

Why doesn't God say "enough"? Experience of living with bipolar disorder in rural Ethiopia

Abstract

Rationale: Little is known about the specific experience people living with bipolar disorder in rural, low resource settings, where conditions that disrupt normal social interactions are often highly stigmatized and evidenced-based treatments are rare.

Objective: To explore illness experience, coping strategies, help-seeking practices, and consequences of illness among people with bipolar disorder (PBD) and their family members in rural Ethiopia as an initial step for developing psychosocial intervention grounded by the experiences of PBD.

Method: A qualitative methods using in-depth interviews were carried out with 27 individuals (15 PBD and 12 caregivers). The participants were identified on the basis of previous community-based research among people with severe mental illness. Interviews were carried out in Amharic, audio-recorded, transcribed, and translated into English. Data were analyzed using thematic analysis. Our approach was informed by phenomenological theory.

Result: Three major themes emerged: expressions and experiences of illness, managing self and living with otherness, and the costs of affliction. PBD and caregivers were concerned by different forewarnings of illness. Stigma and social exclusion were entwined in a vicious cycle that shaped both illness experience and the economic health and social life of the household. Nonetheless, PBD and caregivers learned from their experiences,

developed coping strategies, and sought relief from trusted relationships, spirituality, and medication.

Conclusion: Our findings suggest that psychosocial intervention could be used to strengthen existing resources, in order to improve the lives of PBD and their family members. However, pervasive stigma may be a barrier to group and peer support approaches.

Keywords: Bipolar disorder; Severe mental illness; Lived experience; Stigma; Qualitative research; Phenomenology; Ethiopia

Highlights

- Chronicity of illness and the need for ongoing care are the major sources of burden
- Stigma is pervasive, affecting social and economic lives of the entire household
- People with bipolar disorder learn from experience to find coping strategies
- Relief was found in spirituality, medication, and close trusting relationships
- Results indicate that culturally adapted psychosocial interventions may help

Introduction

Bipolar disorder (BD) is a type of mood disorder that comes and goes over an individual's lifetime. The Diagnostics and Statistical Manual of Mental Disorders (DSM-V) and the International Classification of Disease (ICD) defined BD as a disease that includes manic and depressive episodes which alternate or coincide, with the occurrence of mania the defining feature of the disorder . During depressive episodes, people with bipolar disorder (PBD) experience depressed or low mood, and loss of interest, whereas elated or irritable is the central feature of manic episodes. According to 2013 global burden of disease report, the prevalence of BD has increased by 49.1% from 1990 - 2013 . In Ethiopia, the prevalence ranges from 0.5% - 1.8% . A research from high income countries (HIC) suggests that living with symptoms of BD is often fraught with difficulties for affected individuals and their families. Little is known about the experience of living with BD in low and middle-income countries (LMICs) settings. However, poverty and inadequate mental health services arguably heighten the adverse social consequences of illness, while culture inevitably shapes understandings, experience, and responses. Findings from research conducted in the global South are needed in order to address this important gap in the global evidence-base.

Social cohesion and social support have positive impact on reducing illness experience and improve physical and behavioural outcome . However, relationship problems, stigma, and unemployment are commonly

ascribed to illness by PBD and their family members . PBD are often misunderstood by the communities in which they live and blamed for their illness, frequently develop a negative view of self, and sometimes hide their illness due to experience and expectation of negative reactions from others . The stigma attached to illness is not limited to the PBD, but affects other members of the family, which, in turn, undermines social support and exacerbate social difficulties for all family members .

So far, qualitative work from sub-Saharan Africa (SSA) has focused mainly on perceptions and illness experience among people understood to be living with “serious mental illness”. For many living in the region, the biomedical model is not the primary means of understanding and categorizing distress . Distinction by disorder is therefore uncommon. Nonetheless, it might be expected that different patterns of expressions of illness within the category of “madness” might lead to variation in experience, perception, and knowledge. The experiences of people living with BD in SSA have not yet been explored.

The World Health Organization (WHO) identified BD as a priority condition for intervention in the mental health Gap Action Programme (mhGAP): because of the severe impact of the illness upon individuals, associations with violations of human rights, and the existence of evidence-based treatments . Authors have suggested that the impact of BD may be particularly pronounced in LMICs where the treatment gap for evidence-based care is high, and where stigma and economic impacts are known to be prominent.

The results of population-based studies from rural Ethiopia suggest that PBD experience a high relapse rate (66%) and low continuous remission (5%) .

Existing evidence, mainly from HIC, indicates that the right kind of psychological, social, and spiritual actions can improve the course of disease . For example, showing understanding and providing a space to listen to the concerns of a person with BD , helping the person to come to terms with the diagnosis and treatment , and promotion of self-care and self-management can lead to better outcomes for PBD. Involvement in religious practices and sharing feelings with other people has been shown to combat isolation and improve wellness .

Our recent review of psychosocial interventions for BD in LMICs, showed that psychological interventions can be successful in low resource settings: improving social support, enhancing self-management in the context of stressful life events, and reducing relapse rates, symptom severity and hospital admission . Understanding modifiable psychosocial factors and how they influence the course of illness is crucial to developing interventions that improve the lives of people living with BD.

Collection and analysis of illness narratives of PBD is necessary in order to understand the context in which BD emerges, the way in which illness is understood, perceived and managed, and the consequences of living with illness for PBD and their families. This data will be critical to the design and development of interventions that seek to bolster and support family and community resources to help PBD and their families to live better

lives. Our study used in-depth qualitative interviews to explore experiences, beliefs, and understandings of PBD and their family members in rural Ethiopia in a community where mental healthcare is available and participants in our research had some experience of accessing treatment.

Methods

Design: The study design was qualitative and informed by phenomenological theory. We wanted our work to articulate the experiences of PBD in rural Ethiopia, whose voices are absent from the academic literature. We anticipated that participants' realities would be embodied in social experience. We therefore selected a research approach that allowed our data to be grounded in the experiences of those living with BD and their family members. Our aim was to provide a thick description of how different participants experienced and described the meaning of living with BD, in order to build a composite description of the essence of the experience for individuals living with this condition in this community. Our description consists of "what" individuals experienced and "how" they experienced it .

