Unmet needs of patients with Bipolar Disorders for psychosocial interventions at Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia: a Qualitative study

Research for Partial Fulfillment of the requirements of the Postgraduate Program in Psychiatry

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December 2017

Acknowledgements

I would like to express my heartfelt gratitude to my advisors Dr. Charlotte Hanlon and Dr. Benyam Worku who have been of great help in the development of this research. I would like to acknowledge the financial support of AAU. I would like to thank all the participants in the study.

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Abstract

Introduction

The evidence base for psychosocial interventions for bipolar disorders has been largely developed in a Western cultural context. Limited data are available about the unmet needs for psychosocial care of people with bipolar disorders in low- and middle-income countries.

Objective

To explore unmet psychosocial needs of people with bipolar disorder and the acceptability of potential intervention approaches.

Method

A qualitative research design was used. Participants were recruited from people with a clinical diagnosis of bipolar disorder who are receiving out-patient follow up at Amanuel Mental Specialized Hospital, Addis Ababa, Ethiopia. Purposive sampling was used based on educational level and gender. Sampling was continued until theoretical saturation was achieved, Nine interviews were done. In-depth interviews were audio recorded, transcribed in Amharic and translated into English. Thematic analysis was used to identify key themes.

Results

The main findings of this study are participants anticipation of narrow biomedical care during their treatment, with a particular focus on medication. It was also apparent that they expected clinicians to tell them what to do, indicating a paternalistic clinician-patient interaction. Nonetheless, the participants reported a number of psychosocial problems. But their repertoire of support was narrow for fear of stigma. Some respondents also considered psychosocial stress to

be part of life's pattern. Participants were amenable to the idea of having a regular counseling for psychosocial problems, but their priorities for 'talking therapy' were around getting information around their illness and, medication side-effects.

Conclusion

Unmet needs for information were apparent and could be readily addressed by implementing expected good practice for mental health care. The acceptability of more focused psychosocial interventions is less clear and compounded by low awareness of the potential benefits.

Introduction

Bipolar disorders are one of the severe mental illnesses, characterized by a relapsing and remitting course. Although clinical and epidemiological research into bipolar disorder has been a relatively neglected area in the past, this illness is receiving more and more attention. The lifetime prevalence of bipolar disorder is estimated to be approximately 1 percent (1).In Africa, knowledge of the epidemiology and burden of bipolar disorder is based mainly on studies from the USA and Europe. In a systematic review of literature from Africa, data from community surveys conducted in Nigeria and Ethiopia indicated a lifetime prevalence estimate of 0.1 % to 1.83 for bipolar disorder (2). In a survey conducted in Addis Ababa, the lifetime prevalence for bipolar disorders was found to be 0.3%(3).

There are effective pharmacological agents that are approved for acute mania, acute depression and for prophylactic treatment (1).Alongside psychopharmacological treatments of bipolar disorders, there is a need for adjunctive psychosocial interventions (4, 5). A study conducted in England showed that there are gaps and limitations in administering psychosocial interventions even in a high-income country setting (6).

In addition, culture shapes which and how psychiatric symptoms are expressed; culture influences the meanings that are given to symptoms; and culture affects the interaction between the patient and the health care system, as well as between the patient and the physician and otherclinicians with whom the patient and family interact(1, 7). Therefore, the applicability of psychosocial interventions for bipolar disorder which have been developed in the West to people with bipolar disorder in Ethiopia cannot be assumed.

There is limited evidence regarding the unmet needs of people with severe mental illness in general, and bipolar disorder in particular in low- and middle-income countries.

In a community-based study conducted in rural Ethiopia, bipolar disorder was found to have a tendency for recurrence and chronicity. This was attributed partly to lack of appropriate interventions in rural settings (8).

Implementation science and cultural adaptation bring valuable insights and methods to how andto what extent treatments and/or context should be customized to enhance the implementation of evidence-based treatments across settings and populations(9).

Rationale of the study

Psychosocial interventions have been used effectively for bipolar disorders in the West. There is no literature about adaptation of these interventions in Ethiopia. Moreover, there is no assessment of the unmet needs for, and acceptability of, psychosocial interventions for people with bipolar disorder and their families.

