Exploring the experiences of family caregivers with people with drug-resistant tuberculosis

Thanduxolo Elford Fana¹,²* and Lizo Sotana³

Abstract: The South African health system faces major challenges: crumbling infrastructure, shortage of beds and health professionals, and a high burden of diseases such as Tuberculosis and HIV/AIDS. The emergence of Drug Resistant Tuberculosis has made matters worse, as some of the burden of care for patients was transferred from nurses at hospitals to families in communities after patient discharge. This study explores and describes experiences of family caregivers caring for family members with Drug Resistant Tuberculosis living at home. The data from purposively selected family caregivers, caring for family members living with Drug Resistant Tuberculosis, were collected through in-depth interviews using a pretested interview guide. Saturation was reached at the 11th interview. All interviews were audio-taped, transcribed verbatim, analysed using Tech's Eight Steps for Data Analysis, and emerging themes reported. Three themes that emerged were: issues in relation to provision of care, caregiver's attitudes towards caregiving, and community attitudes and practices towards family caregivers. The study showed that respondents experienced challenges such as buying and preparing of nutritious food, attending to hygiene needs and management of treatment of side effects. Poverty, finance and time were barriers to caregiving roles. Participants experienced

© 2021 The Author(s). This open access article is distributed under a Creative Commons Attribution (CC-BY) 4.0 license.
physical and psychological exhaustion, social exclusion, and stigmatisation. There is a need to increase coverage of the Ward-Based Outreach Teams and Community Healthcare Workers, and intensification of TB and HIV/AIDS health education in communities. Training and education on infection control, palliative treatment, and home-based medical care should be provided to families before a patient is discharged. Stakeholder relations need to be improved and collaboration fostered.

Subjects: Multidisciplinary Psychology; Health & Society; Public Health Policy and Practice

Keywords: caregiver; experience; family; multi-drug resistant tuberculosis; tuberculosis

1. Introduction

Tuberculosis (TB) is among the oldest diseases known to human beings yet remains one of the top 10 current causes of death globally, as well as the leading global infectious disease killer. In 2018, approximately 1.5 million people died from TB, including 251 000 people with HIV. An estimated 10 million people also fell ill with TB including 5.7 million men, 3.2 million women, and 1.1 million children. The World Health Organization (WHO), through the ‘End TB Strategy’, planned to eradicate death, disease and suffering due to TB by 2035. WHO seeks to reduce TB deaths by 95% and to cut new cases by 90% between 2015 and 2035 and to ensure that no family is burdened with catastrophic expenses due to TB (World Health Organisation, 2019). In this regard, the emergence of Drug Resistant Tuberculosis (DR-TB) poses a serious threat to TB control efforts globally, and impedes the achievement of the vision to end TB by 2035, because of lengthy, toxic and high costs of its treatment. DR-TB can be classified as Multi-Drug Resistant TB (MDR-TB) or Extensively Drug Resistant TB (XDR-TB). MDR-TB is defined as TB where there is in-vitro resistance to both isoniazid and rifampicin. XDR-TB is MDR-TB with additional in-vitro resistance to any fluoroquinolone and any of the three, second line injectable anti-TB drugs (T. E. Fana et al., 2018).

In 2018, about 0.5 million people fell ill with DR-TB. Only one in three had accessed treatment, and of those treated, only 56% were successfully treated. Globally, WHO estimated that 3.4% of new cases and 18% of previously treated cases of TB were of the MDR-TB or Rifampicin-Resistant TB (RR-TB) strain. The three countries with the largest share of the global burden were India (27%), China (14%), and the Russian Federation (9%). Globally, 3.4% of new TB cases and 18% of previously treated cases had MDR-TB or RR-TB, with the highest proportions (>50% in previously treated cases) in countries of the former Soviet Union (World Health Organisation, 2019). MDR-TB is a major driver of antimicrobial resistance worldwide and threatens hard-earned gains made in the global TB response over the past 20 years (T. E. Fana et al., 2018). Diagnosis and treatment of MDR-TB remain a major challenge, with only one in four affected people currently detected, and even fewer being treated successfully (Livingston et al., 2013).

South Africa (SA) is ranked third highest after India and Russia in MDR-TB and third highest in XDR-TB notifications, after India and Ukraine, amongst the 30 highest TB burdened countries (Fana, 2019; UNAIDS, 2018). TB is an opportunistic disease prevalent among most of the HIV infected people. The high number of people infected with TB and HIV, and the emergence of MDR-TB in SA has created a burden on the already underdeveloped public healthcare delivery system (Coovadia et al., 2009; Majumdar & Mazaleni, 2010). During the initial outbreak of the MDR-TB in SA, the management of all MDR-TB cases was centralised and then decentralised after the passing of the deinstitutionalised and decentralisation policy for management of MDR-TB in 2011 (Chingonzoh et al., 2018; Livingston et al., 2013; Ndjeko, 2014). The purpose of this policy was to reduce the costs associated with hospitalisation and allow for community-based care. Consequently, much of the burden of caring for those living or infected with MDR-TB fell onto the shoulders of their families and communities, as is the case with people living with HIV and AIDS. In this context, family caregivers are an extension of the healthcare system, and therefore the support that caregivers provide impacts positively on care recipients’ quality of
life, and represent significant cost-saving to healthcare systems (South African Department of Health, 2009; Tsiilolo & Davhana—Maselesele, 2009).