Context: This study was conducted in adjacent sites: Butajira and Sodo district, both are in the Gurage Zone, Southern Nations, Nationalities and Peoples' region (SNNPR), Ethiopia. Most of the population in this area speak Guragigna as their mother tongue, but Amharic serves as the official language of the region and is generally well understood. The area is predominantly rural, with an economy based upon subsistence farming and small trade, characteristic of the majority of Ethiopia. Butajira district is

located 130 km from Addis Ababa, the capital of Ethiopia. The total population of the districts is estimated to be 321,056 . The majority of the population are Muslim, and Butajira town is the center of a health and demographic surveillance site (HDSS), which has been functioning since 1987 . Sodo district is adjacent to Butajira, located about 100 km south of Addis Ababa, the capital of Ethiopia. The district has 58 *kebeles* (sub-districts) and a total population of 161, 097 . In Sodo district, most of the population are Ethiopian Orthodox Christian (97%).

The sites selected for this study are atypical in terms of availability of mental health services compared to other districts in Ethiopia. In Sodo district, as part of the PRIME project, all primary health care workers were trained to provide mental health care for selected priority mental disorders based on the WHO's mhGAP , whereas mental health research activities have been carried out in the Butajira area for the last 20 years, which also supported mental healthcare provision.

Researcher positionality: The research team in Ethiopia is based in a clinical department in a university, with most investigators working as mental health professionals. We acknowledge that this context has influenced the framing of the study, the lead author's interaction with study participants and our interpretations of the data . Nonetheless, it was the lead author's intention to support participant's to "tell their story", as much as possible minimizing her influence upon narratives. To facilitate this, questions were asked so as to elicit spontaneous descriptions of experiences,

for example: “can you tell me about some of the problems you have experienced”, probing to encourage participants to elaborate, and, where appropriate, asking for detail about what they described. Where she was unsure of meaning, MD sought clarification by reflecting back to participants what she thought they had said, using their own terms and expressions and checking that she had an accurate understanding. MD tracked how her position as a female biomedical researcher from Addis Ababa University influenced the research process and findings by keeping a field journal to record “thoughts, feelings, uncertainties, values, beliefs, and assumptions” .

Participants: Participants in the current study were either: people identified as having BD and receiving mental health care or, those who were on treatment but who were documented as currently discontinued taking medication by the health centers found in Sodo district and Butajira town. Because previous quantitative research suggested that sociodemographic factors such as age, gender, educational, occupational, and marital status were associated with clinical/functional outcomes , we selected participants purposively on the basis of these key characteristics. Our approach to recruitment is as follows. Given the vulnerability of participants, in the first instance, we approached a gatekeeper (primary care clinician) to gain an initial assessment of the eligibility of potential participants, particularly with respect to the person’s current mental health and capacity to participate in the study. Field coordinators then approached all potential participants, informed them about the purpose of the study and gauged their willingness

to participate. A total of 31 participants were approached by field coordinators and 27 agreed to participate. Four participants did not attend at the scheduled interview time because of social obligations: three caregivers were absent because of the death of someone in their village and one PBD could not attend because of an ill relative. Out of 27 participants, 20 were service-user-family caregiver pairs (i.e. 10 caregivers and 10 PBD). Seven participants were unpaired, from seven different families (five PBD and two caregivers).

Data collection: Topic guides for in-depth interviews were developed to cover the following themes: understanding what respondents noticed as forewarnings of illness, priority concerns of PBD and their caregivers, the factors they felt influenced illness, and the social and economic effects of living with illness (Annex-I and II). Participants were asked to talk about their illness beliefs and strategies they have used to manage their illness, and how these have evolved over time. Topic guides were developed, translated into Amharic, and piloted before the main data collection with two PBD to check for clarity and acceptability. Based on results from piloting, we added some probes that were found to elicit rich responses. Pilot interviews were integrated into the main dataset. For participants from Sodo district, interviews took place in the health center which the PBD was attending. In Butajira, participants were interviewed at the mental health research project office. All interviews were conducted face-to-face by MD in Amharic. Interviews lasted between 40 and 90 minutes. All interviews were audio-

recorded and field notes were taken simultaneously. Data collection was a two-stage process; in the first stage, 21 interviews were completed, transcribed, coded, and analyzed. After discussion of these results with co-authors, we decided further interviews were necessary in order to fully explore coping strategies. Six further interviews were conducted in this second stage of data collection.

Analysis: We used thematic analysis, which was conducted in three stages and was influenced by interpretative phenomenological analysis . First, during familiarization and coding, all the first stage interviews were transcribed, translated to English, and imported into Open Code 4.03 software for analysis. Two members of the research team (MD, CH) independently carried out line-by-line coding of three randomly selected transcripts. Whenever a new concept appeared in the text, the coders assigned codes and wrote a code definition. They met to refine codes, developing a common codebook through discussion of individual code definitions and assignment. MD coded the remaining transcripts based on the codebook, developing and defining new codes where necessary. The second stage involved using OpenCode to facilitate data retrieval and comparison of concepts within each code before grouping of similar or related codes together into clusters with the aim of capturing the essence of particular themes. Themes were then reviewed to check that they were a credible distillation of experience. In addition, themes were checked to see whether they were clearly and concisely defined with an informative name.

Finally, quotes from a range of participants were selected to illustrate themes, and the themes that were not well-represented were dropped.

Ethical approval: Ethical clearance was obtained from the Institutional Review Board (IRB) of the College of Health Sciences of Addis Ababa University (Reference Number 04/17/Psy). Written informed consent was obtained from each participant. For participants who were illiterate, the interviewer read out the information sheet in front of another person, known to the participant, who was literate and able to confirm that full and accurate information was given. In these cases, a witness statement was included in the consent form in addition to the participants consent, which was indicated by a thumb print. Confidentiality was ensured by anonymizing identifying information and assigning a unique ID code to all interviews.

Results

A total of 27 participants were interviewed (15 PBD and 12 caregivers). Among them, nearly half (12/27) were female, two-thirds (18/27) were married, and about a third were farmers (n=10) and illiterate (n=11). Seven out of 12 caregivers interviewed were the spouse (wife/husband) of the PBD. Findings are organized into three main themes: expressions and experiences of illness, managing self and living with otherness, and the costs of affliction that included **Themes** s, as *Sub-themes* e 1.

