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Full Length Article

Community care worker perceptions of their roles in tuberculosis care and their information needs



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ABSTRACT

Background: Community care workers (CCWs) inhabit a central role in the management of tuberculosis (TB) patients in South Africa. CCWs attend training courses, but training is not standardised at either the national or provincial level.

Objective: To explore perceptions of CCWs of their role in TB care and TB information needs.

Methods: CCWs working with TB patients were recruited from Grahamstown Hospice and local primary healthcare clinics in Grahamstown. Focus group discussions and semi-structured interviews were conducted with 14 CCWs using a question guide. Data were thematically analysed.

Results: Three themes emerged from data analysis. Firstly, altruism was identified as the major motivational factor, with a desire to help others often stimulated by previously caring for sick relatives. Some CCWs had experienced being patients needing care, which motivated them to become involved in offering patient care. Secondly, CCWs reported great fulfilment and pride in their work as they believed they made a meaningful impact on patients' lives and in the surrounding community, and were respected for this contribution. Thirdly, most identified a need for further training and access to additional information about TB, particularly MDR- and XDR-TB, in order to reinforce both their own knowledge and to educate patients about drug-resistant TB.

Conclusion: CCWs were motivated and proud of their contribution to TB patient management and the education they provided to patients and to lay community members. Ongoing training was identified as a need, along with access to quality information materials to improve their knowledge and facilitate patient counselling.

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1. Introduction

Tuberculosis (TB) remains a global public health concern with 1.5 million deaths in 2014 and an estimated nine million people infected. The epidemic is worsened by a growing resistance to TB medication and the increase in HIV-associated TB cases, which is highest in the African region, a region that accounts for a quarter of global TB cases (Takarinda et al., 2015, p. 30; World Health Organisation [WHO], 2015, p. 10). South Africa, a high TB-burden country, incorporated the Directly Observed Treatment Short Course (DOTS) strategy into the South African National TB Programme established in 1994. This programme faced the challenge of trying to implement policies in the previously disadvantaged, under-resourced public healthcare system (Churchyard et al., 2014, p. 234; South African Department of Health, 2004). Subsequent innovations in the DOT strategy led to the involvement of community participation in TB service delivery (Ayles et al., 2013, p. 1184; WHO, 2003).

The use of community members in healthcare was first advocated at the Alma Ata conference in 1978 when primary healthcare (PHC) introduced the concept of community care workers (CCWs) who shared a common language, culture and living environment as patients and who would contribute to PHC by improving access to healthcare services (Hall & Taylor, 2003, p. 18; WHO, 1978). Although different names are used to refer to CCWs, they are generally defined as healthcare workers carrying out functions related to healthcare delivery, trained in any way in the context of the intervention but having no degreed tertiary education (Lehmann, Friedman, & Sanders, 2004, p. 2). CCW programmes have played key roles in satisfying the demand for essential services, increasing the uptake of health services and improving the management of various conditions. In South Africa, support for CCW programmes grew with the launch of the 2010 initiative to re-engineer PHC (Naledi, Barron, & Schneider, 2011, p. 22) and the programmes have demonstrated success in targeting adherence for chronic diseases, as well as promoting social development by assisting local communities with water and sanitation, processing of welfare grants, and food security (Chopra & Wilkinson, 1997, p. 373; Friedman, 2005, p. 177; Wilkinson & Davies, 1997, p. 702).

In high-burden TB and HIV settings, CCWs have assisted in reducing patient load on formal healthcare workers by taking over supervision and support of patients (Maher, Van Gorkom, Gondrie, & Raviglione, 1999, p. 762; Wilkinson & Davies, 1997, pp. 702–703). CCWs in South Africa see patients both at PHC clinics and at their homes, thereby decentralising TB services. With good knowledge of their own communities, CCWs are able to refer TB suspects to clinics, trace treatment defaulters, improve TB education and increase community awareness of TB (Dudley et al., 2003, p. 54; Kironde & Bajunirwe, 2002, p. 74; Kironde & Kahirimbanyib, 2002, pp. 16–17).

