

Community perceptions of barriers to management of chronic psychotic disorders and knowledge and attitudes about long-acting injectable antipsychotic medication: qualitative study in Dar es Salaam, Tanzania

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Background

Low- and middle-income countries (LMICs) experience a disproportionate burden from chronic psychotic disorders (CPDs), which are the most disabling conditions among people aged 10–24 in Sub-Saharan Africa. Poor medication adherence is seen in approximately half of individuals with CPDs in Sub-Saharan Africa, and is a major driver of relapse. A CPD treatment approach that combines the use of long-acting injectable (LAI) antipsychotic medications with a brief and practical customised adherence-enhancement behavioural intervention (CAE-L) was recently developed and tested for use in the USA.

Aims

To use a qualitative cross-sectional analysis to gather information on potentially modifiable barriers to management of CPDs, and assess attitudes about LAIs from community participants in Tanzania. Findings were intended to refine the CAE-L curriculum for use in Tanzania.

Method

In-depth interviews and focus groups were conducted with 44 participants (patients with CPD, caregivers, mental healthcare providers). All interviews and focus groups were audiotaped, translated, transcribed and analysed using content analysis, with an emphasis on dominant themes.

Results

Findings indicated that promoting medication adherence and management of CPDs in the Tanzanian setting needs to consider the individual with CPD, the family, the healthcare setting and the broader community context.

Conclusions

Qualitative findings enabled the study team to better understand the real-time barriers to medication adherence, LAI use and

management of CPDs more broadly. Refinement of the CAE-L is expected to pave the way for an intervention trial for individuals with CPDs that is culturally and linguistically appropriate to the Tanzanian setting.

Declaration of interest

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Keywords

Low and middle income countries; psychotic disorders; long acting injectable (LAI); stigma and discrimination; adherence.

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Background

Chronic psychotic disorders (CPDs), which include schizophrenia and schizoaffective disorder, cause symptoms such as hallucinations, delusions, disorganised thinking and reduced motivation, that result in impaired quality of life. CPDs are found globally, but low- and middle-income countries (LMICs) experience a disproportionate burden because of pervasive stigma, problems with access to care, and an insufficient healthcare workforce. CPDs have been found to be the most disabling condition among people aged 10–24 in Sub-Saharan Africa.^{1–4}

Treatment for CPD consists of psychosocial and pharmacological interventions, such as antipsychotic medications. Unfortunately, CPD relapse is quite common because of medication non-adherence, which results in hospital admissions, treatment resistance and cognitive impairment, caused by progressive

structural brain damage.^{4,5} Additionally, poor adherence inflicts a large economic burden, not only on patients, but on families and society in general.^{6–8} Poor adherence is seen in approximately half of individuals with CPD in Sub-Saharan Africa, and is a major driver of relapse.^{9–12} The limited number of studies carried out in Sub-Saharan Africa, suggest that comorbid depression, poor medication adherence and side-effects, were the factors most likely to increase CPD relapse.^{13,14}

Long-acting injectable antipsychotic medications and behavioural therapy

In order to address medication non-adherence, long-acting injectable (LAI) antipsychotic medications may be an option for some patients.¹⁵ LAIs can be given monthly, eliminating the need for

taking daily medications, which is often viewed as a stigmatising behaviour. Findings from a recent Swedish study of 29 823 patients with schizophrenia found that LAI antipsychotic medications were the pharmacological treatments with the highest rates of relapse prevention.¹⁶ LAIs have been shown to alleviate psychotic symptoms and reduce relapse in a small study in Tanzania.¹⁷ However, medication alone is unlikely to modify long-term attitudes and behaviours. Recently, a research team, from Case Western Reserve University in the USA, developed and tested a new treatment approach to CPDs that combines LAI medication with a brief and practical psychosocial intervention entitled customized adherence-enhancement behavioural intervention (CAE-L) for individuals with CPDs who were non-adherent to treatment and were homeless ($n = 60$). CAE-L is flexibly delivered as a series of up to four treatment modules based upon an individual's reasons for non-adherence (adherence barriers). In this study, use of CAE-L was associated with good adherence to maintenance LAIs (76% at 6 months) and dramatic improvement in concomitant orally prescribed medication, which changed from missing 46% of prescribed medication at study enrolment to only 10% of prescribed medication at study end. Most importantly, there were significant improvements in psychiatric symptoms and functional status.^{18–20}

Aims

In order to refine and test the CAE-L for a Sub-Saharan Africa population, we conducted a qualitative cross-sectional exploratory analysis to gather information on potentially modifiable barriers to the management of CPDs, and assess attitudes about CPD medication and use of LAIs from community participants in Dar es Salaam, Tanzania.