Key

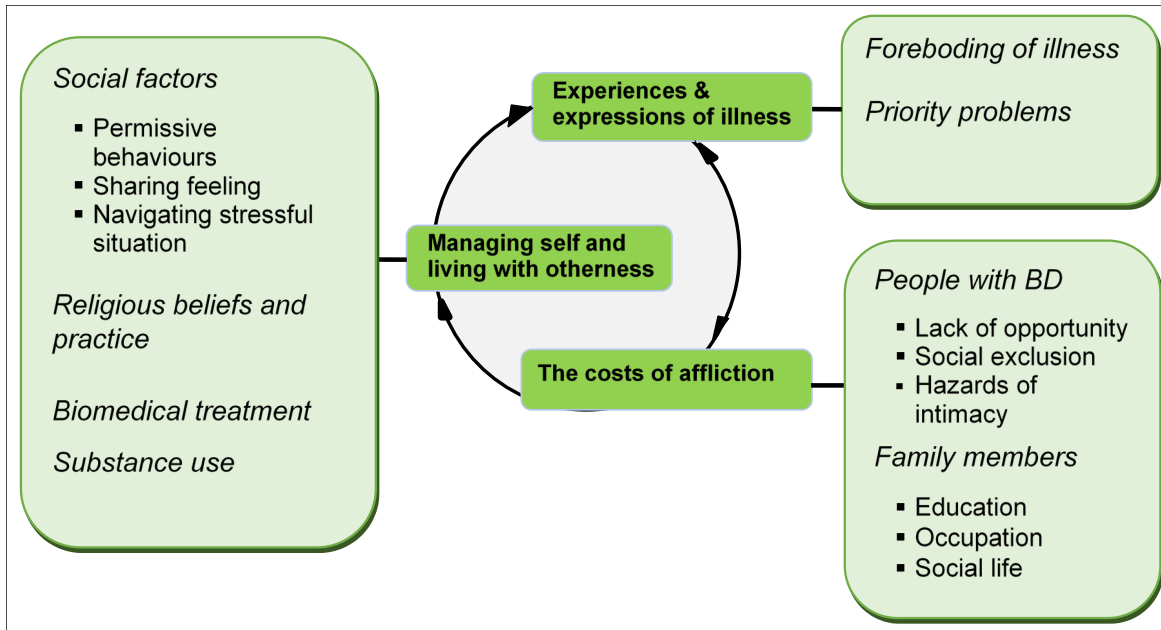


Figure 1: Themes and subthemes for experience of people with bipolar disorder

1. Experiences and expressions of illness

1.1 Forebodings of illness

Most caregivers described increased irritability, aggression, loss of respect for others, disturbed sleep, carelessness about what the PBD said or how they dressed, and laughing or talking to themselves as common signs that the PBD was beginning to experience an illness episode. These signs triggered worry for caregivers. One caregiver described the problems as

“every time when he starts to insult us, and quarrel with other people for irrational reasons as well as when he talks to himself, I will be aware of his situation and conscious about his illness. He doesn’t violate others’ rights when he is normal. So, I feel worried when he starts to argue with people and becomes aggressive”

25-year, Female-Caregiver ID014, Butajira

While some PBD also identified sleep disturbance and irritability as common forewarnings of upcoming illness episodes, they also noticed other signs, including heavy-headedness and lack of interest in activities or, alternatively, feeling unusually energetic and excessive talking. Recognition of these signs often induced anxiety and sometimes triggered actions from the PBD designed to contain or treat the illness:

“I feel heavy headed (ጠጠጠጠጠ ጠጠጠ ጠጠጠ) ... there is a time that I become disinterested to do something that I planned to do. Then I realize that I’m going to get sick”

23-year, Male-PBD, ID20, Sodo-district

“At the beginning, I increase talking and my mind gets occupied with something and I feel anxious...umm... I talk too much and say things that are culturally inappropriate, I know that I’m going to have illness, so I tell them [family members] to chain me....”

30-year, Male-PBD ID23, Butajira

1.2 Differing priorities of PBD and family members

Sleep disturbance and aggressive behavior were the biggest concerns for caregivers, associated with threats to the safety and health of others:

“... During his illness, he was not sleeping the whole night. At that time, I was worried that he might slit the throat of one of my children; so, we were not sleeping, we were suffering a lot ... we don’t need anything else than to get him sleeping well. When he sleeps well, all the family members feel well and the children start to gain weight...”

above all lack of sleep is very much difficult...” 35-year, Female-caregiver ID013, Butajira

However, some PBD were mostly concerned about the incurable nature of the illness and the social consequences of living with lifelong illness (and medication). These ruminations were distressing and led to questioning why they had been singled out for affliction.

“.... I’m always asking myself ‘how long am I going to take medication?’; I ask God how long I will live with this illness? why doesn’t God take this illness off from me? Why doesn’t God say enough? Is it for as long as I live? Am I taking medication until I die? People considered me as mentally ill who can’t think and do things by myself, aggressive, and insulative. I’m always crying and praying in front of God. I don’t know why, God made me inferior than other people. I don’t know when he will tell me ‘enough!’ [participant distressed]” 27-year, Female-PBD ID005, Butajira

2. Managing self and living with otherness

2.1 Quarrels and sharing feelings: the role of social relationships in shaping illness experience

Participants reported that periods of illness would occur after a period of wellness. They described how longstanding animosities formed the backdrop to particular incidents which were seen as turning points, precipitating transition into illness.

Permissible behaviors: making sense of conflict and disagreement

Most participants described a circular relationship between social factors and the intensity of the illness. Negative social interactions had the effect of triggering illness; concurrently, the illness had the effect of worsening social conflict. PBD explained that ongoing disagreements and conflict were a major cause for the origin of their illness, a trigger during a period of wellness and an exacerbator during an illness episode.

