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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