Organisation of health services in Tanzania

In primary and secondary levels of care in Tanzania, mental health services are provided free of charge; including both consultation fees and medication, although all clinical investigations are cost shared. Mental health services are delivered by mental health and general registered nurses, non-degree prescribers (clinical officers), medical doctors and, to a less extent, social workers. At tertiary levels of care, consultation fees are heavily subsidised and provided at no cost to clients. Services are delivered by psychiatrists, clinical psychologists, mental health and general registered nurses, psychiatry residents, medical doctors, occupational therapists and social workers; organised in mental healthcare teams that service clients from the four law enforcement catchments of the city. At this level, for patients covered by the National Health Insurance Fund, the costs of antipsychotic medications as listed in the National Formulary is included in the coverage. For individuals with no health insurance, a cost share has been introduced for antipsychotic and other psychotropic medications whereby, at a minimum, patients are required to pay at least 46% of the costs of medication or costs may be waived altogether. When patients seek a waiver of payments for drugs, the decision regarding the proportion of drug costs they will be charged is based on a professional social worker's assessment of the client's social support structures. The social work teams also work with clients and their family members, (who are their primary caregivers), to help strengthen family and community social support structures. This assessment may be done in collaboration with the client's ten-cell leader; the lowest level of government at community level. The ten-cell leader position is voluntary and people elected into office often belong to the political party overseeing welfare in a particular constituency. However, they do have roles related to conflict resolution and social protection of people inhabiting on average 50–100

households in their jurisdiction. Often, if the client is unemployed and has no relatives living in the city, cost-share payments for antipsychotic medications are waived.

Method

Setting and participants

Participants were recruited from The Department of Psychiatry and Mental Health at the Muhimbili National Hospital, a national referral hospital, with a 70-bed psychiatric ward, located in urban Dar es Salaam, Tanzania. This hospital is the only psychiatric national referral centre and serves a population of approximately 4.5 million. Patients are referred from four catchment zones that include three regional public and private hospitals. Follow-up clinics are also held at the district level in four facilities; most are stable back-referrals to clinics run by psychiatric nurses. Approximately 75% of patients are rural-dwelling individuals who live by agriculture/farming. Muhimbili has an estimated 1000 hospital admissions per year. A 2015 clinical audit found approximately 26.0% of patients had schizophrenia and the most commonly prescribed discharge medication was oral haloperidol (75% of patients). There were 16% treated with the LAI fluphenazine decanoate. Antipsychotic side-effects were managed with trihexyphenidyl (Artane).

In order to enhance the credibility and validity of our study findings, multiple types of informants/stakeholders involved with CPD care and treatment were recruited as participants.²¹ Patients were sampled by age and gender and clinical diagnoses (schizophrenia or schizoaffective disorder) made by their treating psychiatrist, had a history of medication non-adherence, and were involuntarily ($n = 12$) or voluntarily ($n = 3$) admitted to hospital at Muhimbili National Hospital following a relapse of their illness. All 15 patient participants were stable enough to provide informed written consent. In addition, 14 family members/caregivers to these individuals and 15 healthcare providers who had experience interacting with patients at this facility were recruited for the study. For qualitative research, this sample size of 44 participants is within the recommended number of 20–50 individuals for achieving theoretical saturation.^{22,23}

A sampling grid, designed to provide variability in gender and age, was used in the recruitment of these participants. Consistent with the focus on broad generalisability to CPDs in Sub-Saharan Africa, only individuals who were unable to provide informed consent were excluded. The qualitative study team, composed of both Tanzanian and US investigators, met regularly via video conferencing to develop and refine the interview guide and data-collection process. The study was approved by the institutional review boards of both Muhimbili University of Health and Allied Sciences in Dar es Salaam, Tanzania and University Hospitals of Cleveland in Cleveland, Ohio, USA. Additionally, all participants signed an informed consent form.

Study design

In this cross-sectional exploratory qualitative study, a thematic analytical approach was used to develop a deeper understanding of the issues surrounding barriers to management of CPDs. In this approach researchers move their analysis from a broad reading of the data towards discovering patterns and developing themes.²⁴

Qualitative data collection and analysis

The original English language semi-structured interview guides were revised with consideration for the cultural context by the study team composed of Tanzanian and US mental health

clinicians and researchers, and translated into the native language (Swahili). Both face-to-face interviews and focus groups, conducted by clinical experts in this native language, were used to collect narrative data. These data collection methods allow interviewees to express their opinions and ideas in their own words, and they are an appropriate strategy for learning the vocabulary and discovering the thinking pattern of the target audience, as well as for discovering unanticipated findings and exploring hidden meanings.^{22,25} The in-depth interviews were conducted with 15 in-patients with CPDs in a small private office at the hospital. Two separate focus groups, consisting of 14 family caregivers of the interviewed patients, and two separate focus groups consisting of 15 healthcare providers were conducted in a conference room at the same facility. All 44 participants were interviewed in Swahili, the local language. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to improve the comprehensiveness and credibility of the interviews and focus groups.²⁶

Participants' views on perceived barriers to management of CPDs, and knowledge and attitudes about the use of LAI medication for CPDs were explored in both interviews and focus groups. A semi-structured interview guide, adapted and translated from the CAE-L study, focused the discussion on these main topics and specific topic-related questions. For example, under the topic, 'barriers to managing your mental illness,' the following question was asked of the patient participants 'What kind of things might get in the way, or prevent you from managing/taking care of your mental illness?' For the family members, the same question was asked, but from their perspective: 'What kind of things might get in the way or prevent your relative from managing/taking care of his/her mental illness?' Additionally, the healthcare providers were asked to respond to the same question regarding their patients with CPDs.

Under the topic 'knowledge and attitudes about the use of LAI medication for CPD' all participants (patients, family members, healthcare providers) were queried about what they knew about LAIs, what they thought about the use of LAIs for CPDs, what their experiences were with taking it (patients) or prescribing it (healthcare providers) and, what they perceived as benefits versus negative consequences of LAIs. The guide also included examples of follow-up probes such as 'would you explain further,' 'please describe what you mean,' and 'would you give me an example'. At regular intervals during the interviews and focus groups, the interviewer focused on confirming and verifying with participants what was said and discussed (member checking). All interviews and focus groups were audiotaped, transcribed verbatim and translated into English by clinical experts on the Tanzanian side. All personal identifiers were removed from the final transcripts.

