RESEARCH ARTICLE

BEING DIAGNOSED WITH MULTI-DRUG RESISTANT TUBERCULOSIS: EXPERIENCES OF PATIENTS FROM RURAL KWAZULU NATAL, SOUTH AFRICA

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INTRODUCTION

Tuberculosis (TB) is one of the fastest growing epidemics in the world, and sub-Saharan Africa accounts for 79% of the disease burden. South Africa accounts for over one quarter of all TB cases in the region and has the third highest incidence of TB cases in the world. The increase has been driven mainly by the high prevalence of HIV in the population, where 80% of HIV infected people are co-infected with TB. Globally, HIV co-infection has overwhelmed and disrupted established TB control programs, causing increase in the treatment failure rates and increased the opportunity for TB to emerge and spread among both HIV-infected and uninfected persons. Multi-drug resistant (MDR) tuberculosis is defined as disease caused by Mycobacterium tuberculosis with resistance to at least two anti-tubercular drugs Isoniazid and Rifampicin. MDR-TB is currently a major public health problem worldwide. WHO estimates show that in 2011, there were about 310,000 cases of MDR-TB among notified TB patients with pulmonary TB in the world. South Africa is among the countries that has experienced a dramatic rise in MDR-TB cases over the past decade and is rated as having the highest number of drug-resistant TB cases in the world. In 2011, there were about 10,085 cases of MDR-TB among notified TB patients with pulmonary TB in South Africa. Factors that favor the development and spread of MDR-TB are incomplete or inadequate therapy, prolonged infectiousness of patients due to delayed diagnosis of MDR-TB, and the absence of effective therapy. In developing countries including Sub-Saharan Africa, MDR-TB is further exacerbated by increase TB-HIV/AIDS rates and hospital infrastructure that is limited or non-existent. Furthermore, MDR-TB has been associated with poorly managed TB control programs, unenforced hospital infection control, and poor adherence to treatment. Although treatment for MDR TB is becoming increasingly available in resource limited settings, up to 48% of patients who receive second-line drugs have been reported to default from treatment. Recent data from well-developed countries show that only a small proportion (7.0%) of patients with MDR TB were able to completely adhere to treatment over the entire treatment course. Completing MDR-TB treatment is more challenging than completing first-line TB treatment because MDR-TB treatment often requires longer duration, is considerably more complicated, expensive, and toxic, and results in lower treatment success rates. Treatment default poses a public health threat because individuals who do not complete therapy are more likely to remain infectious. A major public health concern is failure to adhere to MDR-TB treatment may result in primary transmission of MDR-TB in the community, where the majority of MDR-TB patients are cared for. Currently, there is generally poor understanding of the reasons why TB and MDR-TB patients discontinue or default from treatment. Furthermore, there is a gap in literature on the social consequences of MDR-TB diagnosis. The fear attached to TB underlies the beliefs, attitudes, actions and behaviors of the whole community when interacting with patients, how much more when the patient is diagnosed with MDR-TB which is often perceived as fatal by communities. The lack of qualitative data might explain the lack of in-depth information on the reasons TB and MDR-TB patients discontinue or default from treatment. This

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ABSTRACT

Multi drug resistant tuberculosis (MDR-TB) is a public health problem worldwide, and South Africa has experienced significant rise in MDR-TB cases over the past decade. Of concern is that only a small proportion of patients adhere to MDR TB treatment completely. This study explored the experiences and social consequences of being diagnosed with MDR-TB. In-depth and semi-structured interviews were conducted with 50 patients receiving MDR-TB treatment in a community clinic in rural Kwazulu Natal, South Africa. More females (63.6%) than males (36.4%) were infected with MDR-TB in this sample. Twenty one (63.6%) patients were co-infected with HIV. Of the 33 patients interviewed, 24 (72.2%) were treated for TB, and 8 (24.2%) were hospitalized for TB treatment prior to the onset of MDR-TB. A quarter (24.2%) experienced stigma and rejection after disclosure of MDR-TB diagnosis. Patients interrupted medication when they had no food, had no money to pay for transport to collect treatment, and when the clinic ran out of stock. Stigma and rejection were also cited as reasons for non-adherence. Family support is crucial in the life of MDR-TB patients. Healthcare providers need to create awareness about MDR-TB to strengthen family capacity to provide support for patients with MDR-TB. © Copy Right, IJRSR, 2013, Academic Journals. All rights reserved.

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study will used a qualitative approach to explore the experiences and the social consequences of being diagnosed with MDR-TB among patients receiving treatment from a community clinic in rural KwaZulu Natal, South Africa.

MATERIAL AND METHODS

Study design

A qualitative design was used to explore the experiences of patients diagnosed with MDR-TB.

Study setting and population

The study was conducted in a primary health clinic attached to Ngwelezana hospital where the patients were diagnosed with MDR-TB. This hospital does not have admission facilities for MDR-TB patients, but refers them to the King George hospital for admission and treatment of MDR-TB. On discharge, the patients are referred to the primary health clinic for their monthly injections. The study recruited adult MDR-TB patients who were receiving treatment at the primary health clinic. The names and addresses of MDR-TB patients were obtained from the register at the TB clinic in Ngwelezana hospital. The nurse in charge of the clinic and the patient tracing team from Ngwelezana Hospital assisted with the recruitment of the patients. During the study period, 50 patients who were diagnosed with MDR-TB were able to be traced and invited to participate in the study.

