Distributed impact of Severe Mental Disorders in rural Ethiopia, a qualitative study.

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Abstract

Aim: To explore the distributed impact of Severe Mental Disorders (SMD) among people with lived experience of SMD, their family members, and community members.

Methods: We conducted in-depth interviews with family key informants of people with SMD (n=32), people with SMD (schizophrenia, bipolar disorder, and major depression) (n=10), and community members (n=6) in rural Ethiopia. The study was nested within a long-standing population-based cohort of people with SMD. Interviews were conducted in Amharic and were audiotaped. We conducted thematic analysis.

Results: All except one respondent described multidimensional impacts of the illness on the person with the illness, family members, and the community. We identified four themes: stress and physical tolls, lost expectations, social disruption, and economic threat.

Family members reported stress and hopelessness even to the extent that they sometimes wished the individual with the illness would die; some had also tried to harm themselves. Family members reported that their relationships with each other and with the wider community were disrupted significantly. Spouses and children did not get the support they needed leading to disappointed expectations; left alone in caring for children, unable to go to school or dropping out early. The study participants with SMD also spoke about the effects of their illness on other family members and the community which appeared to be a source of shame and self-isolation. Both the family and the community respondents reported the economic effect of the illness which may result in selling assets, debt, unemployment, forced migration, and food insecurity. The community members reported the economic burden and danger related with aggressive behaviour of the person with SMD while the person with the illness and their family members blames the community for the stigma and discrimination against them.

Conclusion: SMD has profound consequences on the person with the illness, their family members, and the community. Future interventions for SMD should consider household level interventions to address economic and care needs and mitigate intergenerational impact. The community should be considered as a resource as well as target for intervention.

Introduction

Severe mental Disorders (SMDs), mainly schizophrenia, bipolar disorder and major depression, are conditions that may be chronic and/or recurrent in nature and can lead to serious impairment in one or more areas of functioning \(^1\). SMD has many adverse impacts on the individual, their family members and the community where the person lives \(^2\). These impacts may be particularly pronounced in low-and middle-income countries (LMICs) because the treatment gap for mental disorders is high and family members assume almost all the responsibility of caring for the affected person \(^3\).
Studies from high-income countries reported increased risk of serious psychological and physical health problems in family members of people with SMD. Gupta et al. (2015) stated more health care utilization and hospitalization in these family members when compared with families with no person with SMD. Higher mortality, poorer school performance and higher odds of being placed in special classes were reported in children of people with SMD. Family members’ ability to pursue their regular activity was reduced. Family social status, cohesion within the family, and participation in social activity has been shown to reduce over time.

Studies from LMICs have focused mainly on financial impact, food insecurity, living standards, stigma, and child labor as distributed impacts of SMD. Financial impact has been found to be related to the cost of care, loss of earnings, cost of treatment side effect, and stigma. The impact may last for extended periods of time and end up in severe food insecurity and poor living standards. Children may be required to take part in income generating activities to support an ill parent.

The community is not immune from the impact of SMD. Close neighbors may be obliged to support affected families. On the other hand, there are high levels of discrimination and violence against people with SMD and their family members. This can be a barrier to help seeking behavior and can distance the family from social events and vital support networks.

Though there is abundant evidence regarding the "burden" associated with caring for a person with SMD, the current treatment modality is highly centered on the person with the illness instead of being family inclusive. Even when some researchers report the impact of the illness on the whole family, they just explore the burden without showing the extent and dimensions of the impact.

Moreover, these impact reports focus on the impact of parental illness on children and originate mainly from high income countries where the social welfare system is well organized. Thus, higher quality evidence from low and middle-income countries is warranted. In this study we explore the lived experience of people with SMD, their family members and neighbors, through qualitative interviews carried out with a sample recruited from the Butajira community-based study on SMD. The results, in addition to offering the needed evidence, will help development of a comprehensive family-focused interventions.