The differences in literacy level, cultural differences and access to information between the developed world and developing countries restrict direct translation of 'evidence-based' psychosocial interventions into practice. This research explored the gaps in the unmet needs of people with bipolar disorders and acceptability of potential psychosocial interventions.

Research questions

- What is the existing psychosocial care accessed by people with bipolar disorder?
- What are the perceived unmet needs in the existing psychosocial care?
- How acceptable would adaptation of Western-derived, evidence-based psychosocial interventions be for people with bipolar disorder?

Objectives

General

To explore unmet needs regarding psychosocial interventions for patients with bipolar disorder and acceptability of potential psychosocial interventions

Specific

- Explore the current access to psychosocial care
- Explore unmet needs for psychosocial care
- Assess the acceptability of adaptation of Western-derived, evidence- based psychosocial interventions into the Ethiopian context

Methodology

Study design

A qualitative research design was used.

Study setting

The study was conducted in Amanuel Mental Specialized Hospital, Addis Ababa. Amanuel hospital is the only specialized public psychiatric facility in Ethiopia. The hospital provides emergency, inpatient and outpatient psychiatric services. The inpatient department has emergency, mood, psychoses, addiction, geriatric and forensic units. The outpatient department

has psychoses, mood, neuropsychiatric and general medical services. People with bipolar disorders are seen by the mood case team, consisting of psychiatrists, psychiatric nurses and psychiatric residents. If admission is warranted, patients are admitted either to the emergency ward or the mood ward based on the severity of the illness. The interviews were conducted from September 2017 to November 2017.

Study Population and Sampling technique

The study population will be people with bipolar disorder who are receiving out-patient care at Amanuel Mental Specialized Hospital. Participants were selected purposively by a clinician working in the out-patient clinic who fulfilled the following criteria

Inclusion Criteria

- All people with a diagnosis of Bipolar I disorder who have follow up in Amanuel Mental Specialized Hospital.
- Age 18 years and older
- Able to give informed consent
- Live in Addis Abeba

Exclusion Criteria

- In acute bipolar episodes
- Unable to communicate in the language of the interview, Amharic

Potential participants were approached face-to-face and the purpose of the study was explained by a clinical or psychiatric nurses working in the outpatient clinic. Participants were given a detailed information sheet. Written informed consent was obtained. For people who cannot read or sign, the information sheet was read out loud and the person was asked to give fingerprint. For

people who opt out of the audio recording only, the interview will be conducted using detailed notes.

Sampling continued until theoretical saturation was reached. Data collection

All the interviews were conducted by the researcher in Amharic. After introduction and reading out the information sheet, all were asked to sign the consent form. Ethical clearance was found from AAU psychiatry department and Amanuel mental Specialized Hospital. Nobody opted out of the audio record. There were concerns about the voice records being used for media. It was clarified that it will not be used for media and it will be deleted once the translation was done. The concern regarding media was included under the information given for the subsequent participants. All the interviews were conducted in quite office in the in one of the wards. All the records were transcribed. And seven of them were translated in to English. Two of the transcriptions were coded in Amharic with pertinent quotes translated in to English after discussion made with advisors.

Interviews were loosely structured around the problems patients face in relation to their illness, with whom they discuss their problems, whether or not they have had counseling before, their expectations of psychosocial interventions in the health facility, how much their needs have been met and if they would come for regular counseling. There were probes on with whom they discuss their problems including family, friends, religious leaders and health professionals. For patients who would come for regular counseling, there were follow up probing questions about duration, frequency, preferred professional and anticipated challenges.

Analysis

The audio record was transcribed. It will be supplemented with the field notes. Then it wastranslated into English. The whole document was read repeatedly and first impressions were jotted down. Then coding was started using Open Code 3.6 computer software was used for data management. At first codes were descriptive labeling. There were plenty of codes. Then coding was repeated refining, expanding and rejecting codes. The codes were categorized into higher order categories based on their similarities. Important themes were generated by inductive analysis.

Results

Socio-demographic characteristics of Participants

A total of nine participants participated in the study. The interviews lasted between 0.3 and 0.92 hours, with a mean duration of0.54 hours. The age of respondents ranged between 20 and 55 years. There were four males and five female respondents. Five of the respondents were married, three were single and one was separated. The duration of their illness ranged from six months to 19 years and the number of previous episodes ranged from one to more than 10.

