

# Adherence and Perception of Care Among Patients with Multidrug Resistant Tuberculosis in North Central Nigeria

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**Abstract:** The efforts geared towards control of Tuberculosis is threatened by the spread of multidrug resistance. Severe forms of multidrug resistant TB termed Pre-extensive (Pre-XDR) and Extensively Drug resistant (XDR) TB have been reported by different countries including Indian, China, Russia and Nigeria. Previous studies have shown a strong association between these various forms of resistance and non-adherence. The study was conducted to identify the factors affecting adherence, assess level of adherence and the perception of care among Multidrug resistant clients in North Central Nigeria. Specific & structures Questionnaires were administered to 96 MDR TB patients and 67 healthcare providers (representing 50% of each of the professional group). Few patients and healthcare providers were later selected from the number that responded to questionnaires and were involved in Focus Group Discussion. Responses from participants showed that the factors affecting adherence were alcohol addiction (72.9%), lack of social support (88.5%), feeling cured (28.1%), access to treatment centre (46.9%), non-payment & inadequate incentives/enablers for patients to continue treatment (38.5%), Stigma and discrimination (31.3%), financial difficulty (25%), treatment side effect (39.6%) and long treatment course & high pill burden (55.2%). Patients' level of satisfaction on care was high (66.7%) indicating a satisfactory perception. This study revealed that factors affecting non-adherence were multifactorial and patients' perception on MDR TB care was satisfactory.

**Keywords:** Adherence, Perception of MDR TB Care, Multidrug Resistant Tuberculosis, North Central, Nigeria

## 1. Introduction

The efforts geared towards control of Tuberculosis (TB) and Multidrug Resistant Tuberculosis (MDR TB) is

threatened by the spread of multidrug resistance including its severe forms. Increasing rate of Pre-XDR and XDR TB which are severe forms of MDR TB have been reported at 65 countries. Nigeria is among the 30 high burden countries for

TB, MDR TB and TB-HIV. [26]. High prevalence of Pre-XDR TB among the multidrug resistant TB cases has been reported in Nigeria [4].

According to previous studies carried out, development of Multidrug resistant TB has been majorly linked to treatment non-adherence and loss to follow up. [25, 16, 29]. Despite many national and international efforts made in preventing and controlling TB as well as implementing DOT in almost all parts of WHO regions, patients still fail to complete their treatment to be declared. [17, 18]. Reports show that a considerable number of TB cases fail after several treatments, many relapse after completion of the treatment, many undergo retreatment after completion of treatment, and many developed MDR-TB among retreatment cases (20%) throughout the world [19].

Severe forms of multidrug resistant TB termed Pre-extensive (Pre-XDR) and Extensively Drug resistant (XDR) TB have been reported by different countries. Previous studies have reported high prevalence of Multidrug resistant Tuberculosis and factors responsible for the increase in the prevalence of MDR TB in Ethiopia, Indian, China and Russia. [20]. They found a strong association between these various forms of resistance and multiple incomplete treatment regimens, non-adherence, poor infection control practices, and mutation of the resistant TB strains. Nigeria is not excluded from the list of countries that have reported high prevalence of MDR TB and Pre-XDR TB [4]. In South Africa, medication adherence was found to be significantly higher for antiretroviral than for TB medications due to the long treatment course for MDR TB patients as well as adverse drug reaction [22]. In South Western zone of Nigeria, the Prevalence of Pre-XDR TB was reported to be as high as 16.7%. It was assumed that abuse of fluoroquinolone (one of the second line anti-TB drugs) could be the reason for the high frequency of fluoroquinolone resistance observed in the study.

Treatment adherence is considered a primary determinant and a proxy for treatment success. Treatment failure, increase mortality, development and spread of drug resistance, prolonged infectivity are possible poor health outcome of non-adherence to TB therapy and this pose a serious health risk for individuals and communities [21]. Non-adherence to treatment has been reported to be a major factor in development of drug resistant tuberculosis which is due to patient, health worker and health system factors. Major challenges include poor provider-patient communication, inadequate knowledge about a drug and its use, not being convinced of the need for treatment, fear of adverse effects of the drug, long term drug regimens, complex regimens that require numerous medications with varying dosing schedules.

