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Experiences of community care givers caring for clients with tuberculosis in eThekwini district, KwaZulu-Natal Province, South Africa

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Abstract

Tuberculosis (TB) is still a leading cause of deaths in low and middle income countries especially Sub-Saharan Africa. It is estimated that around 70% of adult new cases of tuberculosis in South Africa are co-infected with the human immunodeficiency virus (HIV). TB is curable if the clients take a full uninterrupted course of drug therapy. Treatment interruption presents a problem for clients, their families, the community, and the health personnel caring for them. The National Department of Health (NDOH) introduced the community care giver (CCG) programme to assist health professionals with the control and management of TB. The study aimed to explore and describe the experiences of CCGs caring for TB patients and to identify the support systems available for them. A qualitative exploratory descriptive design was used to conduct the study. Purposive sampling, guided by data saturation, was used to select the 24 participants that were included in the study. The experiences of the CCGs included facing several challenges in caring for TB patients in the eThekwini district. The challenges were; insufficient work kits, failure to access protective clothing, exposure to communicable diseases, insufficient stipends, no career paths, poor supervision and support. Negative experiences of CCGs might have contributed to demoralisation and poor performance resulting into poor care given to TB patients in the communities.

Keywords: Community care givers, community-based TB care, primary health care (PHC), tuberculosis treatment, treatment defaulter.

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Introduction

Tuberculosis (TB) is one of the leading causes of death in low and middle income countries, especially those in Sub-Saharan Africa (SSA). In some of these countries, TB is an epidemic because of the increased susceptibility conferred by human immunodeficiency virus (HIV) infection (National Department of Health [NDOH], 2009a). South Africa is one of 22 high burdened countries that contribute about 80% of the total global burden of all TB cases and has the seventh highest TB incidence in the world. Approximately 70% of adult new cases of TB in South Africa are co-infected with HIV. TB accelerates HIV

disease progression and is the most common cause of morbidity and mortality among HIV infected people (NDOH, 2010).

TB is curable if clients take a complete and uninterrupted course of appropriate drug therapy, provided that the patient does not have multiple drug resistant (MDR) TB (NDOH, 2009a). TB treatment defaulter rate remains high in South Africa, ranging between 11.1% and 7.1% from 2001 to 2009. This create a barrier to achieving more than 85% treatment success and 85% cure rates as set out in the national targets for the country, thus creating the potential for MDR TB to develop (NDOH, 2007-2011). Treatment interruption presents a problem for clients, their families and the community, and for the health personnel caring for them. One of the consequences of inadequate and incomplete treatment is the development of Multi-Drug (MDR) or Extreme-Drug Resistant (XDR) TB (NDOH, 2009a). Not only are these forms of TB more difficult to cure, requiring longer periods of more expensive treatment, but these patients can spread MDR and XDR TB throughout their communities and infect other people with these TB strains.

South Africa has included TB management as one of the priority programmes for the country in its strategies to achieve millennium development goal (MDG) number 6, target 8 which is to halt and reverse the incidence of TB by 2015(NDOH, 2012). One of the aims of the TB programme is to organize TB services so that the patient has treatment as close to home/work as possible and to directly observe and support treatment. The Directly Observed Treatment Support (DOTS) strategy was adopted by the World Health Organization (WHO) in 1991 (NDOH, 2009a). According to the DOTS strategy, a patient takes his/her treatment at home or at the work place on daily basis. The treatment supporter can be an existing the community care givers (CCG) trained to provide DOTS (NDOH, 2009a), a family member, a colleague or an employer.

The NDOH introduced the CCG programme to assist health professionals in the control and management of various health conditions including TB. The CCGs also assist with conveying health information to the community about TB prevention, identifying and referring suspected TB cases for screening, tracing treatment defaulters and supporting those on TB treatment. There are CCGs that get stipends from the NDOH and those that work on a voluntary basis. The CCGs work in the community but are affiliated to a PHC clinic in the area. All the CCGS that are affiliated to eThekwini Municipality receive a stipend from the Department of Health.