**Methods**

Study setting and design

This qualitative study was nested within an existing community-based cohort on SMD in Meskan and Mareko districts, Southern Nations Nationalities and Peoples’ Region (SNNPR), Ethiopia. The central town where the study is based is Butajira, which is 132 km south of the capital, Addis Ababa. It is a predominantly rural area and subsistence farming is the main occupation. The population is predominantly Muslim by religion.
There is one Zonal general hospital and 13 health centers in the districts. There are also several private clinics. Mental health care is provided in an outpatient clinic in the general hospital, staffed by psychiatric nurses. Most people concurrently seek help from traditional healers and religious places.\textsuperscript{13}

The Butajira cohort was established between 1998–2001 from a screened population of 68,368 adults. Participants were originally identified with a two stage procedure: initial household screening with the Composite International Diagnostic Interview (CIDI) and community key informants, followed by a confirmatory diagnostic interview using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN). A total of 919 people with SMD (358 with schizophrenia, 346 with bipolar disorder, and 215 with major depression) were identified at baseline.\textsuperscript{14}

Participants

Individual face-to-face in-depth interviews\textsuperscript{15} were conducted among family key informants (n = 32), people with SMD (n = 10) and community members (n = 6). The family key informants and people with SMD were selected on the basis of residence (urban vs rural), illness severity and specific diagnosis. The family key informants include parents (n = 7), siblings (n = 9), spouses (n = 8) and offspring (n = 8) (aged 18 years and above) of a person with SMD. These family key informants reported the impact of the illness on a total of 309 family members. We interviewed people with SMD to assess their perspectives on the impact of their illness on others. Community members were interviewed to provide insight into the relationship of the person living with SMD, their family and the wider community. The community members were identified because of their roles in leadership and social participation in their villages (Fig. 1). We continued sampling until theoretical saturation was achieved, when neither new information nor new themes emerged in two consecutive interviews.

Data collection procedure

One adult key informant nominated by the household members reported on the family experience. With the help of the participant, we drew up a detailed family tree and used this as a framework to enquire about the impact of the illness on each family member. We also asked about the interaction of the community with the person living with SMD.

All the in-depth interviews were conducted in Amharic, the official language of the region. Interviews were audiotaped. The first author conducted all the interviews and took notes detailing non-verbal expressions. All interviews were carried out in a private space in either the participant's residence or at the field research office of the psychiatric department, Addis Ababa University, according to the participant's preference. The interviewer introduced himself, his role in the research and spoke about their family member's illness before each interview to create a better rapport so that the participants were free to talk.

Data processing and analysis
All the in-depth interviews were transcribed in Amharic. The first author (WF) translated the interviews with feedback from one of the co-authors (AF) to clarify meaning in some interviews. We have presented two case studies of families to illustrate the multi-faceted and cross-generational impacts of having a family member with SMD. This also helps us to present the unfragmented narrative and changes over time which may be lost in the thematic analysis. We have analyzed the remaining data thematically using OpenCode 4.03 software in parallel with data collection. This helped us to apply constant comparison with the emerging data.

After repeated listening to the audio files and reading the transcripts, the primary author developed initial codes by carrying out open coding on two transcripts. This initial framework was discussed with other authors (AF & TC), in order to assess relevance and appropriateness of codes and to refine definitions and descriptions. Coding of the remaining transcripts was done based on the agreed codes, with new emerging codes identified and added by the primary author. After examining the links between the initial codes, we developed subthemes. Then we defined and named the themes after the subthemes were reviewed for patterns, and relationships across the groups (people with SMD, their family members and community members). Comparative analysis was done between family members and across categories of SMD. Illustrative quotes were selected for each theme or subtheme.

Data quality measures

We undertook several procedures to ensure the quality of data. We interviewed different family members (parents, siblings, spouses and offspring), people with SMD, and community members to help us to understand all the possible dimensions of experience and triangulate findings. We involved more than one family member of the same person with SMD to get multiple perspectives on shared experiences.

Results

Demographic characteristics

Forty-two (87.5%) respondents had received some formal education. Their age ranged from 25–69 years. Thirty (62.5%) of them were Muslim and the remaining were Christian. Most (85.42%) of the participants lived in rural areas (Table 1).
### Table 1
Participant characteristics

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Person living with SMD</th>
<th>Family members</th>
<th>Community member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis (SCZ, BPD, MDD)</td>
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<td>NA</td>
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<tr>
<td></td>
<td>BPD (4)</td>
<td></td>
<td></td>
</tr>
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<td></td>
<td>MDD (2)</td>
<td></td>
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</tr>
<tr>
<td>Sex (male/female)</td>
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<td>Male (19)</td>
<td>Male (4)</td>
</tr>
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<td>49</td>
</tr>
<tr>
<td>Education</td>
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<td>No formal education (4)</td>
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</tr>
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<td>Spouses (8)</td>
<td></td>
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<td></td>
<td></td>
<td>Children (8)</td>
<td></td>
</tr>
</tbody>
</table>

BPD: Bipolar Disorder; MDD: Major Depressive disorder; NA: Not Applied, SCZ: Schizophrenia

### Thematic analysis

In the thematic analysis we developed four themes: stress and physical tolls, lost expectations, social disruption, and economic threats.