“My half-brother always speaks to me as if the house and place/land that I’m living currently does not belong to my father. He even threatened me to get me to leave... so this makes my illness worse... when my illness was back last time, he was accusing me of being a thief...he insulted me as a thief” 34-year, Male-PBD ID018, Sodo-district

Labelling of the person with BD as mentally unwell aggravated social interactions, providing a rationale for grievances from community members while causing frustration for the person with BD and caregivers alike: PBD get frustrated because of their illness label, any disagreement is perceived as being due to their illness. Not being allowed to express “normal” response to the disagreements is perceived to have a negative effect, making the patient angrier, and potentially triggering or worsening their illness.

‘...there can be disagreement among people but, when we quarrel with anyone, they say “go to Amanuel hospital [mental hospital] if you finish your medication” ...they don’t take it as a normal behavior of people, which is very annoying for him [patient], even for me.’

25-year, Female-Caregiver ID014, Butajira

Concomitantly, caregivers perceived that the PBD was sensitive to minor day-to-day disagreements which were seen to trigger their illness.

“Every normal individual may have some issue when they are living in marriage.... For him [patient] minor disagreement is enough to bring his illness back, despite taking medication properly...” 22-year, Male-caregiver ID021, Butajira

The dilemmas of ‘Sharing feelings’

Participants expressed different perceptions regarding sharing their feelings with others; some people with BD shared their feelings with families and friends because they felt that they received an appropriate response, a sense of solidarity and support that made them feel better.

“I share my feeling to my sisters, brothers and friends too and it helps me a lot. They let me know that I am not the only person who has a problem; it can happen to anyone ...they tell me that they even sometimes experience similar problem, but they tried to tolerate and let the challenges pass. Thus, they advise me not to give up and so on”. 23-year, Male-PBD ID20, Sodo-district

Some other PBD stated that, although they recognized the value of sharing their feelings with others and noted the damaging effects of not doing so, they felt unable to discuss with others due to their belief that no one wanted to hear them. Alternatively, they lacked a confidante whom they trusted sufficiently not to divulge personal information to others.

“I don’t share my feeling to other people because loving people is possible but, trusting all is difficult. No one is able to put aside their own problems to help me or they may even say she said this and that, and I don’t want to be a topic of discussion in my neighborhood coffee ceremony ...I keep everything to myself and I know that not sharing my internal feeling harms me”. 27-year, Female-PBD ID002, Butajira

However, some caregivers believed that the person with BD did not want to, or was incapable of, discuss their problems in such a way that would allow them to meaningfully address them. Rather, caregivers complained about destructive behavior, irresponsibility, and a lack of engagement in problem-solving.

“He does nothing; rather he gets angry and insults people around him or breaks anything he finds near to him without taking consequences into consideration, rather than looking for a solution”. 42-year, Female-Caregiver ID027, Sodo-district

Other caregivers reported that PBD do nothing to solve their problem or ask people to help them.

“He doesn’t know how to solve problems with planning... umm... there is no discussion; he just keeps asking God to do something miraculous for him” 35-year, Female-caregiver ID013, Butajira

***“I leave the place and go somewhere to console myself”:* navigating stressful situations**

Most participants spoke of trying to avoid troublesome social experiences which they associated with the beginning of illness as being more helpful than getting help after they had become unwell.

Some PBD preferred to avoid social events of situations which they perceived to be stressful:

"I believe that there is problem related to this. I don't feel good when there is crying/ shouting when someone die because the shouting makes me emotional and I absorb the sorrow. People with mental illness are like a sieve, all the sorrow goes through his body and hurts him a lot (ጠባብሽ ጠባብ ጠባብ ጠባ ጠባብጠባ ጠባ ጠባ ጠባ ጠባ ጠባ ጠባ ጠባ ጠባ) ...so I will see my condition and If I feel unwell, I leave it"

48-year, Male-PBD ID 003, Meskan-Woreda

Caregivers explained that by understanding the factors that exacerbated illness, they could modify their interactions with the PBD to reduce provocation in an effort to decrease the potential for return of illness:

"when he [patient] talks loud because of anger, we don't respond to him, I keep quiet...so that he becomes calm...umm...if someone gets angry and talks loudly, it is good to be quiet, otherwise it makes the person more angry and brings the illness back"

25-year, Female-Caregiver ID014, Butajira

Some PBD reported taking actions to change their surroundings; for example, chatting with friends or leaving a situation in order to neutralize their bad feeling.

“In order to forget a situation that makes me worried, I leave the place and go somewhere in order to console myself ...I know the things that make my illness worse, so I try to control them” 30-year, Male-PBD ID017, Butajira

2.2 Managing symptoms “avoiding and using substance”

Participants take lesson from their illness experience to avoid or use substance in order to manage their symptoms. Some participants reported a positive role of alcohol use and khat, to improve their sleep and medicate their illness symptoms

“Sometimes, he [he patient] has sleep problem so, he disturbs the families wake-up from his sleep and going here and there. Thus, he drinks alcohol to sleep well so that he doesn’t disturb anyone.” 63-year, Male-Caregiver ID012, Sodo-district

On the contrary, most participants agree that avoiding substance use like khat and alcohol was helpful to improve sleep and relationships with others, while also reducing the risk of directly triggering or worsening their illness.

“... I was chewing a lot so it has worsened my illness. Now, I stopped chewing for the last eight years because of my religious convictions. It [stopping chewing] has helped me a lot. For example, now, I sleep well, I have good relationship with others, I spend my time with my wife and

children and I'm not irritable as before, I also eat well..." 30-year, Male-PBD ID017, Butajira

2.3 Strength and healing: the role of religious beliefs and practices

There was a broad agreement among participants that religious practices such as praying, going to holy water (holy water is water that has been sanctified by a priest for the purpose of baptism, the blessing of persons, places, and objects, or as a means of repelling evil and treatment of illness) and listening to religious song were a positive influence upon the person's emotions, helping them to feel calm and encouraged when they experienced personal or interpersonal problems.

"I read the bible and listen to religious songs on Sunday. When I read the bible, it helps me to feel hope, for example, the bible says, 'blessed is the man that endures temptation...' So, it reassures me and helps me to be strong. It indicates how common it is for people to face several problems and how much we should be strong. Everything written in the bible is true, so it gives me energy and helps me not to think too much" 23-year, Male-PBD ID20, Sodo-district

Some participants reported that things happened according to the will of God. Therefore, they came to accept problems that could not be reversed or changed and found this acceptance calming:

"My illness started because of grief related to the death of my brother and became worse when my mother and my children died... I realized

that I couldn't return things that are already lost. Everything happened in the will of God, he created us and we will pass, our time is already known by him so now I stopped worrying about them. I thank God and tell him to keep the rest of the children safe". 27-year, Female-PBD ID002, Butajira.