The competent management of CCGs is central to meeting service delivery objectives. CCGs' support elements should include balanced workloads, supervision, community awareness about their existence, activities and roles as

well as assisting them to deal with the emotionally taxing environments in which they might be performing their duties (NDOH, 2009b). The use of CCGs has been identified as a strategy to address the growing shortage of health workers, especially in low income countries (Lehmann & Sanders, 2007). There is robust evidence that CCGs can undertake actions that lead to improved health outcomes, especially in the field of TB management. For CCGs to be able to make an effective contribution, they must be carefully selected, appropriately trained and continuously supported (Lehmann & Sanders, 2007).

Although South Africa already had approximately 72 000 CCGs during 2011, health outcomes are still sub-optimal especially in the areas of maternal, child health and TB programmes (NDOH, 2012). The TB treatment default rate is still above the national target of less than 5% (NDOH, 2007-2011). This could be attributed to inadequate support and supervision, random distribution of service with poor coverage in some areas, no community links with community based-services or with services offered at fixed health facilities or no targets have been set for coverage to be reached (NDOH, 2012).

The purpose of the study was to explore and describe the experiences of CCG caring for TB and to identify the support systems available for them. The research questions which guided the study were:

- What were the experiences of CCGs who were caring for TB patients in the community in the eThekwini District?
- What support was being given to the CCGs to perform their duties?
- What challenges were experienced by the CCGs in caring for TB patients in the communities?
- What were the recommendations of the CCGs regarding solutions to the challenges that they experienced in caring for TB patients?

Methodology

A qualitative, exploratory, descriptive design was used to conduct the study. Purposive sampling, guided by data saturation, was used to select the participants. Only the CCGs who had been employed for at least two years, and who were affiliated to eThekwini Municipality PHC facilities were included in the study. All the other CCGs were excluded from participating in the study. The eThekwini Municipality PHC facilities are located in the three sub-districts within the eThekwini district. The sub-districts, for the purpose of this study are referred to as A, B and C in order to maintain confidentiality and anonymity. Semi structured interviews that were guided by the interview guide and supported by probing where necessary were used to collect data. Elements of trustworthiness such credibility, confirmability, dependability and transferability were ensured during the study. Credibility of data was ensured by investing or

spending more time in the field, prolonging the engagement with study participants, using the same main question for all CCGs interviewed on different dates and getting feedback from participants regarding research findings and interpretations of data so that all interpretations were participants' viewpoints. There was on-going documentation regarding the researcher's decisions about data analysis and collection process in order to develop and maintain an audit trail. Objectivity and neutrality of the data ensured confirmability through a reflective analysis and inclusion of large amounts of data in the written report. The researcher also provided the description of the research setting and research processes to ensure transferability of research results. The validity and reliability of the interview guide was established through a pilot test conducted with three CCGs. It was clear from the responses of the participants that the questions were realistic and understood by the participants.

Data collection took place from March 2014 to April 2014. Six municipality managed facilities were used as venues for interviews or study sites. Permission to conduct the study was obtained from the provincial and municipal department of health because although the CCGS were employed by the provincial health authority, they were affiliated to the municipal health authority. Data were collected by conducting semi-structured interviews with 24 participants in isiZulu and recorded using a voice recorder and field notes. All the interviews were conducted by the researcher.

A thematic analysis of data was used. The transcripts of the interviews were transcribed verbatim and translated into English by the interviewer who was fully bilingual in English and in isiZulu. The supervisor of the study, who is also fully bilingual in English and isiZulu, agreed that the English translations reflected the contents of all interviews accurately. Transcripts were carefully read, and patterns and themes were identified. Data were organised into categories which were further arranged into themes and sub-themes (Polit & Beck, 2012).

Results

A total of 24 interviews were conducted. The number of CCGs interviewed from each PHC facility ranged from two to seven. Table 1 presents the number of interviews conducted in each PHC facility. Five major themes and several sub-themes emerged from the thematic analysis of the data obtained during the semi-structured interviews. These are presented in Table 2.

