

Community Perception to Directly Observed Treatment Short Course among Tuberculosis Patients in Bahirdar, North Ethiopia (A Qualitative Study)

Hilawe Agizachew

Kidanemihret Higher Clinic, Bahirdar, Ethiopia

Meaza Demissie

Addis Continental Institute of Public Health, Addis Ababa, Ethiopia

Teshale Fikadu*

Arba Minch College of Health Science, Arba Minch, Ethiopia

Abstract

Background: Tuberculosis rates in the world remain high, especially in low- and middle-income countries including Ethiopia. International tuberculosis policy generally recommends the use of directly observed treatment short course to ensure treatment adherence. Even though Ethiopia adopted directly observed treatment short course in the early nineties, its' proper implementation is questionable. An understanding of perceptions of tuberculosis patients to this strategy, directly observed treatment short-course, is important to tuberculosis control programs. The aim of the study was to explore tuberculosis patients' perceptions to directly observed treatment short course in Bahirdar, Ethiopia. **Methods:** The study was conducted in 2013 in Bahirdar town North Ethiopia. A qualitative approach was used. Interviews and focus group discussions were conducted with patients attending directly observed treatment short course, health providers and health manager who were involved in the delivery of directly observed treatment short course in the public sector in Bahirdar town. Data were analyzed using open code software and qualitative content analysis. **Results:** The communities have both positive and negative perception towards DOTS; however the negative perception predominates due to reasons such as socioeconomic impact, its effect on patients work schedule, school attendance and lack of health staff support. **Conclusions:** These findings help to better understand the overwhelmingly negative perception of patients towards directly observed treatment short course. TB control programs should be aware of this and devise alternative mechanisms or interventions tailored to local context.

Keywords: TB, DOTS, Community Perception

1. Background

Ethiopia adopted the DOTS Strategy and has been implementing it since early 1990s and the STOP TB Strategy for TB control since 2006. Overall, DOTS coverage among government hospitals and health centers has reached to 95%. Though recently studies are showing a decline in the incidence and prevalence of tuberculosis in the country, Ethiopia is still one of the countries with high burden tuberculosis and also has large number of MDR TB cases [1-8].

With the change in treatment regimen, from INH and ethambutol (EH) in the continuation phase to RH (rifampicin and INH) the observed treatment has also changed from two months, which is only in the intensive phase, to six months which is the whole course of treatment. Although DOTS daily medication with fixed-dose is convenient to take and effective with minimal side effects, to attain full compliance with the medication, patients have to sacrifice important family responsibilities, and their work. The TB health workers need to convince the patients and need to deal with patient-specific problems; otherwise patients' trust on the effectiveness of TB treatment might be eroded. Novel strategies and more flexible options will have to be devised to ensure compliance to the DOTS and achieve higher cure rates without compromising patient choice [9-19]. This study was aimed at assessing the perception of patients and the challenges in relation with the application of DOTS.

2. Methods

2.1 Study Settings

The study was conducted in Bahirdar town 565 Km North-West of Addis Ababa, the capital city of Ethiopia. The town has an estimated total population of 298,098. Health facilities in the city included three hospitals, ten public health centers and fifteen private clinics. All the hospitals, health centers and five private clinics are part of DOTS program which offer short-course tuberculosis chemotherapy free of charge [20].

Participants were recruited from two public health facilities in Bahirdar, Ethiopia and data collection (in-depth interview and FGDs) took place from July 20-August 10, 2013.

2.2 Study design

A qualitative study design was used to explore tuberculosis patients' perception towards DOTS based on phenomenological approach. This design helped to describe the meaning and significance of the experiences in detail. Study participants were selected due to their knowledge or exposure to the phenomenon.

