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Lived experiences of persons on tuberculosis treatment in Nairobi County, Kenya: a mixed methods study

Joan Ondiro[1*], Faith Onyangore[2], Reagan Onyango[3], Lenah Muema[4] and Dickens S. Omondi Aduda[1]

Abstract

Background Tuberculosis program effectiveness is majorly measured by disease severity and treatment response without integrating patient perspectives. Yet, it's a critical dimension in clinical decision-making that enhances health worker-patient interactions and increases individuals' sustained engagement with treatment, thereby benefiting the people affected and the wider public by mitigating the infection risk. This study assessed the lived experiences of persons affected by tuberculosis who were on treatment in Nairobi County, Kenya.

Methods A cross-sectional study was conducted in May 2023 among 392 persons with drug-susceptible pulmonary tuberculosis in five facilities in Nairobi County. Participants were selected through simple random sampling and interviewed by semi-structured questionnaires and focused group discussions. Data on prevention and control strategies, facility preference, medication burden, interaction with healthcare workers, and the socio-economic effects of the disease were collected. Quantitative data was analyzed descriptively using frequencies, percentages, means, and standard deviations while qualitative data was transcribed, coded, and thematically analyzed.

Results The sample consisted of 245 males and 147 females aged between 3 and 74 years. Despite the high rating of their interactions with the healthcare workers, the findings show insufficient knowledge of the prevention and control strategies of TB. Additionally, food insecurity resulting from an inability to afford recommended meals, medication burden such as high pill burden especially where there are coexisting medical conditions, undesirable taste and size of the TB tablets, adverse drug events, economic burden due to loss of income, and stigma from the family and community were reported to affect treatment outcomes.

Conclusion Treatment outcomes are influenced by multi-level factors such as low knowledge of TB prevention and control strategies, stigma, food insecurity, medication burdens like pill number, size, taste, and adverse drug reactions, facility preference, and economic hardships including loss of income. Understanding the individual needs of persons with TB will help develop interventions that are specific to them for better treatment outcomes.

Keywords Tuberculosis, Disease severity, Patients, Adverse drug events, Socio-economic

*Correspondence:
Joan Ondiro
joanondiro@gmail.com
[1]Jaramogi Oginga Odinga University of Science and Technology, Bondo, Kenya
[2]University of Kabianga, Kericho, Kenya
[3]Kenya Wildlife Conservancy Association, Nairobi, Kenya
[4]Kenya Agricultural and Livestock Research Organization, Nakuru, Kenya

Introduction

Tuberculosis (TB) remains a public health concern with 10.6 million infections and 1.6 million deaths reported worldwide in 2022 [1]. Even with free treatment in public facilities, Kenya is still ranked among the high-burden countries with an incidence rate of 426/100,000 and a higher burden in urban areas [1–3]. The country further reported 90,560 drug-sensitive cases in 2022 with Nairobi County contributing 15% (12,163) of the cases [4].

Tuberculosis is curable and its transmission can be prevented by early identification and treatment, thereby preventing relapse and drug resistance [5, 6]. The current World Health Organization (WHO) recommended regimen for treating drug-susceptible TB is a combination therapy that involves an intensive phase for two months of isoniazid, rifampin, pyrazinamide, and ethambutol, then a continuation phase for four months of isoniazid and rifampin, following the DOTs (directly observed therapy) approach [7, 8]. Persons who interrupt TB treatment end up with adverse outcomes such as treatment failure, resistance to TB drugs, and death [5]. Achieving desired treatment outcomes in a demanding and lengthy treatment regimen with associated side effects requires a patient-focused approach, which is advocated for through the WHO End TB strategy(2015), that considers a patient as a primary figure in healthcare delivery and acknowledges their personal and social circumstances in a bid to provide high-quality TB services [7, 9].

Even though Kenya is implementing DOTs, and has instituted additional measures such as patient education, adherence counseling, and substance abuse counseling during treatment initiation, cumulative incidence of treatment interruption remains high at 4.5% among new TB cases and 8.5% among retreatments [10]. Like most TB programs worldwide, the current treatment approach leans towards prioritizing case detection, TB notification and treatment adherence over the specific needs of the affected individuals, with a "one size fit all approach" regardless of the different social and cultural contexts [8, 11]. For instance, the Kenya national TB guidelines (2021) attempts to give a patient centered approach to TB care through new diagnostic technologies, shorter term regimens for treating latent TB and more individualized care for drug resistant TB patients [12]. However, the fact that the perceptions of the patients are not captured has led to scarce evidence on what works and how to implement this approach since these perceptions are neither part of the routine data collected nor routine care, leading to a lack of understanding of the inward perceptions of the patients that may drive them to continue or discontinue medication [13].