However, some participants noted that there were difficulties in using spiritual treatment in the form of holy water and biomedical treatment (medication) simultaneously. For some, this was a matter of creating confusion about which treatment had been effective, while for others, the two paradigms were more fundamentally incompatible because they believed that dependence on holy water necessitated abandoning biomedical treatment as it required a demonstration of faith.

".... she was not taking medication when we were in the holy water site because people told us it is not right to use holy water and medication simultaneously. Because this will make it difficult to know which bring the change, I mean the medication or the holy water"

50-year, Male-Caregiver ID011, Sodo district

2.4 "Nothing helps him other than medication": the role of biomedical services

Both PBD and caregivers emphasized the power of biomedical treatment in alleviating symptoms of illness:

“the only thing that helped him to feel better is medication especially the injection. Nothing helps him other than medication” 32-year, Female-Caregiver ID015, Sodo-district

All participants agreed that treatment discontinuation was a major problem that could trigger the patients’ illness after remission and worsen the illness once it had returned. However, most participants explained that treatment-related issues such as increased weight, feeling sleepy during the day time, and being unable to wake-up in the morning were common reason to stop taking their medication.

“I’m taking the medication at night-time. I always feel sleepy in the morning even though I slept for a long time in the night.... Every morning, our neighbor asked me whether I slept well or not...Thus, I sometime stopped taking it not to be sleepy or to be fully awake”

30-year, Male-PBD ID23, Butajira

Some PBD adjusted their dosage and/or took medication breaks according to their perceptions of their illness status: increasing their dose when symptoms persisted and reducing/stopping when they felt better. Without the involvement of healthcare professionals, this sometimes-had adverse consequences, leading to a return to illness:

“he[patient] doesn’t take medication when he is well ... they [health professionals] are also have not informed us to take medication while he is feeling well.... if he is normal, he doesn’t take medication” 25-year, Female-Caregiver ID014, Butajira

Other participants reported that they stopped their medication because they perceived that medication was not curative.

“The medication didn’t cure them fully but it gives her sleep and made her patient....so some people advised her to stop taking it for a week and try to see how she felt without medication and she stopped... then she got seriously sick and came...”

50-year, Male-Caregiver ID011, Sodo district

Fear of stigma and of side effects of medication during pregnancy were also commonly described as reasons to discontinue treatment. Participants reported feeling negative judgments from the community related to frequent visits to the health facility, which sometimes prevented visits to the clinic, despite recognition by the person living with BD that they were unwell.

“...I feel as if people saying to me that I am frequently going to hospital because of getting treatment free rather than being unwell. So, I didn’t go to hospital immediately after feeling unwell...” 36-year, Female-PBD ID025, Sodo-district

Whereas, some caregivers described patients’ unwillingness to take their medication as a reason for non-adherence.

“... There is a time that he refuses to take his medication. Because of that, in such times we will give him the medication without letting him know, we dilute the medication with the tea or coffee or milk and give it to him” 35-year, Female-Caregiver ID 013, Butajira

3 The costs of affliction

3.1 Lost opportunities

Some PBD and caregivers described that during younger ages, dropout from school was one of the main negative consequences of illness, leading to early curtailment of education:

“. when I was a student, I couldn't attend properly and I couldn't write using pen and book like my friends. I was quarreling with the school community unless I missed the class...so I stopped because of fear of worsening of symptoms at that time....”

30-year, Male-PBD ID 017, Butajira

Participants explained that ill-advised decisions made during the illness period played a role in the economic problems they were experiencing.

“...previously, I had assets like sheep, goats and chickens and I was trying to do different things. But, after I got sick, I felt as if they were not important and I sold them when I felt annoyed. I think I decided to sell them because of the illness because previously I was not planning to sell them...” 23-year, Male-PBD ID020, Sodo-district

Others reported the negative consequence of illness upon their ability to work and acquire assets compared to other members of the community.

“sometimes he [PBD] gets sick during harvesting time, he may not be able to hold a sickle ...umm... no one helps him... when he tried to harvest, he feels tired and his hand couldn't hold the sickle properly so the time passes before we gather the crop”

32-year, Female-Caregiver ID015, Sodo-district

Participants described the direct and indirect cumulative effects of the illness on the affected person and the household economy over time, starting from a young age; some participants stated that they sold their assets to cover the treatment and other related costs:

“At the beginning, we sold my grandmother’s land for transportation and different costs to go to different holy water places... during the illness period my grandmother asked people for help and to take me to Addis Ababa Amanuel hospital”

27-year, Female-PBD ID005, Butajira

3.2 “I’m not happy. I feel shame”: living with social exclusion

PBD and caregivers were concerned about direct or indirect social exclusion of PBD due to their illness, for example, some reported that people excluded them from social participation and behaved towards them in ways that would never normally be acceptable:

Last time, my cattle entered another person’s farm and were grazing there; because of that, the owner of the farm was hitting my cattle. My son [person with BD] asked him why he hit the cattle and he [owner of the farm] tried to hit him with an axe but he ran away & escaped. If the cattle were belonging to another person, they may not have tried to hit that person. 63-year, Male-Caregiver ID012, Sodo-district

Additionally, other participants reported that stigma shaped their interactions with members of the community, as well as restricting the social roles they were allowed to play:

“I don’t know why but people, including my family members, change their direction when they see me on the street, not to talk to me as if they didn’t see me.... I feel isolated when they react to me in this way... people were calling me crazy and were not wanting to communicate with me” 48-year, Male-PBD ID 003, Meskan-Woreda

The stigma and misunderstanding of PBD were also mentioned as barriers to express their feelings and get help, leading to feelings of loneliness.