Table 1: Number of interviews conducted

Sub-District	PHC Clinics	Number of Interviews
A	1	5
	2	3
B	1	4
	2	7
C	1	3
	2	2
Total	6 PHC clinics	24 participants

Table 2: Overview of themes and sub-themes

Themes	**Sub-themes**
Accessibility of kits used by the CCG's.	Insufficient supply of kits.
	Alternative means of making kits available to the CCG's.
Accessibility of protective clothing.	Promotion and supply of uniforms for the CCGs.
	Procurement and supply of protective clothing.
	Alternative ways of getting protective clothes.
Safety and security of the CCGs.	Vaccination against communicable diseases.
	Safety allowance.
Training and development of the CCGs.	Transparency on criteria on further training and development.
	Age limits regarding the selection of the CCGs.
	Lack of career pathing of the CCGs.
Financing of CCG Programme by the Department of Health.	Stipend received by the CCGs.
	Employment benefits for the CCGs.

Accessibility of kits used by the CCG's

The participants stated that they had problems pertaining to accessing kits in performing their duties. The kit included gloves, adult nappies, soap, masks, hand rubs, disinfectants, linen savers and bandages. It is the responsibility of the eThekwini district office to procure, store, supply and deliver kits to all CCGs working in the district. The participants commented about insufficient supplies of kits that were issued to them and the problems experienced in trying alternative means of accessing kits such as borrowing the kits from the PHC clinics or buying the kits on their own. The PHC clinics were not prepared to spare them supplies from the clinics stocks or they would give them very minimal supplies while buying the kits on their own was also expensive and they resorted to buying wrong kits.

Insufficient supply of kits

The participants verbalised that they were not given order kits according to their patients' needs. In most cases kits given to them are not enough; hence they were supposed to share the kits among themselves. They also reiterated that the number of patients and their individual needs were not considered when kits were issued by the district office. Insufficient supplies of kits interfered with their work performance and also exposed both the CCGs and the patients they cared for to cross infection with TB, and possibly also with HIV and many TB patients in South Africa are co-infected with HIV. This was evident in the following statements:
"We are told by our supervisor to share the kits because they are not enough. This disturbs our work because we need everything in those boxes to care for our clients" (Sub-District b: Participant 1).
"Sometimes I do not use gloves to bath the client because in most cases we get very few gloves and they get torn quickly. I know that I might get diseases but what else can I do; I just take it as I am helping another human being" (Sub-District c: Participant 3).

The participants also emphasised that they encountered challenges to collect kits from the district office. There was no transport to deliver the kits to CCGs but, they were expected to collect the kits themselves using public transport at their own expense. This was highlighted in the following statement:

"Even if the kits are available at the district, we have to contribute money from our pockets so that one of us can collect them" (Sub-District a: Participant 2).

Alternative means of making kits available to the CCGs

The participants stated that they had been advised that they could request supplies from the PHC facilities to which they were affiliated. However, this was also not working. The PHC facilities did not provide CCGs with supplies due to limited stocks available in the PHC facilities. Other CCGs ended up buying domestic gloves to use as they felt they are more durable than the gloves issued to them. This was evident from the following statement:

"The sister at the clinic sometimes gives small amounts of gloves but she always tells us that gloves can only be used by clinic staff because stocks are limited" (Sub-District a: Participant 3).

Accessibility of protective clothing

The participants stated that protective clothing such as face masks, safety shoes, raincoats and hats or umbrellas are not provided to them. They were of the opinion that they were subjected to contracting infectious diseases especially because they also traced TB defaulters including MDR/XDR-TB patients.

Supply of uniforms for the CCGs

CCGs raised concerns that they were using their own clothes when caring for patients in their communities, as a result they were not recognised and respected by the communities as they looked like any other community member. They verbalised that they carried infections home; their shoes got torn easily especially during rainy seasons when they had to walk in the mud:
"We are given yellow jackets only. These jackets are the same as those used by road constructors. They can be used by anybody who claims to be a CCG because there are no names written there that identify us as CCGs. These jackets are very hot especially in summer" (Sub-District c: Participant 4).

Procurement and supply of protective clothing

The CCGs raised concerns that the NDOH does not supply protective clothes. They referred to things such as face masks, gloves, safety shoes and raincoats or winter jackets. They emphasised that since they also trace TB defaulters, including MDR/XDR TB patients, they needed protective clothing. Worries were also raised that when doing household profiling, they spent more time exposing themselves to infections. This was identified in the following comment made by one CCG:

"I wish the Department of Health can always supply us with face masks especially because when we are doing household profiling, we spend many hours in one house or shack to fill the complicated profiling form. This exposes us even more to TB infection" (Sub-District b: Participant 5).

