

Community Caregivers' Experiences and Programmatic Strategies to Improve Active Case Finding in Community Tuberculosis Care in Botswana 2016-2021

Unami Modongo-Mathebula¹, Mary Moleki¹, Tefera Agizew²

¹Faculty of Health Sciences, University of South Africa, Pretoria, South Africa

²Department of Family Medicine and Public Health, Faculty of Medicine, University of Botswana, Gaborone, Botswana

Email: unamim05@gmail.com

How to cite this paper: Modongo-Mathebula, U., Moleki, M. and Agizew, T. (2024) Community Caregivers' Experiences and Programmatic Strategies to Improve Active Case Finding in Community Tuberculosis Care in Botswana 2016-2021. *Journal of Tuberculosis Research*, 12, 105-118.

<https://doi.org/10.4236/jtr.2024.122007>

Received: December 20, 2023

Accepted: June 14, 2024

Published: June 17, 2024

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Abstract

Background: The community tuberculosis care program was started to reduce the impact of TB and increase successful treatment outcomes, thus contributing to meeting WHO targets on TB. According to the Botswana Ministry of Health, community tuberculosis care was introduced with the main goal of reducing tuberculosis-related morbidity and mortality among communities through the expansion of direct observed therapy and community involvement to community settings. The community caregivers were to support tuberculosis patients throughout their treatment period until they were cured or had completed their treatment. **Settings:** Two major cities of Botswana, Francistown and Gaborone, with more than twenty-two health clinics offering tuberculosis care. **Objective:** To investigate community caregivers' experiences and identify programmatic strategies to improve active TB case findings under the community TB care (CTBC) program in Botswana during 2016-2021. **Methods:** We adopted a descriptive qualitative research design, followed by convenience purposive sampling. We obtained consent and interviewed 40 participants who met the inclusion criteria, 16 out of 73 in Gaborone and 24 out of 38 from Francistown. **Results:** We interviewed 40 caregivers with a mean age of 43.4 years. Accepting the caregiving role was identified as the main experience by more than two thirds of the caregivers. While at least more than two-fifth felt obligated to care for the patient at home due to personal relations. More than half of the respondents found caregiving difficult or frustrating due to some challenges encountered during the caregiving role. Behavioral modifications were suggested under different subthemes as

strategies to improve active case finding. **Conclusion:** Acceptance was the major experience in CTBC. Intensification of known programmatic strategies was suggested by caregivers to improve tuberculosis active case finding in CTBC.

Keywords

Community Experiences, Caregivers, Active Case Finding, Tuberculosis, Community Tuberculosis Care

1. Background

The World Health Organization (WHO) estimated that 10 million people developed and 1.5 million of them died from TB globally in 2018; therefore, targets were set to reduce TB deaths by 95% and incidence by 90% by 2035 [1]. Given the targets and milestones set by the WHO and the high estimated incidence rates of 275 per 100,000 TB in Botswana [1], the country needed strategies to facilitate and improve TB prevention, care and control leading to TB reduction, and to meet the WHO's "End TB Strategy 2016-2035" plan [2] [3].

The community TB care (CTBC) program was started to reduce the impact of TB and increase successful treatment outcomes, thus contributing to meeting WHO targets on TB [4]. According to the Botswana Ministry of Health and Wellness, CTBC was introduced with the main goal of reducing TB-related morbidity and mortality among communities through the expansion of direct observed therapy (DOT) and community involvement to community settings [5]. TB has resulted in a lot of deaths and remains one of the deadliest infectious disease in the world. Any new initiative or best practice on TB identified need to be shared. It is from this research that the researcher noted that the Botswana national TB program needed vigorous advocacy, communications and social mobilisation activities to help build public knowledge in Botswana as indicated to be inadequate in the evaluation report on CTBC in 2012-2013 [6]. Having information on the community experiences, we can incorporate the best practices to foster positive attitudes and practices that contribute to powerful efforts to eliminate TB. The information for this study will inform the policymaker on how to implement CTBC effectively so that the BNTP can meet the set target of TB elimination.