To ensure consistency and transparency of the coding, focus groups and interview transcripts were coded and analysed separately by both USA and Tanzanian (C.B. and I.L.) qualitative investigators; discrepancies were resolved by discussion. We used a grounded theory approach to data analysis, encompassing open, axial and sequential coding, and the constant comparative method to generate constructs (themes) and elaborate the relationship among them.²⁴ A separate coding dictionary, that included mutually exclusive code definitions, was then constructed for the interviews and focus groups. The coding structure for each was reviewed after a preliminary analysis of a subsample of transcripts, and each dictionary was refined through comparison, categorisation and discussion of each code's properties and dimensions.^{23,27} Integrating insights from a variety of sources and interpretations enabled the researchers to build a deeper picture of perceived barriers to management of CPD and facilitate validation through cross verification.²⁸

Results

Characteristics of the participants

Characteristics of the participants are presented in Table 1. Most of the patient respondents were in-patients about to be discharged from the psychiatric hospital. Gender was almost equally divided, and there was a wide variation in number of years of education and reported duration of their CPDs. Oral haloperidol was the most frequently prescribed medication (80%), with fewer prescriptions of chlorpromazine among the first-generation antipsychotic (FGA) medications. Among the second-generation antipsychotic (SGA) medications, most commonly prescribed were risperidone and olanzapine, whereas quetiapine was less frequently prescribed. However, taking few antipsychotic medications and having relapse-related admissions to hospital in the past year, were reported. Almost all the patients reported being employed in jobs that ranged from selling 'goods' on the street and driving lorries, to being in a profession such as teaching and nursing. However, having CPD very often interfered with their ability to work consistently.

Family caregivers were mostly married women with a wide range of education and years of caregiving for their relatives with CPDs. Most reported being employed, in addition to caring for their relatives; but more often than not, this employment was interrupted because of the patient's illness. The mean number of patient relapses in the past year reported by the family caregivers was much higher than those reported by their relatives with CPDs.

All healthcare providers (psychiatrists, psychiatric nurses, occupational therapists, and a clinical psychologist) had a wide range of years in practice (1–36 years) and served in both the in-patient and out-patient settings at Muhimbili National Hospital.

Barriers to management of CPD

As presented in Appendix 1, transcript-based analysis generated six major barriers to management of CPDs that emerged from discussions with 44 respondents consisting of patients, family caregivers (FCGs – in two groups FCG1 and FCG2), and healthcare providers (HCP – in two groups HCP1 and HCP2): (a) knowledge barriers, (b) medication barriers, (c) attitudes and belief barriers, (d) psychological barriers, (e) behavioral barriers and (f) lifestyle barriers.

Knowledge barriers

Diagnosis and causes. Although most of the patients couldn't specifically name their 'psychiatric' diagnosis, they knew they had a 'mental illness' caused by a variety of factors that included stress, hereditary, substance misuse, being unmarried, and witchcraft:

'Mental illness has a lot of things, there is stress, life problems, substance abuse, and there is one which has caused my mental illness, smoking cigarettes, I have been told to quit or to reduce. I was told cigarettes has a lot of Nicotine, so it stays in the blood and affects the blood leading to cause of this illness.' (Patient respondent 4)

'My patient says he has been bewitched. He doesn't think of any other cause. According to our law, there is no witchcraft, but I don't agree to it. For those who are bewitched, there are medicine men who can really treat them by using herbs.' (FCG2 respondent 2)

Medication barriers

Function of medications. Although most patients and their caregivers reported knowing how the prescribed psychiatric medications worked, healthcare providers felt otherwise:

Table 1 Characteristics of the participants (*n* = 44)

Variable	Patients (<i>n</i> = 15)	Family caregivers (<i>n</i> = 14)	Healthcare providers (<i>n</i> = 15)
Age, years: mean (s.d.) range	34.7 (6.38) 23–47	50.8 (14.1) 20–69	40.4 (8.8) 30–58
Marital status, <i>n</i> (%)			
Single	10 (67.0)	5 (36)	4 (27)
Married	5 (33.0)	9 (64)	11 (73)
Gender, <i>n</i> (%)			
Woman	8 (53)	10 (71)	10 (67)
Man	7 (47)	4 (29)	5 (33)
Education level, years: mean (s.d.) range	9.53 (3.73) 4–16	8.14 (3.11) 4–16	18.93 (2.4) 16–21
Employment, <i>n</i> (%)			
Employed	13 (87)	11 (79)	–
Unemployed	2 (13)	3 (21)	–
Provider occupation, <i>n</i> (%)			
Psychiatrist	–	–	8 (53)
Clinical psychologist	–	–	1 (7)
Psychiatric nurse	–	–	4 (27)
Occupational therapist	–	–	2 (13)
Diagnosis, <i>n</i> (%)			
Schizophrenia	10 (67)	–	–
Schizoaffective	5 (33)	–	–
Illness duration, years: mean (s.d.) range	14 (6) 2–25	–	–
Treatment status at interview, <i>n</i> (%)			
In-patient	12 (80)	–	–
Out-patient	3 (20)	–	–
Number of antipsychotic medications taken, mean (s.d.) range	1.5 (0.91) 1–4	–	–
Number of reported CPD relapses in past year, mean (s.d.) range	1.87 (0.91) 1–3	6.4 (2.8)	–
Years of caregiving to patient, mean (s.d.) range	–	10 (6) 2–25	–
Caregiver relationship to patient, <i>n</i> (%)			
Mother	–	8 (57)	–
Father	–	3 (21)	–
Siblings	–	3 (21)	–

CPD, chronic psychotic disorder.