A family is a group of people that are related to each other, either by blood, marriage or adoption, and live together for a long time (Tsiilolo & Davhana—Maselesele, 2009). Family members take care of those who are incapable of caring for themselves because they suffer from MDR-TB and other diseases. Patients who receive treatment at home also expect some form of assistance and support from family members. Family care practices and family care systems have been the foundation of communities for generations, and in terms of the South African National Health Plan, families have a significant role in caring for patients and maintaining continuity of care when they are discharged from the hospital (Demmer, 2011; Du Toit & Van Staden, 2007). In this regard, family members are responsible for; providing emotional support, ensuring continuity of care by administering treatment, monitoring treatment adherence, side effects and scheduled appointments, washing, cooking and feeding their sick family members when they are discharged from the healthcare facilities (Du Toit & Van Staden, 2007).

Some family members have other full-time responsibilities such as being full-time employees and students. Families influence a patient’s psychological adjustment and road to their recovery, and work as advocates for their sick relatives. They provide physical, emotional and financial support to the sick in most cases, without any form of training, recognition or support, and/or financial incentives (Demmer, 2011).

Caring and staying with MDR-TB infected persons may cause disruptions and present family caregivers with challenges and problems which are difficult to deal with. Family members of TB patients are stigmatised and ostracised in their communities for staying with infected people. Those with TB are regarded as dirty, eating bad food and having bad hygiene habits (T. Fana et al., 2013; Ma et al., 2019). They also experience pain, guilt, resentment and the shame of watching loved ones suffer from illness; and the pain and inability to accept the worsening health conditions of a family member despite efforts to take care of them (Sukumani et al., 2012).

Several studies published show that family-caregiving often leads to emotional, physical, social and financial burdens, resulting in families experiencing significant stress. Other studies showed that family-caregiving remains a predominantly feminine activity, attributed to several societal and cultural demands on women (Ahmed et al., 2018; Sharma et al., 2016). Other published studies found that the support that caregivers provided positively impacted on the recipients’ quality of life, and resulted in a significant cost-saving with regard to the healthcare system (Lambert et al., 2017). Therefore, although family caregiving has been the subject of research in various parts of the world, there are not many studies that have used a qualitative approach. There is much that remains to be understood about why people take on strenuous caregiving duties, how they approach their caregiving responsibilities, and the consequences of taking up the role of a caregiver, especially in low middle income countries’ settings such as SA, where the burden of diseases such as HIV and TB have also changed the demographic profile of families, social structures and norms, with men and children are increasingly assuming roles as caregivers. Further, to the best of our knowledge, no qualitative studies published that explore the experiences of family caregivers caring for family members with DR-TB within the local context, despite the fact that it is a high TB burden area.

Quantitative studies are meant for in-depth understanding of issues and phenomena, rather than generalizability, as it is the case with qualitative studies; therefore, the qualitative studies that have been published in other parts of the world have applicability to the context in which they were conducted. A qualitative study will make a significant contribution because it allows the researchers to explore and describe caregiving experiences of the participants in their natural setting, given the complexity of caregiving and changing demographics, family structures, norms and roles.
In recent years, the research has focused largely on experiences of MDR-TB infected and those of healthcare workers’ caring for MDR-TB infected people. There is a dearth of literature on experiences of family caregivers. At the time of undertaking this research, the Nelson Mandela Bay Metropolitan Municipality was one of the districts with the highest number of MDR-TB patients in the Eastern Cape Province (Chingonzoh et al., 2018; T. E. Fana et al., 2018). With the decentralisation and de-institutionalisation of MDR-TB management, some of the MDR-TB patients were treated as outpatients and therefore some of the responsibility for care was transferred to family members at home, as other patients were still too ill to take care of themselves. In other instances, this occurred even when some family members have other duties to perform, besides caring for discharged patients. It is because of the above that the researcher has decided to undertake this study to examine the experiences of family caregivers caring for their family members living with MDR-TB.

2. Methods

2.1. Design
A qualitative research design was followed to explore and describe the day-to-day experiences of family caregivers, caring for family members living with MDR-TB in their homes, in the Nelson Mandela Bay Metropolitan Municipality, in the Eastern Cape Province of South Africa, from August to September 2016. The researchers observed, described and later documented the lived experiences as related by the study participants.

2.2. Population, sampling method and sample size
The population consisted of family members from Ward 40 in the Nelson Mandela Metro who were caring for people living with MDR-TB at home. It is in this specific metro where in 2008, 118 patients with MDR-TB fled from two hospitals to spend the festive season with their families. It was also in this metro that MDR-TB patients used their illness to scare off staff and security guards in order to run away from centralised MDR-TB hospital.

The researchers purposively selected the site because data showed a high prevalence of TB, defaulter rates, poor living conditions, overcrowding, poverty and lack of services in the area.

The family caregivers were selected purposefully due to their experiences and knowledge of caring for people living with MDR-TB. A TB register was used to select patients and track their families with the assistance of TB outreach team members. An initial visit was made to a total of 25 families to request them to participate in the study, establish if they met the inclusion criteria and schedule a second visit with eligible participants. A participant information sheet was used to brief the participants about the study purpose, objectives, data collection method, and process. After this initial visit (process) only 14 participants were eligible to participate in the study (four did not meet the inclusion criteria and seven said no they do not want to participate in the study). During the second visit, each participant was briefed about the study objectives and the interview process before the start of the interviews by the researcher. The researcher also obtained verbal and written consent from the participants before collection of data (interviewing). The saturation point was reached at the 11th interview.

The selection of the participants was based on the following criteria: participants were residents of an informal settlement in Ward 40 in the Nelson Mandela Bay Metropolitan Municipality who had taken care of a family member living with MDR-TB for at least three months. Further, the person living with MDR-TB should have been sick to a level that they were incapacitated. The family caregiver should have been 18 years and above on his/her last birthday and should have given consent to participate in this study. Accounts and views of family members who were not directly involved in taking care of people living with MDR-TB were ignored. The sample in this research consisted of only one member of each family. Both males and females were chosen to participate in the study.
2.3. Data collection

Data were collected through face-to-face semi-structured in-depth interviews with the participants in their homes. The interviews were conducted as normal conversations with the purpose of producing more in-depth information about the participant.

