


RESEARCH ARTICLE

Support and unmet needs of patients undergoing multidrug-resistant tuberculosis (MDR-TB) treatment in southern Nigeria

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Summary

Multidrug-resistant tuberculosis (MDR-TB) is presently a major public health threat. MDR-TB patients face diverse financial and psychosocial difficulties. Researchers conducted in-depth interviews based on interview guides with 42 participants. Data were analyzed using categorization, coding, generation of themes, and thematic memo writing. The key findings were as follows: Out of the 42 patients, 30 (71.4%) were males and 12 (28.6%) were females. All patients received financial stipends for transport and monthly social support. The patients however needed more financial support than they received (suggesting high unmet financial needs). Patients suffered depressive mood before and during treatment but received inadequate mental health/psychosocial care and treatment. Patients developed hearing impairment as a major adverse drug reaction, but the care and treatment they received were inadequate. In conclusion, the programmatic support provided for MDR-TB patients' financial and mental health/psychosocial needs and auditory drug side effects fell short of their need. Programmes for control of MDR-TB should increase budgetary allocations and ramp up mechanisms for provision of

mental health/psychosocial support and care/treatment for drug side effects.

KEYWORDS

financial incentives, multidrug-resistant tuberculosis, psychosocial support, social protection, unmet needs

1 | INTRODUCTION

Multidrug-resistant tuberculosis (MDR-TB) is presently a major public health threat, worldwide.¹⁻³ Generation and transmission of MDR-TB are on the rise because of a number of factors, which include poorly treated drug-susceptible TB, weak health systems especially poor management of supply and quality of anti-TB drugs, airborne transmission in public places,⁴ and poverty-related conditions such as slum dwelling, overcrowded conditions, and poorly ventilated housing especially in areas with high prevalence of MDR-TB.

The World Health Organization (WHO) estimated that 480 000 MDR-TB cases occurred in 2014, but only about 123 000 cases were reported to the organization.⁵ In the same year (2014), WHO estimated that 3.3% of new TB cases and 20% of previously treated TB cases were MDR-TB cases, while 190 000 died from the disease.⁵ Globally in 2016, estimated 248 000 people died from drug-resistant tuberculosis.⁶

Nigeria has a very high burden of TB and, in 2017, notified a total of 104 904 cases, with an estimated 5400 MDR-TB/rifampicin-resistant tuberculosis cases.⁷ With the factors that fuel MDR-TB generation and transmission rife in the country, the burden of MDR-TB is high and rising.⁸ The report of the National Drug Resistant TB Survey conducted in 2012 indicated that the prevalence of MDR-TB in Nigeria was higher than the WHO estimates. Resistance to Isoniazid (INH) was 9.6%, while resistance to Rifampicin was 7.9%.⁹ Other studies have also confirmed the high burden of MDR-TB in the country.⁸ In 2014, Nigeria notified 798 MDR-TB cases but put only 423 cases on MDR-TB treatment.⁵ While the burden is high and on the increase, the capacity for programmatic management is lagging behind as evidenced by only 423 cases being put on treatment in 2014.⁵

The management of MDR-TB is not only clinically challenging but also financially and economically demanding to the health system. The economic resources required to manage a case of MDR-TB is 300 times more than that required for the management of drug-susceptible TB, and the drugs are not only very expensive but also potentially toxic.⁹

The experience and management of MDR-TB are also very challenging to the individual patients and their households. It rapidly depletes the economic and financial resources of patients and their households.⁹

The economic and financial impact is often more devastating for the poor, who are paradoxically more prone to the disease.^{10,11} Worse still, the poor do not usually seek care for TB treatment on time because of social and economic factors.^{3,12-15} When they do seek care, it is often at inappropriate care providers, and by the time they eventually reach TB treatment centres, their financial and economic resources have been severely depleted,¹⁶ a pattern generally observed in care seeking for various chronic health conditions in developing countries.