'I may not know because I am not a pharmacist, but they stabilize my brain. I don't find myself ok if I am not on medication. When you are off medications, you will still hear the voices, see flashing lights, and fear impending death.' (Patient respondent 8)

'Most of the patients do not know how the medications help them. They have a low level of understanding such that they cannot know the mechanisms of action of the medications to the point of curing them.' (HCP1 respondent 4)

Perceived helpfulness of medications. As far as perceived helpfulness of the prescribed medications, responses ranged from helpful, sometimes helpful, and not at all helpful:

'It removes anger, and helps me to reach an agreement with others.' (Patient respondent 6)

'It is very helpful but they sometimes are not. This is because this problem does not go away despite taking the medications.' (Patient respondent 11)

'Most of the patients believe that the medications they use are helpful. Some believe that the medications do not cure them, and others refuse to take them completely because they think that they will make them impotent.' (HCP2 respondent 5)

Lack of educational materials. All three groups of respondents felt strongly that the lack of educational materials about CPDs was the largest barrier to improving knowledge about this chronic illness, not only for patients, but for family caregivers and the community at large:

'When I fell sick for the first time, there were people who suggested that I should be taken to the traditional healers and others suggested prayer services. This is because there were not informed with leaflets, otherwise they could identify it

earlier and get me to hospital. There should be topics about self-awareness, stress management, and causes of illness in the leaflets.' (Patient respondent 14)

'These leaflets should be provided such that the community around the patients would be able to read and understand. They should not only be read by the patient but also the community so that they may know as to what kind of support they can provide to the patients.' (FCG1 respondent 3)

Attitudes and belief barriers

Help-seeking behaviour and the choice of treatment are, for the most part, influenced by sociocultural attitudes and beliefs about mental illness. For instance, there were negative attitudes about taking psychiatric medications because they did not provide a 'cure' in a relatively short time:

'The majority of patients have negative attitudes, because they think that they can be cured after two weeks.' (HCP2 respondent 5)

Although religious beliefs were seen as helpful in the day-to-day lives of patients and families dealing with CPDs, they sometimes posed a barrier to medication adherence:

'When I stop taking my medications, it's because there is a special thing I am doing like praying. We normally have annual recollection at our church at the beginning of the year. We fast as well; therefore, I do not take medications in that time. I do not get headaches regularly – and I think the prayers that I make help me in that.' (Patient respondent 13)

Cultural beliefs of family caregivers were also perceived as interfering with the day-to-day management of the patient's mental illness.

'They [caregivers] can tell you that the patient should not do anything. Then you can tell them to involve the patient in washing his/her own clothes or get the food on his/her own from the dining. Then they tell you that the culture does not allow the man do so and he should have everything done for him.' (HCP1 respondent 1)

Psychological barriers

Stigma. Having a mental illness was associated with being 'different' and/or 'dangerous', and the stigma associated with these illnesses was perceived to be an important barrier to management of CPD and medication adherence:

'My patient is hiding that he takes medications because he doesn't want to be known to have mental illness. He says that the women will deny him a date.' (FCG1 respondent 7)
'I think the great obstacle can be stigma. That is, self-stigma or stigma from other people from the community. Therefore, these two can make the patient not wish to continue with treatment, or use of medications.' (HCP2 respondent 1)

Stress. In addition to the stigma attached to their mental illness, patients felt that external stressors such as poverty and unemployment, were also viewed as barriers to care:

'Stress affects me to a great extent and this affects the disease condition itself. I believe that my great problem is stress and it's because of stress I get all these problems. This means that I cannot do any progress when I am stressed. Therefore, if I do away with stress, I can be fine. I can even take medications and recover. Without doing away with stress, I cannot get better Even if I take the medications.' (Patient respondent 6)

Loss of self. The loss of self, or the sense that dreams and aspirations had vanished and could not be retrieved, was perceived by both patients and their family caregivers as a contributing to feelings of despair and being different:

'I had my dreams before and getting sick has made me different from my fellows. My fellows have been able to make a lot of progress. So, this illness affects me such that I cannot do some other things as my fellows do. You know I am 26 and as a young adult, there are things that I have to do and I can't and I feel abnormal about it. (Patient respondent 8)
'My son had the passion to become an artist since the beginning, and he went into despair as he was not able to make it.' (FCG1 respondent 4)

Depression. Depression was viewed as a major obstacle to medication adherence, seeking clinical care and triggering relapses:

'Sometimes depression can make me stop taking the medications. I might stay like that for 4 days without taking the medication. Then I may start experiencing symptoms of being overtalkative. Then I get back on my medications.' (Patient respondent 11)
'A depression triggers the illness episode and discouraged my patient from coming to the clinic.' (FCG1 respondent 1)

Fear of hospital admissions and addiction to medications. Fear of being admitted to hospital often influenced patients' decisions to seek treatment because of the severity of illnesses among the in-patients, and the stigma associated with psychiatric hospital admission.