All the respondents except one described multidimensional impacts of the illness on the person with the illness, family members, and the community where the person lives. There were differences in the extent, distribution, and type of impact across the participants. The exception was reported by a daughter of a woman with MDD who had recovered within a year. She said though there were problems during the acute stage, the mother recovered, and everything became fine again.

**Stress and physical tolls**
Family members mentioned the stressful nature of having a family member with SMD. The stress was related to behaviour of the person, economic consequences of the illness, and stigma. The stress was perceived by respondents to result in an increased susceptibility to accidents, suicidal behaviour and sleep deprivation.

... I think too much, and I cannot sleep, which is affecting my health ... My father died due to a car accident because he was incredibly stressed and did not hear the horn of the vehicle... he survived two or three times before... This all is related with her [her mother's] illness [daughter of a woman with bipolar disorder_IDI_12]

Family members also reported feelings lonely and sad. Observing a family member in the street shouting and exhibiting odd behaviour and fears of developing the same illness triggered such feelings. The level of stress was reported to be especially high when the person ran away, when the person had to be physically restrained and during relapse. The stress and hopelessness made them wish the individual with the illness would die and some had tried to harm themselves (3 suicide attempts, and 5 reports of suicidal ideation)

... This year I pray to take one of us (either my mother or me), I do not want to live such life... once I try to harm myself, but God saved me [Daughter of a woman with bipolar disorder_IDI_12]

Both family members and community respondents reported physical injury inflicted by the person with the illness. Aggressive behaviours made handling by the community difficult.

... When I go out from home, he [the person with the illness] hit me with stone, I became unconscious and they took me to hospital... I may have died by then, but God saved me [brother of a man with schizophrenia_IDI_16]

... They [people with SMD] might blind an eye or break teeth, if they killed someone, they did not get arrested. They are dangerous especially for women. They beg in the streets. They do not work; they have a profound impact on the community [community member_ IDI_36]

People with SMD also saw the stress and physical tolls caused by their illness but also reported the incorrect actions by their own family members and the community up on them. The actions include discrimination, tying them up for extended periods, reducing care overtime, rape, and other violence against them.

... First, they used to hit me because I disturb them so much. I used to drink too. When I got home late, they would show me harsh face and not talk to me. I did not have any peace, their care reduced over time. My mother was sick at that time too. She was the one who would say do not hit him, he is ill. People used to assault me in the street, they do not believe in me and some throw a stone on me [man with schizophrenia_IDI_25]

Lost expectations
Family members were unhappy because their affected family member fell short of their expectations and they were unable to do anything about it.

... She was a very good student. Her friends lead their own life. But my daughter still lives with us. She is not married; I would have grandchildren by now. Sadly, I did not do enough to help her [Father of a woman with schizophrenia_IDI_01]

Spouses and children did not get the support they needed or expected. Spouses get married to people with SMD without being aware about the illness or because they were in remission. Most spouses of people with SMD thought about divorce because they did not get adequate care and support but did not go through with it because of their children, thinking of the better days and fear of God.

...All my thoughts are with my mother. I do not worry about myself or my marriage. We [with her husband] fight about it. He says you are not acting like a married person; you do not take care of the household. We fight day and night about it...who knows, we may end up in divorce [daughter of a woman with MDD_IDI_20]

... I may not marry him if I knew he had the illness. My home is far from here. His sister eases our marriage... now he does not work. He is verbally and physically aggressive, it is exceedingly difficult to handle him. His friends work, they care for their children, and they fulfill their basic needs (food and clothing). Our children go to school in their bare foot while the others do not. Thinking of my children, I am still with him [wife of a man with schizophrenia_IDI_07]

Spouses of people with SMD reported negative effects on their intimate relationship. For some, they reported being forced to have sexual intercourse when they did not want it, and other times their own sexual desires were unfulfilled. Some respondents reported that they struggled to plan the number of children they wanted to have and ended up either with too few or too many children.

... We do sexual intercourse as he wishes, if he took the injection he does not even know where he sleeps. We do not do it like other healthy couples. So, we do it when he becomes well and desires to do... [Wife of a man with Schizophrenia_IDI_04]

Children may not get the care they needed irrespective of which parent is affected by illness. They may also become care takers of their parent with SMD, do the farm work and household activities, take part in income generation activities, and may be forced to migrate to fulfill the needs of the family. Respondents with SMD also reported this mentioning their failure to provide the appropriate care for their children.