2.3 Study participants and sampling procedure

Patients were invited to participate in the study through oral invitation provided by the tuberculosis focal person working at the TB clinics during the study period. With purposive sampling technique adult TB patients on DOTS, nine for in-depth interview (five males and four females) and ten for FGD (six male patients and four female patients), were selected from public facilities. In addition, two health professionals from the health facilities and one health manager from the regional health bureau were selected for in-depth interview which helped to ensure trust worthiness through data source triangulation. The purposive sampling was used to involve participants who share particular characteristics and had the potential to provide rich, relevant and diverse data pertinent to the research question. This also allowed exploring perspectives from different groups here from patients and health care providers.

The number of participants was in such a way that an attempt was made to have participants varied in terms of their socio demographic characteristics giving emphasis to age, sex, educational back ground and occupation. This purposive recruitment for the study participants was conducted until the required number of participants with the required participant characteristic was attained and to the point of saturation.

Data were collected using both in-depth interviews and focus group discussions. In order to capture a diversity of views, a maximum variation sampling strategy was used when recruiting participants. Individual interviews were conducted with patients (five men, four women) who had been on DOTS for at least two weeks. Subsequently, two focus group discussions were conducted with a total of ten patients (six men and four women) who underwent treatment for TB when the study was conducted. In addition, three health professionals (two clinical nurses and one health officer) were interviewed individually.

2.4 Data collection tools

2.4.1 In depth interview guide

Semi structured interview guide was used for the in-depth interview involving TB patients on DOTS program. It consisted of eight questions. This open ended interview guide had pre-set questions which addressed perception on the delivery of DOTS, how they rate services under DOTS, what were its weaknesses, what did they expect and why. In addition socio demographic information including age, sex, marital status, education and occupation were collected.

Regarding the interview guide for the in-depth interview for the health professionals and health managers, it addressed the implementation of DOTS, what they think about patient's perception towards DOTS, challenges and areas of improvement in the implementation of DOTS.

2.4.2 Focus Group Discussions points

Each focus group was homogenous in terms of the various socio demographic characteristics for the purpose of making group discussions more interactive, and allowing individual freedom. Pre-set focus points were used for the focus group discussion. Similar topics were covered in the focus group discussions, and issues that arose in the interviews were brought up for further discussion.

2.5 Data collection procedures

After pretesting, audio-recorded individual interviews and focus group discussions were conducted by the investigator in Amharic which is the local language of the area. Individual interviews took place in private rooms. The interview took place with the help of an assistant for note taking and tape recording. Once again the FGDs were conducted by a moderator and attended by a note-taker which lasted 45 minutes to one hour. In all groups, the moderator encouraged participants to become actively involved in the discussion and ensured that each participant had an equal chance to contribute. This was ensured by doing the data collection in a separate room and explaining anonymity of participants, the tape recorded data and transcripts were handled only by the investigator and unique codes were used for identification.

Data collection was continued until the point where new interviews were not yielding new results, with saturation level reached. Field notes were made during the interviews and focus group discussions in order to maintain contextual details and non-verbal expressions for data analysis and interpretation. One patient refused to participate since she had no time for the interview as she left a young infant at home.

2.6 Data management

In addition to tape recording all interviews and FGDs, note taking took place as a supplement for contextual detail. The investigator transcribed daily each interview. The data were familiarized through repeated listening

and reading in order to ensure data cleaning. Then the transcribed Amharic version was translated to English. The cleared translated data was imported to open code 3.6 computer software.

2.7 Data analysis

The analysis method was thematic content analysis a process which involves systematically examining the data and other notes in order to identify themes and develop categories. It went through the process of systematically reducing the massive raw data to identify concepts and themes relating to the research question i.e. identifying how the participants perceive DOTS.

The final analysis was done using Giorgi's (1975) phenomenological method which appeared understandable and applicable to this study. Giorgi recommends a four-step analysis procedure: getting a total impression, identifying meaning units, abstracting the contents of individual meaning units, and summarizing their importance. The material was read and listened to several times to get an overview and subsequently units of meaning that represent different aspects of participants' perceptions about DOTS were identified. A list of codes was then created and the material was coded. The content of each code was condensed and summarized in order to make generalized descriptions concerning existing perceptions about DOTS (21).