“...everybody at home says to me ‘you don’t feel shame when you always say I’m feeling unwell’...One day, my husband said to me ‘I wish your illness to be real’...so I get angry and feel alone, I also don’t tell them when I feel unwell or I don’t go to the health facility unless it is serious” 32-year, Female-PBD ID025, Sodo-district

Many PBD and caregivers described the compounding effects of exclusion upon social isolation: with exclusion causing people with BD to avoid socialization due to feeling less confident, inferior, and ashamed about living with a mental illness.

“Previously, I didn’t have fear to talk with people but now I’m not happy, I feel shame, I’m not motivated to talk and I don’t want my voice to be heard so I don’t talk during social gathering, I just sit and

hear what they are saying because people around me think that I am dangerous (both men and women talk as if I'm dangerous)"

50-year, Female-PBD ID09, Sodo-district

Some other participants reported that culturally, people chew khat in group during the social and cultural ceremony. Therefore, they use to chew khat with other community member as a mechanism to improve social integration.

"Previously people were calling me 'Ebid' (crazy) ...I was isolated from others, so Khat created an opportunity for me to socialize, to share my ideas with other people. The more we get together, the better we know and understand each other so they don't stigmatize me. So, Khat is a good solution for me" 48-year, Male-PBD ID 003, Meskan-Woreda

3.3 The hazards of intimacy

Participants described the difficulties they had regarding establishing sexual relationships, getting married, and maintaining spousal relationships:

"previously when I planned to marry, people said he is mentally ill..., many of them were not willing to have marital relationship with me because of my mental illness....my former wife also went abroad without my consent/consulting me." 30-year, male-PBD ID17, Butajira

Other participants explained their experience of divorce and community interference in their relationships.

"I have been divorced for nine years. my neighbors and community members were supporting him [her husband]- everybody said, he has

to get married to another woman and lead his own life... they decided that I had to leave the house with my children, so he took all of the assets, the land and house and got married to another woman”

27-year, Female-PBD ID002, Butajira

Other participants described that they were scared to establish sexual relationships, anticipating divorce due to having mental illness.

“Previously, I stayed without getting married because my illness came back every time so I feared that it may work as a cause for disagreement and divorce ...” 27-year, Female-PBD ID005, Butajira

Caregivers described negative impacts of their relatives’ illness on their children’s education, relative’s work, and social lives. These negative impacts arose from caregiving responsibilities, for example, trying to prevent or manage difficult behaviors, including threats of harm to self or others:

“If he got sick, I look after him and caring for him is my responsibility, I couldn’t do anything and I also sit with him. We spent the night without sleep too but he is alert in the next day also so how can I work? I was sitting and waiting him day and night...”

35-year, Female-Caregiver ID13, Sodo-district

Discussion

To the best of our knowledge, this is the first study to explore the lived experience of living with BD in a rural LMIC setting. Our phenomenology-informed approach supported thick description and enabled in-depth

exploration of the different domains of experience of the life-world, bearing witness to the experiences of marginalized individuals, whose voices are largely absent from the scientific literature and wider society. We acknowledge that our study was framed by the larger goal of developing a culturally appropriate primary care intervention. While designed to be broad and expansive, our overall aim inevitably shaped which aspects of lived experience we prioritized in our topic guide. Our results therefore represent a particular perspective, which recognizes a role for the health system in supporting PBD and their families in LMIC settings. The study took place in a setting which was unusual in Ethiopia: where biomedical care was available and accessed in a community where extensive mental health research had taken place. Our results therefore represent experiences of illness in a context where there is arguably greater awareness of “mental health” and more therapeutic options available than would be the case in most rural Ethiopian communities.

Our findings demonstrate that for PBD, illness is located in a constellation of life problems, primarily rooted in the social (see Figure 1). Occurrences in the social world were seen both as the cause of the first period of illness experienced, and as a stimulus for moving from being well to unwell. The most significant consequences of illness for the PBD were social, for example, lost income generation opportunities, were perceived to be due to social exclusion. It is not just the PBD who is living with the illness, but the consequences of living with mental illness are also felt by the whole

family. Our findings suggest that if successful interventions are to be developed, they must take account of these models of illness, ensuring that social outcomes are prioritized. For example, in a study carried out in Midwest, participants living with BD identified several helpful behaviors from friends, family, and colleague that better enable them to both cope with illness and feel more socially connected, these included: talking and listening to the person living with illness, encouraging PBD to value themselves and their contributions, expression of love, and active support for help-seeking and treatment.

In our study, narratives were strongly rooted in the social world, with disrupted relationships seen as both a consequence and a cause of illness, which, in turn, led to broader socioeconomic impacts. Participants described the vicious cycle that resulted from fractious social encounters and antagonistic relationships that triggered and intensified the illness, in turn, leading to a worsening of relationship problems, social exclusion, stigma, and lack of support, and often hostility, from the community. Findings from other studies have described similar changes between PBD and the communities in which they live, with service-users describing circular relationships linking feeling misunderstood by the community and being blamed for their illness, leading to poor interpersonal and marital relationships and subsequently a lack of social support leading to further alienation.

Participants were aware that their experience of stigma had resulted in the internalization of their “spoilt identity”, causing them to hesitate in

sharing their feelings, lose confidence over time, and experience a sense of inferiority and shame about living with a mental illness. In addition to this problem, stigma and exclusion from work opportunities were perceived as a significant barrier to acquiring assets, leaving them unable to support themselves and exposed to another layer of stigma that became inseparable from that which was due to their illness. As have been elsewhere, consequences of illness were pervasive, affecting not just the PBD and their primary caregivers but stigmatizing the whole household/family . Participants described the negative consequences on children's education and family member's ability to work, which they connected to impoverishment .

Participants who visited religious places or traditional healers for their illness did so because: they believed their illness was caused or activated by supernatural power, or, they preferred to visit religious places because they believed that religious practice works as a means to combat stigma and improve wellness. Studies about mental health in other sub-Saharan African countries have suggested that supernatural explanatory models and stigma can prevent seeking help from biomedical services; authors have suggested that these findings highlight the need for collaborative work with culturally recognized healers . Others reported substance use to improve social involvement and sleep. The important role of khat in facilitating social, cultural, and religious activities was previously described in a study that examined the reasons for substance use among people living with severe mental illness carried out in the same setting . While in rural Ethiopia,

findings suggest substance use is perceived as a way bridging social gaps, research from north-west England described how PBDs used drugs and alcohol to manage their mood and anxiety symptoms .