The interviews were prearranged. The researcher established a rapport with the participants by paying attention to what the participants were saying. The researcher did not interrupt the participants and was not judgemental. The participants were asked the following question by the researchers:

(i) Can you please share with me your experiences of caring for your family member that is living with MDR-TB at home?
(ii) What are the challenges that you experience when caring for him or her?
(iii) What form of support are you receiving in order to make your caregiving role for family members living with MDR-TB at home more manageable (from your family, friends, and community and healthcare facilities)?

The conversations were tape-recorded by the researcher and later transcribed verbatim by two research assistants. Field notes were taken during the interviews and observations were made. The demographic profile, verbal and nonverbal expression of the burden and challenges associated with caring for family members were also taken note of. The interview sessions continued until the 11th participant when the saturation point was reached. Data saturation occurred when no new themes emerged from the last three interviews (9 to 11).

The average duration of the interviews was 60 minutes. The researcher observed, described, and later documented lived experiences as related by the research participants.

2.4. Data analysis

All the interviews were coded using an inductive approach and thematic analysis, drawing on techniques from constant comparative and iterative methods. This involved line-by-line analysis of each interview, naming each line and segment of data, grouping categories and contents of the categories, and also identifying deviant cases. A comparison was done between and within the interviews. Discussions were held and consensus reached throughout this iterative process between the research team members. A qualitative software program, NVivo 10, was used to manage the data.

The transcripts and field notes were repeatedly read, analysed and initial thoughts were noted for each participant, by each research team member, separately. Meetings were then held among research team members. Findings from the data were shared and compared for similarities and differences. Discussions regarding the identified and emergent themes were held and consensus reached between the research team members. This first part was done within a case analysis in each transcript and to note themes. Afterwards, the themes were compared from one case to another across all transcripts and themes relevant to the research questions. After clearly defining and categorizing each working theme, the analysis proceeded by discussing it at length during research team meetings in order to maintain the integrity of the responses. Data was evaluated against the aims of the study and divergent themes were examined by returning to the data. The iterative process of reflection and triangulation of the data ensured trustworthiness of the study. Data from the in-depth interviews and reflective engagements are presented through quotes. The field notes from observations were utilised to inform and confirm the three themes that were identified during data analysis. The research team participated in doing this and decisions were finalised collectively, by consensus, by the research team.
2.5. Validity and reliability of the data
To ensure validity and trustworthiness of the results of this qualitative study, the research team employed the following strategies: prolonged engagement, member checking, and triangulation of data from various data sources. The researcher prolonged the engagements with the participants by using in-depth interviews and asking probing questions to ensure long contact with the respondents. The research team read the transcripts several times, compared their results, and this led to the emergence of themes and subthemes as a measure of ensuring trustworthiness of the data. During the writing of the draft article, the emergent themes were compared with the transcripts individually and as a whole, while the findings from the observations and field notes were used to validate the interviews, which promoted reflexivity. Member checking was done with three research participants who were visited by the research team in order to check whether they were in agreement with the preliminary findings of this study, which they were.

2.6. Ethical considerations
The researcher obtained permission to conduct this study from the following authorities: University of Fort Hare Higher Degrees Committee, Department of Public Administration. Permission was also obtained from the participants through informed consent. The participants also gave consent for observations and audio-recording of the interviews. The researchers also informed the participants that they were to participate in the study voluntarily and were not going to receive payment in exchange for the information. The participants were also told about their right to withdraw from the study at any time should they feel like doing so, without any fear of being victimised for doing so. The researcher, with the help of the TB tracer team leader, negotiated access to the participants. No information that was obtained from the participants was shared with anyone else other than the research team and for the research purpose. The audio recordings were kept under lock and key in a computer protected by password that was kept in a locked office of the primary investigator.

3. Findings

3.1. Demographic profile of the respondents
The results in Table 1 indicate that there were 11 participants; that most of the respondents were females; between 36 and 45 years old, unemployed, married, and had high school education. Majority of participants had been family caregivers for at least 13 to 24 months. The results also show that the majority of their households had a monthly household income of less than US$100.

The findings show that the majority of the respondents were mainly dependent on government financial assistance in the form of either monthly child support (US$23), old age or disability grants (US$97) and had 3–4 household members.

3.2. Themes emerging from the data
Themes that emerged from the data collected through in-depth semi-structured interviews with family caregivers can be categorised into three main themes: issues related to caring, family caregivers’ attitudes towards caring and community attitudes and practices towards family caregivers.

3.2.1. Issues related to provision of care
Family caregivers indicated that having to look after their sick family members was a burden to them. Some of the respondents indicated that caregiving for family members living with Drug Resistant Tuberculosis was physically, emotionally, financially and mentally demanding. Some of the respondents revealed that they have to juggle between their occupations and being family caregivers.

At the clinic they say we must give the patients balanced meals. I have to look for piece jobs to get the money. I still have to find time before and after work to cook, feed, give
medication and wash him as he is very weak and cannot do anything for himself. (Participant 1: 36-year-old female, farmworker)

He messes on his pants, vomit on his clothes and the bed. I am tired, I need to do my home works, and by the time I finish preparing supper I am too tired and just want to get into my bed. (Participant 2: 27 years old male student)

Some of the family caregivers perceived caring for their family members as an exhaustive and frustrating task.

