

LIVED EXPERIENCES OF MEN AND WOMEN DIAGNOSED WITH TUBERCULOSIS AT A RURAL COMMUNITY IN SOUTH AFRICA

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Abstract

The study was qualitative and phenomenological, and aimed at exploring and describing experiences of living with tuberculosis. It took place in Limpopo Province of South Africa amongst purposively selected people living with tuberculosis. Thirty-six were eligible but eight participated due to data saturation. In-depth interviews were conducted in Sepedi. Interviews were transcribed verbatim and translated to English. The researchers analysed data independently, using Tesch's method and agreed on the themes. They ensured trustworthiness and observed research ethics. Four females and four males aged between 20 and 68 years participated. They shared diverse experiences of living with tuberculosis, presented in four themes and six sub-themes. They include experiencing disease stigma, social support, physical and emotional effects of tuberculosis, and treatment side effects. As service delivery institutions, clinics should identify and explore experiences of patients who are customers. Knowledge of these experiences should enable healthcare managers to deliver responsive healthcare services.

Key Words: Patient experiences, Tuberculosis, responsive health services, social support, disease stigma.

Introduction

In 2018, the World Health Organization identified South Africa as among countries that are highly challenged by tuberculosis (TB) in the world (World Health Organization, 2018). Due to failure to address poverty by governments of some countries, TB is still a public health challenge even though it is preventable and curable within six months of taking treatment under supervision and support (Benatar & Upshur, 2010). Failure by the health care system to effectively manage TB in most countries has led to the disease remaining one of the public health challenges globally (World Health Organization, 2018; Thomas, Shanmugam, Malaisamy, Ovung, Suresh, et al., 2016).

Review studies show that TB is associated with poverty and lack of food security (Balinda, Sugrue, & Ivers, 2019; Warren, 2017; Pedrazzoli, Houben, Grede, de Pee, & Boccia, 2016). Another review study shows that people living in poverty are at a greater risk of being infected with TB when they are in contact with those already living with it at homes, at places where people meet in large numbers such as hospitals, boarding schools, prisons and workplaces as well as in public transport systems such as taxis, buses and trains due to their weakened immune systems (Auld, Shah, Cohen, Martinson & Gandhi, 2018). Stigmatization often occurs against people living with or suspected to be living with TB, and this makes the control of TB very difficult (Daftary, Frick, Venkatesan & Pai, 2017). A qualitative study amongst African men with a history of living with TB reveals that some people are stigmatized as a result of living with TB, or being suspected of living with TB (Chinouya & Adeyanju, 2017).

Studies show that TB needs an extensive treatment plan of up to six months, which can be prolonged to reach complete recovery (Maria, Aryani & Arista, 2015; D'Ambrosio, Centis, Sotgiu, Pontali, Spanevello & Migliori, 2015). An extensive treatment plan is a burden to patients, and some may terminate it before they reach complete recovery. Because of this burden, social support is required to ensure adherence to and completion of treatment. Such support can be in many ways such as treatment reminders and tracers using mobile health technologies (mHealth) or home visits. Families, friends and health professionals as well as community health workers (CHWs) can provide these forms of social support to people living with TB. (Alipanah, Jarlsberg, Miller, Linh, Falzon, Jaramillo, & Nahid, 2018; Sukumani, Lebeso, Khoza & Risenga, 2012).

Understanding patients' experiences of living with TB helps health system managers to design and deliver responsive health care services. Patients' experience refers to subjective and objective view of the quality of TB care that they receive from health care services (Holt, 2019). Positive patient experiences may lead to adherence and proper use of TB health care services, while negative patient experiences may lead to defaulting and abuse of the health services.

Methods

Study design

This study used qualitative approach with a phenomenological design. A phenomenological design is suitable for studies that explore lived experiences, thus we found the design suitable for our study as it aimed to explore and describe lived experiences of TB patients (Moxham & Patterson, 2017).

Study setting, population and sampling

The study area selected was selected rural communities of Bakenberg local area in Limpopo Province of South Africa. Health facilities in the area included eight primary health care (PHC) clinics and some indigenous health practitioners. People living with TB and accessing treatment at the eight PHC clinics were purposively selected for the study. TB registers were used to identify participants meeting the inclusion criteria. Thirty-six (36) participants met the criteria but eight participated due to saturation of data. Included in the study were adult men and women willing to share their experiences and on the continuation phase of TB treatment, which means they should have more than two months on TB treatment.