... our children did not get the care they need... the two kids are the one who care for their mother so that they may not go to school which affects their school performance, they don't play with their friends... this one [pointing to one of his daughters] is the one who makes coffee for her. My fear is if they share the illness from their Mom... [husband of a woman with bipolar disorder_IDI_02]
Children reported poor school performance. Some were unable to go to school, had frequent absenteeism or dropped out early.

My father and mother are divorced [long pause], I am living with my mother and the other two are living with my father [he is married to another woman]. My mother was selling Tela And Areki [local liquors]. I frequently dropped out of school, I was a good student but I could not proceed. She had frequent admissions. My mother works when she is fine, but now am here with her (daughter of a woman with bipolar disorder_IDL_12).

... our daughter was assigned to attend Aksum University [one of the Universities in Ethiopia], she said it would take up to 5 years to finish...but I did not have the money to send her....so, she went to Arab country. She was not successful there ...she came back... this would not be like this if it was not for his [her father's] illness. [wife of a man with bipolar disorder_IDL_17]

Social disruption

Family members of people with SMD faced difficulties in forming social relationships and participating in social events, both within the family and with wider society. These difficulties were reported to be mainly due to aggressive behaviour of the person, lack of time for social events, and being unable to fulfil expected social roles. The impact was reported to be different across family members; parents failed to maintain their social relationships; they may separate or get divorced, while children failed to form their own relationships outside the family.

...Our social event participation is not the same. We used to take part in these events including neighbors’ coffee ceremony. Now we do not take part in such events because we cannot do our part, she used to make coffee in our turn... [husband of a woman with bipolar disorder_IDL_02]

The community tended to ignore (overlook) these families in social events even for major occasions such as mourning and wedding. Family members also reported discrimination by the community which was related with their lack of participation in social events.

Conversely, the community respondents mentioned the possible positive role the community might have in taking care of people with SMD. These include widening social support of people with SMD through linking them with religious and community leaders, creating awareness and stigma reduction.

... I think connecting each family with religious and community leaders may be helpful. For example, if I have one family, I can contact them, I told you about one guy with mental illness, I try to support him, ... He comes to church; I give him advice and he appreciates it. These people should be listened but, we do not listen them. This support works in HIV/AIDS and it will work in mental illness [community member_IDL_41]

Economic threat
People living with SMD and their family members universally described living with economic hardship. Respondents with SMD also spoke of the economic costs of their illness, describing how being ill inhibited them fulfilling their roles, as well as incurring additional costs:

*My illness makes me a very weak farmer which affects my family ... they spent a lot in my treatment, they sold many sheep and goats... [a man with bipolar disorder_IDI_23]*

Family members described the cumulative costs of illness, loss of assets, ultimately leading to economic demise. The diminished economic status of the household was signified by the absence of essential assets, and compared to what others in the community (living without the burden of SMD) had managed to achieve:

*... Previously we used to have two oxen and milk cows, but after his illness we pay for treatment and other related costs and now we do not have those... Before his illness, the land was processed early, and it gives a superior product. But after his illness, the land was given to other people because he could not work it, so we get half of it. All this creates a huge economic crisis... [son of a man with MDD_IDL_05]*

*... We do not even have a house which protect us from rain, you know the main thing is house, but you can see our house and see our neighbors [pointing to their neighbors’ house] [wife of a man with schizophrenia_IDL_04]*

Managing the costs of illness could be all-consuming, with long-term and severe impacts, enduring beyond the lifetime of the person living with SMD. Participants regretted these economic consequences and expressed concern that the burden would be passed on to younger generations:

*... I borrowed a lot for traditional treatment. I did not finish the payback. The interest makes it difficult to manage. The effect is still there after my brother died. Since my focus was also on him, now I cannot feed my family. I am getting older now. My fear is transferring my debt to my children [brother of a man with schizophrenia (died)_IDL_13]*

Case study one: A woman with Bipolar disorder

Tadelech (name changed) is a farmer, mother of three. We interviewed Tadelech, her mother and husband. The illness started twenty-three years ago when Tadelech was a student. She was reported to have been very aggressive and was chained up for two years before she was taken to a psychiatric hospital. Now, she is well, though the illness is episodic, returning every two-three months.