Table 1. Demographic profile of respondents

| Variable                              | Number of participants |
|---------------------------------------|------------------------|
| **Gender**                            |                        |
| Male                                  | 3                      |
| Female                                | 8                      |
| **Age**                               |                        |
| 18–25                                 | 3                      |
| 26–35                                 | 1                      |
| 36–45                                 | 4                      |
| 46 upwards                            | 3                      |
| **Employment status**                 |                        |
| Unemployed                            | 7                      |
| Employed                              | 4                      |
| **Educational status**                |                        |
| Primary education                     | 4                      |
| High school education                 | 6                      |
| Tertiary education                    | 1                      |
| **Main source of household income**   |                        |
| Social grants (child support, old age and disability) | 7      |
| Full time employment                  | 2                      |
| Sessional employment                  | 2                      |
| **Monthly household income**          |                        |
| Below US$100                          | 5                      |
| 101- US$200                           | 2                      |
| 201-US$300                            | 2                      |
| 301US$ up                             | 2                      |
| **Duration as family caregiver**      |                        |
| 3 – 12 months                         | 3                      |
| 13–24 months                          | 7                      |
| Above 24 months                       | 1                      |
| **Number of people living in household** |                    |
| 1–2                                   | 2                      |
| 3–4                                   | 7                      |
| 5 and above                           | 2                      |
He is very weak and sick and I have to do everything. He is not getting better, and I have a young daughter to take care of. I am tired, and I am human and I can only do so much.
(Participant 3: 24-year-old female, cashier)

Taking care of him is physically draining, and he has to wear nappies now. He is too heavy for me. What is worse is that my mum is not willing to assist me in taking care of dad.
(Participant 4: 21-year-old female tertiary student)

Some of the family caregivers indicated that they do not have enough time to fulfil the needs of their sick family members.

He was the breadwinner and now that he is sick and I have to do everything for him. I had to find a job and I do not have time to look after him. When I come from work, I am tired, yet I still have to cook and assist the two boys with their homework.
(Participant 5: 40-year-old female housekeeper)

Some family caregivers decided to give up their daily occupations. Some are dependent on social grant as a source of income. Other family caregivers indicated that they negotiated with their employers to place them permanently on day shifts in order to be with their sick family members at night.

When his conditioned worsened, I decided to quit my job, so that I can take care of her.
(Participant 6: 55-year-old female, unemployed).

The social assistance grant is too little for this family. How can I survive from 100 USD? I have to buy food, clothes, pay rates and bills from such a small amount.
(Participant 7: 38-year-old female, unemployed)

Things could have been worse. I am security guard, and I had to request to work day shifts, so that I can look after her at night. I would have been out of work by now, if my supervisor refused. And how was I going to survive and support my wife.
(Participant 8: 57-year-old male security officer)

Family caregivers also reported challenges related to the drugs’ adverse effects on patients and infection control.

He can no longer hear properly. Sometimes when I am talking to him, he does not respond. It irritates me.
(Participant 9: 43-year-old female, unemployed)

I cannot lift him. I struggle to take him out of the bed so that I can make it up and wash him. His feet are sore, he is weak, and hence he cannot stand especially for long period.
(Participant 10: 19-year-old male scholar).

He says when he was working we enjoyed being with him, now he is sick we find excuses to be away from him. That pains me, I have lost their father because of this TB.
(Participant 11: 54-year-old female, unemployed)

Dad always complains that we are the ones that are killing him with cold when we open windows and he shout at me and says I want him to die like mum.
(Participant 4: 21-year-old female tertiary student)

Family caregivers also revealed anxiety, burnout and stress-related symptoms.

Sometimes I feel it is too much and I wake up with terrible headaches in the middle of the night. Sometimes I do not sleep at night yet I must go to work in the morning.
(Participant 8: 57-year-old male security officer).
She will cry when I was her and beg me to leave her because of the pain from the injections. I will go out of the room with tears in my eyes and then take shots of brandy to settle my nerves (Participant 10: 19-year-old male scholar)

Family caregivers also expressed unresolved grief that stemmed from the death and trauma of seeing deteriorating health conditions of family members due to Drug Resistant TB infection.

This disease have robbed me of family. I think I am cursed. I have no one to talk to nor assist me with my wife. My family have abandoned us since the death of my children. (Participant 8: 57-year-old male security officer)

It is still like a dream. My husband and two of my daughters were diagnosed with TB and they died within a year. I am not well but I have to force myself to work because we have no source of income. (Participant 11: 54-year-old female, unemployed)

Some family caregivers expressed fear for infection while others had no such fears.

I have already lost my children and now it seem as if their mother is going to follow them. I try to act brave but to tell you the truth I am scared of being infected. (Participant 8: 57-year-old male security officer)

I am taking care of my child. I am not worried about being infected. I pray the living God and I have faith in Him. God will protect me. (Participant 11: 54-year-old female, unemployed)

Family caregivers expressed experiences of social isolation

Our family have abandoned us. They used to visit us and now that mum is sick no one ever visit nor bother to call and ask how we are doing. (Participant 2: 27-year-old male student)

My girlfriend does not visit me anymore. When she see me, she changes direction. It is as if I am the disease. (Participant 10: 19-year-old male scholar)

3.2.2. Caregivers’ attitudes towards caring

Some of the family caregivers expressed love, support and sympathy, and believed that the little that they were doing was well received and appreciated. Some family caregivers expressed impatience, hatred, lack of support and blame.