The findings are presented in three themes: (1) expectations of psychiatric care, (2) stigma of seeking psychosocial support, (3) unmet needs, priorities and preferences for psychosocial care

1) Expectations of psychiatric care

Participants' expectations of psychiatric care were narrowed to a biomedical conceptualization of treatment and a paternalistic clinician-patient relationship.

Narrow expectations of care

Specifically, most of the participants expressed their expectation of the psychiatric treatment as coming regularly to take their medications. Additionally, they have expectations of discussions mainly on how they are doing in terms of clinical symptoms, whether or not they are taking their medications and if they are having medication side effects. The majority of participants reported being happy with their follow up visits. They expressed their gratitude to the service, especially how it has helped them be better in comparison to how they used to be. Some of them voiced doctors changing, not getting adequate time as problems. Most of them had never received counseling about their psychosocial concerns and appeared to have no expectation that this could be an integral part of psychiatric care. However, one participant spontaneously reported having received counseling by a psychologist about relational problems and reflected that it had helped her. This participant expressed her wish to get counseling on relational problems and matters related to abuse. But late in the interview, she stated "…*The key things are the medication and prayer."*

Some of them stated the need to be open with their clinician. When asked to elaborate, however, most expressed things that revolved around medication, feeling states, medication side effects and physical symptoms. One of the participants said he doesn't intend to talk anything besides the medication and his symptoms. The following quote illustrates how their expectations are mainly about the medical care.

> *"For example if I feel something new, sleepless or dizziness, I will ask my doctor if it is related to medication dose. He may decrease the dose, or tell me to continue the same dose…"* IV001

Another illustrative quote

> *"When I face problems I ask my doctor if I am taking the medications properly. I had itchy eye and I took eye drops.*" IV003

Expectations of a paternalistic clinician-patient relationship

Most of them expect counseling as an opportunity to ask questions, to be listened to, asked about their symptoms. Most of them stated they expect treatment that is deemed suitable by their clinician. Furthermore, some of them expressed expectation of encouragement by their clinician. The following quotes capture

> *"…Using your medical knowledge, you are the professionals. You tell us what to do and we will do it. You tell us what not to do and we will not do it.*" IV002

> *"…The questions are helpful for me. For example if the doctor says 'do physical exercise..' I listen to him and exercise. They know more and they tell me frankly…and it is helpful.*" IV003

2) Stigma of seeking psychosocial support

They are reserved in seeking help from elsewhere, mainly because of fear of stigma and discrimination, which makes their needs at most partially met.

Participants expressed their pursuit of help for the problems they face from their family members. Most of them reported they depend on their family members who, live with them in the same household, will tell them how they are doing symptoms, reminding them to take their [patients'] medication. Significant majority of them expressed themselves as spiritual and explained the positive impact of spirituality. Nonetheless, they described the help they get from

religious leaders as something related to the religious matters. Among them, some fraction said they visit religious leaders to consult them on matters of religion. One patient expressed his religious transformation. He stated*"... my Khat chewing, cigarette smoking and adulterer days are behind me."*And described how he drives meaning from something bigger. In his words he said*" I now live for something beyond myself."* On the other hand, a participant mentioned the need to stay at home and not go to religious places until one gets better.

Most of them confide in close family members for fear of stigma and discrimination. The following quote illustrates

> *"To be honest with you, my wife, my son and some of the in-laws know. But I keep it a secret from others for fear of stigma." IV002*

Most of them described their reservation seeking help or disclose their illness to friends for fear of stigma and discrimination. Similarly, most don't want to disclose their illness to relatives or colleagues. Some voiced the society's lack of awareness as the cause. The following quote illustrates it

> *"...you know I was sick in the office and there is impression created on people. People may see you like you are mad. And it took years to change that. Awareness should be created on the treatability of the illness. It will take a while to change people's attitude." IV005*

One participant, who has been diagnosed six months ago with bipolar illness, has a differing opinion about stigma and discrimination. He said he has never experienced stigma or

discrimination and he said people will understand one's illness and if one has done a misdeed, he just needs to apologize.