Data collection method and procedure

One of the authors conducted in-depth interviews using an interview guide for seven months. Interviews were conducted at the patients' homes at times agreed with them. Participants were interviewed once during the data collection period and an audio recorder was used to capture the information. Immediately after each interview, the interviewer took field notes to record contextual observations. The interview guide was used to collect biographical data and contained a central question with some possible probing questions (see Table 1). The interview guide was translated from English into the local language (Sepedi) by the authors as they speak both languages. All interviews were conducted in Sepedi as the preferred language for participants.

Table 1: Interview guide

Biographical data	Age	Gender	Educational status	Marital status	Employment status
Central question	What are your experiences of living with tuberculosis (TB)?				
Possible Probing questions	<ul style="list-style-type: none"> • How did you know you have TB? • What are your concerns about living with TB? • How do you feel about the process of collecting TB treatment? • How do you feel about the care provided to you at the clinic? • What can you say about your interaction with your family? • How will you feel if other people know you have TB? • What can you say about your interaction with members of the community? • What is your understanding of TB? • How do you feel now after talking to me about you condition? 				

Data analysis method

Analysis of data started during data collection to ensure sufficient probing. The interviewer transcribed each interview before conducting the next one. This enabled the interviewer to be aware of issues to probe and thus improve the interview technique with the next participant. This approach enabled the interviewer to be aware of reaching data saturation, thus discontinuing further interviews. At the end, all audio-recorded interviews were transcribed verbatim and translated from Sepedi into English. During transcribing, the audio recordings were played several times. This facilitated immersion into the data. The researchers independently analysed the transcripts using Tesch's open coding method with the following steps (Theron, 2015):

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- Making a list of topics from the ideas.
- Coding by writing condensed topics adjacent to the relevant segments of the transcript.
- Finding and turning best expressions of the topics into themes.

The researchers used reflexivity and bracketing to exclude preconceived ideas or biases as recommended for qualitative researchers (Grove, Burns & Gray, 2012). After independently analysing the data, the three researchers met to discuss and agree on the themes. Copies of the transcripts and field notes were sent to an independent coder for analysis. Thereafter, the researchers and the independent coder met to reach agreement on the final themes.

Ethical considerations

The study was part of Master of Public Health (MPH) research project, as such, ethical clearance was provided by the university's research and ethics committee (TREC/119/2015:PG). Permission to access the participants was given by the Department of Health, to which the PHC clinics reported. Participants gave informed consent to participate and were made aware of their rights to refrain from answering some of the questions or to withdraw completely from the study if they felt uncomfortable. The study had the potential to cause emotional harm, as such, the researchers arranged with professional nurses at PHC clinics to provide counselling if needed and to refer others to psychologists and social workers. To ensure anonymity of participants and of PHC clinics as well as that of professional nurses working at those clinics, the participants were requested not to mention names during the interviews.

Trustworthiness

The researchers used credibility, transferability, conformability and authenticity as strategies to ensure trustworthiness (Polit & Beck, 2009). The interviewer spent about seven months with the participants, interviewing them individually until reaching saturation of data. Deliberate probing during interviews enabled the interviewer to comprehend the lived experiences of participants. The interviewer repeatedly rephrased the participants' responses to confirm that accurate information was captured as recommended in qualitative interviews (De Vos, Delpont, Fouché & Strydom, 2011). Furthermore, the researchers used an independent coder to also code the data. Thereafter, they met to compare and discuss the codes to confirm the findings. It is recommended that qualitative researchers provide detailed descriptions of the method and findings so that the audience can evaluate the applicability of the study to other settings (Polit & Beck, 2009). To satisfy this, we provide (in this paper) full description of data collection, analysis and interpretation method as well as the findings, which are supported by direct quotes from the participants.

Results

Four females and four males aged between 20 and 68 years participated in the study. Only two participants were employed, one completed Grade 12 while two had no formal schooling. The participants shared diverse experiences of living with TB, which are discussed in four themes and six sub-themes. Themes are theoretical relationships that emerge after the researchers have examined data by categorizing and sorting them into groups to look for patterns (Theron, 2015). As Charlick, McKellar, Fielder and Pincombe (2015) recommend, the themes are summarized in Table 2 to help readers have an overview before getting into individual themes.