Data collection

In-depth interviews were conducted with 13 patients and semi-structured interviews with 33 patients. Semi-structured interviews were conducted to collect data on patient’s socio demographics, history of TB treatment, onset of MDR-TB, hospital admission for TB treatment, and exposure to MDR-TB. This was followed by in-depth interviews to further explore some of the concepts that emerged from the survey. The semi-structured interviews were conducted at the clinic and the in-depth interviews were conducted in the homes of the patients. In-depth interviews were conducted in IsiZulu and were audio recorded with the permission of the patients. Data were collected by a trained research assistant.

Data analysis

The audio tapes were transcribe verbatim in IsiZulu and translated into English. Content analysis was used to analyze the data. The transcripts were read thoroughly to identify key concepts or themes. The transcripts were then coded using NVivo 8 qualitative software. The emerging themes are presented thematically and direct quotations from the participants are used to emphasize what the data show. Qualitative data was analyzed using STATA version 10 statistical software package. Summary statistics was used to calculate and interpret the mean, median, and to obtain frequency tables for discrete variables like gender.

RESULTS

A total of 33 patients on MDR-TB treatment participated in structured interviews. There were more females 21 (63.6%) than males 12 (36.4%) in the sample. The age of the patients ranged between 16 and 59 years, and the mean age was 34.9 years (SD=10.9 years). With regards to HIV status of the patients, majority 21 (63.6%) were co-infected with HIV and were receiving antiretroviral treatment. Three quarters 24 (72.7%) of patients were treated for TB while 8 (24.2%) were hospitalized for TB treatment in the past 12 months prior to onset of MDR-TB. The patients were asked about the reaction of the family to disclosure of MDR-TB diagnosis, 25 (75.8%) had a positive reaction while 8 (24.2%) patients were rejected and isolated by their families and friends. The majority 27 (81.8%) had good adherence to MDR-TB treatment while 6 (18.2%) defaulted or interrupted their treatment (Table 1).

<table>
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<th>Variables</th>
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<td>Positive</td>
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<tr>
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Themes

Data analysis of thirteen in-depth interviews with MDR-TB patients generated four themes; dealing with MDR-TB diagnosis, disclosure of MDR-TB to family, reaction of family and friends to MDR-TB diagnosis, and adherence to MDR-TB treatment.

Dealing with MDR-TB diagnosis

For most patients, the MDR-TB diagnosis was difficult to accept, so because patients only learned about MDR-TB during diagnosis. Most got the information on MDR-TB from the health care workers after diagnosis and did not know where and when they were infected. Patients reported feelings of pain, sadness, fear of death and dying, and hopelessness. I never thought that I was going to live… I thought I was going to die. I first got HIV, then TB and now MDR-TB. I was hurt, when I had MDR-TB I was still dealing with HIV, I kept on crying because I was hurting (Female participant, 43 years). I asked myself why am I the first one to be diagnosed, why am I the first one and not other persons… it had to start with me so that others could see. I was hurt because it separated me from my family and I stayed in a foreign place for a long time (female participant, 41 years).

Disclosure of MDR-TB to family

Most of the patients informed their family members about the MDR-TB diagnosis. Most reported that they were very sick when
they were diagnosed and that they informed their families from whom they could get support during treatment
I was too sick and weak, I was vomiting and had headache (Female participant, 42 years).
I was too sick such that I couldn’t even walk on my own (Female participant, 29 years).
I was too sick, I would lie there and the only thing that was left was for me to die (Female participant, 55 years).
I told them at home because I wanted to live and they could support me (female participant, 43 years).

**Reaction of family and friends to MDR-TB diagnosis**

Patients reported about the reaction of family members after being told about the MDR-TB diagnosis. The data revealed that patients experienced mixed responses and reactions from family and friends after being informed about the MDR-TB diagnosis. However, quarter of the participants reported being discriminated by the people they disclosed to.

They were scared, they could not even visit me, they could not even call me to say come and stay next to me. I stayed alone until I went to hospital (female participant, 41 years).

My friends deserted me but my mother even though she passed away she accepted and even at home they accepted me (male Participant, 37 years).

My family should have supported me when I was in hospital, they didn’t even visit me (Male participant, 31 years).

I was hurt because people discriminate against you if you have this disease because they think you are going to infect them (female participant, 42 years).

The data further show that few participants reported that they were accepted and had empathy and support from their families.

My family accepted me because they were visiting me in hospital and they were even bringing me food (Female participant, 33 years).

My family was supportive emotionally because even when I told them that I have MDR-TB, they are the ones that encouraged me that 6 months of injection is nothing, it will soon pass (female participant, 36 years).