Patient experiences, which are a direct report by patients regarding treatment, health practices and a profound life-changing experience may impact all aspects of a patient's life. These reports, which do not include the interpretation of the responses by a clinician or anyone else, are an important tool in the evaluation of the effectiveness of treatment interventions from a patient's perspective and ensures that they are involved in the decision-making process [14, 15]. Previous studies have suggested some risk factors for low TB treatment adherence such as stigma, poor socio-economic status, inadequate knowledge of TB, and treatment side effects, difficulty accessing treatment, and poor communication between healthcare providers and patients [5]. None other than the persons affected by TB themselves are best placed to provide the much needed evidence from their experiences that then allows for a deeper understanding of how treatment impacts their overall health, care, and daily life and thereby help in developing patient centered approaches that responds to their specific needs [16]. In Kenya, few studies have assessed the lived experiences of persons affected by TB. This study explored the lived experiences of persons with TB who were on treatment in Nairobi County, Kenya.

Methods

Study design and setting

This was a cross-sectional, mixed-method research conducted in five facilities in Embakasi, Langata, Ruaraka, Starehe, and Dagoretti sub-counties, Nairobi County. Both qualitative and quantitative data was collected in focus group discussions (FGD) using FGD guides and semi-structured questionnaires respectively. Data included socio-demographic characteristics, lived experiences, experiences with the health care system, and social and economic experiences.

Study participants

All persons (including children) with drug-sensitive pulmonary TB in the continuation phase of treatment in public facilities were recruited from TB clinics, with the youngest being 3 years and the oldest 74 years.

Sampling procedure

All public facilities with TB clinics were selected. A two-stage cluster sampling procedure was adopted to cluster health facilities using the county TB caseload data from January 2021 to December 2021.First, five sub-counties with the highest TB cases were purposively selected. These are: Embakasi, Langata, Ruaraka, Starehe and Dagoretti. Secondly, facilities with the highest TB cases within the selected sub-counties were purposively selected. Participants were then selected using simple random sampling criteria where from the TB clinic, patients who came for their appointments were randomly selected. Purposive sampling was employed for the selection of FGD participants.

Table 1 Sample size calculation by in 5 selected sub counties in Nairobi County,2023

Sub-county	Health Facility	*N*	*n*	Adjusted *n*	Male sampled	Female sampled	Total sampled
Embakasi East	Mama Lucy Kibaki Hospital	1,477	170	187	123	75	198
Langata	Mbagathi Hospital	627	72	79	52	33	85
Ruaraka	Mathare North Health Centre	118	14	15	10	5	15
Starehe	Rhodes Chest Clinic	470	54	60	38	22	60
Dagoretti	Riruta Health Centre	269	31	34	22	12	34
Total		**2,961**	**341**	**375**	**245**	**147**	**392**

Sample size determination

Using the *Raosoft* online sample size calculator [17] with a 5% margin of error and a 95% confidence interval, a sample size of 341 was determined. Further, a 10% adjustment to cater for incomplete responses provided a final sample size of 375. For qualitative data, FGD ($n=4$) was conducted, each with six participants [18] as shown in Table 1 below.

Data collection

Before the interviews', written consent was obtained. Children below 18 years had their parents/guardians consenting on their behalf. No child was directly interviewed, the caregivers answered the questions on their behalf. For quantitative data, semi-structured questionnaires, which were pretested, were administered by research assistants. The questions included socio-demographic information, individual factors affecting treatment outcomes, experiences with the healthcare system, and social and economic effects of TB. For qualitative data, FGD guides were administered by the first author. Data collection stopped when saturation was achieved and there was no new information forthcoming. Audio recorders were used during FGD.

Data analysis

Quantitative data was analyzed using *R* statistical software (version 4.3.2). Categorical variables were described using frequencies and percentages, while continuous data was characterized using means and standard deviations. Analysis included establishing knowledge level on prevention and control strategies, reasons for missing appointments, facility preference, as well as the pill burden such as the taste, size, and side effects, experience with health care workers (HCW), and the socio-economic effects of the disease. Qualitative data was manually analyzed where data was transcribed as soon as possible, while still fresh in the mind, trying as much as possible to align to original information and not to lose meaning. Using deductive (which were previously determined) and inductive coding, emerging themes were identified which were then used to develop narratives.