'Yes, when the illness is severe, one can be *afraid* to come to the clinic because of the fear that he will be admitted. In the hospital, there is being cured and there is increasing the illnesses, because in the ward there are many people and the ones you are living with aren't good people because they are superstitious and might harm you.' (Patient respondent 4)

'Yes, some of the patients are afraid of being admitted. As we said earlier, they are stigmatized in the community, as people do not listen to them.' (HCP2 respondent 8)

And many patients feared being addicted to psychiatric medications:

'Yes, I have had fear like that (addiction). I continued to take the medication, but I still had the fear that maybe the body will get addicted to those medications.' (Patient respondent 12)

Behavioural barriers

Irrational and harmful behaviours. Patients and caregivers provided anecdotal evidence of how the symptoms associated with medication non-adherence disrupt lives, and often result in behaviours that are harmful to themselves and others:

'I am affected so much because, sometimes they find that I walk naked. Relatives, then capture and dress me. When they later tell me about it, it becomes shameful. I remember, for the whole period of 17 years being ill, I have walked naked three times.' (Patient respondent 7)
'The problem is serious because you cannot be close to the patient all the time. For instance, I am here now and the patient is in the street. She can do anything there in the street. It's no wonder to hear that she has beaten someone up. Then the police officers beat her up and detained her for 4 days.' (FCG1 respondent 6)

Medication non-adherence. Barriers to medication adherence included denial of illness and medication side-effects such as numbness, weight gain, weakness and tiredness, and loss of libido:

'These medications are making me gain weight and have increased my appetite. This is why I take breaks on medication such that I can stay for 3 months off medication so as to cut down weight. I do gain weight to 100 kg, and if I stay off medication for 2 months, the weight goes down to 65 kg.' (Patient respondent 7)
'They tell us several things, like being weak, losing ability to work, loss of libido. Some do experience body stiffening as the side effect of medications.' (HCP1 respondent 6)

For some patients, there was also the possibility that being seen taking medications might give others the impression that they were in the presence of someone who had a highly contagious disease:

'I don't like to take medication for my mental illness because a lot of people who see that I am using medication might think I am HIV infected, or I might be seen as a tuberculosis patient.' (Patient respondent 1)

Substance misuse. All three groups of respondents agreed that alcohol and substance misuse was a major barrier to medication adherence. There were some patients who completely stopped taking their medications when they drank alcohol or misused other substances:

'I had a lot of stresses, I was travelling long distances and I thought in trying them (substances) a bit, I can somehow be relieved. So, when I take alcohol, I was also stopping to take medications.' (Patient respondent 4)

And there were patients who took their hospital medications while misusing substances:

'Even now I can drink alcohol as well as taking the medications. But I drink local made alcohol, the one which is called "Mbege" (locally made alcohol using banana) which you drink but you

don't get drunk. Having the mental illness and drinking alcohol are most compatible.' (Patient respondent 15)

Use of traditional healers. The use of traditional healers to cure mental illness was very prevalent among patients and families. Some patients were told to stop taking their hospital medications while they were under the care of the traditional healer:

'My sister lied to my father that she is taking me to the pastor, but she took me to the traditional healer instead. He told me I was possessed by the demons that bring death and exposed me to smoked medicine and gave me some liquid medicine to take. It did not help me completely, but I stopped taking the hospital medications for about 3 months.' (Patient respondent 11)

'It affects them (the patients) because the majority stop taking the hospital medications when they are started on the herbs. Therefore, you find that the patient is not getting better and is experiencing relapse.' (HCP1 respondent 3)

Other patients combined both traditional and Western medications:

'I have my traditional healer and I do combine both services. I was trying to seek for services from both alternatives. He (healer) gave the medicines to burn and produce smoke. I went on taking the medications (for my mental illness) and coming to the clinic as usual.' (Patient respondent 3)

Lifestyle barriers

Lack of support. All respondents noted the lack of support from family, friends and the community at large:

'It is lack of support. My brothers don't understand. They don't care for other people and wish to see me dead.' (Patient respondent 9)

Healthcare providers noted that it was often the relatives, themselves, who mislead the patients about management of their illness:

'From my experience, I have seen patients who are motivated to take the medications, and who knows that the medications are helpful to them. The problem is that their relatives tell them that they are not psychiatric patients, but that they are bewitched. The relatives are the ones who tell them to stop taking medications whenever we start them on medications. They then take the patients to the traditional healers, so the support figures have influence over the patients.' (HCP1 respondent 2)

Access barriers to medications. As a result of financial constraints, limited availability of medications and lack of transportation to dispensing sites, which are often located far from their homes, the ability to access psychiatric medications proved to be a significant barrier for patients and their families:

Financial constraints. Poverty was a major issue for patients and their family caregivers, and often the choice had to be made between buying medications and putting food on the table:

'Some complain that they experience problems as regards to getting food at home. Therefore, they say that they stop taking the medications because they do not have enough money for food.' (HCP1 respondent 7)

'Considering that the illness has no cure, if one is to take care of oneself all the time, it will be very hard, because lack of money to buy the medication. It's the most important issue.' (Patient respondent 6)

Transportation and limited availability of medications. In addition to lacking money for medications, many patients who lived in rural areas faced the challenge of getting to the dispensing sites. In some

instances, those who were able to make the journey, found out that the medications were unavailable:

