

## **The perspectives of Supporters of Tuberculosis Direct Observation Treatment on volunteering in an informal settlement of Johannesburg**

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### **Abstract**

*Tuberculosis has increasingly become a public health threat faced by overstretched public health systems in poor resourced areas. South Africa is one of the high burden settings in sub-Saharan Africa. TB supporters are increasingly used to cover the shortfall of health care workers in the provision of health care services for TB patients in South Africa. Despite the numerous challenges they face in rendering services, they continue to volunteer. This study explores the motivation of TB DOT supporters for volunteering and caring for TB patients in a poorly resourced area from their perspective. Focus group discussions were conducted with 60 participants (57 females and three males) purposefully selected from four civil society organizations in an informal settlement of Johannesburg in South Africa. Thematic data analysis aided by the use of NVivo version 10 qualitative data analysis software was applied. Participants reported the following reasons for volunteering: Career opportunities, keeping themselves busy, passion for TB work, sense of altruism, history of own illness, and religious calling. The source of motivation for volunteers is both internal and external. Their motivation for volunteering is of benefit to them, the communities and the country. It is of importance that they are supported and rewarded for doing their work so as to strengthen the public health system in its effort to control TB.*

Key words: TB DOTS, supporters, volunteering, informal settlements, South Africa

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## **Introduction**

The burden of TB continues to rise with about 8.6 million people estimated to be infected globally (WHO, 2013). South Africa ranks third amongst countries with the highest burden of TB worldwide (WHO, 2012). Furthermore, being one of the countries with a high burden of TB, the escalating pattern of drug-resistant TB, and TB/HIV co-infection compounds the picture of the TB epidemic in the country (Abdool-Karimet et al., 2009). The problem of limited health and financial resources is a global phenomenon that also negatively impacts on efforts to control TB and other infectious diseases (WHO, 2008, Dye et al., 2005). The South African public health system has not been spared from the shortage of financial and human resources experienced by other sub-Saharan African countries and battle with an overstretched health care system (Shisana et al., 2002).

To mitigate the problem of strained health care systems decentralization of services to communities through task shifting is one of the globally recommended strategies. The idea of task shifting is about appropriately moving specific roles from highly qualified healthcare workers to health workers who have received shorter training and lesser qualification to increase the efficiency of human resources for health (WHO, 2008). The South African health care system has adopted this idea of task shifting by using community-based health workers (CBHWs) who are mainly volunteer caregivers to perform duties that would otherwise be performed by health care professionals (Friedman 2002; Schneider et al., 2008). One such example of task shifting in South Africa is the incorporation of TB supporters as CBHWs into the direct observation short-course strategy (DOTS) program, which is one of the key global strategies for managing TB (WHO, 2009). Patients, in this case, receive their treatment under direct supervision of TB supporters for the duration of their treatment.

Evidence from the literature shows that TB supporters like other CBHWs in poor resourced areas face numerous challenges in their work. Documented challenges include poverty experienced by patients, walking long distances, working long hours, lack of remuneration, and lack of supplies (Mamba & Ntuli, 2014, Makoae & Jubber, 2008; McInerney & Brysiewicz, 2009, Moetlo et al., 2011). Despite these challenges, TB DOTS supporters continue to volunteer. There is limited available information on reasons why TB DOTS supporters volunteer as narrated by themselves. It, therefore, becomes necessary for stakeholders to understand what motivates them to volunteer as they form an important component of the health system in TB management so as to strengthen the health care systems that are partly dependent on them. The aim of the study is to explore the motivation of TB DOT supporters for volunteering and caring for TB patients in a poorly resourced area from their perspective.

## **Methods**

### **Study Design**

The study was conducted from April to December 2014 in an informal settlement in Johannesburg district, South Africa, from four Community Based Organisations (CBOs). The CBOs provide TB DOT support and other community based services including orphans and vulnerable children (OVC), Community Action Teams, Woman Abuse, and Stop Crime. The study population consisted of male and female TB supporters who have worked for one year

in a TB program in the area. The participants were recruited from a population of home based carers. A TB DOT supporter in the study was defined as any adult trained in the DOTS strategy. The participants were recruited from a population of home based carers from Johannesburg District. The recruitment of the participant was done through the assistance of the management of the CBOs.