Tadelech did not remember how the illness had started. “I was a student and then things became different, later when I became well, they [her family members] told me what happened. I was ashamed”. But her mother remembers every aspect. “It was very difficult to take, semay medru neber yezorebgn [everything was upside-down]”.
In the early days her parents were responsible to take care of her. When she became well, she got married and afterwards most of the responsibility for care fell to Tadelech’s husband, as reported by her mother. “As a mother, I am very concerned about her but thanks to God she had a caring husband”. Tadelech also spoke about the support of her husband. “If it was not him, he may ask for divorce. He is very supportive”. They are living in the same village which helps her mother to provide care for her grandchildren especially when her daughter is unwell. Tadelech’s mother also helped in fulfilling social duties on her behalf, for example, attending ceremonies related to mourning, weddings and when someone gives birth.

Tadelech’s mother feels sad because her daughter was not successful; “I think she could have done more if it was not for her illness, she was a very good student. I see her while she gets tied up her hands and legs”. At the same time, she reported being thankful because her daughter got better, got married and had children, despite her difficulties.

Tadelech’s mother thinks their close neighbors are supportive, but the larger community and the local administration are not. “The administration forced her to do irrigation work. They know about her illness, but they still demand her to come and do the work. They did not do this to other people with other illnesses such as hypertension”. But Tadelech thinks no one is supportive. “Everyone is against me. Forget the support, they laugh at me, they talk behind my back”.

Tadelech’s husband said it was difficult to decide to marry her because his family and friends were against it because of her illness. “There were many people who said do not marry her. They said this girl is mentally ill. What if she got ill later, how would you handle the economic situation with a mentally ill person? I said it is on God’s will. He gave us this illness so he will also take it away. I said it is no one’s business and we got married. When she gave birth to the first child, the whole village did not believe it because she used to be tied up with chains all the time”.

He describes how he tries hard to fulfil the needs of the family without much help from his wife or from other people. Tadelech’s illness forced him to sell cattle and to try different treatment alternatives. He also reported additional responsibilities to participate in social events because his wife cannot. This was very difficult for him, but he tries everything to take care of Tadelech and their children. “I have sold my cattle, portion of my land, and do other tiresome things, it is very difficult but, I have to take care of my family”.

Their children are 14, 10 and 7 years old. All of them are in school but he is not sure if they are performing well or badly. He thinks that they did not get the care they need. He also fears that they might develop a similar illness. Tadelech feels the same. “I would have taken care of them, now they take care of me especially when the illness relapses”.

Case study two: A man with Schizophrenia

Seid (name changed) is a farmer in his 40’s. We interviewed his wife and daughter. The illness started twenty-seven years ago. Seid’s wife reported that he still has some disturbing symptoms [such as: being easily irritable, verbally and physically aggressive against his family members]. We included eleven
family members in the family tree (parents, spouse and children); of these eight live in the same household.

The couple were married while he was in remission. His wife was not aware of his illness and regrets marrying him. They have been separated many times because of his behaviour and disability but people help them reconcile. She thinks she is not getting the care she needs as a wife. “He did not take care of me, treat me like a wife”. On the contrary he was aggressive towards her, even resulting in physical injury. She also complains about their sexual life. Due to all these burdens; she has tried to end her own life on two occasions. “I have tried to throw myself in to water but people have seen me. I have also tried to poison myself”

The illness affects the family finances. The main reason for this is that Seid is unable to carry out the farm work properly. This has resulted in a decline in their economic status. “Our neighbors have corrugated iron roofed house but ours cannot even protect us from rain.”

The illness also affects their children. All (six) of them dropped out from school early and they cannot lead their own life. "His friends care for their children; they fulfill their basic needs (food and clothing). Our children go to school in their bare foot while the others do not. My children are the ones who work. They are the ones who farm, they do everything."

“I was not clear about my father’s illness” said his daughter. He used to have aggressive behavior and had frequent quarrels with her mother. She discovered about his illness when she was in her tenth year. She thinks that she did not get enough care in her childhood. “He did not take care of me as a father, I am jealous of the others, they [father of other children] buy them clothes, school materials and safeguard them from harm but [crying] ..“Now, she is neither in school nor able to lead her own life.

The family also report that they are ashamed because he begs people in the street for food and other things. This affects their relationship with their neighbors. They do not blame their neighbors because they attribute the problem to Seid. Their close family members are not around which worsens the social support.

**Discussion**

We conducted a qualitative study to explore wider effects of SMD. All except one respondent described multidimensional impacts of the illness on the person with the illness, family members, and the community. Unlike many earlier studies, we included interviews with people with SMD themselves, and the community members in addition to a substantial number of family members across multiple generation. This helps us to explore the interrelationships and different perspectives on life with SMD.