In a nut shell participants of the study get help mainly from family members. But the help they get is limited. They don't seek help from elsewhere for fear of disclosing their illness and/or stigma and discrimination.

3) unmet needs, priorities and preferences for psychosocial care

Unmet psychosocial needs and priorities

Participants mentioned various unmet psychosocial needs. Some of them mentioned poverty as the cause of their problems. None of them saw the need to get psychosocial counseling about the ups-and-downs of life. They mentioned they just need to be strong and accept that as a fact of life. Others mentioned abuse, unemployment, cost of living, housing difficulties. A few of them mentioned relational problems as unmet psychosocial needs. One participant voiced his unmet needs like this

> *"At the risk of being repetitive, what I need right now is housing. If I could get a house, I would be happy." IV002*

All but one, considered the idea of regular counseling to be acceptable. For the majority of them anticipated counseling involving being listened to, being able to questions, encouragement to express themselves. Most participants hope for information on illness, the medications, medication side effects, duration of treatment and the effect of drugs like chat[an indigenous amphetamine like stimulant leaves], alcohol.

Most of the participants don't see the need to get counseling about ups-and-downs of life, getting back to normal life after an illness. Their reasons being these are inevitable things in life and one needs to be strong and accept it.

Preferences

Most of them expected the counseling to be in the form listening by the clinician and later suggestions in the form of advice. Probing on what topics they would like to get counseling for, most replied that it should be based on the clinicians' knowledge. It is exemplified in the the following quote

> *"… If they use their knowledge and include what will be helpful for us." IV 006*

Nearly half of the participants wish to have individual counseling mainly to maintain privacy and fear of being disturbed by other patients. Some stated indifference to whether it be given individually or in a group. A few of them preferred group as it might offer them an opportunity to learn from each other.

Discussion

In this qualitative study the experiences and anticipation regarding counseling was explored. Moreover, other sources of support were probed with the aim of exploring the unmet needs of patients and acceptability of counseling. Patients face various problems including mental illness symptoms, medication side effects and physical symptoms. Most of these problems are encountered in the context of interpersonal problems, stigma and discrimination which makes the problems all the more difficult. On a larger scope, problems around unemployment, housing problems and poverty have been mentioned. However, the awareness and experience of interventions to address psychosocial challenges were almost non-existent.

In this study three themes have emerged regarding the unmet needs and acceptability of psychosocial interventions. They will be discussed separately.

1) Expectation of psychiatric care

The patients' expectation of psychiatric follow up as involving mainly their symptoms and things around the medication might be due to the fact that most of them never had counseling or any other form of psychosocial intervention. It was implicitly stated that their expectation of counseling would involve any interaction with a clinician. A case in point would be a participant who mentioned he had had counseling but up on clarification stated it was a-one time interview with a clinician and how he was asked things like what the time was, what the date was, who the prime minister was. The things mentioned above seemed like cognitive assessment than any form of psychosocial intervention. It was difficult to translate psychosocial interventions since it is a Western construct and without Amharic equivalent. Admittedly, the Amharic phrase"yemikiragelgilot" doesn't exactly translate in to psychosocial interventions. It was

intentionally chosen over “yenigigir hikimina” which literally translated is “talk-therapy” but was felt to be difficult for people to comprehend.

It could be related to the strangeness of the concept. Because of low expectation they don’t report unmet need. Of course, it may be that they don’t have unmet needs… but maybe they have little information and awareness about treatments that could help them, because of low availability/exposure to them and years of just getting the minimum from services. This speculation is corroborated by the fact that one of the participants who had counseling before expects to get counseling about relational problems could indicate that having experienced some sort of counseling earlier will promote seeking counseling for psychosocial interventions.

There was a tendency among participants to be advised and be given what is deemed important by the clinician. This might be the paternalistic model of care. In addition it could be due to the ‘code of honor’ or viewing the clinician as an authority figure. (BenEzer 2006). This could be in sharp contrast to the western medical code of ethics which leans towards autonomy than beneficence.