Additionally, MDR-TB patients, besides facing these economic difficulties, also contend with prolonged period of treatment, adverse effects of the potentially toxic drugs,⁹ loss of jobs, discrimination, stigmatization and economic stagnation as they are often too weak to continue running own income-generating activities. Thus, they experience harrowing economic, financial, and psychosocial difficulties, which they apparently may not be able to handle alone. The WHO End TB Strategy includes minimization of catastrophic costs faced by TB-affected families by 2020.¹⁶ A core component of the strategy is that all TB patients should receive social protection, poverty alleviation, and actions on other determinants of tuberculosis.¹⁶ Thus, programmatic social protection strategies aimed at cushioning

the socio-economic challenges for MDR-TB patients have been introduced in some contexts, including Nigeria. But from patients' own perspective, evidence clarifying what their needs are and to what extent such support achieved its objectives is crucial but lacking. Moreover, it remains unclear how MDR-TB patients perceived the support given.

To our knowledge, there is dearth of evidence on the experiences and perception of support and unmet needs of patients undergoing MDR-TB treatment. Such evidence is necessary to guide programme development and/or modification concerning provision of social protection interventions that will enable MDR-TB patients to go through the treatment and serve as safety net for them during and immediately after treatment.

2 | MATERIALS AND METHODS

2.1 | Study design

This was a qualitative research conducted among patients undergoing MDR-TB treatment in southern Nigeria.

2.2 | Study setting/population

The researchers sought to cover the three geo-political zones in southern Nigeria, namely, south-east, south-south, and south-west zones. Each zone is made of six states except for south-east that has five states. In each zone, purposive sampling was used to select one state, and the states were Ebonyi State (south-east), Cross River State (south-south), and Ogun State (southwest). The main factor that determined the state that was selected is the availability of MDR-TB patients receiving treatment in the community. Thus, patients were drawn from the three states, with each state contributing 14 patients.

Given that the patients were of diverse socio-demographic and economic backgrounds, the researchers used purposive sampling frame in order to capture most of the socio-demographic and economic backgrounds. The variables inputted in the sampling frame included age, sex/gender, primary occupation, educational level, residence (rural, semi-urban, urban dwellers), and phase of MDR-TB treatment (intensive phase versus continuation phase). A total of 42 patients were selected such that these key variables were included in their characteristics. To reduce costs of the investigation, data were collected during routine TB control programme supervision visits.

2.3 | Study instrument

The key instrument in the study was an in-depth interview (IDI) guide. The IDI guide had sections A to D. Section A had items on socio-demographic characteristics. Section B had items on financial support versus needs. Section C contained items on psychosocial support versus needs, while Section D contained items on clinical support versus needs. Interview guide items contained mainly open-ended questions, some with riders for further probing of the issues under investigation. There were also a few semi-structured questions.

2.4 | Validation of research instrument

We assessed whether the research instrument (interview guide) would collect the data it was meant to collect by first asking three tuberculosis control programme (including MDR-TB) experts among the researchers to critically examine the contents of the instrument. The experts reviewed it and made suggestions, which were used to revise the interview guide. Then this first version of the interview guide was pretested by using it to conduct interviews with five MDR-TB patients in Enugu State, which is a state in south-eastern Nigeria but not one of the study states. Experiences and findings from the pretest were used to revise the draft and develop the final version of the guide.

2.5 | Interview process (data collection)

The researchers carried out the interviews, and each interview lasted approximately 45 minutes. Interviews were conducted in English Language or native vernacular in a few instances where the patients did not understand English Language. In such instances, a translator was used, but patient's responses were written by the interviewer in English Language. Written responses were read and translated back to the patients in their own language to ensure that understandings and meanings of their responses were not lost in translation. Data collection (the interviews) took place between March and September 2015.