**Adherence to MDR-TB treatment**

The participants were asked about their experiences of taking MDR-TB treatment and were asked to report if there was a time when they ever stopped taking their MDR-TB medication. The data show that only a few participants reported stopping MDR-TB treatment. Various reasons were cited for stopping treatment.

I was very happy to stay at the hospital because here at home you find that some days we go to bed without having eaten, we don’t have food. You see…, you don’t take your treatment properly because you have not eaten. You don’t take your pills because your stomach is empty and don’t have food. Right now it will be better if they can take me to a safe place because I am currently not taking treatment, and I drinking alcohol and I am going to die (female participant, 55 years).

We encounter problems in Ngwelezana hospital…, they don’t give us food parcels. You find that sometimes you don’t go to collect treatment on the scheduled day because they do not give us an ambulance to take us to the hospital to collect our treatment(male participant, 37 years).

We sometimes have a problem here in the local clinic, they keep on saying the treatment has not been ordered (male Participant, 36 years).

**DISCUSSION**

The study found that more females 21(63.6%) than males 12 (36.4%) were infected with MDR-TB. Two thirds (63.6%) of the patients were co-infected with HIV. Of the 33 patients interviewed, 24 patients (72.2%) were treated for TB and eight patients (24.2%) were admitted for TB treatment prior to the onset of MDR-TB. There was a general low level of awareness and knowledge of MDR-TB in the community. The study participants only learned about MDR-TB when they were diagnosed, while family members learned about MDR-TB when the participants informed them about their diagnosis. Since most patients learned about MDR-TB only after they were diagnosed, it was difficult for most to accept the MDR-TB diagnosis. They associated MDR-TB with death and dying, most reported feelings of pain, sadness, and hopelessness when they first learned about their MDR-TB diagnosis. The study found that most patients informed their family members about the MDR-TB so that they could get support during the course of treatment. They also disclosed to their family because they were gravely ill at the time they were diagnosed and depended entirely on family members for care and support. Yet, not all the patients received the desired support, some of the patients received negative reactions and discrimination after disclosure of the MDR-TB diagnosis. They experienced acts of stigmatization, isolation and social rejection by their families and friends. Patients reported that family members and relatives refused to share cups and dishes with them. The family often kept their dishes separate from the rest of the family members for fear that they might be infected. Other studies also found that patients are rejected by close relatives, and that the main cause of stigmatisation is fear of infection13,14.

The study found that only a few patients reported non-adherence to treatment. Non-adherence meant interrupting or stopping taking of treatment. A treatment interruption is when a patient misses a prescribed dose of MDR-TB treatment for at least 1 day but for a period of less than two consecutive months 14. The current study findings should be viewed in the context of high proportion of defaulters and loss to follow up reported during data collection. Only 50 patients from the 85 that were registered as MDR-TB in the TB register at Ngwelezana Hospital could be traced. The study can therefore not report on the causes of treatment default among the lost to follow up. Patients reported that they lacked transport money to travel to the hospital to collect treatment. Similar findings about difficulty of paying for transportation to the clinic to collect their medication were reported in Tanzania15. Patients interrupted medication because they had no food. In this study and others, patients were told not to take the medication on an empty stomach 15. Other reasons for non-adherence were related to the health care system. The patients mentioned the long distance they had to travel to the hospital for follow up and to collect treatment as a reason for interruption of treatment. In addition, patients could not adhere all the time because the local clinic ran out of stock. The long duration of treatment with particular reference to the injection, was also cited as a reason for non-adherence. As already mentioned, most patients experienced stigma, isolation and social rejection by their families and friends. Patients who interrupted treatment were rejected by their family, Social stigma, isolation, and ostracism are commonly stated reasons for interrupting and defaulting TB treatment in other studies 5,13,16. It is encouraging that not all patients were non-adherent, adhering patients were counselled and educated about MDR-TB during their long stay in hospital and they understood the implications of
non-adherence. In a study conducted in Tanzania, the patient’s intention to adhere was a major determinant of adherence. The intention to adhere helped the patients to cope with the perceived barriers to adherence [3].

CONCLUSION
The study found low levels of awareness and knowledge of MDR-TB in the community. The ignorance about MRD-TB and the fear of infection reinforced stigma, isolation and the rejection experienced by MDR-TB patients. The study further found that stigma, isolation, and rejection were also responsible for non-adherence among MDR-TB patients. Because the patients were depended on their families for support, those who were rejected by their families also lacked transport money to travel to the hospital to collect treatment. While some interrupted treatment because they had no food and could not take the medication on an empty stomach. The findings suggest that family support is crucial in the life of MDR-TB patients especially in the light of the prolonged duration of MRD-TB. There is urgent need to create awareness about MDR-TB to strengthen the family and the community’s capacity to provide care and support for people diagnosed with MDR-TB. An increased awareness of MDR-TB will also serve as stigma reduction intervention.

Ethical considerations
The study had ethical clearance from the Research and Ethics committee of the University of Limpopo MEDUNSA Campus (MCREC) prior to the implementation of the study. Permission to conduct the study was obtained from Ngwelezana hospital and Thokozani primary health care clinic. Informed consent was obtained from all the patients before data collection.

Acknowledgement
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References

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