The implementation of CTBC has identified some problems, including a lack of administrative support at all levels of authority; hence, the CTBC has experienced many challenges, some of which include the problems experienced by caregivers (Example) [6]. From 2012 to 2013, the Botswana CTBC evaluation report indicated that contact tracing was conducted in only 53% of registered TB cases [6]. The report also identified some challenges that included not receiving enough supervisory support and a lack of contact tracing [6]. The TB treatment outcome success rate was 74.3% in 2009 [5], and Botswana in their 2013-2017

strategic plan aimed at achieving 90% by 2017 [7]. The WHO's "End TB Strategy" has the goal of ending the TB epidemic globally with zero deaths and zero infections post-2015 [8]. The community caregivers were to support TB patients throughout their treatment period until they were cured or had completed their treatment, providing education, contact tracing, active case finding, and defaulter tracing. It was important for the researchers to know if after some years of community TB care, what the community experiences are [9]. This study aimed to assess community caregivers' experiences and identify programmatic strategies to improve active TB case findings under the CTBC program.

2. Materials and Methods

We adopted a qualitative descriptive research method to investigate and describe the experiences of patients with active case finding of TB diagnosis. Qualitative research provided the researchers with in-depth knowledge of the problem under study and helped to identify best practices by understanding the participants' experiences in community TB care.

The Roy Adaptation Model (RAM) and Health Promotion Model (HPM) were used to guide this study in exploring and describing the experiences and contributions of active case finding on community TB care in Botswana and to develop strategies to facilitate and improve TB active case finding.

The RAM viewed an individual/group as an adaptive system with three different levels which were described by Roy as integrate compensatory and compromised life processes. These processes supplemented each other to maximize adaptation and adaptation lead to optimal health and finally to quality life [10] [11]. While the HPM viewed an individual holistically, that is for both their physical and social being. It had three major categories of addressing the health promotion in everyone, which needed to be considered as it was related to the RAM model in this study, which were: individual characteristics and experiences, behavior-specific cognitions and affects and lastly the behavior outcomes [11]. These categories assisted the processes in the RAM to come-up with strategies of how to address the challenges that have been identified while investigating the experiences within CTBC.

The RAM and HPM, conceptual models guided the study, generated variables for the study and assumptions on which the study was based. The two models supported the topic under study very well and both can be used in practice. The researcher felt that the RAM and HPM concepts associated well and assisted in developing strategies to facilitate and improve active case finding of TB diagnosis within CTBC. The environmental stimuli from RAM and the individual characteristics and experiences from the HPM together helped the researcher to identify how the best practices can be used to develop strategies to facilitate and improve active case finding in CTBC. The adaptive modes and levels from RAM and behavior outcomes from HPM gave more answers on how the caregivers/treatment supporters have adapted hence more directions on the development of the expected strategies to facilitate and improve active case find-

ing in CTBC.

The community experiences on CTBC were investigated and best practices were identified. The investigations informed the researcher how the community has adapted for them to be coping with their role of caregivers'/treatment supporters for TB patients in CTBC. The experiences identified were used to develop strategies to facilitate and improve active case finding in CTBC.

2.1. Setting and Sampling

According to the Ministry of Health [6], Gaborone and Francistown had the highest number of TB patients registered in the CTBC in Botswana hence they were selected as study setting. African Comprehensive HIV/AIDS Partnerships [9] reported that Gaborone City had 880 and 750 TB cases registered in ACHAP-supported sites in 2012 and 2013, while Francistown City had 432 and 350, in 2012 and 2013 respectively.

We conducted non-probability sampling, where respondents were selected by non-random methods, and not every person had an equal opportunity to be included in the sample. We performed convenience sampling because numerous respondents had missing contact information, which made it difficult to find them. A convenience sample was used for the readily available respondents. We determined the sample size by data saturation when no new information was identified. Therefore, we observed data redundancy in 40 participants. We reviewed their clinical documents from seven clinics in Gaborone city and nine clinics in Francistown to identify their caregivers and then interviewed them. Caregivers whose patients were still on treatment during 2018 were interviewed as key informants from July 2016 to December 2018.