2.6 | Data analysis

Manual qualitative data analysis was carried by members of our team who are versed in qualitative data analysis. Each data analyst had a set of indigenous categories that had been deductively generated a priori from literature review (including Programmatic Management of Drug-resistant TB [PMDT] programme documents). Analysts read the transcripts again and again, extracting key information from the transcripts in line with the categories. Besides the indigenous categories, analysts identified additional categories that emerged in the course of going through the transcripts (emergent categories). The decision to allow identification and inclusion of emergent categories (as opposed to using only indigenous categories) was to capture the *emic* perspectives. It has been argued that capturing *emic* perspectives at the early stage of data analysis by identification and inclusion of emergent categories helps enrich data analysis results, as it helps to capture vital information that might otherwise have been missed. With the categories in place, analysts coded the data based on them (categories).^{17,18}

Furthermore, analysts went through the transcripts again, reviewing them for emergent themes. This was followed by development of conceptual themes from these initial themes. Analytic memos were written on the conceptual themes. Direct quotes were included in appropriate thematic areas of the memos to depict the perspectives of the participants in their own words.

The first four transcripts analyzed by the data analysts were exchanged and reanalyzed by other analysts. This was to check for interresearcher discrepancy in analysis. No significant differences were observed. The minor difference observed was the coding of provision of transport fare within the category of unmet need instead of financial support. Two more times in the course of the data analysis, researchers (analysts) randomly exchanged their transcripts in order to assess interresearcher discrepancies, but none was detected.

3 | ETHICAL CONSIDERATIONS

The study adhered to the general international requirements of research governance and ethics, and ethical approval was obtained from the institutional review boards of GLRA.

Patients were told the objectives of the study and duly informed of their right to participate or not participate. They were made to understand that their refusal to participate had absolutely no repercussions. There were also informed that they could withdraw from the study at any time, without fear of victimization. On the other hand, they were informed that participating carried no financial rewards.

Besides explaining their rights as research patients including the right to withdraw or refusal of participation, patients were informed that their responses would be kept confidential, anonymous, and not traceable to them. They were also assured of the confidentiality of their identity. To this end, the identity of the patients has been replaced with codes, and their responses anonymized in the results and subsequent sections. Only patients who gave informed consent took part in the study.

4 | RESULTS

4.1 | Socio-demographic and clinical characteristics

Of the 42 patients, 30 (71.4%) were males and 12 (28.6%) were females. The mean age (standard deviation [SD]) of the patients was 39.8 years (SD: 11.0). The majority of the participants were artisans and traders. Ten (23.8%) of the patients were HIV positive. The socio-demographic and clinical profiles of the patients are presented in Table 1.

4.2 | Financial support and unmet financial needs

All the patients stated that they received financial stipends. They explained that they were fully informed by the State TB and Leprosy Control Officer, the MDR-TB Focal Person, and/or the Medical Officer directly managing their condition that they would be receiving financial support. They were entitled to N500 (2.5USD) daily transport fare and N5000 (25USD) monthly social support.

They were probed further about the financial support. Here are some of their responses:

I need the money. I don't get money from any other source since this sickness came upon me. It is my only income. (NB, 32 years, female, widow)

The allowance is very, very helpful. I just can't wait to receive it each month because it solves crucial problems for me. (MU, 51 years, male)

I receive my allowance every month, and that's okay for me. I use it as it comes, and so I have to get it just as one month is finishing. My business collapsed because of this sickness, and so we depend on this. (PA, 42 years, male)

TABLE 1 Distribution of participants by sociodemographic and clinical characteristics

	n	%
Total	42	100
Gender		
Male	30	71.4
Female	12	28.6
Mean age [SD]	39.8	[11.0]
Primary occupation		
Farmers	4	9.5
Artisans	18	42.9
Traders	8	19
Civil servant	6	14.3
Unemployed	4	9.5
Student	2	4.8
HIV status		
HIV positive	10	23.8
HIV negative	32	76.2

SD = Standard deviation; HIV = Human immunodeficiency virus

The people that sent us this money, they really know we need it. That is why they send us every month. In fact, my own finishes before the month end but I know I will get at the end of the month. It gives me a lot of hope. It reduces much suffering for me. (UE, 33 years, male)

The researchers sought to find out how the patients used their stipends. The patients' responses indicated that they utilized the money to handle four major financial issues, namely, transportation, feeding, children's school fees, and resuscitation of failing small-scale business/petty trade.