2) Stigma of seeking psychosocial support

It could be speculated that people from lower income countries might get more social support complementary to or replacing the medical care. But the study clearly showed otherwise. The social support they get was limited to family members close in whom they can confide in. It is of note that the finding of low social support goes against the general assumption that social support may be better in “developing countries” because of the extended family and community networks (Fekadu A. 2014)

Stigma and discrimination seemed to impair the support seeking from close ones. Fear of stigma got in the way of disclosing illness to colleagues and employers. Thus it impairs taking the time off work to attend regular counseling. Participants expressed being considered inferior, being cognitively impaired and labeled as crazy and occasionally "ye Amanuel Ibid" [which means crazy from Amanuel (the only public mental specialized hospital).

Religious places and traditional healers which are thought to be common stations along the journey to seeking help, were not emphasized. This, again, could be due to the experiential benefits of treatment. Still religious people were consulted but more for spiritual matters than things related to the illness.

3) Unmet needs, priorities and preferences for psychosocial care

Some of the unmet needs expressed poverty, housing and employment are the unmet needs. These are important as social determinants of health. But the remediation might require higher policy-level changes than clinical. Regarding the attributes of a clinician sought by participants,most of them demanded that their physicians hear them out, encouraged to talk, offer them the opportunity to ask questions. These items are included in the Mental Health Service Satisfaction Scale for low income countries. (Mayston et al 2017). This is in line with what is supposedly done in a psychiatry follow up visit. But practically, it falls short of the ideal. Some of the reasons include, but not limited to, centralized psychiatric service in the country leading up to high burden in Amanuel Hospital and comparatively low number of professionals.

Some of the topics requested to be included in the 'counseling' are cause of illness, nature of illness, duration of treatment, drug side effects, use of substances like alcohol, khat. These

elements are included in the psycho educational interventions(Perry A et al 1993) but may not be applied uniformly in the routine setting of the out-patient clinic.

Limitation of the study

As the study was conducted on relatively a few numbers of patients, which may make the generalizability of findings difficult.

The participants may have been aware of my status as a psychiatry resident and been inhibited to express any views that they thought could be considered critical.

Recommendations

We recommend that active listening, offering opportunity to ask questions shall be part of the regular psychiatric care.

The changing of clinicians should be addressed.

Some of the psycho educational aspects could be incorporated in the as-is treatment.

Demand creation about counseling by actively seeking for psychosocial problems they face.

Working as a team and engaging psychologists in the treatment.

There should be awareness creation about mental illness to address stigma in the community.

Data Collection Form

Appendix I

ID

Age

Gender

Marital Status

Duration since diagnosis of the illness

Current medication

Number of episodes

Relationship with the interviewer

Appendix II

Topic guide for patients and their family

1. How helpful has the care been that you have received? In addition to medication, what other care do you think is important?
2. Did you have a chance to speak with someone about your condition, problems you are facing?
3. Have you ever received counseling during your treatment?
4. If yes,
    a. What were the elements of the counseling?
    b. What was the setting like?
    c. Who offered the counseling?
    d. How helpful was it for you?
    e. How could it have been improved?
    f. To what extent do the interventions meet your needs?
5. What additional care/support do you need?
6. What are some of the things you would like to get improved?
7. How important is it to you to be able to speak about your problems?
8. Who is the best person for you to talk to? Family? Friends? Someone from religious institution? A health worker?
9. What are the areas you would like to get counseling for?

Probe

    a. Getting back to normal functioning i.e. rehab
    b. Working out how to deal with problems?

c. Helping to cope with life's ups and downs

d. To help with relationships

e. To help to prevent getting unwell again etc.

10. Who would be the right person to deliver the interventions?
11. Would it be possible for you to come for regular counseling or psychosocial intervention? What length of session would be convenient? How frequently would you want to come?
12. Would you prefer talking treatment 1 to 1 or as part of a group? What are your reasons for this?
13. What are the challenges regarding
    a. Setting
    b. Interviewer
    c. Mode

Budget

Item	**Unit Price**	**Quantity**	**Total Price(ETB)**
Pen	5	4	20
Notepad	2	30	60
Printing	1.5	300	450
Photocopy	.5	300	150
Payment for nurses	50	10	500
Transcription	30	300	9000
Translation	40	300	12000
Contingency(10%			2218
Total			24398

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