Table 2 Sociodemographic characteristics of persons living with TB in Nairobi County2023

Characteristic	Overall, *N*=392	Female, *N*=147	Male, *N*=245	*p*-value
Age				0.2
Mean (SD)	35(14)	34(15)	35(13)	
Median (IQR)	35(17)	32(17)	36(16)	
Education Level				0.8
Secondary Level	152 (39%)	60 (41%)	92 (38%)	
Tertiary Level	96 (24%)	33 (22%)	63 (26%)	
Primary Level	79 (20%)	32 (22%)	47 (19%)	
University	46 (12%)	15 (10%)	31 (13%)	
No formal education	19 (4.8%)	7 (4.8%)	12 (4.9%)	
Marital Status				0.021
Married	195 (50%)	69 (47%)	126 (51%)	
Single	137 (35%)	46 (31%)	91 (37%)	
Children	23 (5.9%)	15 (10%)	8 (3.3%)	
Divorced	18 (4.6%)	7 (4.8%)	11 (4.5%)	
Widowed	12 (3.1%)	8 (5.4%)	4 (1.6%)	
Widowered	7 (1.8%)	2 (1.4%)	5 (2.0%)	
Occupation				0.050
Casual labourers	115 (29%)	42 (29%)	73 (30%)	
Businessman/woman	109 (28%)	38 (26%)	71 (29%)	
Not employed	62 (16%)	34 (23%)	28 (11%)	
Formally employed	55 (14%)	16 (11%)	39 (16%)	
Student	49 (13%)	16 (11%)	33 (13%)	
Other	2 (0.5%)	1 (0.7%)	1 (0.4%)	
Income (Ksh)				0.013
Mean (SD)	12,835(15,003)	10,391(12,933)	14,301(15,965)	
Median	9,000	6,000	10,000	

Results

The study consisted of 392 respondents who were all eligible, consented, and completed the surveys. Of these, 245(62%) were male while 147(38%) were female. The mean age was 35 years,115(29%) were casual laborers while the median income was Ksh 9000. Table 2 shows the sociodemographic characteristics of the respondents.

Patient-related experiences

The findings indicate a notable low level of awareness regarding TB prevention and control strategies. A considerable proportion of the participants, 274(70%) expressed strong disagreement with the statement that TB is curable, 98 (25%) disagreed, while only 20(5%) agreed. Additionally, 239(61%) respondents strongly disagreed that early diagnosis and treatment can serve as a control measure while 133(34%) disagreed. On misconceptions about transmission, 208(53%) strongly disagreed that spitting in the open could enhance the spread of the disease, while 157 (40%) disagreed. Similarly, 220(56%) strongly disagreed that covering one's mouth while coughing could minimize the spread of TB, as 153 (39%) disagreed. Additionally, half of the respondents, 196(50%), strongly disagreed that well-ventilated houses could help minimize the spread of TB, while 176 (45%) disagreed. On wearing masks as a preventive measure, 212 respondents (54%) strongly disagreed, while 157(40%) simply disagreed.

A person with TB said "I wasn't shocked with the diagnosis because this is a family disease. I am the fourth one in the family to get infected"-Male person with TB.

Another said;

"We don't share cups, plates and bathing basin. I have mine separated and well known by everybody so that we don't mix them up. My food is served in specific utensils"-Male person with TB.

Reasons for choosing a particular facility over the other were observed to include; accessibility, 28(59%), availability of drugs 27(57%), friendly HCW 26(55%), and availability of laboratory and x-ray equipment 17(36%). Further, 113 (29%) persons with TB changed facilities in between treatment (mean=2) with 44 (30%) women visiting more facilities than men, 69(28%) mainly because of relocation 41 (52%), facility accessibility 25 (32%), lack of laboratory services 16 (21%), and poor staff attitude 8(10%). Long distance to facility 28 (32%) was also associated with missed appointments.

Healthcare related experiences

An assessment of the relationship between patients and HCW indicated that 176 (45%) respondents rated the courtesy of the staff as excellent, their listening rated at 157(40%) excellent, explanations regarding the disease rated at 157(40%) while knowledge of the HCW when describing medicine usage, dosage, and possible side effects in an understandable manner rated at 167(42%) excellent. A patient said;

"They are courteous, respectful and listen well."-Male person with TB.