All patients mentioned using part of the money for transportation. They had to pay for transportation to and from the health care facilities where they received their medicine. This was particularly important for the patients who were in the first phase of their treatment. In such cases, they needed to move from their residence to the health care facilities where they received their daily treatment. Expectedly, these were ambulant cases and not those with severe illness, as the latter would not be managed in the community. Patients who lived closer to the health care facilities or had a community health worker giving them treatment considered themselves fortunate as they spent less on transport fares.

I come here [Health Centre where the interview took place] everyday to take my injection and tablets. I was discharged after spending three months in the hospital [an MDR-TB treatment centre] and told I would complete the treatment at home. So, the money has been very, very useful in paying my transport. (NH, 46 years, male)

I take *okada* [commercial motorcycle transport] from my community to come here. This is the nearest health centre to me. I have been doing so for four months now. You can agree with me that the money they give us is so useful. (BK, 50 years, female)

"Where could I have got money to pay my transport to go for my daily injections?" queried a 58-year-old man. He said he spent the first 3 months of his treatment as an inpatient and was thereafter sent home to continue receiving treatment in the community. As far as he was concerned, the programme was doing a lot for the patients by giving them stipends.

A 32-year-old woman captured the utility of the stipend for feeding thus,

This one na God send. Na this money wey I dey carry buy food for myself and little children. Since my husband left, things hard so much for us. Then I come become sick, and I no dey fit do my trading again. (NB, 32 years, female, widow)

The pidgin English translates thus,

This stipend is God's gift to us. It's with this money I feed myself and my little children. Life became very difficult when my husband died, and even worse when I became sick with this disease and could not continue with my trading.

The woman had lost her husband to HIV/AIDS and was sick herself. With three young children, aged 6, 8, and 10 years, and no source of income as a result of her inability to carry on with her petty trading, she found the stipend as a source for her household's feeding. She lives in an urban slum, a bit close to the health facility where she received treatment.

Only five patients volunteered information that they used part of the stipends to pay for school fees for the young children. According to a 41-year-old man, he had just returned from the hospital admission, and the money

was useful as he took part of it and his wife made it up from her little savings, and they paid school fees for two of their children.

I came back from admission and my children's second term school fees were due. I had no money since I am no longer going to my workshop. But my wife had been making serious efforts in her hairdressing business. So, she made up the little money I saved from the stipend and we paid our children's school fees. It was just January, and she had made some money plaiting women's hair during Christmas. (TO, 41 years, male)

Remarkably, a woman had stringently saved her stipends and made use of it to resuscitate her petty trading. She excitedly showed the interviewer her wares she displayed in her front yard. She said she was fortunate her house was close to the health centre where she received her treatment, and so she could walk. She saved her stipends and was able to start up her microbusiness again. In her words [Pidgin English],

Oga, I don save small oo because I dey collect it for one month at a time. My house e no too far from the clinic where I dey take my medicines, so as I begin well small small, I begin dey save as I dey waka go take the medicine. The money e come grow; I carry am start my business again. You dey see the things wey I dey sell.

Translated into standard English:

Sir, I have made a small saving from the stipends because I received it on a monthly basis. My house is not very far from the health facility where I receive my treatment, and so when I began to regain my strength I started to save as I usually walk to the facility. I used part of the stipends I saved to resuscitate my business. You can see my wares displayed. (MS, 54 years, female)

In spite of the utilization of the stipends in handling diverse financial needs and although the patients were grateful to the TB programme for providing the stipends to them, they stated that the stipends were not enough to meet their financial needs.