'The other challenge is availability of these medications. You find that most of the medications are available here at Muhimbili or at the larger pharmacies. So, for the patient who come far away from town, she/he may not get these medications from the local pharmacies.' (HCP1 respondent 4)

Market forces, and the belief among many that mental illness was not treatable, also seemed to play a part in contributing to the availability of certain medications:

'The challenge with these medications is that the drug sellers focus on the latest brand available. If it happens that the users are upcountry and they use a certain medication less frequently, it will not be mostly available in the market. However, if people know that mental illness can be treated by medications and make use of them, the drug sellers will make these medications available. Contrary to that, some medications will not be available because, the sellers focus on business. Unavailability of medications is not because the sellers do not want to sell them, but people do not buy and use these medications, and do not believe that mental illness is treatable by using medications. As we said, majority of people go to the traditional healers for alternative treatment.' (HCP2 respondent 5)

Access barriers to clinical care. Many of the same barriers to accessing medications applied to accessing clinical care: financial constraints, transportation, and availability of services:

'Moreover, as I said earlier, these services (psychiatric) are no longer available at no cost as before. The patients have to pay for them. Therefore, one requires bus fare and money to pay for her/his treatment. Those patients who come from far have to incur costs for their meals and accommodation.' (HCP2 respondent 5)

'Services are not available everywhere, it is only here and at Mwananyamala. Because in case of my illness, I have to go to Mwananyamala to get a certain unknown form, and then come here and you find that you have to wait for a doctor for a long time. Therefore, it is a waste of time. The doctors are not available all the time.' (Patient respondent 13)

Bureaucratic red tape. In addition to financial constraints, transportation issues and limited access to care, there was an inordinate amount of bureaucratic red tape that made it even more difficult to access clinical care:

'The other issue is, the regulation that we have may be difficult to the patients as regards coming to the clinic. The nature of our patients is that one may stay at home and come to the clinics when all his/her medications are over. Then when s/he comes to the clinic, we tend to abide to our rules that s/he should not get the services because it is not his/her clinic appointment day. We do turn them away several times and one may decide to go without medications until it is his/her turn.' (HCP1 respondent 1)

Lastly, there was the ever-present stigma about mental illness that prevented patients from seeking clinical care, and for physicians to choose medical specialties other than psychiatry:

'The other issue is about the environment where one finds it stigmatizing to attend the psychiatric clinic. Most of the patients tend to ask for an appointment outside the hospital setting as you give them the first appointment. The patients would wish to be attended in the environments that people cannot see them as psychiatric patients. The majority wish to go for follow-up clinics at other private facilities, though, there are few such clinics.' (HCP1 respondent 1)

'The doctors who specialize in mental illness are stigmatized and if one were to specialize, the majority would not wish to specialize in psychiatry.' (HCP2 respondent 6)

Summary of findings on perceived barriers to management of CPDs

Participants in this study cited a paucity of community-wide CPD education, negative attitudes, and cultural and religious beliefs about mental illness as significant barriers to care. Psychological issues such as stress and stigma, as well as medication non-adherence, substance misuse and the use of traditional healers, were also described as contributing to the problem of management of CPDs. Additionally, access barriers to obtaining medications and clinical care, as well as a paucity of family and community support, were also seen as major barriers to psychiatric care.

Knowledge and attitudes about LAI

Finally, the participants in this study were very vocal about LAI antipsychotic medications. As can be seen from Appendix 2, participants were familiar with LAIs, with most patients having heard about them, as well as having had the experience of receiving them. The prevailing attitudes towards LAIs was that it reduced stigma, was convenient, increased adherence and brought 'mental stability'. All participants had questions and concerns about LAIs regarding their side-effects, as well their availability and affordability. Additionally, healthcare providers questioned appropriate space and privacy for giving the injections.

Discussion

Main findings

In this well-characterised sample of participants in an urban/suburban Tanzanian population, qualitative analysis identified a number of barriers to management of CPDs that spanned individual, family/community, and healthcare provider/ healthcare system domains, and are consistent with McLeroy's²⁵ social ecological model of health behaviour. This model posits that behaviour, actions and events, are influenced by individual, interpersonal, organisational, community and policy factors.

Use of FGAs versus SGAs

Our findings that SGA prescriptions were so rare despite being off patent, may be because the cost of SGAs compared with FGAs is comparatively higher, deterring availability, especially in a large tertiary care service. Clinical recommendations in this setting are to use SGAs only when patients' symptoms are non-responsive, or when adverse effects develop with FGAs. It is important to note since the launch of the National Mental Health Programme in the 1980s, the study facility sees, each year, an increasing number of persons with mental health disorders – most with CPDs. Across the four catchments, once-weekly out-patient follow-up clinics see an average of 240 patients per week (60 patients a day, 4 days in a week) and approximately 600 people that have substance use disorders who receive opioid substitution therapy daily (7 days a week).

Refining CAE-L for the Tanzanian setting

Information obtained in this qualitative study have important implications for informing and refining the CAE-L curriculum for a Sub-Saharan Africa population. Our findings indicate that promoting adherence in the Tanzanian setting needs to consider the individual with CPD, their family, their healthcare setting and the

broader community context. All of these individuals are stakeholders in an effective model of care. Accordingly, we have refined the original CAE protocol to include approaches that are most relevant to them, and which address the six key barriers to care: (a) knowledge barriers, (b) medication barriers, (c) attitudes and belief barriers, (d) psychological barriers, (e) behavioral barriers and (f) lifestyle barriers.