The specific aim of this research was to identify factors responsible for non-adherence and assess perception of care and services among Multidrug resistant clients. Addressing these factors is important because of the role they play in determining treatment adherence. Prioritizing patients through listening to them and treating them as ultimate stakeholders in

treatment program would help to develop consistent adherence, retention of patients and reduction of the prevalence of MDR-TB cases. A better understanding of these factors would inform development of interventions to strengthen a patient-centered approach for the delivery of TB programs and services. In North Central Nigeria, no such study has been conducted.

## 2. Method

### 2.1. Study Setting

This was a qualitative study conducted at Benue, Kaduna and Plateau States among Multidrug Resistant TB patients enrolled into treatment at community and facility-based treatment centres. The 3 states where this study was conducted are grouped under the North Central Zone. Benue State has a population of 4,253,641 with 23 Local Government Areas (LGAs). Plateau State has estimated population of about 3.5 million with 17 LGA, Kaduna has a population of 6,113,503 with 23 LGA. Each State has TB and Leprosy Control Program being overseen by the National TB and Leprosy Control Program. National Tuberculosis and Leprosy Control Programme (NTBLCP) adopted a community-based treatment approach to the management of Drug Resistant Tuberculosis (DR TB) to complement facility or hospital-based treatment approach. DR TB data from communities and facilities are collated by DR TB focal person in each state and reported to the State TB and Leprosy Control Program Manager, who in turn report to the NTBLCP. There are 3 major facility-based treatment centres in the 3 states used for the study which are St. Vincent Hospital Aliade, Benue; National TB and Leprosy Training Centre (NTBLTC) Saye, Kaduna and Jos University Teaching Hospital, Plateau.

### 2.2. Data Collection

Three Questionnaires were designed for patients, healthcare providers at the treatment centre and healthcare providers at the States TB Program. Collection of data took place from July 2020 to December 2020. The questionnaires were piloted among forty-five patients and thirty healthcare providers based on questionnaire pilot sampling of Lackey and Wingate [23]. This was to refine the questionnaire to ensure clarity, understanding, and acceptability. Questionnaires were reviewed before data collection for the study commenced. The questionnaires were administered to participants by trained data collectors and Focus Group Discussion conducted. Focus Group Discussion was conducted in English and dialects of participants. The discussions had in participants' dialect were audio recorded and later translated to English.

### 2.3. Study Participants

Primary target population were Multidrug resistant TB patients at Drug Resistant TB treatment centres while the secondary target population were the healthcare providers. The minimum sample size for the number of participants who were interviewed was calculated using EPI INFO version 7

StatCalc [24].

### 2.4. Ethical Considerations

Ethical approval for the study was obtained from the States' Ministry of Health Research Ethical Committee. Permission to conduct the study at the facilities was granted by the institutions. All participants gave their informed and written consent before participating in the study, and their anonymity, privacy and confidentiality was respected.

### 2.5. Data Analysis

Data were entered in Microsoft Excel, coded and later imported into IBM SPSS (Version 16) for statistical analysis. Descriptive statistics were used to analyze categorical variables from respondent's socio-demographic and clinical characteristics and were presented as frequencies and percentages in tables and charts. Inferential statistics were applied depending upon the nature of data and variable.