Alternative ways of getting protective clothes

The participants commented that other means to ensure that staff had protective clothing were available for other employees and not for the CCGs. The participants commented that other government employees were given annual uniform allowances which allowed them to save on their personal clothes but no allowance was given to the CCGs, as stated:

"Other employees like the clerks, nurses and cleaners are either issued with uniforms or given a uniform allowance but we are not given anything, why are

we not considered because we are also providing the service and we are mostly exposed because we go out to the community? Actually, we only get yellow jackets and these are very hot especially in summer. We use our own shoes and clothes and it is very hard for us" (Sub-District c: Participant 3).

Safety and security of the CCGs

The participants were concerned about their safety while doing their work. They stated that they travelled long distances in an unsafe environment when doing home visits. Being females and subjected to homes where the patients are only males posed the risks of being sexually abused.

Vaccination against communicable diseases

The participants were worried that they were at risk of contracting infectious diseases because they were excluded from vaccinations such as swine flu (SARS) and hepatitis B. These vaccinations were only given to permanent government health care workers. They felt that they were also at risk of contracting infections because they worked with sick people including TB defaulters as identified in the following statement:

"I always hear that nurses get injections to protect them against infections as they nurse the patients, why are we not given as CCGs because we also work with sick people" (Sub-District b: Participant 6).

Safety allowance

The participants expressed their concerns about being exposed to risks while doing their work. The risks included; dog and snake bites, sexual abuse and contracting infectious diseases like MDR/ XDR-TB. The feeling was that they needed to be compensated through monetary incentives as explained in the following statement:
"I wish the government can give us danger allowance on top of our stipend because we work under very dangerous conditions" (Sub-District a: Participant 3).

Training and development of the CCGs

The participants expressed concerns about how the CCGs were selected for further training and development.

Transparency on criteria on further training and development

The participants stated that there was no clarity on the nature of training and development available for the CCGs; and were concerned that the training for the CCGs was limited to health-related issues yet they were expected to work in other government programmes as well:

"Truly, I do not know how the Department of Health selects people for training. I heard that they need to have matric to be selected, but there are many CCGs with matric who are not selected" (Sub-District a: Participant 1).

Age limits regarding the selection of the CCGs

The participants also expressed their dissatisfaction with the age limit that was used as the criteria for selection of the CCGs to go for training and development. They were of the opinion that age should not be used as one of the criteria for selection:

"I do not understand why the age needs to be considered. The age should not be the factor we should all be given an opportunity" (Sub-District b: Participant 6).

Lack of career pathing of the CCGs

The participants expressed their concerns regarding access to advertised posts stating that the CCGs should be prioritised when posts were filled because they already had work experience compared to the general public.

"I wish the district can recognise the work we do and consider us when the permanent positions become available, not to give posts to people that [have] never done voluntary work" (Sub-District b: Participant 4).

Financing of the CCG programme by the Department of Health

The participants verbalised several concerns regarding issues salaries and conditions of service. One concern was that they needed to renew their contract each year in order for them to receive their stipends.

Stipends received by the CCGs

Participants were also concerned about the amount of the stipends that they received at the end of the month despite the years of experience and increased workloads. They further stated that they had employment numbers as government employees, yet they were constantly reminded that they were not

employed; hence they were receiving a stipend not a salary. This was expressed in the following words:

"I suggest that the stipend of the CCGs that have longer service be different from those who are newly contracted. I think it would be fair like that because some of us have more than ten years' experience, yet they get same stipend like the new ones" (Sub-District c: Participant 5).

Employment benefits for the CCGs

The participants expressed their dissatisfaction with the fact that they were not entitled to all the employment benefits. This was evident in the following comments:

"I wish the government can consider us as full time employees so that we can also enjoy employment benefits like all the other employees" (Sub-District a: Participant 2).