Patients expressed gratitude to the PMDT programme for the stipends but stated that they actually needed more than they received. They argued that being very sick with DR-TB impaired their ability to fend for themselves; thus, their actual financial need was much more than being catered for by the programme. In the words of one of them,

This is a terrible disease which makes it impossible for one to be able to earn income to look after one's family. I have been sick for over one year now. I was first treated for TB for eight months before I was told the disease had become worse and that I needed to go for admission. So, for well over a year, I have not worked because I did not have the strength. So, I need more money. If the programme can give us more money, it will certainly help us a lot. (MK, 48 years, male)

Asked what he would use more money to do, he answered,

My brother, you yourself know what a man with a family will need money for. I need to feed my family so that they will not starve. My wife is an *akara* [bean balls] seller. I need money for transportation. Do you know my stipend is hardly enough for my transportation each month ... I cannot do my trading any more. (MK, 48 years, male)

Other patients mentioned experiencing similar financial needs.

4.3 | Mental health and psychosocial support and unmet needs

Thirty-one patients (73.8%) noted that they felt helpless, worthless, hopeless, and sad and had suicidal ideas before commencing the treatment and during the treatment. Before the treatment, their feelings stemmed from experiences of stigma and discrimination and inability to continue their work or business or, in the case of a student, his education. Twenty patients felt that the efforts to manage their low mood while on treatment were inadequate and unhelpful. A student patient shared his experience thus,

I felt like dying. I was very sad all the time. I kept getting weaker and weaker. At a time I could no longer cope with my studies. (TU, 28 years, male, student)

The researcher probed further.

Researcher How was your feeling of sadness handled while you were on admission?

TU They called a Doctor they said is a Psychiatrist. But to be honest, the attention I received was very inadequate. I saw the Psychiatrist about twice.

A 35-year-old man narrated his story of low mood and its management:

I was treated for TB, and I did not improve. They started another round of treatment, and then I had to do tests to determine if the TB had become resistant. Meanwhile, I kept losing weight. As my condition worsened, I could no longer cope with my business. I had to close my shop. Many of my friends abandoned me. I felt very sad. At a time, I thought dying would be better for me. I just wanted to die. (EY, 35 years, male, HIV positive)

The researcher probed further on the low mood.

Researcher How was your low mood handled while you were on admission?

EY Initially, my low mood continued to the point that I just wanted to die. I insisted they should discharge me. I wasn't helped much. I was discharged to continue treatment in the community, but this wasn't possible as there was nobody to administer the treatment. I was re-admitted and this time around I was seen by a Psychiatrist. The support I got from the Psychiatrist helped though not much, but my family's support was tremendous, and this helped to relieve my sadness. I felt better.

Researcher Why do you think the attention from the Psychiatrist did not help?

EY His services were too infrequent. If he had come frequently enough, I believe he would have helped me, but his visits were not enough. I was seen only twice.

The key areas pointed out by the patients where there were dire needs for them included effective treatment of the low mood, counselling them on how to manage issues of stigma/depression, giving them adequate information/counselling on drug adherence and drug adverse effects, supporting them to reintegrate into the society, including their social networks.

4.4 | Support and unmet need for drug side effects: hearing impairment

Some patients complained that their hearing was good before they started the MDR-TB treatment but that they developed hearing impairment in the course of the treatment. Although they stated they had their hearing assessed, they all stated that they did not receive adequate attention.

In the words of a 36-year-old patient,

My hearing was good before I started treatment. I had no problems with it at all. But I noticed changes in my hearing when the treatment started, and it got worse and worse. I complained repeatedly and was told I would be seen by an ear doctor. The programme manager, I can vouch for him, made many attempts to get the ear doctor to see me. When finally I was seen by the doctor after about four months, I could barely hear. He did some tests, advised that changes be made to my medication. I learnt that I was supposed to receive a hearing aid, but I have not yet got one, after another four months. (IO, 36 years, female)

The statement by IO captures the experiences of other patients who had hearing impairment as a result of the treatment. The services of ear-nose-throat (ENT) doctors had been hard to get in the programme as the ENT specialists are few in the country.