## 3. Results

*Table 1. Demographic Characteristics of study participants for assessment of adherence factors.*

Patients			Healthcare workers		
Variable	Frequency	Percentage	Variable	Frequency	Percentage
Age (mean 33.57±0.5)			Age (32.78±0.5)		
Sex			Sex		
Male	53	55.2	Male	32	48
Female	43	44.8	Female	35	52
Marital status			Marital status		
Single	25	26	Single	10	15
Married	63	65.6	Married	57	85
Divorced	5	5.2			
Widowed	3	3.1			
Separated					
Religious affiliation			Years of experience in TB		
Muslim	45	46.9	<1 year	4	6
Pentecostal	16	16.7	1-3 years	21	31.4
Catholic	31	32.3	4-6 years	29	43.2
Orthodox	4	4.2	7-10 years	12	18
Residency			>10 years	1	1.5
Urban	69	71.9			
Rural	27	28.1			
Education					
No formal education	5	5.2			
Able to read & write	9	9.4			
Primary	18	18.8			
Secondary	47	49			
Higher Institution	17	17.7			
Profession			Profession		
Student	15	15.6	Doctors	11	16.4
Farmer	23	24.0	Nurses	19	28.4
Housewife	3	3.1	Pharmacist	5	7.5
Petty trading	21	21.9	M & E Officer	9	13.4
Unemployed	22	22.9	Lab Scientist	7	10.4
Public servant	5	5.2	CHEWs	6	9
Civil servant	1	1.0	Others	10	14.9
Others	6	6.3			

*Table 2. Common factors affecting adherence reported through FGDs & questionnaire.*

Patient related	Alcohol addiction, lack of social support, non challant behavior of not taking drugs as symptoms have been relieved
Healthcare Provider related	Treatment centre access related, Inadequate enablers for patients to continue treatment, Lack of social support programs
Socio-economic status	Stigma & discrimination, Financial difficulty, unable to take care of comorbidities due to financial constraint
Medication related	Side effect of treatment, long treatment duration & high pill burden

**Table 3.** Reasons for non-adherence to MDR TB treatment.

Variable	Frequency			Percentage		
	Yes	No	Partial	Yes	No	Partial
Available caregiver at home	85	11	0	88.5	11.5	0
Knowledge about progress of treatment	81	14	1	84.4	14.6	1
Not necessary to continue with treatment as symptoms have been relieved	27	68	1	28.1	70.8	1
Treatment is no more necessary as I am old	4	92	-	4.2	95.8	-
Treatment course is too long & dose too large	53	43	-	55.2	44.8	-
Caregiver does not really support	13	83	-	13.5	86.5	-
Forgetting to take drugs	13	83	-	13.5	86.5	-
Cannot cope with the side effects of the drugs	38	58	-	39.6	60.4	-
Comorbidity makes me interrupt treatment	25	71	-	26	74	-
Strict adherence to Doctor's advise	79	14	-	84.9	15.1	-
Not satisfied with healthcare provider's services	8	85	-	8.3	88.5	-
Financial difficulty	24	72	-	25	75	-
Long distance to treatment centre	45	51	-	46.9	53.1	-

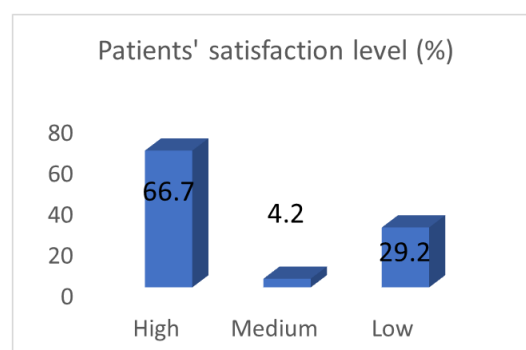
Tables 2 and 3 are summaries of the factors that affect adherence and treatment outcome. Healthcare workers identified alcohol addiction as a factor negatively affecting treatment adherence. Healthcare provider reported that the alcohol abuse makes the patients to be stubborn, not to understand information during counselling and therefore makes them not to adhere to instructions. Other factors

identified were lack of support (88.5%), feeling cured (28.1%), access to treatment centre (46.9%), nonpayment & inadequate incentives/enablers for patients to continue treatment (38.5%), Stigma and discrimination (31.3%), financial difficulty (25%), treatment side effect (39.6%) and long treatment course & high pill burden (55.2%).