When considered in the context of our systematic review of psychosocial interventions for PBD, findings from our qualitative study have important implications for intervention design and delivery. Participants practiced a range of self-management strategies, and where necessary, sought help from more formal healing services, namely, Holy Water sites and medication. PBD and caregivers accumulated knowledge over time and used this knowledge to inform their behaviours. For example, PBD avoided situations they knew to be stressful and sought help from biomedical services when they recognized they were unwell. It has been suggested that self-care strategies improve knowledge and skills by empowering and helping PBD to take responsibility for their illness . Understanding life with BD, particularly knowledge of warning signs and factors which aggravate or exacerbate illness, may help PBD to accept their diagnosis and treatment, as well as encouraging them to be proactive regarding early signs of illness and reducing risk of relapse . The results of our qualitative study are consistent with findings from our systematic review, which suggested that health education may be effective in improving self-care . We found stigma to be inescapable and debilitating in participants' lives, limiting the extent to which they felt comfortable sharing their feelings or participating in social

events. This will need to be addressed if group therapy or peer support, where sharing of knowledge may be helpful, is to be considered.

Limitations

While our aim was to capture emic experiences, our position was etic with regard to diagnosis. As highlighted above, this study was carried out by a clinical researcher with a particular approach, whose aim was to develop a psychologically informed intervention, located in the health system. These characteristics mean that the scope of the study was narrowed, accepting the existence of a recognizable disorder, aligned broadly with DSM and ICD criteria. This means that our study lacks the flexibility to consider the possibility of the existence of culturally bound syndromes that share some features of BD. Participants were people who had been diagnosed with BD and received care within the biomedical system. Our sample size enabled us to explore the aspects of experience of most relevance to our overarching study aim. However, our sample was highly unusual in Ethiopia and it is likely that participants' explanatory models have altered over time as a result of their experiences of treatment. This was not the main focus of this study and the development of explanatory models over time was not explored. We did not carry out member checking. However, the interviewer, who was also the lead researcher, is indigenous to Ethiopia, has good knowledge of local idioms and during interviews, ensured that she had understood participants' meanings by summarizing and repeating back to them what they had said. It is difficult to separate the different factors that

shaped participants' responses in the interview. For example, in other work with people living with mental disorder in Ethiopia, we found that pervasive stigma of "madness" inhibited free discussion of opinions and experiences of illness, although this was less obvious in this study, it seems inevitable that stigma constrained responses .

Conclusion

People with bipolar disorder and caregivers routinely recognize and act upon early warning signs as a means of coping with illness, but caregivers and PBD prioritize different signals. Stigma is intrinsic to illness experience, as a driver and consequence of illness. This circular relationship leaves PBD and their families socially alienated, which, in rural Ethiopian communities, results in a loss of economic opportunities. Nonetheless, some PBD benefit from close trusting relationships with family members and friends and many PBD and family members described how their spiritual beliefs and religious practice, and medication use helped them to cope. In the context of availability of spiritual, social, and biomedical resources, our study findings indicate the need for psychosocial intervention, to bolster self-help strategies, address internalized stigma and augment social support.

Competing interest: None

Funding

"This work was supported through the DELTAS Africa Initiative [DEL-15-01] The DELTAS Africa Initiative is an independent funding scheme of the African

Academy of Sciences (AAS)'s Alliance for Accelerating Excellence in Science in Africa (AESA) and supported by the New Partnership for Africa's Development Planning and Coordinating Agency (NEPAD Agency) with funding from the Wellcome Trust [DEL-15-01] and the UK government. The views expressed in this publication (manual) are those of the authors and not necessarily those of AAS, NEPAD Agency, Wellcome Trust, or the UK government."

This PhD study is also nested in the Programme for Improving Mental health care (PRIME). PRIME was funded by the UK Department for International Development (DfID) [201446]. The views expressed in this article do not necessarily reflect the UK Government's official policies.

and Addis Ababa University.

Reference

- Ae-Ngibise, K. et al., 2010. 'Whether you like it or not people with mental problems are going to go to them': A qualitative exploration into the widespread use of traditional and faith healers in the provision of mental health care in Ghana. *International Review of Psychiatry*, 22(6): 558-567.
- APA, 2013. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. American Psychiatric Publishing.
- Billsborough, J. et al., 2014. Listen, empower us and take action now!': reflexive-collaborative exploration of support needs in bipolar disorder when 'going up' and 'going down. *Journal of Mental Health*, 23(1): 9-14.
- Cappleman, R., Smith, I. and Lobban, F., 2015. Managing bipolar moods without medication: a qualitative investigation. *Journal of affective disorders*, 174: 241-249.
- Carlson, J.A., 2010. Avoiding traps in member checking. *The qualitative report*, 15(5): 1102-1113.
- Cresswell, J.W., 1998. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