Love

Today I am what I am and where I am because of the hard work of my father. I love him and am proud of him despite the condition that he is in today. I can never abandon him. (Participant 4: 21-year-old female tertiary student)

Looking after my mother health needs allows me to show her how much I love her. No one is more important to me than she is and no one can replace her. (Participant 10: 19-year-old male scholar)

Support

I had to do the best I can to take good care of her so that she can be in good health again. (Participant 8: 57-year-old male security officer)

Sympathy

I will not abandon her in this time of need. I have to sacrifice my time in order to accommodate her condition. (Participant 2: 27-year-old male student)
Impatience

I wake up early daily wash, cloth, cook, feed give medication. He tells me he does not want this and that pill. He then vomits everything. I have to keep up with that nonsense, it is almost a year, and he is not getting better. I have a life after all. (Participant 7: 38-year-old female, unemployed)

Resentment and hatred

I did not sign up for this when I married him. Why should I be busy caring for an old man, who messes all over the house? When am I going to have time to look after myself and my child? (Participant 3: 24-year-old female cashier)

Lack of support

I have to juggle between my schoolwork and taking care of my dad. Mum is not looking after him. They used to fight and mum is now saying it is payback time.

Sometimes I have to steal food for dad so that he can have his medication. (Participant 4: 21-year-old female tertiary student)

Blame

You know what, I am partly to blame for the condition that my husband find himself in today. I should have looked after her wellbeing a bit earlier. Sometimes I feel like I have failed in my duty as his wife. I hate seeing him helpless like this. (Participant 6: 55-year-old female, unemployed)

3.2.3. Community attitudes and practices towards family caregivers

Family caregivers revealed experiences of social exclusion, isolation and stigmatisation.

Two of my children have already died and now my husband is sick. People say I am witch and they once chased me away from my house but I refused. They accuse me of killing my family. (Participant 6: 55-year-old female, unemployed)

I no longer get invites to traditional ceremonies in the community. They say I must stay home, because I will infect other people. (Participant 11: 54-year-old female unemployed)

I find it hard to get transport to the clinic to collect treatment. Taxi drivers drive past us even though they have space. (Participant 7: 38-year-old female, unemployed)

In the community, I opt to stay home because people stare at me when I walk in the street with my mum. (Participant 2: 27-year-old male student)

Support and appreciation

Sometimes nurses serve me quickly when I go to collect treatment. Our neighbour always comes by to check on us and family members appreciate what I am doing for my father. They send us money on a monthly basis so that we can buy things that we need. (Participant 4: 21-year-old female tertiary student)

4. Discussion

This exploratory study provides valuable insights into the experiences of family caregivers caring for family members infected with MDR-TB in resource poor settings in the Eastern Cape Province of South Africa. The findings of this study highlight the need for a reduction of poverty levels; increased income security; the development of a freely accessible system of home-based medical
and palliative care; and an informal and formal system of counselling and support through clinical, community and home-based care.

The study further highlights the need for increased knowledge and awareness about causes, transmission, prevention and management of TB. The results also highlight the need for the ward-based outreach teams (WBOT) and community health workers (CHW).

The results of this study revealed divergent accounts of the experiences of family caregivers when caring for family members living with MDR-TB at home. These divergent experiences were framed into three themes: issues related to provision of care by family caregivers, family caregivers’ attitudes towards caring and community attitudes and practices toward those caring for the infected family members. The results show that poverty strongly influenced the family caregiver’s ability to provide care for family members living with MDR-TB. Some of the family caregivers had no source of income. Others had little income reducing the family’s ability to provide necessities such as groceries payment of bills, and this is consistent with the findings of previous studies (Chimwaza, 2005; Majumdar & Mazaleni, 2010; Sukumani et al., 2012). The struggles to provide food or at best well-balanced meals and insufficient money places the sick person’s health at risk, as it promotes treatment default and this is consistent with previous research findings (Chanda & Gosnell, 2006).

Families play a crucial role in supporting people infected with TB; therefore, there is a need to put emphasis on reducing poverty and increasing income security in order to allow families time to fulfil this supportive role rather than worrying about food provision (T. Fana et al., 2013; Tsililo & Davhana—Maselesele, 2009). The findings of this study further highlight a need for community health workers and a freely accessible system of home-based care, which will assist in alleviating the burden of care from the family caregivers.

The results of this study also show that family caregivers caring for family members living with MDR-TB also lived hectic lives. They struggled to balance the demands of their family care giving role, social life, and full-time occupations, similar to the findings of the previous studies (Demmer, 2011; Mashau & Davhana-Maselesele, 2009). The findings from this study also revealed that family caregivers caring for family members living with MDR-TB also experienced stress, anxiety and burnout. This is consistent with the findings of the previous research where high risk of ill health was found among people that were over-occupied with family, community and their own lives (Mthembu et al., 2016; Senthilingam et al., 2015).

This study highlights the need for government intervention and the development and delivery of healthcare programs that will assist in reducing the burden of family caregivers attending to family members living with MDR-TB and thereby promote their wellbeing and health.

The study revealed that some family members experienced grief as they have watched some of the family members die because of MDR-TB, while others are watching daily deterioration in health conditions of their family members, which was consistent with the findings of the previous studies (Mashau & Davhana-Maselesele, 2009; Tsililo & Davhana—Maselesele, 2009). In order to help them to cope with illness or death of family members, a formal or informal system of counselling and support should be availed through clinical, community and home-based services.

In South Africa, there is an unequal distribution of resources in the healthcare system, with more resources found in private than in public sector, and more in urban areas than rural areas. People living with MDR-TB and family caregivers caring for family members living with MDR-TB should be provided with counselling, health education, care, support and information on infection control of tuberculosis. Community-based healthcare workers that are skilled in palliative and home-based medical care should be used so that the quality of care that is provided for people living with MDR-TB can be improved. This can also assist to decrease the burden of care and resulting healthcare.
issues for family caregivers caring for family members living with MDR-TB (Majumdar & Mazaleni, 2010; Tsililo & Davhana—Maselele, 2009).