2.2. Target Population

The target population consisted of community members in the CTBC who met the following inclusion criteria:

- Man or woman above 18 years of age.
- Willing to participate and provide a written consent.
- Able to communicate in English or local language (Setswana).
- Cared for a TB patient who was currently (or prospectively) registered with the CTBC program being an Individual, family member, or relative with TB patients at home.
- TB patients and their caregivers within the study timeframe.
- The exclusion criteria included:
 - Cared for a TB patient who was not registered with the CTBC program being an individual, family member, or relative with a TB patient at home.
 - TB Patients and their caregivers that were outside the study timeframe.

2.3. Data Collection Methods

We used an in-depth interview guide with open-ended questions informed by

the core categories of Roy adaptation model (RAM) and the stimuli and adaptation of the health promotion model (HPM) [10] which were individual characteristics and experiences and used an observational tool that recorded the caregiver's reaction resulting from behavior outcomes during the interview. The interviews were conducted at the participants' homes after obtaining verbal consent from their patients and permission to write notes while they answered. This allowed them to relax and provide adequate information without being intimidated by a foreign environment. The interviews were conducted in English or Setswana. The language that was used to document responses depended on the participants' preference, so we could obtain complete information and reduce the interviewer's biases in personal views and misinterpretation. The principal investigator and researcher thereafter translated the responses into English during the analysis. Interviews were conducted by trained field workers with experience in TB/HIV research after signing confidentiality agreements. Data collection commenced from 04 July 2018 to 14 December 2018.

2.4. Data Analysis

We conducted data analysis concurrently with the process of manually collecting data to determine the point of saturation when no new information was identified. We divided the data into two sections as follows: 1) descriptive statistics for demographic data and 2) narrative data for community experiences in active case finding and strategies subjected to content analysis by naming and categorizing phenomena through close examination. Codes were generated by coding word for word and sentence by sentence, which were then assembled into prominent themes. The themes were categorized according to the components provided by RAM and HPM and aligned to answer research questions in the study.

2.5. Ethical Considerations

We obtained permission from the University of South Africa ethical committee and the Botswana Health Research and Development Committee at national level and districts involved. All enrolled patients provided written informed consent.

3. Results

3.1. Demographic Characteristics of Respondents

A total of 40 caregivers were enrolled, their mean age was 43.4 years, 80% (n = 32) were female, 65% (n = 26) completed secondary education and above, and 52.5% (n = 21) were employed as shown in **Table 1**.

3.2. Community Experiences

This study aimed to identify community experiences as guided by RAM and HPM, and programmatic strategies to facilitate and improve active case finding within the CTBC.

Table 1. Demographic characteristics summary of respondents (n = 40).

Characteristics	Frequencies (40)	Percentage (%)
Age-Mean	43.4	
Sex-woman	32	80
Marital status	26	65
- Single	12	30
- Married		
- Divorced & Widowed	1 each	5
Education-None	1	2.5
- Primary	13	32.5
- Secondary and above	26	65
Employment-None	19	47.5
- Employed	21	52.5
Religion-None	14	35
- Christian	26	65

3.3. Adaptation

Positive and negative adaptation has been identified through many major themes that emerged in this study under different questions that were used to address the main phenomena being studied. In the analysis of adaptive modes, the self-concept mode relates to the psychological aspect of the individual or personal self and how a person/individual behaves at any given time [10].

Themes that emerged from the data while exploring community experiences relating to self-concept were that caregivers:

- Had accepted their role.
- Felt obligated to their role due to their relationship with the patient.
- Well informed about TB.
- Found their role difficult or frustrating due to challenges encountered.

3.4. Self-Concept

Caregivers had accepted their role.

Accepting the caregiving role was the main theme that emerged in 65% of respondents (n = 26). They were fine with caring for their patients at home and found it easy.

The responses for indicating acceptance are provided below in subthemes:

3.5. Experience of Caring for Patients at Home

- “The patient is fine, so caring for them is also fine” (Caregivers 7, 11, 14, 36).
- “It is okay to give the patient medication at home as long as I follow instructions given at the clinic” (Caregivers 19, 20, 24).
- “It has been easy to give the patient their medication” (Caregivers 6, 22).