The renewed focus on PHC in South Africa has highlighted several issues facing the effectiveness of CCWs. Currently, employment of CCWs by either non-profit organisations (NPOs) working with healthcare centres or by the national Department of Health has resulted in a number of different types of CCWs who provide similar services but do not work

together (Friedman, 2005, p. 167). Due to this fragmentation of roles, CCWs often lack the skills to deal with healthcare issues that are outside the range of their training. Lack of co-operation between the community-based NPOs and the Department of Health has resulted in varying curricula, non-standardised training (Friedman, 2005, p. 168) and inconsistent support and supervision offered to CCWs in the different programmes (Friedman, 2005, p. 169; Clarke, Dick, & Lewin, 2008, pp. 680–681).

1.1. Research problem statement and objectives

It has been documented that CCWs have privileged insights into the social determinants of health in communities and that there is a need for these insights to inform health policies. Despite this realisation, CCW accounts of their own roles and practice have been lacking which may be one of the factors hindering the integration of CCWs within formal health systems (Oliver, Geniets, Winters, Rega, & Mbae, 2015, p. 2). CCWs are often the only health workers having contact with patients, affording them a unique opportunity for education and counselling. The effectiveness of this role in contributing to improved health outcomes depends on adequate supervision by professional healthcare workers, usually nurses, who have received formal training at a higher educational institution (Puchalski et al., 2012, p. 1492; Watkins, Rouse, & Plant, 2004, p. 218; Wares, Singh, Acharya, & Dangi, 2003, pp. 333–334). CCW success in influencing patient outcomes also depends on the quality of their training in developing a good knowledge base, as well as access to appropriate TB-related information to ensure constant maintenance and updating of knowledge. The objectives of this study, therefore, were to explore the perceptions of CCWs of their role in TB care, and their TB information needs.

2. Method

2.1. Study design and context

This research formed the first phase of a larger study designed to meet the information needs of CCWs. The research design selected for this study was exploratory and qualitative in nature (Patton, 2002: pp. 1–10) as it sought to understand the context of CCW practice and their place within the healthcare system based on their own reported experiences and perceptions. Employing the qualitative approach (Patton, 2002: pp. 1–13) assisted in exploring the information needs of CCWs which would lay the foundation for subsequent phases of the study.

This study was conducted in Grahamstown in the Eastern Cape, a province of South Africa in which 57% of the population live in poverty and 7.2% have not received any schooling (Eastern Cape Socio Economic Consultative Council, 2012). The South African healthcare system consists of a private and a public sector with the majority of Grahamstown patients reliant on the latter, being served by six local PHC clinics which manage TB patients with uncomplicated TB. Each clinic employs CCWs classified into general home-based carers, lay counsellors and TB-specific DOT supporters. Grahamstown

Hospice is a non-governmental organisation (NGO) that provides palliative care for end-stage diseases including TB. Hospice employs generalist CCWs to provide home-based palliative care for TB patients.

2.2. Initial discussions

Preliminary meetings were held with the District Health Office (district pharmacist, manager of PHC outreach teams, TB programme manager, clinic facility managers) in order to explore the context of CCWs working in Grahamstown and establish whether the proposed study would be supported. In a meeting with the clinical skills manager of Grahamstown Hospice, the project was presented and the possibility of recruiting CCWs for the study explored. Discussions identified a gap in the availability of simple, easily understood TB information for CCW training and for CCW-patient interactions that focused on patient education. The project was supported in principle by both groups. Ethical approval was obtained from the Eastern Cape Department of Health and Rhodes University Faculty of Pharmacy Ethics Committee (PHARM 2014–10).

2.3. Recruitment of study population

Inclusion criteria included employment as a CCW by either Grahamstown Hospice or the provincial Department of Health (either TB-specific or generalist) and involvement in the routine care of TB patients. Facility managers of the PHC clinics and the Grahamstown Hospice manager informed their CCWs about the study during one of their routine meetings. Although CCWs were encouraged to participate in the study, they were made aware of their option to decline. CCWs were recruited by purposeful sampling which allows the selection of a specific group of participants to learn about the issues of central importance to the purpose of the study (Patton, 2002: p. 230).

2.4. Interview process

Discussions and interviews were conducted over a period of five months (July–November 2014) at Grahamstown Hospice and three PHC clinics. Two focus group discussions (FGDs) (Patton, 2002: p. 385) were conducted at Grahamstown Hospice, with four CCWs in each group. Semi-structured interviews were conducted at the PHC clinics, with two CCWs participating in each interview. All sessions were conducted in a private room at each facility.