The need for psychosocial support was also evident from the findings in this study. Some family caregivers caring for family members living with MDR-TB experienced isolation, lack of acceptance, social exclusion, ill-treatment and discrimination in their families, healthcare facilities, and community. Support for TB infected and affected communities is mentioned in the South African National Tuberculosis Guidelines (South African Department of Health, 2009, 2011). Previous research has revealed that lack of support, stigma and discrimination fuel the spread of diseases as it acts as a barrier to access adequate healthcare services and support systems (Fana, 2019; Javed et al., 2016). The findings of this study highlighted a need for reinforcement of the National Tuberculosis Guidelines to improve adherence and quality of care.

The guidelines also highlighted the need for intensification of health education and awareness campaigns to increase knowledge, reduce stigma, and promote acceptance of people living with MDR-TB and those caring for them in the community. The findings of this study highlight the need for improvement of healthcare workers training in order to ensure that they are knowledgeable of their psychosocial supportive role, which would encourage early health seeking behaviour that encourages treatment adherence among community members.

In South Africa, education is viewed as one of the strategies for management of TB. In this study, there was poor knowledge and awareness about MDR-TB. These findings are consistent with the findings of the previous studies (Fana, 2019; Javed et al., 2016). Knowledge and awareness of the causes, signs, symptoms, transmission and management of TB is important in high-risk populations and resource poor settings. Some of the respondents feared being infected by the family members with MDR-TB while others experienced no fear and disregarded infection control practices because they believed the living God protected them from infection. These misconceptions and incorrect beliefs about transmission and prevention of MDR-TB are similar to those of previous studies (Luba et al., 2019; Senthilingam et al., 2015). The findings of this study further highlight the need for intensive community health education and awareness campaigns in order to improve attitudes, infection prevention, and health seeking behaviour. The findings of this study further highlight the need for intensification of education efforts as part of the TB management strategy in South Africa.

The need for physical, emotional and financial support was also evident from the findings in this study. The study revealed that some family caregivers attending to family members living with MDR-TB struggled with stress and burnout from juggling between full-time occupations and family caregiving roles such as administration of treatment and monitoring of side effects. It was also found that they were also responsible for sourcing money, buying groceries, cooking, feeding and washing, picking up bedridden family members who were sick, and cleaning the house. The above aspects were consistent with findings of the previous studies (Burtscher et al., 2016; Kanyerere et al., 2016; Sukumani et al., 2012).

The findings of this study also showed that other family caregivers showed sympathy, indicating that they had positive attitudes towards caring for relatives living with MDR-TB at home, consistent with the findings of previous studies (Chinenye, 2018; Lambert et al., 2017; Sagbakken et al., 2008). This study also showed that some respondents had strong feelings of anger, hatred and resentment, consistent with the findings of previous studies. These feelings were sparked by lack of appreciation, rudeness and uncooperative behaviour of patients (Chinenye, 2018; Kohli et al., 2012; Lindsey et al., 2003). The decentralised and deinstitutionalised MDR-TB management policy was aimed at promoting accessibility and acceptability of MDR-TB and its treatment within the communities. The research results have revealed that research respondents were rejected, excluded, ill-treated, stigmatised, and discriminated by
not only in the community but also by family members and healthcare practitioners. These findings are consistent with experiences of caregivers of people living with other chronic illnesses (Kohli et al., 2012; Van Deventer & Wright, 2017; Ilja et al., 2017). These results further highlighted the lack of knowledge and disregard for the basic human rights of all citizens as enshrined in the South African Constitution.

5. Limitations and strengths of this study
The study was limited to resource poor settings in the Nelson Mandela Bay Metropolitan Municipality in the Eastern Cape Province of South Africa and it focused on family caregivers caring for family members with MDR-TB. This study was a qualitative study, limited to the local Xhosa people, and as such, its findings cannot be transferable to other cultural groups and districts or metros. A purposive sampling method was used to select participants for this study. Selection bias might have occurred as potential participants who left their places of residence early and returned late from work and school were left out of this study as it was conducted during weekdays from 8:30 to 15:30. This had a potential of affecting external validity; however, the sample is similar to that of other studies and research has also shown that majority of caregivers are females compared to males (Fana, 2019; Livingston et al., 2013). It is recommended that similar studies be done among other cultural groups and on a broader scale. This study provided an understanding of the experiences of family caregivers regarding caring for family members living with MDR-TB. Its findings can be used as evidence to develop public policies for the promotion of health, quality of life, and well-being of family caregivers and people living with MDR-TB.

6. Implications for practice education and research
This study was conducted with family caregivers caring for family members in an informal settlement within an urban area. There is a need to conduct a similar study with family caregivers caring of family members living with MDR-TB in formal settlements, urban and rural areas. The results from this study can be used as a basis for the development of intervention programs that can deal with the challenges of the family caregivers caring for family members living MDR-TB.

7. Conclusion
In this study, the experiences of family caregivers caring for family members living with MDR-TB were explored. Family caregivers caring for family members living with MDR-TB explained their roles and the challenges that they faced when they were caring for family members living with MDR-TB in their homes. This study showed those family caregivers experienced challenges that had the potential of hindering treatment adherence and completion by family members living with MDR-TB. This study further highlighted needs of family caregivers, which needed to be addressed in order to improve home care (such as financial, psychological and medical). It is recommended that family caregivers be given education and counselling when caring for family members at home.