Caregivers felt obligated to their role due to their relationship with the patient.

3.6. Characteristics of the Respondent's Relationship to the Patients

The relationship of the caregiver to the patient was also collected. The relationship can influence how the caregiver reacts to environmental stimuli. Out of the 40 respondents, 35% (n = 14) were siblings to the patients, 22.5% (n = 9) were parents and community health workers were also caregivers and accounting for 22.5% (n = 9) who were directly observed therapy (DOT) supporters.

Many caregivers were a blood relative to the patient as shown in **Table 2**, and therefore felt their role was obligatory. When asked about their experience taking care of the patient under the CTBC program, at least 40% (n = 16) said they felt obligated to care for the patient at home.

Such responses are provided below:

- “The patient is my mother. I don’t have a choice” (Caregiver 21).
- “The patient is my child and therefore my responsibility.” (Caregiver 39).
- “It is okay, but difficult because the patient’s mother is deceased, and as the patient’s father and her being a woman, because I have to bathe her and take care of her without assistance” (Caregiver 23).

3.7. Caregivers Were Well Informed about TB

At least 28% (n = 11) of respondents were informed about TB and treatment, and their responses were as follows:

- “As the caregiver, I know what TB is, that it is preventable, and what medication my patient is taking for treatment” (Caregivers 9, 12).
- “As the caregiver, I am well informed about TB disease and its treatment” (Caregivers 1, 3, 4, 5, 10, 13, 14, 15, 28, 33, 34).
- “As the caregiver, I know everything there is to know since I am a doctor/health worker” (Caregivers 2, 6).

3.8. Caregivers Found Their Role Difficult or Frustrating Due to Challenges Encountered

Frustration was another main theme that emerged during the interviews from at least 55% (n = 22) of respondents, who indicated that they had no choice, and it was their responsibility to take care of the patient even though it was frustrating and challenging.

Some respondents said the following:

- “My patient was difficult and stubborn to work with as he would sometimes be angry with me, but the situation improved with time” (Caregiver 5).
- “The patient is sometimes not very cooperative, and they become difficult to deal with” (Caregiver 10).
- “It was challenging to me as caregiver, but it is my responsibility because they must be cared for and educated about TB” (Caregivers 3, 4, 5).

An answer from the previous section also touched on this theme:

- “As the caregiver, it is okay, but difficult because the patient’s mother is deceased, and as her father and my patient being a woman, I have to bathe her and take care of her without assistance” (Caregiver 23).

Table 2. Respondents' relationship to the patient (n = 40).

Relationship to the patients	Frequencies (40)	Percentage
Sibling	14	35
Parents	9	22.5
Partner	4	10
Other Relatives	4	10
Community Health worker	9	22.5

3.9. Participants' Suggested Strategies When Asked How to Improve Active Case Finding

3.9.1. Interdependence

The interdependence mode addresses the adaptive behavior expected from both individuals and groups from their interdependent relationships as they provide and receive love, respect, support, and value from their families, relatives, friends, and colleagues [10]. When participants were asked how the TB program could improve active case finding, several themes emerged that related to the interdependence mode:

- Intensifying health education on TB disease.
- Door-to-door TB screening campaign.
- Investigating chronic coughers.
- Intensifying contact screening and tracing.

3.9.2. Intensified Health Education on TB

Health education was identified by at least 43% (n = 17) as an existing strategy that needed to be intensified to assist in improving active case finding and was a subtheme that emerged frequently during interviews.

Given below are common statements some respondents provided:

- "Teach the caregiver more" (caregiver 25).
- "Educating the community about TB" (Caregivers 10, 14, 17, 21, 27, 31, 38, 39).
- "Giving education to those affected by TB, patient and Family" (caregiver 7, 11).

3.9.3. Door-To-Door TB Screening Campaign

Door-to-door campaigns were identified by 35% (n = 14) to improve active case finding.