### **Data collection**

Data was collected through focus group discussion (FGDs) using an open-ended focus group guide. Both authors were trained in conductive qualitative research using FGDs but the first author was actively involved in data collection together with a trained research assistant. The research assistant was trained on the objectives of the study, preparation for and conducting FGDs, administering an informed consent and issues of confidentiality. Both authors were involved in the development of the FGD guide which was developed in English and then translated into South Sotho, which is a language common among the participants. All the FGDs were conducted from the four CBOs in private, in one of the consulting rooms.

Before starting with the FGD, researcher explained the aims and objectives of the study to the participants and administered the informed consent. The FGDs were audio-recorded with permission from the participants. Before conducting the FGDs, informed consent was obtained from the participants. A brief demographic questionnaire was also developed and used to collect quantitative data. Socio-demographic information was collected at the end of the FGD

### **Data analysis**

Having translated and transcribed the data, the researchers spent hours reflecting on possible meanings and relationships, and systematically making sense of the data. Initial analysis of the interviews began during the fieldwork after recording the FGD. The first author listened to voice recordings a number of times, transcribed verbatim in Sesotho and then translated the verbatim transcriptions into English to identify and refine the emerging themes and sub-themes. Manual coding of the transcript was the first step towards data reduction and identification of themes and sub-themes and was performed by both authors. This process led to the first version of the code list which was developed from the emerging themes. On reaching an agreement between the two authors, the code list was later refined and finalized. The data was then imported into NVivo 9 qualitative data analysis software, and the process of applying codes was initiated. The final qualitative data was presented in the form of quotations.

The demographic data was captured using in a spreadsheet to produce a dataset used for descriptive statistics of the sample. The credibility of the study was ensured by verbatim transcription of the data, conducting the study in South –Sotho which is the own language of the participants, peer debriefing between the investigators, voice recordings of the FGDs, and using NVivo 9 a computer software aiding in data analysis.

### **Ethical consideration**

Ethical approval for the study was obtained from the Medunsa Research and Ethics Committee of the University of Limpopo. Permission to conduct the study was granted by the

Management of the City of Johannesburg Department of Health and Management of the CBOs. Written informed consent was obtained from TB Supporters. Privacy and Confidentiality during and after the FGDs were maintained.

## **Findings**

### **Socio- demographic data**

The sample of the study consisted of 60 TB DOT supporters with age range of 18-55 years. All the participants resided in the informal settlement where they cared for TB patients on a daily basis. Marital status was as follows: 58.3% (n=35) single, 23.3% (n=11) divorced and the rest married. Majority, 90% (n=57) were females. Slightly less than half, (45%) had a tertiary qualification. With regards to whether they regularly received a stipend or not, an overwhelming majority 90 % (n=54) received a stipend irregularly, and 5% never received a stipend at all. Sixty percent (n=36) walked to work.

### **Themes**

The following six themes were identified during the analysis: a sense of altruism, religious obligation, personal experience and family history, need to keep busy, passion for TB support and career path.

#### **Sense of altruism**

In this study participants reported that they volunteered because they were concerned with human suffering and wanted to help others. Some of the participants explained as follows;

*“I have seen my community going through a lot, and I have seen a need to help my community” (45 years old female).*

*“I was worried about people who are sick particularly those who do not have someone caring for them” (33 years old male).*

*“You see so many people are sick, and they need some help; and I can assist anytime when they need me” (45 years old female).*

#### **Religious obligation**

Some of the TB supporters in the study described their work as a “calling” and expressed their love and dedication for the sick in the community.

*“I was influenced by my church background, I was always passionate about helping. I am learning more about the project to help me to realize how I can help my community but you have to be passionate otherwise, you will not get far” (34 years old female).*

*“Mmm..., for me working as a TB supporter is a calling from God. I work because I love my community, and I don’t want them to suffer; I like the work and like helping the community” (45 years old female).*

#### **A history of own and family illness.**

In this study, the data revealed that some of the TB DOT supporters joined the program to gain more knowledge to save their families and community. This was related to their personal experience as TB sufferers, and also having to support family members affected by TB;

*“I was motivated after my mother’s death, she was an HIV activist, and I was her DOT supporter when she was taking her treatment. After her death, I saw the good work she was doing, and now I’m following in her footsteps”* (22 years old female).