8. Recommendations
Family caregivers caring for family members living with MDR-TB at home should be provided with some form of financial incentives, which will enable them to make provision for necessities for themselves and the sick people, as the study revealed that some of them experienced financial problems. It is also recommended that communities start soup kitchens and vegetable gardens at homes and make use of unused spaces in the community such as churches and school grounds in order to assist with some of the food and poverty-related challenges that had a potential of hindering treatment adherence. Family caregivers should be offered basic palliative, home-based and medical care training in order to capacitate them for their family caregiving role before discharge of the sick from the hospitals takes place.

Counselling and psychological support should be offered to caregivers to improve their well-being and ability to deal with the challenges and stress of caring for family members living with MDR-TB. They should be educated in nutrition and infection prevention, and control measures. This will also assist improve the quality of care, lack of knowledge and awareness about TB, and
preparation of nutritious meals. Another recommendation is that of extending the coverage and reach of Community Health Workers and Ward-Based Outreach Teams' programs in the area. The above-mentioned interventions will also assist in alleviating the burden of care from the family caregivers. There should be improved communication between health professionals, the NGOs, CBOs and communities.

Acknowledgements
We would like to thank all the participants for giving consent and participation in this study and sharing their experiences of caring for family members living with MDR-TB.

Funding
The financial assistance of the National Research Foundation (NRF) through the South African Research Chairs Initiative is hereby acknowledged. Opinions expressed and conclusions arrived at are those of the author and not that of the NRF.

Author details
Thanduxolo Elford Fana1,2
E-mail: unruthanduxolo@gmail.com
ORCID ID: http://orcid.org/0000-0003-4439-2555
Lizo Sotana1
E-mail: lizosotana@yahoo.com
1 Centre for Health Policy, School of Public Health, University of the Witwatersrand, Johannesburg, South Africa.
2 School of Government and Public Administration, University of Fort Hare, Bhisho, Eastern Cape, South Africa.
3 Police Officer, VIP Protection Unit, South African Police Services, and a PhD in Development Studies Candidate at the University of Fort Hare, Alice, Eastern Cape, South Africa.

Availability of data and materials
The data collected and analysed during the study, which relates to this paper, is not publicly available due to the conditions of the ethics approval; however, it is available from the corresponding author, upon receipt and consideration of the request.

Competing interest
The authors have no competing interest to declare.

Citation information
Cite this article as: Exploring the experiences of family caregivers with people with drug-resistant tuberculosis, Thanduxolo Elford Fana & Lizo Sotana, Cogent Social Sciences (2021), 7: 1906494.

References
Ahmed, S. I., Farooqui, M., & Hassali, M. A. (2018). Facilitators and barriers affecting adherence among people living with HIV/AIDS: A qualitative perspective. Journal of Patience Experience, 1–8.
Bartscher, D., Van Den Bergh, R., Toktosunov, U., Angmo, N., Samieva, N., & Arechaga, E. P. (2016). “My Favourite Day is Sunday”: Community perceptions of (Drug Resistant) Tuberculosis care in Kara Suu District, Osh Province, Kyrgyzstan. Plos One, 11(3), 1–16. https://doi.org/10.1371/journal.pone.0152283
Chanda, D., & Gosnell, D. (2006). The impact of tuberculosis on Zambia and the Zambian nursing workforce. American Nurses Association, 11, 61–69.
Chimwaza, A. (2005). Caregivers experiences with care for HIV/AIDS patients in Malawi [Unpublished master’s thesis]. University of Malawi.
Chinenye, N. M. (2018). Evaluation of knowledge, attitudes and practices of TB diagnosed patients in Rwanda towards TB infection. Case of TB diagnosed patients in Kigali Urban and rural health facilities. International Journal of Scientific and Research Publications, 5, 1–19.
Chingonzoh, R., Manesen, M. R., Madlava, M. J., Sopiseka, N., Nokwe, M., & Emwerem, M. (2018). Risk factors for mortality among adults registered on the routine drug resistant tuberculosis-reporting database in the Eastern Cape Province, South Africa, 2011 to 2013. Plos One, 13(8), e0202469. https://doi.org/10.1371/journal.pone.0202469
Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. Lancet, 374(9692), 817–834. https://doi.org/10.1016/S0140-6736(09)60951-X
Demmer, C. (2011). Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: An exploratory study. AIDS Care, 23(7), 873–879. https://doi.org/10.1080/09540121.2010.542123
Du Toit, D. A., & Van Staden, S. J. (2007). Nursing sociology. Butterworth Publishers.
Fana, T., Mayekiso, T., & Gwondure, C. (2013). An assessment of community member’s knowledge of Drug Resistant Tuberculosis and HIV and AIDS in the Eastern Cape Province, South Africa. Africa Insights, 43, 59–73.
Fana, T. E. (2019). HIV and AIDS knowledge among the resident of informal settlements in Port Elizabeth, South Africa. International Journal of HIV/AIDS Prevention, Education and Behavioural Sciences, 4, 57–65.
Fana, T. E., Ijeoma, E., & Eyles, J. (2018). A qualitative descriptive, cross sectional study about knowledge levels of Drug Resistant Tuberculosis among residents of Port Elizabeth, Eastern Cape Province, South Africa. Journal of Health and Medical Sciences, 1(1), 27–41. https://doi.org/10.31014/ajhrs.1994.01.01.5
Ilja, O., Susan, L., Courtney, A., Mark, Y., Saint-Cyr, M., Kerry, K., Josephine, D., & Macaulay, A. C. (2017). When one is sick and two need help: Caregivers’ perspectives on the negative consequences of caring. Patient Experience Journal, 4, 1–8.
Javed, H., Tahir, Z., Hashmi, H. J., & Jamil, Z. (2016). A cross-sectional study about knowledge and attitudes towards multidrug – Resistant and extensively drug – Resistant tuberculosis in a high burden drug resistant country. International Journal of Mycobacteriology, 5(1), 1–7. https://doi.org/10.1016/j.ijmyco.2015.09.001
Kanyerere, H., Harries, A. D., & Taylor-Smith, K. (2016). The rise and fall of tuberculosis in Malawi: Associations with HIV infection and antiretroviral therapy. Tropical Medicine and International Health, 21(11), 101–107. https://doi.org/10.1111/tmi.12630
Kohli, R., Purohit, V., & Karve, L. (2012). Caring for caregivers of people living with HIV in the Family: A response to the HIV pandemic from two urban slum communities in Pune, India. Plos One, 7(9), e44989. https://doi.org/10.1371/journal.pone.0044989
Lambert, S. D., Bowe, S. J., Livingston, P. M., Heckel, L., Cook, S., Kowal, P., & Orellana, L. (2017). Impact of informal caregiving on older adults’ physical and
mental health in low-income and middle-income countries: A cross-sectional, secondary analysis based on the WHO’s study on global AGING and adult health. BMJ Open, 7(12), e017236. https://doi.org/10.1136/bmjopen-2017-017236