The data was open coded and emerging concepts were delineated, conceptual clusters were formed to develop analytical categories which were then summarized and illustrated with direct quotes from the interviews to answer perception towards DOTS. Care was taken throughout to ensure that the investigator engaged with the words of the participants. The investigator identified concepts, themes, and patterns by reading and listening several times and used thematic content analysis to inductively develop relevant themes. These represent related themes and included positive and negative perceptions to DOTS. The positive perceptions are related to uninterrupted supply and free anti-tuberculosis drugs while the negative perceptions are related with; livelihood, social, school, stigma, professional practice and organization of care. The study considered the perspectives of tuberculosis patients attending DOTS, health manager, and health care providers regarding DOTS.

2.8 Ethical consideration

The ethical clearance was obtained from Gondar University Ethical review board. Informed (verbal) consent was obtained from the study participants after thorough explanation of the purpose of the study.

3. Results

A total of twenty two individuals, twelve males and ten females, participated in the study. The composition of the participants was: one health manager from Amhara Regional State Health Bureau, two DOTS health providers from the health centers and nineteen patients on DOTS. Twelve participants were involved in the in-depth interview while ten were part of the two focus group discussion, one group of six male participants and one group of four females.

Perception to DOTS

Generally patients perceive the DOTS program in two ways, negatively and positively. Nevertheless the predominant focus was on the negative aspect than the positive. The negative perception resulted because of different reasons such as its socioeconomic impact, its effect on work, school attendance and lack of health staff support.

Theme one: Negative perceptions to DOTS

A nurse described patients negative perception as follows, *"I think the community dislikes DOTS. When they finish the first two months they feel like unloading heavy weight from their shoulders....."*

Conflicting with livelihood

Both patients and nurses felt that DOTS is too rigid. It has no room for patients' concern particularly the livelihood of the lower class.

A twenty years old male narrated *"I was supporting myself, however the daily medication attendance persuaded me to give up. My best opportune time for work coincided with the time of the medication. I am no more able to cover my expenses for food and house rent. I became dependent on my families, who are living in the country side, for food while the renter considered my situation and did not urge me to pay now."*

A nurse also described, *"Patients do not like the daily medication attendance about nine out of ten patients do not like it and in particular field workers and private employees.....I knew a private employee at an internet café who was fired in two weeks due to his DOTS schedule."*

A twenty nine years old male was not sure how to deal with DOTS, *"I have used up all my sick leave and annual leave for the medication attendance. I am left with no choice. I do not know what to do as I am given a final warning by my boss. Unfortunately the long waiting time here, the medicine should be taken empty stomach and need additional time for breakfast made me unable to get to office on time."*

Social issues

Participants indicated that family and community issues are very important part of their lives and they are

expected to attend, however they are unable to do that because they have to come daily to the clinic.

Twenty five years old male patient described how his friend defaulted *“He was attending daily medication with me when he was told the death of his brother. He begged for three days’ extra medicine but no one listened to him. He went and never came back. I am scared if same kind of event happens to me along the course of treatment.”*

In addition, a clinical nurse made statements that suggested something similar,

“A man who had regular DOTS attendance and received a court order some other place was not able to get the medication from the nearby health facilities and ended up in defaulting.”

School absenteeism/drop out

Clash with classes including exams and drop out of school is what concerns students who are attending DOTS as described below.

An eighteen years old student stated, *“I missed one or two classes because I did not find the DOTS nurses on time. The assigned nurse was not around; there was no replacement; I should wait for her. I reached school late and got punished many times.”*

Similarly another male student stated *“.....I was a student however the rigid schedule here forced me to drop out. I missed many classes and was not able to sit for exam...”*

Health service/ attitude of health providers

Tuberculosis patients attending DOTS complain of the hostile attitude of health staff and unpleasant clinic visit hour.