Discussion

The findings of the study revealed that the CCGs who were caring for TB patients in the community in eThekwini District were experiencing several challenges such as interfering with the execution of their duties and the welfare of CCGs as government employees. The concerns included insufficient and irregular supplies of kits in the execution of their work. It is the responsibility of the district office to procure, store, supply and deliver kits such as; gloves, face masks, adult nappies, soaps hand rub, linen savers and bandages to all CCGs working in the district. Uwimana et al. (2012) in their study conducted in KwaZulu-Natal, on training of CCGs, stated that inconsistency of supplies and commodities such as kits needed to be resolved to increase uptake of TB and HIV health services. The participants were also concerned about the supply of uniforms and protective clothing by the provincial Department of Health as they were only issued with yellow jackets. According to Schneider and Lehmann (2009), the precarious location on the margins of the formal health system of the CCGs, resulted in the failure to recognise them as health system's employees entitled to employment benefits like uniform allowances or supplies. Ogunmefun et al. (2011) recommended that the NDOH should provide the necessary support, training and incentives such as uniforms and transport to enable the CCGs to expand their services from the current ratio of 1:17 to 1:250. They further suggested that the NDOH should institute a proper remunerative system for the CCG programme that will enable them to be contracted by districts so that they have job descriptions, performance agreements, uniform reimbursements as well as stable and dependable incomes through stipends.The current study's findings indicated that CCGs were working mainly in informal settlements in dangerous

situations. As a result, they felt exposed to communicable diseases. Safety concerns included the absence of vaccinations for swine flu and Hepatitis B and the inadequate use of masks for protection against inhaling TB germs. The Occupational Health and Safety Act (Act no. 85 of 1993) as amended by the Occupational Health and Safety Act (Act no.181of 1993) section 8, states that an employer has a duty to provide and maintain a working environment that is safe and without risk to the health of his/her employees and to provide personal protective equipment. Odendaal et al. (2011) states that establishing and maintaining high morale among the CCGs is an important component of ensuring the delivery of quality services. The unavailability of supplies and the experienced lack of recognition of their contributions, might have impacted negatively on the morale of the CCGs. The participants were concerned about processes and procedures concerning the training and development of CCGs. There were no clear set criteria and requirements neither for selection nor for further training. Consequently, some CCGs felt that others were favoured over themselves. Ogunmefun et al. (2011) recommends that the Department of Health should facilitate the process of providing formal training to more CCGs, especially for those with matric or grade 12, and that CCGs without training should be provided with adequate standardised training to capacitate them with the required skills to perform their expected tasks adequately. Odendaal et al. (2011: 33) maintains that sustained monitoring and evaluation of the CCGs and paying attention to their training needs were necessary to ensure that patients receive quality care.

The CCGs commented that their stipends were small for the amount of work involved and that their years of experience were not considered, and no increments applied to their stipends. Odendaal et al. (2011) recommended that the stipends should be increased to recognise the DDGs' valuable contribution to health service delivery. Ogunmefun et al. (2011) highlighted that non-payment of stipends to CCGs resulted in poor performance and lack of commitment similar to findings reported by Lehmann and Sanders (2007) and by Friedman et al. (2010). According to Friedman et al. (2007), most CCGs in South Africa were single unemployed women, with no matric or other qualifications, aged 20-40 years who were desperately in need of living wages. Community Care Worker Management Policy framework which is the Policy on CCG management recommends that at least R500 be the stipend in the first NQF level. This stipend should increase to R1000 as they move to the next levels; possibly even higher than R1000 as years of service increase and or training as CCGs completed (Department of Social Development 2009b). Therefore, the experience and training of the CCGs should be considered when paying stipends.

Limitations of the study

This study consisted of a small number of participants, conducted in one district, as such, is not transferable to other districts and or other parts of South Africa. Only

CCGs affiliated to eThekwini Municipality clinics were interviewed, so it is therefore difficult to generalize the study findings to CCGs working with KZN Provincial facilities. All study participants were Africans mainly working with African clients in informal settlements, and as such, the results cannot be generalized to other race groups in formal houses.