Lindsey, E., Hirschfeld, M., Tlou, S., & Ncube, E. (2003). Home-based care in Botswana: Experiences of older women and young girls. Health Care Women International, 24(6), 486–501. https://doi.org/10.1080/07399330390199384

Livingston, G., Barber, J., Rapaport, P., Knopp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., & Hoe, J. (2013). Clinical effectiveness of a manual based coping strategy programme (START) in promoting the mental health of carers of family members with dementia: Pragmatic randomised controlled trial. BMJ, 347(oct25 2), 62–76. https://doi.org/10.1136/bmj.f6276

Luba, T. R., Tang, S., Liu, Q., Gebremedhin, S. A., Kisasi, M. D., & Feng, Z. (2019). Knowledge, attitudes and associated factors towards TB in Lesotho: A population based study. BMC Infectious Diseases, 19(1), 90–96. https://doi.org/10.1186/s12879-019-3688-x

Ma, E., Ren, L., & Wang, W. (2019). Demographic and socioeconomic disparity in knowledge about tuberculosis in-inner Mongolia, China. Journal of Epidemiology, 29(4), 312.https://doi.org/10.21888/jpe.JE20140033

Majumdar, B., & Mazelien, N. (2010). The experiences of people living with HIV/AIDS and of their direct informal caregivers in a resource-poor setting. Journal of the International AIDS Society, 13(1), 1–9. https://doi.org/10.1186/1758-2652-13-20

Mashou, N., & Davhona-Maselesele, M. (2009). Experiences of HIV/AIDS home-based caregiver in Vhembe District, Limpopo Province. Curationes, 32, 40–47.

Moller, V., & Erstad, I. (2007). Stigma associated with tuberculosis in time of HIV/AIDS: Narratives from the Eastern Cape, South Africa. South African Review of Sociology, 38(2), 103–109. https://doi.org/10.1080/21528586.2007.10419170

Mthembu, T. G., Brown, Z., Cupido, A., Rozack, G., & Wasung, D. (2016). Family caregivers’ experiences regarding caring for the older adults with chronic diseases. South African Journal of Occupational Therapy, 46(1), 83–88. https://doi.org/10.17159/ 2310-3833/2016/V46n1a15

Ndjeka, N. (2014). Multi-Drug Resistant TB: Strategic overview on MDR-TB care in South Africa: National Department of Health: South Africa.

Polland, E., & Mayers, P. (2009). Experiences of informal female caregivers providing care for people living with HIV in Dar es Salaam, Tanzania. Journal of the Association of Nurses and AIDS Care, 20(6), 481–493. https://doi.org/10.1016/j.jona.2009.05.002

Sagbokken, M., Frich, J. C., & Bjune, G. (2008). Barriers and enablers in the management of tuberculosis treatment in Addis Ababa, Ethiopia: A qualitative study. BMC Public Health, 6, 2–14.

Senthilingom, M., Pietersen, F., McNerney, R., Riele, J. T., Sedres, P., Wilson, R., & Dheda, K. (2015). Lifestyle, attitudes and needs of uncured XDR-TB patients living in the communities of South Africa: A qualitative study. Tropical Medicine and International Health, 20 (9), 155–161. https://doi.org/10.1111/tmi.12532

Sharma, N., Chakrobarti, S., & Grover, S. (2016). Gender differences in caregiving among family – Caregivers of people with mental illnesses. World Journal of Psychiatry, 6(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

South African Department of Health. (2009). National Tuberculosis Management Guidelines.

South African National Department of Health. (2011). Management of Drug-Resistant Tuberculosis: Policy Guidelines.

Sukumani, J. T., Lebese, R. T., Khoza, L. B., & Risenga, P. R. (2012). Experiences of family members caring for tuberculosis patients at home in Vhembe district of the Limpopo Province. Curationes, 35, 1–9.

Tsilio, A. R., & Davhona – Maselesele, M. (2009). Family experiences of home caring for patients with HIV/ AIDS in rural Limpopo Province, South Africa. Nursing Health Sciences, 11(2), 135–143. https://doi.org/10. 1111/j.1442-4018.2009.00437.x

UNAIDS. (2018). Global HIV & AIDS statistics. http://www.unaids.org/en/resources/fact-sheet

Van Deventer, C., & Wright, A. (2017). The psychosocial impact of caregiving on the family caregivers of chronically ill AIDS and/or HIV patients in home-based care: A qualitative study in Zimbabwe. 5 African Journal of HIV and Medicine, 18(1), a718. World Health Organisation. (2019). Tuberculosis report. http://www.who.int/mediacentre/factsheet/fs104/en