**Table 4.** Responses to Patient-Healthcare Provider relationship.

Variable	Frequency			Percentage		
	Yes	No	Partial	Yes	No	Partial
Feeling at home when attended to by HCW	78	15	3	81.3	15.6	3.1
Feeling stigmatized	30	64	2	31.3	66.7	2.1
Feeling your privacy is respected	74	12	10	77.1	12.5	10.4
Incentives or enablers to continue treatment	54	37	5	56.3	38.5	5.2
Receive counselling & health information	89	5	2	92.7	5.2	2.1
Understand the health information	85	2	9	88.5	2.1	9.4
Nurses & other HCWs always available when needed	71	2	23	74	2.1	24
Do you think all information shared are kept confidential?	82	3	11	85.4	3.1	11.5
Waiting time too long?	36	50	10	37.5	52.1	10.4
Treatment preference at treatment centre or home?	57	26	13	59.4	27.1	13.5
Will you recommend this treatment type to a friend who has MDR TB	89	6	1	92.7	6.3	1.0
Do you know about the progress of your treatment?	65	35	0	63.6	36.4	0
Patient's satisfaction level	Frequency			Percentage		
	High	Medium	Low	High	Medium	Low
	64	4	28	66.7	4.2	29.2

In table 4, out of all the patients that participated in the interview and focused group discussion, 81.3% of patients noted that they felt at home when healthcare workers attended to them. The proportion of patients who felt their privacy was respected were 77.1%. Patients who complained that they did not receive monthly incentives which was to be for transportation & social support were 38.1%, Patients who received counselling & health information were 92.7%, patients who understood the health information were 88.5%, patients felt their information were kept confidential, were 85.4% and 52.1% did not take waiting time to be too long. Participants that preferred receiving treatment at the treatment centre were 59.4% while 27.1% preferred home treatment. Participants who noted that they can recommend the treatment type to a friend who has MDR TB were 92.7%, patients who knew about the progress of their treatment were 63.6% while 36.4% did not know.

**Figure 1.** Patients' satisfaction.

About 66.7% of the patients responded that their satisfaction was high, patients who indicated that their satisfaction was neither high nor low were 4.2% and 29.2% indicated a low satisfaction. (figure 1).

## 4. Discussions

This qualitative study was conducted to identify factors affecting MDR TB treatment adherence. Focus group discussion and structured questionnaires were used to obtain information from patients and healthcare providers. The responses from both patients and healthcare providers revealed that factors related to non-adherence to treatment are multifactorial. However, alcohol addiction, lack of social support, feeling cured, long distance to treatment center, non-payment of stipends/inadequate enablers for patients, stigma & discrimination, financial difficulty, side effect of treatment, long treatment duration & high pill burden were the common factors identified to be affecting MDR TB patients' adherence to treatment. Common factors that could affect treatment adherence have been summarized into patient, healthcare provider, socioeconomic and medication related factors. Treatment centre access related or Long distance to treatment centre, inadequate enablers for patients to continue treatment, Lack of social support programs are healthcare provider factor. Medication related factors are side effect of treatment, long treatment duration & high pill burden Patients related factors are alcohol addiction, careless or nonchalant behavior of not taking drugs as symptoms have been relieved. Financial difficulty, lack of money to manage co-morbidities, stigma and discrimination are socioeconomic factors. The findings of this study is in line with a study done in Plateau State of Nigeria which showed that long distance to treatment sites, poor knowledge of duration of TB treatment, alcohol abuse & cigarette smoking were major determinants of treatment interruption. This is similar with a study where it was reported that financial constraint through lack of money, transportation cost and food impacts on TB cases' ability to adhere to treatment till the course is completed [3]. Long distance travelling and financial burdens discouraged tuberculosis DOTs treatment initiation and compliance. They further analysed the distances covered by the patients that affected adherence & found that patients living 0-5 kms away from treatment centre had treatment interruption while many of TB patients who live greater than 5 kms away from the health facility did not adhere. The factor with the highest frequency in this study was long distance to treatment centre. Treatment is free in Nigeria; however transportation is not free. As at the time of this study there were 534 DR TB facility treatment centres & some community based, yet some patients cover a long distance to access treatment centres. In this study, majority of the patients were found to be unemployed, farmers and petty traders who find it difficult to provide good meals for themselves, so having problem transporting themselves to a distant treatment centre is just an understatement. Alcohol intake had significant association with non-adherence and increased odds of poor treatment outcomes and this could be attributed to loss of thoughts & control where patients forget counselling & instructions given by healthcare providers [1-3]. Financial difficulty, feeling cured, social support, incentives reported in this study are also in line with previous qualitative studies [15, 2, 18, 5, 13]. This qualitative study also described