The responses provided are listed below from most suggestions to least:

- "Door-to-door case finding is more effective than conducting it in public places" (Caregivers 1, 3, 4, 5, 13, 28, 29).
- "We should screen for TB in the community" (Caregivers 18, 23, 30, 33).
- "House-to-house campaign because some people do not want to go to the clinic" (Caregivers 20, 34).
- "We should screen for TB in all those related to the patient" (Caregiver 12).

3.9.4. Investigating Chronic Coughers

Investigating all chronic coughers was also identified by at least 20% (n = 8) to improve active case finding.

The provided responses were:

- “Investigate all coughing patients” (Caregivers 26, 37, 40).
- “Treat all coughing patients as if they have TB” (Caregiver 35).

3.9.5. Intensifying Contact Screening and Tracing

Contact screening and tracing is identified by many local, regional, and global TB studies to contribute to active case finding. The strategy is widely used in active case finding, with many gaps still being identified. Intensifying contact tracing was suggested by at least 20% (n = 8) of this study.

Some respondents said the following:

- “Since the first two weeks are critical, all contacts during that time must be traced, screened, and followed-up” (Caregiver 24).
- “Screen for TB in all those related to the patient” (Caregiver 12).

4. Discussion

Our results showed that caregivers accepted their role and were willing to care for TB patients at home, which agreed with previous reports in Botswana, Kenya, and Ethiopia, that reported that the CTBC was widely accepted as it provided privacy for patients to be taken care of in their own community. More than 50% of the caregivers had a duration of more than 4 months caring for the patients which indicated to the researcher, caregivers/treatment supporters were not leaving the caregiving role before the patient complete their treatment. The duration gave the caregivers opportunities to adaptive to the caregiving roles and reduces negative or unpleasant experiences. Out of 40 respondents, 65% (n = 26) indicated acceptance of the caregiving role as they were fine with caring for their patients at home and had found it easy when asked how it has been like caring for the patients while at home on CTBC program. These results were consistent with the findings of a case study in Kenya on “what do community health workers (CHWs) had to say about their work, and how can inform improved program design?”. The findings revealed that CHWs had accepted their role and this contributed to the success of a lot of community initiatives and is considered essential for improving community programs regardless of challenges encountered during the process [12] [13] [14]. The CTBC is based on voluntarism, though 40% of respondents reported they felt obligated to take care of their relatives. These results were also consistent with a study on the supervision of community health workers in Mozambique, where the community health workers reported a sense of belonging, which acted as their motivation [15]. When participants were asked if CTBC made any difference in caring for a TB patient, 38 out of 40 respondents (95%) reported that it made a difference in a positive way and at least 28 out of 40 (70%) felt that it was fine to care for the patient in their own environment, this indicated acceptance of the caregiving role. These

results were consistent with the results of a study on patient and community experiences of tuberculosis diagnosis and care within a community-based intervention in Ethiopia: which also found out that patients were happy to be taken care of in their own community setting and this included screening and diagnosis, and this approach results in a lot of community members being diagnosed with TB [14].

At least 16 respondents felt obligated to take care of the patients when asked how it was like to care for the patient at home under the CTBC program hence emerging of the sense of obligation theme. These results were consistent with a study on “supervision of community health workers in Mozambique: a qualitative study of factors influencing motivation and program implementation” which also identified a sense of belonging from the community health workers and this acted as motivation to them [15].

Regardless of accepted caregiving role, our results on the other hand showed that some respondents had found the caregiving role frustrating and challenging. The presence or absence of support influences the adaptation level of the system and it's important in such situations. The presence of Social and physiological support was very important in caregiving role, as reported by a study on lessons learned from community-based tuberculosis case-findings in western Kenya [16]. The CTBC goal should be to promote positive adaptation to counteract the negativity so that negative thoughts are turned into optimism to promote hope within caregivers [6] [16] [17].