The size of the tablets taken in the intensive phase was observed as a barrier to treatment adherence with more than half of the persons with TB, 198 (51%) reporting as big the size of the drugs.

"In the first phase, the tablets were big and difficult to swallow. I would vomit whenever I took them. But the ones I am taking in this second phase are good in size"- Female person with TB.

More than half of the patients, 205 (52%) also noted that some of the tablets were bitter with only 17 (4%) saying they are sweet.

"The white one, the one we take throughout the treatment period is bitter compared to the rest of the drugs, and it leaves a very bad taste in the mouth. You always feel like you need to take something sweet after taking it"-Female person with TB.

The number of tablets taken were perceived to be many, especially for patients with other existing conditions. The dosage for the TB drugs is determined by weight, with majority of doses being between four to five tablets daily. When combined with other medications for existing conditions like diabetes and hypertension, the number of tablets taken daily increases.

"I am diabetic and hypertensive. When you add me the TB drugs, I end up taking up to ten tablets at a go. I feel these tablets are too many for me"-Female person with TB.

Further, 166 (42%) persons with TB reported side effects in the first month (mean=1.5), with vomiting and nausea the most reported. Among them, 25(11%) failed to take drugs due to the side effects. Additionally, it was the view of the respondents that the current treatment duration was long. The preferred duration for 172 (44%) patients was between 1 and 3 months;

"Six months is not short, it's half of a year. When the duration is long, there are high chances of repeating some mistakes like taking your drugs late. I would suggest the period be shortened."-Male person with TB.

Social experiences

The respondents reported to have experienced stigma where one said;

"When I was diagnosed with this disease, my daughter said that they would put aside a cup and a plate for me. She told me not to get near her. When she gets home, she climbs on her bed with her bread. She says it's up to the three of us who are on TB drugs to take care of ourselves. When I tell her I am going to the clinic for drugs, she asks when I will be done with the treatment. "-Female person with TB.

Another one said:

"I stayed for three months without going to church because I didn't know what people would say when they saw how I looked, since I had lost much weight. I decided to pray in the house until the time when I will feel and look better"-Female person with TB.

This study highlighted the food insecurity experienced by persons with TB. The need for a balanced diet was reported to come at an extra cost that most respondents could not afford.

"When you come for the drugs, they ask you to eat a balanced diet, including fruits, but there are times I don't get anything to eat at all, because I don't have the money to buy. I have been forced to take drugs on an empty stomach several times"-Female person with TB.

Economic experiences

The findings show the impact of the disease such as loss of income and reduced productivity. Most of the respondents were casuals who depended on physical strength to work. They reported having experienced physical weakness at the beginning of their treatment which incapacitated them from working. This led to the interruption of the source of livelihood.

"My job involves walking. Because of how sick I was at the beginning of treatment, I had to stay away from work. That meant that my source of livelihood was affected" Male person with TB.

Another one said:

"I am a businesswoman. From the time I was diagnosed with TB, some of the businesses stalled. My body is still weak so I cannot go back to work now"-Female person with TB.

Discussion

This study explored the lived experiences of persons with TB, who were on treatment in Nairobi County, Kenya. The emerging themes included medication burden such as undesirable size and taste of TB drugs, food insecurity, stigma, economic hardship, reasons for facility preference and low knowledge level in TB prevention and control strategies.

Even though people with TB rated their interactions with the HCW highly, these findings indicate a low knowledge level of TB prevention and control strategies among them, observations which were made earlier in Kenya [19, 20]. This suggests that the patients may not have been given adequate health talk before treatment initiation, which could be attributed to the fact that most TB clinic staff still have other duties assigned to them such as administrative or other routine patient work, leaving them with only limited time to attend to patients, thoughts that align with a study in Western Kenya which indicated that the high workload in the TB clinic may affect the quality of patient care offered [6]. Studies show that inadequate knowledge of the disease and its treatment is a contributory factor to treatment non-adherence, further indicating that individuals with limited knowledge about TB frequently resort to self-administration of medication and consulting traditional healers, which can result in suboptimal treatment outcomes [21]. Therefore, in addition to adequate staffing, there is a need to strengthen the currently available TB awareness programs and health education programs for better treatment outcomes.