the perceptions of MDR TB patients on the care and services they receive from healthcare providers. This study revealed that 81.3% of patients felt at home when healthcare workers attended to them. This is similar with the qualitative study on Nurses and Patients' experiences on quality of care. In their study, they noted that nurses spend 24 hours/7 days every week with patients, gather large amounts of information about patients and therefore remains the first points of contact for patients [12]. The result of their study showed that direct contact with patients is crucial to building and maintaining a relationship of trust, when these patients feel heard and understood, they consider themselves to be in safe hands and feel at home. Similar findings were also reported in Nigeria and Ethiopia that patients' perceptions on health care provider interaction had a significant influence on positive patient experience and adherence to TB treatment. The proportion of patients who felt their privacy was respected were high (77.1%) and this is in line with previous studies [6, 7]. Participants that received incentives were 56.3% while 38.1% of patients complained that they did not receive monthly incentives. However, patient-centered approaches, individualized support and monitoring of treatment adherence, use of incentives to continue treatment, and interventions to return patients who abandon treatment have been reported in the literature to improve TB outcomes and directly affect positive experience and perception of patients on care [10, 11]. Participants that preferred receiving treatment at hospital were 59.4% while 27.1% preferred home treatment. People who preferred taking treatment at home were in their continuation phase, who in the course of the focused discussion noted that the frequent visits to treatment centre makes friends and people around to keep asking why they are always visiting hospital. However, majority still preferred being hospitalized.

Findings of this study indicated that the overall patients' level of satisfaction on care was high. This is contrary to the study which revealed a relatively low satisfaction level with the reason that satisfaction is related to changes in quality rather than quality [8]. Changes in quality can lead to changes in satisfaction, as patients notice improvements. However, our finding is in line with findings of patients' satisfaction study done in Tanzania where a high proportion of patients were satisfied with quality of care [9]. Though the satisfaction score was high, some patients reported their dissatisfaction with the inadequate/lack of incentive package. This incentive plays a big role in retaining patients on treatment as some of the patients in this study were not buoyant to have healthy meals and transport themselves to treatment centers. The observed dissatisfaction of patients on incentive underline the importance of hospital management and TB Program to strengthen the incentive package for patients and this should be seen as an area for improvement.

## 5. Conclusion

Some of the identified factors responsible for non-adherence during TB treatment can be potentially addressed through targeted interventions since they were

categorized under patient-related, health system related, medication related and social related factors. Financial difficulty, lack of social support, treatment side effects and personal factors are associated with non-adherence. From the views of patient and healthcare providers, adherence was conditioned by sociocultural and economic context perspectives. Identifying the majority of factors highlights the areas for opportunities of improvements. Perceptions on care and services received by MDR TB Patients indicated that most patients adhered to their medications, but few who missed treatment appointments were mainly due to perceived wellness, financial difficulty & lack of incentive and treatment side effect. Patients' satisfaction score was high, however patients recommend that the TB Program should strengthen the incentive and social welfare program for MDR TB cases.

## 6. Limitation of This Study

There is the need to further use a larger dataset to include susceptible population which would give a better insight in assessing factors affecting non-adherence, treatment outcome and MDR TB.

## 7. Recommendations

The findings of this study have shown that:

1. There is need for TB Program to strengthen the system to close up system related factors affecting DR TB services and devise strategies to improve treatment outcome.
2. There is need to strengthen surveillance laying emphasis on disaggregated data by States/Zones, to review gaps and proffer targeted solutions.

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