Table 2: Themes and sub-themes of living with tuberculosis

Theme	Sub-theme
1. Stigma	1.1 Non-disclosure and disclosure 1.2 Disconnecting and remaining connected 1.3 Fear of TB and HIV association
2. Social support	2.1 Social support from the family 2.2 Social support from community health workers 2.3 Social support from nurses
3. Physical and emotional effects of TB	
4. Side-effects of TB treatment	

Theme 1: Stigma

Sub-theme 1.1: Non-disclosure and disclosure

Some participants reported their preference not to disclose the type of illnesses they were living with due to fear of discrimination. This is shown in the following statements. *“I would have a big problem if people found out I had TB. I don’t like it; I rather not share. I cannot share my problems with gossipers.”* Another added: *“My friends just know that I am sick, but they don’t know that I have TB.”* Others reported to have disclosed that they were living with TB to some people they trusted. This is evidence by the statements below. A participant said: *“My friends know that I have TB; I told them.”* Another added: *“When I went back to work, I explained my situation to my boss and also disclosed to other co-workers.”*

Sub-theme 1.2: Disconnecting and remaining connected

The study revealed that stigma made some people living with TB to disconnect from other people in their communities. A participant related: *“I’m always at home, I hardly go outside my house because here at my village people are very cruel, they like to gossip about other people. That is why I don’t even have friends.”* Another added: *“I mean I was afraid, to be seen by others when I went to clinic because they were going to talk about me, or maybe gossip about me when I pass by.”* Another participant who disconnected also added: *“Because when I started treatment I was very thin; I was worried how people were going to react when they saw me.”* Although some disconnected from people, other people remained connected and reported that living with TB has not changed their social lives. One said this: *“Most of my friends would visit me at home; share food and water without making me feel dirty or filthy. They even used the same cups that I used to drink water without fear of infection.”*

Sub-theme 1.3: Fear of TB and HIV association

Some participants reported their fear of being infected with Human Immunodeficiency Virus (HIV) during the process of TB diagnosis, and reported relieve when they tested negative for HIV. A participant said: *“I was afraid when my blood was collected for HIV because the nurse told me that TB and HIV go together. My mind just got afraid. And when the nurse told me I didn’t have HIV disease, I was very happy and relieved.”* Another who suspected or feared that he had HIV and not TB infection said: *“I was afraid that I might be having HIV and not TB. So I accepted the TB diagnosis and just told myself I would take TB medication.”* Others revealed their fears of being perceived by other community members as co-infected with HIV even when they were only diagnosed as living with TB only. One participant said: *“I was afraid they were going to start a rumour about me saying that I have HIV. As such, I was afraid my life was not going to be fun anymore.”*

Theme 2: Social support

Sub-theme 2.1: Social support from the family

Some participants enjoyed physical and psychological support from their families whilst others experienced the opposite. A participant said: *“my family is very supportive of me.... from the first day, when I was very weak my mother did everything for me.”* Another added: *“At home, the support is great. They don’t treat me in isolation because of my TB status. They sit with me and help me when I cannot do things for myself.”* A participant who experienced discrimination at home said this: *“My mother said “My child, you must now use your own kitchen utensils and stay in your own house.”*

Sub-theme 2.2: Social support from community health workers

Some participants revealed that community health workers (CHWs) who are commonly referred to as DOTS supporters, home-based carers or caregivers provided them with social support. A participant said: *“...am grateful for the way the home-based carer helped me. She came daily to see how I slept. That woman knows her work very well.”* Another participant added: *“If I forget to go to the clinic, I can still call my home-based carer to collect the medications on my behalf.”*

Sub-theme 2.3: Social support from nurses

Some participants reported enjoying visits to the local PHC clinic, as they never had to queue for consultation like other community members. The following statement shows this: *“I never had to queue for treatment at the clinic, whenever I get to the clinic I am attended first, so I never complained.”* Another said: *“I never had*

problems with the nurses, when I went to the clinic they would ask me how medication was affecting me and asked me to tell them when the treatment was not making me feel well.”

Theme 3: Physical and emotional effects of TB

Some participants revealed the misery caused by the phenomena of living with TB, which included general body pains, bleeding, emotional stress and body wasting. A participant said: *“with me when the signs started, my feet were painful.... I could not walk; I was very thin.”* Another added: *“I could not speak; all I could do was to shake my head when my brother greeted me.”* Another related fear of sleeping due to feelings of drowning in his blood: *“At night when I slept I was like drowning in my own blood, at times I even feared to sleep.”*

Theme 4: Side effects of TB treatment

Some participants experienced discomforts and unusual symptoms, which they associated with side effects of treatment they were taking. These included insomnia, renal impairment and fatigue. A participant said: *“At first I was passing pink-coloured urine which made me worry.”* Another participant added: *“My concern is for me to get TB treatment that will make me very happy and this will be only if I get the real treatment that will make me sleep well and wake up feeling strong to do my daily chores.”*