- Creswell, J.W., 2007. Qualitative inquiry and research design.
- CSA, 2013. Population projection of Ethiopia for all regions at Wereda Level from 2014-2017. CSA Addis Ababa.
- Demissie, M. et al., 2018. Psychological interventions for bipolar disorder in low-and middle-income countries: systematic review. *BJPsych open*, 4(5): 375-384.
- Doherty, E.F. and MacGeorge, E.L., 2013. Perceptions of supportive behavior by young adults with bipolar disorder. *Qualitative Health Research*, 23(3): 361-374.
- Dore, G. and Romans, S.E., 2001. Impact of bipolar affective disorder on family and partners. *Journal of affective disorders*, 67(1-3): 147-158.
- Dua, T. et al., 2011. Evidence-based guidelines for mental, neurological, and substance use disorders in low-and middle-income countries: summary of WHO recommendations. *PLoS medicine*, 8(11).
- Fekadu, A. et al., 2006. Clinical outcome in bipolar disorder in a community-based follow-up study in Butajira, Ethiopia. *Acta Psychiatrica Scandinavica*, 114(6): 426-434.
- Fekadu, A. et al., 2004. Bipolar disorder among an isolated island community in Ethiopia. *Journal of Affective disorders*, 80(1): 1-10.
- Ferrari, A.J. et al., 2016. The prevalence and burden of bipolar disorder: findings from the Global Burden of Disease Study 2013. *Bipolar disorders*, 18(5): 440-450.
- Ganguly, K., Chadda, R. and Singh, T., 2010. Caregiver burden and coping in schizophrenia and bipolar disorder: A qualitative study. *American Journal of Psychiatric Rehabilitation*, 13(2): 126-142.
- Goffman, E., 2009. Stigma: Notes on the management of spoiled identity. Simon and Schuster.
- Habtamu, K., Alem, A. and Hanlon, C., 2015. Conceptualizing and contextualizing functioning in people with severe mental disorders in rural Ethiopia: a qualitative study. *BMC psychiatry*, 15(1): 34.
- Hailemariam, M. et al., 2019. "He can send her to her parents": The interaction between marriageability, gender and serious mental illness in rural Ethiopia. *BMC psychiatry*, 19(1): 315.
- Healey, C., Peters, S., Kinderman, P., McCracken, C. and Morriss, R., 2009. Reasons for substance use in dual diagnosis bipolar disorder and substance use disorders: A qualitative study. *Journal of affective disorders*, 113(1-2): 118-126.
- Hormazábal-Salgado, R. and Poblete-Troncoso, M., 2020. Living with bipolar disorder in Chile: A qualitative study. *International Journal of Mental Health Nursing*, 29(3): 488-497.
- Kebede, D. and Alem, A., 1999. Major mental disorders in Addis Ababa, Ethiopia. II. Affective disorders. *Acta Psychiatr Scand* 100: 18-23.
- Kebede, D. et al., 2006. Symptomatic and functional outcome of bipolar disorder in Butajira, Ethiopia. *Journal of Affective Disorders*, 90: 239 - 249.
- Lan, Y.-F.C., Zelman, D.C. and Chao, W.-T., 2018. Angry characters and frightened souls: Patients and family explanatory models of bipolar disorder in Taiwan. *Transcultural psychiatry*, 55(3): 317-338.
- Lean, M. et al., 2019. Self-management interventions for people with severe mental illness: systematic review and meta-analysis. *The British Journal of Psychiatry*, 214(5): 260-268.

- Mayston, R. et al., 2016. Participatory planning of a primary care service for people with severe mental disorders in rural Ethiopia. *Health Policy and Planning*, 31(3): 367-376.
- Mayston, R. et al., 2020. Explanatory models of depression in sub-Saharan Africa: Synthesis of qualitative evidence. *Social Science & Medicine*, 246: 112760.
- Morton, E., Michalak, E.E., Hole, R., Buzwell, S. and Murray, G., 2018. 'Taking back the reins'—A qualitative study of the meaning and experience of self-management in bipolar disorder. *Journal of affective disorders*, 228: 160-165.
- Moucheraud, C. et al., 2015. Consequences of maternal mortality on infant and child survival: a 25-year longitudinal analysis in Butajira Ethiopia (1987-2011). *Reproductive health*, 12(S1): S4.
- Musyimi, C.W., Mutiso, V.N., Nandoya, E.S. and Ndetei, D.M., 2016. Forming a joint dialogue among faith healers, traditional healers and formal health workers in mental health in a Kenyan setting: towards common grounds. *Journal of ethnobiology and ethnomedicine*, 12(1): 4.
- Negash, A. et al., 2005. Prevalence and clinical characteristics of bipolar I disorder in Butajira, Ethiopia: a community-based study. *Journal of affective disorders*, 87(2-3): 193-201.
- Oud, M. et al., 2016. Psychological interventions for adults with bipolar disorder: systematic review and meta-analysis. *The British Journal of Psychiatry*, 208(3): 213-222.
- Pompili, M. et al., 2014. Impact of living with bipolar patients: Making sense of caregivers' burden. *World Journal of Psychiatry*, 4(1): 1.
- Pontin, E., Peters, S., Lobban, F., Rogers, A. and Morriss, R.K., 2009. Enhanced relapse prevention for bipolar disorder: a qualitative investigation of value perceived for service users and care coordinators. *Implementation Science*, 4(1): 4.
- Ruiz, M. et al., 2019. Congruent relations between perceived neighbourhood social cohesion and depressive symptoms among older European adults: An East-West analysis. *Social Science & Medicine*, 237: 112454.
- September, U. and Beytell, A.-M., 2019. Family members' experiences: People with comorbid bipolar and substance use disorder. *International Journal of Mental Health and Addiction*, 17(5): 1162-1179.
- Shelton, R.C. et al., 2019. Use of social network analysis in the development, dissemination, implementation, and sustainability of health behavior interventions for adults: A systematic review. *Social science & medicine*, 220: 81-101.
- Smith, J.A. and Shinebourne, P., 2012. Interpretative phenomenological analysis. American Psychological Association.
- Speed, D., Barry, C. and Cragun, R., 2020. With a little help from my (Canadian) friends: Health differences between minimal and maximal religiosity/spirituality are partially mediated by social support. *Social Science & Medicine*: 113387.
- Teferra, S., Hanlon, C., Alem, A., Jacobsson, L. and Shibre, T., 2011. Khat chewing in persons with severe mental illness in Ethiopia: a qualitative study exploring perspectives of patients and caregivers. *Transcultural psychiatry*, 48(4): 455-472.
- Thomas, J. and Harden, A., 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1): 45.

- Tjoflåt, M. and Ramvi, E., 2013. I am me! Experiencing parenting while dealing with one's own bipolar disorder. *Social Work in Mental Health*, 11(1): 75-97.
- Wang, Z., Jun, C., Gao, K., Yang, H. and Fang, Y., 2019. Perspective on Etiology and Treatment of Bipolar Disorders in China: Clinical Implications and Future Directions. *Neuroscience bulletin*, 35(4): 608-612.
- WHO, 2004. International Statistical Classification of Diseases and Related Health Problems, 10th revision Volume 2 Instruction manual. World Health Organisation.
- WHO, 2016. mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: mental health Gap Action Programme (mhGAP)-version 2.0. World Health Organization.
- Zergew, A., Hailemariam, D., Alem, A. and Kebede, D., 2008. A longitudinal comparative analysis of economic and family caregiver burden due to bipolar disorder. *African journal of psychiatry*, 11(3): 191-198.