5 | DISCUSSION

Unmet need can be viewed as the shortfall between the support and care needed by an individual and that which they actually receive, as may be perceived by them.¹⁹ Needs may be objective or subjective and perceptual. Indeed, the concepts and debates of “need” versus “unmet need” have featured prominently in the modern provision of welfare support to vulnerable persons. Conceptualization of need should take cognizance of an individual's physical and psychosocial circumstances as well as the sociocultural and economic circumstances.¹⁸

Our results show that the patients appreciated their stipends and found them very useful in handling some challenges. For example, the stipends were useful in paying transport fares to reach the health facilities where they received their treatment for those receiving community-based treatment. Researchers have documented that treatment seeking for tuberculosis involve catastrophic expenditures for individuals as they have to take care of direct and indirect costs.^{14,15} With average of 62% of TB patients in a study sample experiencing catastrophic expenditures that deepened their poverty, many patients came off worse after their treatment for TB. The authors recommended financial and social protection measures for poor TB patients.^{14,15} It is not surprising then that many MDR-TB patients in our study did not have enough money for their transport by the time they were diagnosed with MDR-TB. The long and tortuous care-seeking pathway for TB care had drained them financially.

The stipends received by some of the patients in our study were used to revivify microbusinesses that wound down as a result of the patients' MDR-TB illness. For such patients, while medical treatment gave them back their life, the stipends gave them back their livelihood. It thus helped to mitigate the severe deprivation and dependency that the disease experience had pushed them into. The stipends were indeed a source of social protection that came at the right time, which is in keeping with WHO's recommendation.¹⁶

The poorer the patient, the more impactful the stipends seemed to have as evidenced by the case of the widow, who was HIV positive and had three children. Apparently, she would have starved with her children while she was on treatment as she had no other source of support in the face of stigma and discrimination against persons living with HIV at the time.

The patients felt there was a shortfall between what they needed and what they actually received. This shortfall apparently depended on individual patient's satisfaction with what they received, which in turn, would depend on a number of factors, chief of which may be the magnitude of an individual's need. This postulation itself is, however, subject to debate. For example, would poorer, more deprived people, in greater need be less satisfied? Or would they be more satisfied because some help has come their way? Answers to such questions would need more elaborate research and were outside the scope of this research.

This research found that majority of the needs were common to the patients. These needs included money to buy food for the sick patients and their families, transportation fees, school fees payment, and assistance to become economically independent by way of revivifying moribund business, learning a skill through vocational training, starting up a new income-generating activity, or re-entering employment. These, unarguably, are legitimate needs. The study participants pleaded that the PMDT programme should continue to provide support to MDR-TB patients for these needs, and that the magnitude of the support should be increased.

Our study also found that the MDR-TB patients were given mental health and psychosocial support during their treatment. The main mental health and psychosocial support given was psychiatric assessment and treatment. However, the patients opined that the psychiatric intervention they were given fell short of expectation. They were dissatisfied with the few consultations they had with the psychiatrists. Reasons why these consultations were few are unclear but may be related to the relatively low number of psychiatrists in the country, which may affect their availability to see MDR-TB patients frequently. But it is our considered opinion that it is not only psychiatrists who can and/or should provide mental health and psychosocial care for the patients. There are other professionals in the health and social care sector, such as health counselors, clinical psychologists, and social workers, who can and should be brought in to supplement the inputs from psychiatrists. This is programmatic task shifting. Indeed, we believe that the PMDT programme should begin to think along the line of programmatic task shifting as an approach to addressing shortfall in the care and support for the mental health and psychosocial needs of MDR-TB patients.

The strength of this research is that it is one of first and few studies to systematically explore, in-depth, the support received by, and the unmet needs of, MDR-TB patients in a PMDT programme in a resource-poor country. Findings may provide insights that may be useful in planning for the holistic management of MDR-TB patients in similar resource-poor settings.

This study has its own limitations in that its findings cannot be generalized to broader PMDT programmes in developed countries. Being a qualitative study, statistical inferences cannot be drawn to wider populations.

In conclusion, MDR-TB patients on treatment in Nigeria have unmet economic/financial as well as mental health psychosocial needs, and the impact of these unmet needs on their treatment outcomes is unknown and needs further investigation. Additional strategies including improved funding and task shifting are needed to address these needs.

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