The strategies that caregivers reported as important were existing strategies that needed to be done different, that is, intensifying health education, door-to-door TB screening campaigns, and intensifying contact tracing and screening. Health education was reported as a strategy that could assist in improving active case finding by 43% of the participants. It is important for patients and caregivers to be given sufficient health education on TB, for the caregivers to provide informed care for their patients and contribute to TB treatment; lack of knowledge regarding control and prevention for TB was reported as a challenge that resulted in patients taking longer to be diagnosed or treated. These results were consistent with results from a review which reported that the community had some needs and expectations like support and education that were not meet. Lack of knowledge was negative adaptation, they needed to be changed into positive effective adaptation to promote the health of caregivers and their patients. Therefore, training caregivers on TB and TB treatment contributes to improving their performance [6] [7] [18] [19]. The Botswana national TB program under the community TB care policy and guidelines also have patient's education and supporter's health education as some of the steps under the implementation of CTBC [4]. Patients and caregivers need to be given health education on TB and TB management. There is a need to have a feedback loop which will be evidence that health education was given.

At least a third of caregivers reported that a door-to-door TB campaign to screen household contacts was a strategy that would improve active case finding.

These findings were similar to studies in Africa on household contacts, in which household contact screening was identified as the most effective method for identifying TB cases [20] [21] [22] [23]. Intensifying active contact tracing and screening was also reported in our study as a strategy to improve active case finding. Contact tracing and screening is a widely used strategy that requires more effort. According to the Botswana Community TB Care Guidelines [6], contact tracing is an important strategy for identifying TB cases within the community through family members, patients, caregivers, volunteers, community health workers, health education assistants, and the community at large [6]. Our study findings were like a study in Kenya where optimizing the efficiency of active case finding in health facilities and communities was found to be important for improving TB case detection and control in the community [22]. Active contact tracing and screening have been reported by many TB studies regionally and globally, to contribute effectively and efficiently to active case finding [5] [22] [24] [25] [26]. This was an old strategy that needs to be supplemented for it to be effective. A study on “community attitudes on tuberculosis in Botswana: an opportunity for improving the national tuberculosis program outcomes”, revealed positive attitudes of communities towards TB patients, hence able to live and work with TB patients for better TB outcomes including screening of suspects/contacts. A study on “optimizing the efficiency of tuberculosis active case-finding in health facilities and communities found out that it was important to do both facility and community screening as TB is widely spread throughout the population to improve TB case detection and control. Contact screening and tracing was an old strategy in TB diagnosis but it needed to be intensified using standard operating procedures so that it done intensively and with uniformity [24].

Given the evidence from these findings, more TB management and strategies are needed to facilitate the CTBC in intensifying the identification of more TB cases and improving TB outcomes. A cluster-randomized trial in South Africa on intensified household contact tracing, prevention, and treatment support versus enhanced standard of care for contacts of TB cases, revealed a marginal contribution of contact tracing to TB care. However, with innovative approaches, assistance, the support of the community, and lessons learned while dealing with the community, case finding can improve [15] [17] [27] [28] [29]. Continuous data quality improvement and the CTBC implementing optimized and structured strategies, can also contribute to improving TB case findings and treatment outcomes [27] [29] [30].

Our study had limitations: the data may not be generalizable to the entire population because of the small sample size. Only caregivers who were caring for TB patients during the data collection period were interviewed, hence we are missing information from other caregivers who were involved in the CTBC before the study period.

5. Conclusion

While caregivers reported being willing to fulfill their role, they identified areas

for systematic improvements. The Botswana national TB program could consider structuring and optimizing health education with a feedback loop at all levels of TB care, including the community caregivers structuring adequate counseling for caregivers before they register into the CTBC, developing a communal training module for caregivers to use before enrolment into the CTBC, intensifying door-to-door campaigns for all TB contacts, and optimizing and intensifying contact screening and tracing to improve active case finding.

Acknowledgements

The authors gratefully acknowledge the contributions of the fieldworkers in assisting with the data collection of this study. The authors would also like to thank the Botswana Ministry of Health and the District Health Management Teams for allowing them to conduct the study in their facilities.

Disclaimer

The views, findings, and conclusions presented in this article are those of the authors and do not necessarily represent the official views of the institutions with which they are affiliated.

Conflicts of Interest

We confirm that none of the authors have any conflicts of interest to declare.

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