Facility preference was observed as a factor towards honoring clinic appointments. Patients chose facilities that are easily accessible, have drugs, friendly HCW and equipment in the laboratory and x-ray departments, observations that were made in a cross-sectional study in Kenya, Uganda and Tanzania [20] which suggested that the uptake of health services may be affected by lack of well-equipped facilities and poor road infrastructure. To minimize the travel time while in search of services, to decreases the out-of-pocket expenditure on health and to enhance service delivery and patient experience, the county government should consider opening up more TB clinics through multisectoral collaboration, expansion of diagnostic capacity and training healthcare workers.

Some persons affected by TB failed to take their drugs due to side effects, similar to observations in Ghana [5]. The pill burden including the number of tablets, taste, and size was a identified by the patients as a potential barrier to treatment [22]. Therefore, patients should be continually educated about the expected common side effects and also informed on what to do once they occur [5]. There should also be continuous studies to develop

regimens that include fewer tablets, as well as improving the size and taste of the drugs.

These findings show that the persons with TB were still experiencing stigma through social isolation and isolation of personal belongings, as some family members refused to share items or come near them, observations that are consistent with previous results reported in Kenya and Tanzania [23, 24] where the most common manifestations of stigma included social isolation, fear of contracting TB, verbal abuse, gossip, and unwillingness to share eating utensil. In TB disease, stigma has been shown to manifest as; i)self stigma where persons affected by TB endorse negative stereotypes about the disease and therefore behave or think according to false portrayals and negative messages ii)perceived/anticipated stigma referring to the worry that one will be devalued after a TB diagnosis and is often the result of observing others being stigmatized and iii) experienced stigma which reflects the range of stigmatizing behaviors, messages, and effects experienced by the person affected by TB in different settings, such as at home, in the community, in a health care facility, or at work [24]. Stigma leads to feelings of shame and tainted identity which may cause a delay in seeking health services, leading to delays in diagnosis, treatment, and increased community transmission [23]. There is still need for health education targeting the public and people affected by TB to help minimize stigma. Further, patients indicated that the food available in the households was not enough to provide for the extra nutritional needs while others revealed that they could not afford to buy. Nutritious food is essential to the recovery of TB patients yet, this is not always achieved in Africa's diverse contexts [25]. Food insecurity adversely affects treatment adherence and increases loss to follow up especially among street families, as precious time is dedicated to searching for food [25]. Providing TB patients with supplemental nutrition as well as social and structural support will not only increase their likelihood to continue in treatment and care but also, accelerate their recovery [5].

Conclusion

Our findings suggest the gaps in the current treatment approach and point towards the work that needs to be done to help end TB. The TB program should consider enhancing health education, delivered in a simplified way to the persons with TB and the community, to help increase their knowledge on prevention and control and help reduce stigma. Further work is needed in technological advancement to see the introduction of pills with desirable size and taste for enhanced patient experience. Investments in more TB clinics including laboratory and x-ray services will ensure service accessibility at reduced out-of-pocket expenditure. Additionally, the national TB program should in collaboration with stakeholders consider initiatives that provide social and financial support including food for persons affected by TB.

Strength of the study

The choice of a cross-sectional mixed-study design conducted on a sufficiently large representative sample gives the highest external validity. The mixed methods research using the triangulation design, and convergence model enabled a deeper understanding of the socio-structural issues and lived experiences.

Study limitations

The study only included patients from high volume, public health facilities, which may cause some slight bias. It also included only patients living with drug sensitive TB, potentially locking out experiences of persons with other forms of TB.

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Author contributions

JO was the principal investigator who participated in the study conceptualization, recruitment of study participants, data cleaning and analysis, and manuscript writing. DA contributed to the conceptualization of the research, study oversight, and critical review of the manuscript.FO provided study oversight and a critical review of the manuscript. RO analyzed data and reviewed the manuscriptLM analyzed data and reviewed the manuscript.

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Data availability

The data supporting these findings are available from the first author upon reasonable request.

Declarations

Ethical approval

The study was done in accordance with the Helsinki's declaration guidelines and written informed consent obtained from all participants prior to interviews. Confidentiality was ensured throughout the study while parents and guardians gave informed consent on behalf of children (persons below 18 years). The study was approved by the ethical review committee of Jaramogi Oginga Odinga University of Science and Technology (ERC 35/12/23 – 15/06) and the National Commission for Science Technology and Innovation (License No: NACOSTI/P/23/23921).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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