እድሜ፡.....

ጾታ፡.....

የትምህርትደረጃ፡.....

ሥራ፡.....

ትዳር.....

ሃይማኖት፡.....

የመኖሪያአድራሻ፡.....

ከማን ጋር ነው የሚኖረው/ ምትኖረው.....

ህክምና ከጀመረ/ች ምን ያህል ግዚ ሆነ.....

ከዚ በፊት አልጋ ይዞ/ዛ ነበር? ስንት ግዚ?

አሁን አልጋ የያዘበት/ችበት ምክያት ምንድነው?/ አሁን ሆስፒታል የመጠበት/ችበት ምክንያት ምንድነው (መድሃኒት ለመውሰድ ወይስ ችግር አለ?)

የመጠይቅ መመርያ

- ታካሚው የባህሪ ለውጥ ወይም የህመም ምልክቶችን ማሳየት ከጀመሩ ምን ያህል ጊዜ ሆነ?
- ታካሚውን መንከባከብ ወይም መርዳት ከጀመሩ ምን ያህል ጊዜ ሆነዎት?
- ታካሚውን በመንከባከብ በቀን ምን ያህል ሰዐት ያጠፋሉ?
- መደበኛ ቀንዎት ምን ይመስላል?

✓ ታካሚው ከርስዎ ምን አይነት እርዳታ ይፈልጋል/ትፈልጋለች

✓ የታካሚው ተንከባካቢ በመሆንዎ

✓ በስራ

✓ በማህበራዊ ህይወት

✓ አካላዊ ጠንነት

✓ በኢኮኖሚ እና ስነ ልቦና ጫና ያስከተለው ለውጥ አለ?

- የታካሚው ተንከባካቢ በመሆንዎበህይወትዎ ወይም ኑሮዎ ምን ይመስላል? የህይወትዎ እቅድ ወይም የኑሮዎ ዓላማ ላይ ያመጣው ለውጥ እንዴት ነው?
- .ዘመድዎን ወይም የትዳር ኢጋርዎን በማስታመምዎ/ በመንከባከብዎ ያገኙት አስደሳች ነገር/እንደሽልማት የሚቆጥሩት ነገር ምንድነው
- ዘመድዎን/ የትዳር ኢጋርዎን በማስታመም ውስጥ ያለው ፈተና/ አስቸጋሪ ነገር ምንድነው?
- ታካሚውን/ዋን በዋነኝነት የሚንከባከቡት እርስዎ እንደመሆንዎ መጠን በየእለቱ ለታካሚው እንክብካቤ ከመስጠትዎ ጋር ተያይዞ የሚያጋጥምዎትንችግሮች/ፈተናዎች እንዴት ነው የሚወጧቸው? በአጠቃላይ ለታካሚው እንክብካቤ ከመስጠትዎ ጋር ተያይዞ የሚመጡ ጫናዎችን እንዴት ነው የሚቋቋሟቸው?
- አስቸጋሪ ነገሮች በሚያገጥምዎት ጊዜ ስሜትዎትን የሚያካፍሉት ወይም የሚያማክሩት ሰው አለዎት?
- ከእርሶ ተሞክሮ አንጻር እንደ እርስዎ ያሉ ተንከባካቢዎችን ምን ሊያግዝ/ልረዳ ይችላል? ከሁሉም ወሳኝ እና ለውጥ ሊያመጣ የሚችል ነገር ምንድነው?
- ለታካሚው እና አስታማሚ የግንዛቢ ትምህርት መስጠት ያለ ሚና ምን ይመስሎታል?
- እንደርስዎ ካሉ ለሎች ተንከባካቢዎች ጋር ስለ መግናኘት እና ልምድ ስለ መካፈል ምን ያስባሉ? ጥቅም እና ጉዳቱ?
- ጥያቄዎቼን ጨርሻለሁ። እኛ ያላነሳነው በተጨማሪ መናገር የሚፈልጉት ወይም መደረግ አለበት የሚሉት ነገር አለ? ለሰጡኝ ማብራሪያ በጣም አመሰግናለሁ።

የክፍያ ማረጋገጫ ቅጽ

በአማኑኤል የአዕምሮ ስፔሻላይዝድ ሆስፒታል የአእምሮ ህመም ያለባቸውን ሰዎች የሚንከባከቡ ሰዎች የህይወት ተሞክሮ ላይ መሰረት ያደረገ ጥናት ተሳትፈዋል። ለጊዜዬ እና ለትራንስፖርት ማካካሻ 200 ብር ተከፍሎኛል።

የጥናት ተሳታፊ ፊርማ፡- _____

ቀን፡- _____

የከፋይ ስም፡- _____

ፊርማ፡- _____

ቀን፡- _____