*“I am a TB survivor, I currently have one lung, and this was because I defaulted TB treatment. Hence I am using my experience to teach and motivate the community about the importance of TB medication”* (33 years male).

*“I was in jail, and I got TB while I was in prison, so I am trying to work with the prison to get the number of those that are on parole for discharge so that I can support them in the community. I have seen that the community is afraid of them, this is motivating for me as I am making a difference in the community”* (29 years male).

### **Keeping busy**

Participants responded with pride and excitement regarding their choice in supporting TB patients, citing reasons such as filling the health gap in the community and keeping busy. The following statements support this view;

*“I was at home unemployed, but something in me said I should help my community, I saw that a lot of people needed help, that’s what motivated me”* (45 years female).

*“I was just an ordinary housewife, and my husband wanted me not to do anything because he was looking after us, but one day I was watching TV and I saw a program on HIV/AIDS and TB. Three weeks from there on our priest talked to us congregants about HIV/AIDS and TB; that’s when I started getting involved in helping my community and developing my community”* (46 years old female).

### **Passion for TB support**

Participants expressed a sense of dedication and commitment in rendering their services to the TB patients, and this is expressed by the following statements;

*“I have a passion for my work, I share my skills with my community, I have identified that majority of TB patients are not educated about TB, so I help to correct the misconception, and I give them correct information and about the importance of medication”* (36 years old female).

*“Passion got me started, and even today I still love what I’m doing. I was involved in a car accident, and I became a regular clinic attendee. So while we were waiting for the attention of the sisters, we started talking and found out that there are people who are too sick to the extent that they can’t collect their treatment. So I had a friend at the clinic, and she and I started acting upon this”* (47 years old female).

### **Career path**

Participants felt that volunteering in the community and working for CBOs will assist them to gain job experience and to be considered first when opportunities arise for job opportunities.

*“I joined because I needed job experience so I feel that I can join the job market easy, I have completed B Com degree in 2008, since then I have been looking for a job” (25 years old female).*

*“Okay! I can say we are getting experience by working here and when you want to further yourself in studies for nursing career then you already have experience, I am 18 years and would like to become a nurse; this background is helpful for me” (18 years old female).*

*“I believe that volunteering and on the job training will serve as channels for me to the right paying job and career growth. I have a degree, and I have not been employed for what I studied for, now is an opportunity for one to get employment” (45 years old female).*

### **Discussion**

The results showed that most TB supporters expressed altruistic motives in caring for TB patients and the community. They do this job voluntarily due to their recognition of the devastating effects caused by HIV and TB. Furthermore, the data revealed that there is a sense of commitment and willingness to help without expecting any reward. This is in line with reports by other investigators (Akintola, 2010; Mieh, 2010; Akintola, 2006).

Moreover, data in this study showed that participants have a sense of sympathy and love for the patients, and these emotions are strongly influenced by the participants' religious beliefs and affiliation to different church denominations. They view their job as fulfilling their spiritual obligations and as a calling from God. The literature further shows that the majority of the participants in the various studies volunteered for such service in the hope of receiving some spiritual blessing from God. These findings concur with other studies whereby participants also saw volunteering as a necessary response to their religious teachings and obligations (Mamba & Ntuli, 2014; Maes et al., 2012; Akintola, 2010; McLenerney, 2009).

In addition, our study revealed that some TB DOT supporters were motivated to do voluntary work due to their personal experience of a specific health problem related to HIV and TB. Some of the TB DOT supporters in the study had had a direct experience of family members dying from TB. This is in accordance with the findings of Sobuce (2007), who reported that TB DOT supporters saw assisting others as an exchange, meaning that in future somebody else would take care of them or their family if they were in the same condition.

Finally, it should be noted that this study suffered from limitations inherent to its design. As a qualitative study conducted at a certain point in time, the findings cannot be generalized, and no causal links can be established. Moreover, social desirability may have affected respondents as they answered questions posed to them.

## Conclusions

The findings showed that TB supporters were highly motivated to support TB patients. For most of the dot supporters, motivation was prompted by the love for humanity and sacrifice for the weak in society. However, part of the reason for rendering this type of service was motivated by what they stood to gain in sacrificing such as using volunteering as a gateway to finding gainful employment. The dot supported render an important service to control the spread of TB.

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