The stress in families emanated from balancing their own life with caregiving, taking the blame to themselves, economic problems and stigma and discrimination, in keeping with findings from previous qualitative studies in Ethiopia, New Zealand and Australia. Stress may result in an increased
susceptibility to accident, suicidal behaviour and sleep deprivation which calls for family focused interventions.

Family members also report impaired physical health. The physical health problems were not limited to the primary caregiver, it is distributed to all family members. The burden may be a reason for new illness incidence or it may exacerbate an illness which occurs before\textsuperscript{20}. This can be an important indication to conduct future quantitative research or for the development of medical screening interventions for family members of people with SMD.

The most frequently reported cause for the stress and physical injuries was aggression. The respondents framed aggression as the main symptom of SMD. They also reported it as real threat to family members and the community. These symptoms were considered as the most important factors affecting all family burden domains in similar settings\textsuperscript{9,21}. This is an important area of intervention especially in LMICs where the treatment gap is high. This can be done through mental health treatment provision, improving mental health literacy and help seeking behavior, community reintegration and community inclusion\textsuperscript{22}.

Poor living standard of the household was related with the lack of productivity (person with the illness and family members), cost of treatment (traditional or modern) and indirect costs of stigma and discrimination. This also support the social selection theory\textsuperscript{23} which states that people with SMD are prone for poverty. Participants also mentioned that they pay more for traditional treatments than modern treatment. This is an important area of intervention since the cause is related with mental health literacy. These living standards could be improved through locally available and affordable mental health care provision\textsuperscript{24}.

The illness affects family members’ relationship with each other and relationship with the wider society. The problem starts from blaming each other for the occurrence of the illness. As time goes, family members may become less sensitive, and adapt to the situation. Family members relationship may also be strained due to the role of each family member must play in the care process and the economic problems associated with the illness such as the cost of treatment.

Social interaction and participation in social events are not the same before and after illness\textsuperscript{25}. This resulted from patient related problems such as aggressive behaviour and family member related problems such as being unable to participate in social events. In addition, families may refrain to attend public events fearing stigma and discrimination which may be actual or perceived\textsuperscript{26}. The sum may result in poor recovery and social class drift which were also reported elsewhere\textsuperscript{27,28}.

Spouses and children share the burden with other family members, but some were specific to them. For example, spouses reported sexual impact and inability to plan the number of children. This impact may be pronounced in women because divorce is more acceptable to men\textsuperscript{29} which may force women to stay in the marriage. Children were also unable to go to school, dropout early and have inferior school performance. These were reported in developed countries\textsuperscript{30,31}.
Though the illness had the above-mentioned impacts, families are largely alone in dealing with the problem. They did not get support from the community or from the government and their difficulties were exacerbated by stigma and discrimination. This calls for the need of all-inclusive interventions considering local resources which were also supported by stakeholders in a nearby district.

In earlier studies positive aspect of caregiving were reported but in the current study none of the participants report it. Though we have a question which addresses this aspect, they did not report any positive aspect. This might be related with the illness duration, since our study is done on chronic cases. The result may show the role of culture in burden researches. It will also have a role in clinical practice in such areas because bringing the positive aspect may help for a better coping.

Though we have included the view of substantial number of family members, neighbors, and people with SMD across the three specific disorders, the result may not be generalizable to people with more recent onset SMD because our focus was on long-term impacts of the conditions.

In conclusion, our study shows the profound consequences of SMD on the person with the illness, their family members, and the larger community. Some consequences such as suicide in family members are potentially very serious. Future interventions for SMD should address the needs of family members. The community can be used as an asset in the treatment of SMD. Our study also shows the need for community-based interventions to address stigma and discrimination.

Declarations

Conflict of interest The authors declare there is no conflict of interest

Ethical considerations Ethical clearance was obtained from the College of Health Sciences, Addis Ababa University Institutional Review Board (005/18/Psy). The first author provided an information sheet for the person to read or read it out to them if they were not literate. All participants had the capacity to participate and provided informed consent, either through a signature or indicated consent with a fingerprint. Transcripts were anonymized to ensure people could not be identified by reference to individuals/places and we have given pseudonyms to the case studies. Five participants who reported suicidal behavior were linked to the psychiatric clinic for additional assessment and support.

References


**Figures**
Figure 1

Participant selection procedure

919 people with SMD from the original cohort

Purposively selected

10 people with SMD

32 family members

6 community members

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