The research team consisted of a female African researcher (IO) and her project supervisor (RD) who acted as an observer. The researcher introduced him/herself and presented an overview of the study. Invitation letters, containing information about the study, benefits of the project, confidentiality and the right to decline to participate or leave at any stage during the study, were distributed. CCWs were given time to read the invitation letters and were invited to ask questions. Thereafter, CCWs who agreed to participate in the study signed the consent form. All the CCWs indicated their willingness to continue.

Informed by the study objectives, an interview guide was developed (Patton, 2002: p. 343) to explore the following areas: motivation for becoming CCWs, personal perception of CCW role(s) and training, and TB information needs. Questions in the latter area explored accessibility of information sources, as well as CCW perceptions of knowledge areas that were poorly understood by patients. All discussions were conducted in English, the second language of all the participants. However an interpreter was present to assist in translation to isiXhosa when required. In an attempt to encourage open engagement and honesty in responses, the researcher also ensured that CCWs knew that there were no right or wrong answers. The sessions started with each person introducing herself, followed by an ice-breaker activity to encourage the CCWs to relax, feel comfortable and share information about themselves, with the following being asked: “Please write down one word to describe how you feel about being a CCW”. Thereafter each person showed the rest of the group the word they had written and explained why they had chosen that word. No further writing by the CCWs was required. Paper and pens were provided.

The discussions ended with showing the CCWs examples of different forms of written information materials (A4 simple illustrated TB patient information leaflet, A5 folded booklet, A3 poster). The aim was to ascertain the preferred format of any information to be designed for their subsequent use. Field notes (Patton, 2002: p. 383) were taken by the researcher, and the project supervisor recorded written notes and observations during the interviews. All sessions were audiotaped to ensure verbatim accounts of information provided by the CCWs. The FGDs and semi-structured interviews lasted between 45 min and 1 h. The sessions continued until data saturation, and this was deemed to have occurred after five sessions that included a total of 14 CCWs.

2.5. Trustworthiness

In order to ensure trustworthiness of this research, Cuba's constructs of credibility, transferability, dependability and confirmability techniques were addressed during the research process (Shenton, 2004, pp. 63–75). To ensure credibility, site triangulation was employed by using participant CCWs from both the public healthcare system and Grahamstown Hospice. Having a variety of perspectives from the two groups of CCWs decreased the effect of having local factors in the study findings that affect only one institution, which assisted in showing a more stable view of reality. In addition, the findings were further strengthened by using supporting data from meetings held with key stakeholders from the District Health Office who raised issues that were then addressed in further detail by participant CCWs, e.g. training shortcomings.

Dependability (Shenton, 2004, pp. 71–72) was enhanced via a comprehensive description of the research methodology to ensure that it could be duplicated. Frequent debriefing sessions were also held between the researcher and the project supervisor which assisted in providing a sounding board for the investigator to test the developing ideas and interpretations. Opportunities were created throughout the duration of the study for ongoing peer scrutiny of the research project by colleagues, peers and other academics. The project was presented at two national conferences, improving confirmability

(Shenton, 2004, p. 72) as it allowed other people external to the project to challenge any assumptions and bias by the researcher, thus refining the method. Admission of the researcher's beliefs and assumptions and consciously setting them aside also enhanced the accurate collection and interpretation of data (Hsiung, 2008, pp. 211–226; Patton, 2002: p. 65).

Transferability (Shenton, 2004, pp. 69–70) was achieved by intentionally selecting the study participants and by independent coding by both the researcher and the project supervisor. This was also assisted by audio recording all the responses and taking field notes which enhanced the accuracy of the results as verbatim quotes provided by the CCWs were used.

2.6. Data analysis

Audio-taped discussions were transcribed verbatim and the data analysed thematically (Attride-Stirling, 2001, p. 385). After reading the transcripts, codes were identified based on key words and recurrent issues that emerged from the data. Coding was done independently by the two researchers who later met to discuss any disparities. Thereafter, themes were identified from the coded data and were further refined to ensure their relevance in relation to the objectives of the study. NVivo 10[®] software was used to aid this process.