The finding that stigma was a major barrier to care is consistent with prior research that suggests that stigma may impede people from seeking, or fully participating in mental health services.²⁹ In order to challenge attitudes and beliefs about CPDs, CAE promotes education on these conditions and addresses the importance of CPD medication on CPD recovery. It also addresses lifestyle issues, such as the use of substances and regular medication-taking. An important finding that our qualitative data revealed is that educational, attitudinal, psychological and behavioural barriers cited by patient caregivers were found to mirror those of the patients themselves. Whereas the US version of the CAE intervention was targeted only to patients with CPD, an important modification to CAE in this setting was encouraging family members to participate in the CAE educational sessions. This approach would address the importance of family support and the often-limited access to more formal healthcare supports that may be more available in high resource settings.

Information on how traditional healing approaches and the mainstream medical model of care can coexist needs to be considered in this setting. Our qualitative findings revealed that most of the patients with CPD, and their families, often used both traditional healers as well as mainstream medical psychiatric providers. This finding is consistent with a recent review of 40 studies on schizophrenia from eight countries in Sub-Saharan Africa, which found that most people with CPD were treated by mainstream medical psychiatry and faith/traditional healers.³⁰ Although CAE is mostly a patient self-management approach and does not specifically focus at the provider level, there were some modifications made to the CAE curriculum that concerned providers. First, we included content on working with traditional healers, so as to minimise an adversarial stance, as well as with providers that are embedded in many Tanzanian communities. The overall message that was communicated was that CPD medication is a foundational need, but that individuals might use supplemental approaches to managing stress/wellness. The content also encouraged patients and families to inform all providers (both traditional healers and medical-model clinicians) about all treatment modalities being used. Given the lack of access to nurses or prescribing clinicians in many settings, another modification to the curriculum is the use of social workers to deliver the CAE behavioural modules.

Given our findings of the limited access to clinics and the difficulty in obtaining oral antipsychotic medication, the approach of combining LAI antipsychotics with a behavioural intervention that has the potential to facilitate engagement in care and patient motivation, might prove useful in this setting. Medications can be given monthly, or even less often for some formulations of antipsychotic drugs. If CAE-L is feasible and acceptable, there is a high potential to adapt the intervention package and trial it at mental health clinics in primary and secondary levels of care that already have experience with use of LAI fluphenazine decanoate, often initiated late in illness after poor adherence has set in. Adaptation and evaluation of evidence-based mental health intervention packages at primary and secondary levels of care is important for improved treatment outcomes. We hence view this study as having the potential to augment wider strategies aimed at increasing access to less costly anti-psychotic medications and decisions regarding what mental healthcare packages can be successfully

integrated in primary allopathic care; as well as components that would have relevance for practitioners of traditional forms of care.

Limitations

Our findings on perceived barriers to management of CPD in Dar Es Salaam have implications for informing care, however, there are some limitations. Although focus groups and individual interviews were conducted in Swahili, back translation was not performed. Our results that 87% of the patients were employed may be misleading in that the information is based on self-report, and the question may have been misinterpreted by the participants.

In addition, patients with CPD, their caregivers and mental health providers, who receive or provide care in other settings in Tanzania, may have different experiences on issues related to managing these illnesses. The small convenience sample and the conduct of the study in a single area in Tanzania may limit transferability of the study findings. However, these limitations are offset, to some extent, by the use of rigorous qualitative methods described in the study. These self-report methods are direct, versatile and yield information that would be difficult, if not impossible, to gather by other means. Qualitative enquiry is an appropriate framework for learning how patients conceptualise their experience of disease, and qualitative research techniques have become an integral component to developing health promotion interventions in special populations.³¹

Implications

Integrating qualitative research into the development of the CAE-L intervention allowed the study team to better understand the real-time barriers to medication adherence and management of CPDs from the perspectives of patients, family caregivers and healthcare providers. Importantly, this information will enable modifications to the intervention protocol, and will pave the way for carrying

out a large-scale intervention trial for CPD that is culturally and linguistically appropriate to the Tanzanian setting.

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Data availability

The authors have access to the study data as part of a larger, ongoing US National Institute of Mental Health-funded study. Access continues ongoing. As the larger study is still ongoing, data is not available to the larger scientific community. Once the study is complete and all results are published, interested scientists/researchers may contact the study authors to request data access as appropriate and in compliance with data-use agreements between academic institutions and regulatory entities.

Author contributions

M.S., S.K., J.M., C.B., J.B.L. and I.L. all contributed to either the initial design or refinement of the project design. All authors have approved the manuscript and the report is a reflection of team consensus.

Appendix 1

Table A1 Community perceptions of barriers to management of chronic psychotic disorders in Dar es Salaam, Tanzania (n = 44)

Themes and categories	Illustrative quotations from respondents
Knowledge barriers: causes/diagnosis; medications; and lack of educational materials	'We are speaking that the mental illness comes as a result of marriage issues. If you are not married, this illness can take hold of you. This illness will not knock on your doorstep if you are married.' (Patient respondent 15)
Medication barriers	'My patient knows about the medications but he doesn't believe that they can help him. He has already got into despair. He has used the medications for a long time without significant improvements and he has not achieved what he expected. I think these medications are just bringing short term relief. He is just taking the medications but the disease will still be there.' (FCG1 respondent 6) 'The level of awareness about mental illness in our community, it is still very low. Therefore, we find that we have a need to focus on provision of sustainable mental illness education. This is why some other patients and family delay to come for treatment and will go for traditional treatment.' (HCP2 respondent 4)
Attitude and belief barriers	'You know there are some families that have deep religious beliefs, such that they believe that the patient is to be prayed for, and not to use the medications. Therefore, you find that someone is in prayer services all the time and does not attend the clinics or take the medications.' (HCP1 respondent 2) 'Despite the side effects that make the patients not wish to take the medications for a long time, there are false beliefs around the community that, if you start using the medications, you would never stop them because they have an addictive effect. Therefore, such a belief makes some people avoid taking hospital-based medications.' (HCP2 respondent 6)