A twenty five years old patient stated, *“They should always think how to serve patients. Patients get easily frustrated if not treated well. Nowadays, proper customer service is not only about ethics but also sign of civilization. As I said before she scolded me for being late; in order not to get things worse I accepted as if I was wrong. Other patients may feel hopeless and interrupt treatment particularly illiterates.*

A thirty years old female focus group participant describes the opening time of the clinic, *“The clinic opening time is late for many reasons. One day it got very late because they (nurses) were in a meeting; we went to the meeting hall to remind them, but they told us to go back to the clinic until they finish the meeting”.*

Stigma

Directly Observed Treatment Short course is stigmatizing or exacerbates the stigma related to the disease; this is supported by two tuberculosis patients interviewed.

“I do not quit attending daily medication even if people stigmatize. I take my medicine even if people insult or stigmatize. People think they are healthy but many are not. Those who used to stigmatize are now like us; so I am concerned more on my health, not the social disapproval. I leave that to GOD.”

Unsupervised treatment

Most patients stated that no one really supervised them when they swallow medicine however respondents contested the benefits of coming to the clinic. .

Thirty two years female patient stated, *“To tell you the truth, there was no one who observed while we took medicine. If you do not take, it is up to you. That is the case here. I do not know why they refused to offer us the medicine to be taken at home? ”.*

Fatigue

Fatigue was the other issue raised by patients who were too weak to walk.

Thirty years old female narrated, *“I live near to the clinic but I was too ill; when you are ill, it is difficult to walk to this door. It is near for healthy person but was not for me it used to take me four hours. Now I am better even though I do not know the exact time it takes me to reach here. I try to be fast to reach in time; however the fluid in my lung couldn’t allow me, and I walk slowly.*

Theme two: Positive perceptions to DOTS

The reasons for perceiving it as a sound treatment option was explained by fact that it is offered free and guaranteed a complete supply of drugs.

Uninterrupted supply of anti-tuberculosis drugs

Although the health manager interviewed indicated shortage of anti-tuberculosis drugs, all patients appreciated that they have never encountered any interruption of their medicine.

A thirty years old female patient described as follows: *“No interruption at all rather they checked daily attendance using our patient ID. They tell us to come with the ID so that they check for the daily attendance.”*

Anti-tuberculosis drugs free of charge

All participants are pleased that the treatment is free of charge.

“It is good that the drug is free. If it were not, poor people like us would not have benefitted. That is the good part of it.”

Opinions about TB Treatment

In terms of personal opinions on how the program could help achieve full compliance with treatment from patients, most suggested that drugs should be given to patients at least every week or schedule should be flexible

and individualized.

Twenty years old patient suggested, *“The current schedule is difficult to stick to for six months. It is not only the physical disability but the conflict with work. I prefer weekly visit as it may be acceptable to be late to the office once a week”*.

4. Discussions

This study revealed that although tuberculosis patients perceive DOTS both positive and negatively they predominantly focused on the negative aspect of it. The reason why they perceived negatively include: socioeconomic difficulties, its clash with work, school absenteeism and low level of staff support.

All patients expressed disappointments, especially with regard to the daily medication attendance. The health providers interviewed were also aware of this concern among patients.

The time needed to present for daily medication attendance compromised their other daily tasks. There was a common perception among participants that DOTS, particularly in its rigid way in the first two months, were unacceptable and it is impacting adherence to tuberculosis treatment and tuberculosis control.

Many of the patients were either out of work or in dilemma to choose between work and daily medication attendance. Several reports from other developing countries also showed, DOTs at a health facility often meant that patients had to give up part of their working day to attend their medication. They often face a choice between employment and taking medication for tuberculosis (22-26).