3. Results

From Table 1, CCWs were predominantly female and between 30 and 50 years of age (mean age = 42 ± 6 years). Of the 14 CCWs, 10 had completed high school education and 10 had been working as CCWs for five years or more. Three major themes emerged from analysis of the data: altruism as a motivational factor, the perception of the CCW role as a fulfilling one, and identification of needs to improve training and skills.

3.1. Altruism as a motivational factor

The desire to help others with their health problems was the most commonly expressed reason for choosing to pursue the path of caring for sick people. Some CCWs had family members who had previously been afflicted with long-term

terminal diseases. Others felt that becoming a CCW would fulfil their desire to care for someone in need, a role they had, for various reasons, been unable to fill for their own sick family members.

“What motivated me to be a care worker is because I ... lost my father and ... my mother ... I didn't have enough time to look after them Then I said to myself I wish I can satisfy my heart by looking after somebody and then I joined Hospice. I'm fine now ... because I satisfy my heart now because I did look after other people, sick people” (P7).

Those who had been in a position to take care of sick relatives reported that the experience had familiarised them with aspects of patient care and prompted the will to assist patients who did not have others to care for them.

“My mother had cancer and we have to ... wash ... do dressing, all that stuff.... Some [patients] they don't have others to help them so I thought that maybe I will guide them throughout their difficulties” (P5).

CCWs who had themselves been patients were motivated to assist patients as they regarded themselves as being better equipped to relate to patients and their needs.

A few of the CCWs had wanted to train as nurses in order to help others but were hindered by either financial constraints or inadequate grades. They entered the healthcare system by volunteering at local clinics and eventually becoming CCWs.

“I really wanted to be a nurse when I was at school but when I finished with my grade 12, the money was not there to fulfil my dream but I started [to] volunteer at a clinic” (P3).

Others attested that they were driven to become involved in healthcare services as a result of observing the shortage of staff in health facilities and its negative impact on patient care. CCWs commented that the inability of many in their community to take care of themselves when ill also stimulated the desire to become part of a system that could assist such individuals.

Table 1 – Demographic characteristics of study participants.

| Participant number | Gender | Age (years) | Education (years) | Years as a CCW | Institution |
|--------------------|--------|-------------|-------------------|----------------|---------------|
| 1 | F | 41 | 12 | 3 | Hospice |
| 2 | F | 49 | 12 | 11 | Hospice |
| 3 | F | 40 | 12 | 5 | Hospice |
| 4 | F | 45 | 12 | 3 | Hospice |
| 5 | F | 32 | 12 | 1 | Hospice |
| 6 | F | 47 | 11 | 19 | Hospice |
| 7 | F | 48 | 11 | 7 | Hospice |
| 8 | F | 38 | 12 | 9 | Hospice |
| 9 | F | 40 | 10 | 9 | Public sector |
| 10 | F | 31 | 12 | 9 | Public sector |
| 11 | M | 34 | 12 | 5 months | Public sector |
| 12 | F | 46 | 11 | 22 | Public sector |
| 13 | F | 46 | 12 | 7 | Public sector |
| 14 | F | 45 | 12 | 8 | Public sector |

3.2. Perception of the CCW role as a fulfilling one

Most of the CCWs reported that their roles in clinics and within their communities led to recognition, respect and the formation of trusting relationships. Patients displayed this trust by frequently confiding information that they would not normally disclose to other healthcare workers e.g. forgetting to take their medication. This positive perception from both patients and the community contributed to their satisfaction and pride in their roles as CCWs.

“It is very much interesting to do this thing [work as DOT supporters] and for that matter even in the community they do show you some respect that you are doing something for them” (P11).

The ice breaker question of one word to describe how they felt about being a CCW generated responses including: confident, helpful, inspiration, proud, great, passionate, happy.

“I wrote great. I feel great because I manage to help a lot of people with TB” (P7).

It was apparent from their words that they felt great pride in being a CCW as it enabled them to have a meaningful impact on patients' lives, which stimulated their enjoyment for their work and confidence in their ability to make a difference.