(Continued)

Table A1 (Continued)	
Themes and categories	Illustrative quotations from respondents
Psychological barriers: stigma; stress; loss of self; depression; fear of hospital; admission; and fear of addiction to medications	'I don't like them [people at work] to stigmatize me at the workplace. I don't like them to know about it [mental illness] otherwise they would find a way to make me feel inferior. You know, being called crazy, hurts in the heart.' (Patient respondent 10) 'I feel that I am now wasting time. My classmates have made a step forward. I am now 42 years old but I do not have my own home and live a difficult life with my relatives who just want me to go and pick empty cans in the street.' (Patient respondent 11)
Behavioural barriers: irrational/harmful behaviour; medication non-adherence; substance misuse; and use of traditional healers	'There are complications. For instance, you can beat someone to death, or become bad tempered. I have beaten a young man recently and some people said that it was part of this illness. I beat him and kicked him as well.' (Patient respondent 14) 'I feel that I am no longer sick, why would I have to take these medications, so when I return home from the hospital I usually stop taking the medication, that's why this disease keeps recurring.' (Patient respondent 3) 'It is true that if one is on medication and takes alcohol, she/he can forget to take the medications. Most of the patients who take alcohol have this character.' (HCP2 respondent 3) 'Among the patients we admit in our wards, it may be only one among ten patients that may not have been to the traditional healers. (HCP1 respondent 5)
Lifestyle barriers: lack of family and community support; access barriers to medications; and access barriers to clinical care	'The community does not support them. People scorn and despise the patients with mental illness. There are people laughing at them and treating them with contempt.' (FCG1 respondent 6) 'The medications are helpful to them, but there are times when you don't have money and these medications are expensive. Therefore, you can sometimes have to get off medications while trying to get money to buy him medications. At this time, it happens that his condition gets worse.' (FCG2 respondent 7) 'Some fail to come to the clinics because of stigma. Therefore, if the patient finds that there are negative comments about attending the clinics, she/he feels like there is no need to attend the clinics.' (HCP2 respondent 3)
FCG1/FCG2, caregiver respondent; HCP1/HCP2, healthcare provider respondent.	

Appendix 2

Table A2 Knowledge and attitudes about long-acting injectable (LAI) antipsychotic medications in Dar es Salaam, Tanzania (n = 44)	
Themes and categories	Illustrative quotations from respondents
Knowledge of LAIs	Yes, my friends told me that there is an injection which can be taken every 3 months. I have been wishing to have the injection instead of pills. The injections is done only once and you are good.' (Patient respondent 7)
Prior use of LAIs	'I was getting the injection once a month and I was taking the pills also. The provider said that they are all my treatments for my illness. The injections have stopped because they realized I was doing well.' (Patient respondent 2)
Attitudes about LAIs	
Reduces stigma	'The injections would be good because they are long lasting, but with pills everyone would know that you are taking medication.' (Patient respondent 1)
Convenient	'I think the injection to be the best option because I can be sure that my patient has got treatment. There is no way he can avoid it and it lasts a month.' (FCG1 respondent 4)
Improves adherence	'Most of the patients prefer the injection because it is provided once a month. The relatives also prefer it because it does not need close supervision. The third thing is that it produces good outcomes. The relapse rate is low, such that the patient can stay for some years before experiencing relapse.' (HCP1 respondent 7)
Questions/concerns about LAIs	
Risks and side-effects	'Is there anyone who got side effects from the injections and was brought back and admitted because he/she didn't recover well?' (Patient respondent 7) 'Injections cannot be the first priority if I have other alternatives. There are patients who can get abscesses at the injection site. There are children who have disabilities because of injections.' (HCP1 respondent 1)
Will it cure patient?	'Does this injection make one recover from mental illness? I have heard that the pills they take just relieve the symptoms but not the disease. That is why our patients get disappointed.' (FCG2 respondent 2)
Affordability/availability	'Another question is shall it be free or will we have to pay for it?' (Patient respondent 14) 'Availability of the injections at the hospital is an issue as well.' (HCP2 respondent 4)
Respondents' preferences	
LAIs	'I would like the injection because you only get it once a month. The good thing sells itself but the bad thing walks its way to be bought.' (Swahili proverb). (Patient respondent 15) 'My patient would wish to be switched to the injections because he feels that the pills do not help him.' (FCG1 respondent 6)
Pills	'Most of the patients do not want the injections. It is not a priority to us doctors, also. If the medication has side effects they will manifest easily with injections as it goes directly into the blood stream. We need to provide the pills and if it happens that the patient does not respond, we can provide the injections. We normally aim at avoiding the use of injections if possible. So, it is not our first choice.' (HCP1 respondent 1)
FCG1/FCG2, caregiver respondent; HCP1/HCP2, healthcare provider respondent.	

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