Several studies indicated that having TB and DOTS had consequences for work and patients losing their jobs and the opportunity to work have been reported in other parts of Ethiopia consistent with this. Patients who worked in the private sector and "daily laborers" (persons who are not employed on a permanent basis, but who may meet at a regular point every day to compete with others to be hired for the day) were most affected.(24) This was manifested in patients feeling “forced” to choose between work and attending DOTS.

Participants reported that the rigid nature of DOTS exacerbated the financial problem and were made to consume the little they saved or looked for support from relatives. Some patients also incurred transportation cost when they felt weak. Conflicts between treatment and work and the hidden costs of treatment, resulting in expenses exceeding resources could push people into poverty as shown in other studies. This has created a strong negative perception towards DOTS (27-33).

The findings showed that involving in social issues are very important in the lives of the patients. They perceived that these concerns were not considered by the DOTS providers; as a result many with such kind of social events default from treatment. Such decisions were triggered by the fact that DOTS was too rigid to allow few days’ tablets for self-administration or the health care system is unable to arrange other safe means of treatment delivery when patients have some problems to come for daily treatment. In line with this finding, a study conducted in Addis Ababa found that social obligations like attending funeral was one of the most frequently cited reasons for treatment interruption (24, 26). Participants regarded DOTS as highly inflexible as it did not allow exceptions to family or social events; patients can have more pressing issues to attend to in everyday life, such as taking care of family member, social and cultural events (23, 32).

Student patients also noted their difficulties to manage classes. They were not exceptions for the rigid daily attendance at the health facilities. They were always missing classes as it was not possible to reconcile with DOTS. They suffer more during examination times since the treatment arrangements is time consuming. Studies indicate that where direct observation of treatment by health workers is not feasible, community based DOTS strategies can attain international targets for treatment success. This permits patients to select their treatment supervisor from the community, thereby incorporating social networks as a means to increase adherence (34-38).

Throughout all interviews it was clear that rigid health facility routines and health staff attitudes were viewed by the patients negatively. They faced humiliation, scolding and insult by the staff for not adhering to the system or raising their concerns. Long waiting time was viewed by most patients as extremely disappointing. It took hours particularly on weekends or when staffs have meetings. The long waiting times, inconvenient opening times and uncaring health provider attitudes were seen in other studies in Asia and Africa also. Poor communication among patients and health providers can contribute to treatment non-adherence while support from health providers is crucial to overcome many challenges patients face during the protracted DOTS regimen (12, 28, 30, and 35).

Health staffs have also difficulties in managing issues related to DOTS that were raised by patients who were private employees, field based staff and disabled. These kind of issues should get attention and alternative plans need to be devised for special situations. Although we have observed a perception of both physical and social distance between patients and health care providers; a recent study in North Ethiopia reported that most patients attending DOTS were satisfied with the facilities available and the interaction they had with certain staff (29).

The core idea of DOTS is for treatment supervisors to watch patients while swallowing the medicines. Unfortunately this vital element of DOTS strategy is not practiced the way it has to be practiced; there is no

point of going daily if there is no supervised medication intake.

Limitations of the study

The study was limited to patients attending DOTS in an urban setting and did not include defaulters due to the shortage of resources and time.

5. Conclusions

The overwhelmingly negative perception of patients towards directly observed treatment short course makes it a worrisome issue. Patients often attend daily medication attendance under difficult circumstances and experience significant challenges, many of which are beyond their direct control. The long waiting time and poor health staff support aggravated the negative aspect towards DOTS. DOTS facilities should improve waiting time and ensure professional ethical practice, some alternative mechanism of safe treatment delivery need to be explored tailoring to the local context.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AH involved from the inception to design, acquisition of data, analysis and interpretation, drafting the manuscript, **FT** involved in the inception to design, analysis and interpretation and revises the manuscript, **DM** involved in the inception to design, analysis and interpretation and revises and edits the manuscript for the final submission. All authors read and approved the final manuscript.

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