3.3. Identification of needs to improve training and skill

A wide range of varying responses was received relating to content, duration, frequency and quality of training. Although all reported receiving training, some CCWs felt that it was inadequate as they lacked understanding of how to deal with certain issues, for example explaining to patients how to produce sputum as opposed to saliva, and how to respond to patients when they reported lack of available food as an excuse for defaulting treatment. They felt that one training session without subsequent follow-up training was inadequate, as they needed to both reinforce certain topics and expand their knowledge. They identified a need for being informed about the frequent changes in TB policy or treatment guidelines such as the recent introduction of GeneXpert[®] for MDR-TB diagnosis.

“It's [training] not enough because TB always change, change, change all the time and again” (P14).

CCWs regarded the TB information and advice given to patients, their families and community members as extremely important, particularly information pertaining to adherence and consequences of defaulting therapy. They felt that although patients liked receiving information and learning more about TB, the currently available information materials were either too difficult to understand or were not appealing, making patients reluctant to read them. CCWs identified a distinct lack of easy-to-read TB information for patients. Poor knowledge in most patients was identified as including cough hygiene, general hygiene, signs and

symptoms of TB, transmission of TB, side effects of medication and treatment duration.

“There are also a lot of patients that don't have enough information about TB, then when we tell them they have TB, they will shout and say I don't have TB, where did I get the TB from?” (P10).

The main sources of TB information cited by the CCWs were the nurses with whom they worked, booklets at the clinic prepared by the health department or NGOs, and ongoing training sessions (the latter identified only by Hospice CCWs). If they were unable to answer patients' questions, they would refer the patient to the clinic sister.

“Sometimes at the trainings, the things that we learn we write them down in the notebooks and we tell them [patients] what we have learnt at training. And even the booklets we give them out to the patients to read so if there are any questions they can come to us and ask if they don't understand” (P9).

CCWs recognised that, as drug-resistant TB was becoming common in their communities, they needed more information on the management of MDR- and XDR-TB patients and advising patients on the importance of adherence to prevent resistance. CCWs felt that ongoing training would equip them to better educate and empower both patients and fellow community members.

“We need to update each and every time the new things came. Like there is ... GeneXpert things and MDR things and XDR things et cetera for TB So I need more information to give education, to empower the people outside” (Participant 13).

Trying to ascertain a preferred format for TB information materials proved difficult as the CCWs were unable to articulate their desired type and form of information. However, after being shown a range of different formats they chose the A5 booklet as they felt that this would be easy to carry when seeing patients. They also requested a poster that could be placed in clinics for health promotion purposes. CCWs were particularly enthusiastic about the TB patient information leaflet with pictograms that they were shown, and agreed that having information material in a similar format would make it attractive and educational as the pictograms could enhance patient understanding.

“I think it will [be] helpful when [we] show some pictures because when you talking sometimes they [patients] don't understand what you are talking about” (P8).

4. Discussion

The extensive use of CCWs in TB programmes, combined with a high CCW attrition rate, has resulted in an increasing call for a better understanding of what motivates individuals to become and remain CCWs (Kironde & Bajunirwe, 2002, p. 75). The CCWs we encountered were motivated by a genuine

concern for others, revealing moving personal experiences which stimulated an imperative to help those in need of healthcare. Previous research has acknowledged altruism as a motivating factor for CCWs, with the drive to assist others being influenced by religious beliefs, life stories and experiences (Greenspan et al., 2013, p. 1485).

Although monetary incentives have been previously noted, and financial support of CCWs advocated (Greenspan et al., 2013, p. 1479; Kironde & Bajunirwe, 2002, p. 76; Schneider, Hlopho, & Rensburg, 2008, p. 182), these were not mentioned as a motivating factor. Instead, responses from our participants revealed intense engagement with and enjoyment of their work which was rewarded by the high esteem with which they were regarded within their communities where they received recognition and respect that made them feel appreciated for their efforts in trying to make a difference.

Despite CCWs occupying a low position in the healthcare worker hierarchy (Greenspan et al., 2013, p. 1485; Maes & Kalofonos, 2013, p. 89), their good patient relationships and the appreciation received from patients contributed to their confidence and belief that they were well positioned and able to positively influence health outcomes, endorsing the rationale behind the development of CCW programmes of improving healthcare services in local communities. Similar to other studies (Schneider et al., 2008, p. 182; Sips et al., 2014; Tsolekile, Puoane, Schneider, Levitt, & Steyn, 2014, p. 2), their main role was seen to be the link between patients and the healthcare system. Our study identified a further important role of CCWs within the community in promoting social development and empowering community members through health education.