Discussion

Our study found that some participants feared being stigmatized. A qualitative study amongst people living with TB in Malawi reveals that stigma occurs when members of the community reject people that they perceive to have characteristics that are undervalued in that community (Zolowere, Manda, Panulo & Muula, 2008). This rejection or fear thereof makes some people living with TB to conceal their condition. Quantitative and qualitative studies from South Africa reveal that this concealment may delay or prevent them from seeking help and adhering to treatment (Cramm, Møller & Nieboer, 2012; Mabunda, Khoza, Van den Borne & Lebesse, 2016). We also found that some participants feared that their conditions were assumed as living with HIV. Associating TB and HIV symptoms influences some people living with TB to delay seeking treatment due to fear of being told that they had HIV (Mabunda, Khoza, Van den Borne & Lebesse, 2016). This perceived association is not far-fetched, as some studies reported high incidence of TB among people living with HIV (Phyo, Oo, Harris, Saw, Aung, et al., 2019; Endalamaw, Ambachew, Geremew & Habtewold, 2019). A quantitative cross-sectional study from Ethiopia reports that some people living with TB stigmatize themselves (Duko, Bedaso, Ayano & Yohannis, 2019).

According to a qualitative study conducted in the North West Province of South Africa regarding the experiences of people living with TB on being put on Directly Observed Treatment Short-course (DOTS), social support for people living with TB can improve adherence to treatment and prevent its spread (Serapelwane, Davhana-Maselesele & Masilo, 2016). Our findings show that some participants who received support had a positive outlook of their lives, while others who did not receive such support felt sad and rejected by their families. A qualitative study conducted amongst people living with TB and health workers in Eritrea support this finding by revealing that social support from families enables people living with TB to adhere to treatment (Gebreweld, Kifle, Gebremicheal, Simel, Gezae, et al., 2018). However, another qualitative study from India amongst people living with TB and receiving DOTS from CHWs shows that patients are satisfied with the social support from CHWs (Yellappa, Lefèvre, Battaglioli, Narayanan & Van der Stuyft, 2016).

Our study is in agreement with a qualitative study amongst community members and people living with TB in Malawi which found that some families rejected people living with TB due to fear that they would transmit the disease to the whole family (Nyasulu, Sikwese, Chirwa, Makanjee, Mmanga, et al., 2018). A qualitative study from Limpopo province of South Africa amongst TB coordinators, professional nurses, DOT supporters, community members and people living with TB reveals that negative attitudes by some health workers lead to defaulting of treatment by those living with TB (Mabunda, Khoza, Van den Borne & Lebesse, 2016). It is revealed that some people living with TB are unable to report their dissatisfaction with TB care services out of fear of punishment (Serapelwane, Davhana-Maselesele & Masilo, 2016). An editorial, a qualitative study from Latvia amongst nurses, doctors and social workers involved with delivery of TB control services and a mixed methods study from the Eastern Cape province of South Africa amongst CHWs recommend that collaboration between health professionals, patients, CHWs and family members be adopted to improve compliance to treatment (Verma, Furin, Langer & Traverso, 2019; Kielmann, Vidal, Riekstina, Krutikov, van der Werf, et al., 2018; Okeyo & Dowse, 2018).

According to a qualitative study amongst people living with TB in Indonesia, it is common for people living with TB to claim to have experienced physical pain, and this claim leads to feelings of anxiety (Maria, Aryani & Arista, 2015). Another qualitative study amongst people living with TB in Limpopo province of South Africa support this by revealing that there are perceptions among some people living with TB and some health care workers that TB leads to pain, frailty and emotional distress (Maswangany, Lebese, Mashau & Khoza, 2014). Qualitative studies from South Africa and India reveal that side effects of TB treatment are some of the barriers to adherence. (Mabunda, Khoza, Van den Borne & Lebese, 2016; Yellappa, Lefèvre, Battaglioli, Narayanan & Van der Stuyft, 2016; Maswangany, Lebese, Mashau & Khoza, 2014)

Conclusion

PHC clinics are service delivery institutions while people living with TB are customers. As such, clinics should identify and explore experiences of TB patients with the health services that they receive. Some people living with TB experience disease stigma, side effects of medicines and negative effects of the disease. Others experience social support from their families and from health care workers. Knowledge of these experiences should enable health care facility managers and other policy makers and policy implementers to plan and deliver responsive healthcare services in order to facilitate adherence to treatment and to end the global TB epidemic. To ensure smooth transition and continuity from hospital to community and family settings, people living with TB should be provided with sufficient information on TB medication so they can understand side-effects and adhere until recovery. A possible limitation of this study is the social desirability bias where participants speak positively to interviewers during data collection.

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