Recommendations

EThekwini Health District Office should continue to procure, supply and deliver kits for the CCGs, but storage is to be negotiated with relevant facilities that work with the CCGs for easy access. The ordering and control of kits should be the responsibility of the facility manager. Incentives in the form of uniforms and protective clothes should be considered for the CCGs and should be supplied in accordance with infection prevention and control policies.The policy for vaccination and preventative therapy such as Hepatitis B and influenza vaccines, pre-employment and periodic medical examinations for health care workers should also include the CCGs. The NDOH should have set criteria in place for further training and development for the CCGs and this criterion should be made known to all the CCGs and adhered to at all times. The stipend should increase according to the years of experience for individual CCGs. A broader study involving all the CCGs in eThekwini district on the required support and supervision for the CCGs is recommended.

Conclusions

The CCGs verbalized dissatisfaction on issues such as insufficient supplies of kits, protective clothing not considered for them yet they worked as employees. Procedures and criteria for selection of people for further training were not clear; their safety was not considered as important by the employer. Issues of support and supervision from the clinics and the district were also lacking. CCGs were dissatisfied and discouraged and only working because they did not have any other means to survive.

References

Department of Labour. See South Africa.

Department of Social Development. See South Africa.

Friedman, I., Ramalepe, M., Matjuis, F., Bhengu, L., Lloyd, B., Mafuleka, A., Ndaba, L. & Baloyi, B. (2007). Moving towards best practice: Documenting and learning from existing community health/care worker programmes. Health Systems Trust and National Department of Health. Durban. South Africa. (Online). Available: http://www.unaids.org/bestpractice. Accessed 30 March 2014.

Lehmann, U. & Matwa, P. (2008). Exploring the concept of power in the implementation of South Africa's new community health workers policies. Johannesburg: University of Witwatersrand. (Online). Available: www.equinetafrica.org/bibl/docs/dis64Poliehmann.pdf.Accessed 19 December 2013.

Lehmann, U. & Sanders, D. (2007). Community care givers: What do we know about them? University of Western Cape: School of Public Health. (Online). Available: http://www:who.int/hrh/documents/community_health_workers.pdf. Accessed 19 December 2013.

NDOH. See South Africa. National Department of Health

Odendaal, A., Mtshizana, Y., Lewin, S. & Haisler, H. (2011). A *Formative Evaluation of Integrated Community Based Treatment and Adherence Support Models for TB and HIV Clients.* Bellville: South African Medical Research Council.

Ogunmefun, O., Madale, R., Matse, M., Jassat, W., Mampe, T., Tlamama, F. & Masuku, M. (2011). Audit of community care givers in the district of North West. (Online). Available: http://www.hst.org.za. Accessed 31 October 2013.

Polit, D.F. & Beck, C.T. (2012). Nursing *Research: Generating and Assessing Evidence for Nursing Practice* (9th ed.). New York: Wolters Kluwer/Lippincott Williams and Wilkins.

Schneider, H. & Lehmann, U. (2009). Lay health workers and HIV programmes: Implications for health systems. School of Public Health, University of the Western Cape, South Africa. (Online). Available: http://www.informaworld.com. Accessed 21 May 2014.

South Africa Department of Health (2007-2011). *Tuberculosis Strategic Plan for South Africa*. Pretoria: Government Printer.

South Africa Department of Health (2009a). *The South African Tuberculosis Control Programme*. Pretoria: Government Printer.

South Africa Department of Health (2009b). *Community Care Worker Management Policy Framework.* Pretoria: Government Printer.

South Africa Department of Health (2010). *Strengthening South Africa's Revitalised Response to AIDS and Health.* Pretoria: Government Printer.

South Africa Department of Health (2011). *Provincial Guidelines for the Implementation of the Three Streams of PHC Re-engineering*. Pretoria: Government Printer.

South Africa Department of Health (2012). *Millennium Development Goals Country Report.* Pretoria: Government Printer.

South Africa Department of Labour (2010). *Occupational Health and Safety Act* (Act no. 85 of 1993) as amended*.* Pretoria. Government Printer.

South Africa Department of Social Development (2009). *Community Care Giver Policy Framework for Home Community Based Care.* Pretoria: Government Printer.

Uwimana, J., Zarowsky, C., Haussler, H. & Jackson, D. (2012). Training community care workers to provide comprehensive TB/HIV/PMTCT integrated care in KwaZulu-Natal: Lessons learnt. *Tropical Medicine & International Health,* 17(4), 488-496.