Poor TB knowledge may affect health-seeking and adherence behaviours, impacting on TB control (Mangesho et al., 2007, p. 39). With their knowledge base, CCWs were able to identify deficient TB knowledge areas in their patients that they felt affected TB management. Their role, combined with their good patient relationships, ideally situates them to increase TB awareness in communities and promote adherence among patients. However, their effectiveness depends on adequate training and support from the healthcare system (Haq & Hafeez, 2009, p. 4492). A number of studies support our finding of weaknesses in CCW training (Haq & Hafeez, 2009, p. 4493; Puchalski et al., 2012, p. 1492), aligning with our conclusion of basic training being inadequate, with unacceptable variability in course content and duration. Lack of continuous refresher training, which was emphasised by our CCWs, is a crucial component that reportedly results in loss of skills and knowledge (Haq & Hafeez, 2009, p. 4492; Lehmann et al., 2004; Puchalski et al., 2012, p. 1495).

TB policy and treatment guidelines are constantly being updated, but can only be implemented if all levels of healthcare workers are updated, a deficiency identified by local CCWs. Adequate communication channels between CCWs and other healthcare workers are therefore crucial as they keep CCWs informed on emerging issues (D'Adamo, Fabic, & Ohkubo, 2012, p. 25; Haq & Hafeez, 2009, p. 4493). The reported inability of the CCWs to clarify certain concepts to patients further emphasises the need for experiential training, possibly in the form of role-play, to familiarise them

in dealing with difficult patient interactions (Haq & Hafeez, 2009, p. 4496).

CCWs cited limited sources of available information, importantly identifying a lack of appropriate written materials. It has been recommended that training programmes should develop information materials specifically for CCWs instead of using training materials intended for formal healthcare professionals (WHO, 2010) as, with their limited formal education, CCW information needs are likely to differ from those of other healthcare professionals (D'Adamo et al., 2012, pp. 24–26). They may therefore need materials that contain simpler language, with more illustrations, to cater for their lower educational status (WHO, 2010).

Pictorial information materials such as checklists, cards, booklets and leaflets have been successfully used to enhance CCW roles in malaria, and in maternal and child health (Harvey et al., 2008, p. 169; Nelson et al., 2012, pp. 130–134) and have also been shown to improve knowledge in patients with limited literacy (Dowse, Barford, & Browne, 2014, pp. 1403–1405). The enthusiasm the CCWs showed for pictorial content and their desire to have access to some form of written information has informed our ongoing subsequent research. We have subsequently developed and evaluated the impact of an illustrated booklet containing pertinent TB information for CCWs and for their patient education roles.

5. Limitations and further research

Qualitative research has inherent limitation, with one of the most common being the lack of generalisability of the findings. The CCWs were recruited from one district in South Africa, thus the findings of this study may not be generalisable nationally or regionally within southern Africa. This study reflects the findings of only one class of healthcare worker and did not extend to their TB patients or other community members who interact with these healthcare workers on a daily basis. Further research on exploring the opinions and perceptions of these two groups could facilitate a deeper understanding of the role of CCWs and reveal broader findings on general information needs to enhance patient care.

Exploring the context of CCWs in the healthcare system revealed several shortcomings in terms of the support they receive from the healthcare system such as training, provision of information, communication and supervision. Future health systems-based research on CCW programmes should investigate the degree to which these support factors influence the productivity and effectiveness of CCWs, including an exploration of CCW perspectives on these issues.

Based on the findings of this study that CCWs need access to appropriate TB information, future research could address the development of information to fulfil this need and should evaluate its impact on general TB knowledge as well as on the quality of CCW-patient education interactions.

6. Conclusion

CCWs occupy an increasingly important, central role in TB programmes for both patients and the community. Our

findings illustrate the close engagement of CCWs with their roles, which they view overwhelmingly positively as improving health outcomes as well as providing them with personal pride and fulfilment. Current training is clearly inadequate and highly variable, resulting in unmet CCW information needs. CCWs require additional support through improved basic and follow-up training and by having access to appropriately designed TB information materials.

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