

## **Community care workers in TB care: identifying and meeting their information needs**

According to the 2015 World Health Organisation global tuberculosis report, South Africa had 155,473 new TB cases in the last year, 61% of whom were HIV-positive. The tuberculosis (TB) epidemic in South Africa has resulted in the increasing use of community care workers (CCWs) for the management and supervision of TB patients on treatment. CCWs are increasingly being deployed to address the shortages of healthcare workers. CCWs supervising TB patients often act as information providers, advising and counselling patients on general care and medication use. Their effectiveness depends on appropriate knowledge, adequate training and access to good quality information about TB and TB medicines. The hypothesis for this study was that user-friendly, simple, illustrated information can enhance TB knowledge of CCWs, as well as serve as a practice tool in facilitating their counselling and education of patients. A conceptual framework was used to guide the development of an intervention to test this hypothesis through the following objectives: exploring the roles and TB information needs of CCWs working with TB patients; evaluating baseline TB knowledge and health literacy levels of CCWs; developing simple, illustrated information materials to address CCW TB information needs; and assessing the influence of the information materials on TB knowledge and practice of CCWs. Six CCWs from Grahamstown Hospice and 25 CCWs from six primary healthcare clinics in Grahamstown participated in the study, which was conducted in three main phases. Phase 1 began with focus group discussions and individual semi-structured interviews with 14 CCWs to explore their perceptions regarding their roles in TB care and their information needs. This was followed by individual interviews with all 31 CCWs using a structured questionnaire to collect quantitative data on health literacy and establish baseline TB knowledge. For Phase 2, the design of an A5 booklet was informed by the findings from Phase 1 and contained information about TB and TB medication. Pictograms were designed using a rigorous, iterative design process and were included in the booklet which was translated into isiXhosa and Afrikaans. The booklets were individually distributed to CCWs during an information session in which the topics in the booklet were discussed. Three months after completion of Phase 2, individual follow-up interviews were conducted with all CCWs to measure post-intervention TB knowledge. Focus group discussions or semi-structured interviews were conducted with 19 of the CCWs to explore the role and impact of the information materials on everyday CCW practice. Qualitative data were transcribed and analysed thematically by developing codes and identifying themes. Quantitative results were analysed using the t-test, Pearson Chi-square and a Z-test of proportions at a 0.05 level of significance. The conceptual framework provided a useful lens through which to view, and reflect on, the interaction between the elements of the healthcare system in relation to the results obtained. CCWs associated their roles in TB control with helping patients and having an impact in patients' lives which they perceived as being meaningful. The good relationships with patients noted by study CCWs, as well as the appreciation they received from patients, contributed to their confidence and belief that they were well positioned and able to positively influence health outcomes. This study found that CCWs in the healthcare system were disadvantaged by the lack of support and supervision, deficiencies in training and lack of information materials, all of which reflect a negative interaction between CCWs with the

healthcare system. Use of the booklet resulted in an improvement in CCW knowledge about the disease, TB medication, MDR and XDR-TB and HIV/AIDS and TB co-infection. The mean knowledge score significantly increased from 76.1% at baseline to 85.4% at follow up showing that the use of the booklet had a positive impact on TB knowledge. Poor knowledge areas were identified as being related to TB medication-related knowledge and drug-resistant TB, highlighting the need for additional intervention to improve knowledge in these areas. The health literacy level of CCWs, which was assessed using the modified Newest Vital Signs– South Africa test, showed that the majority of CCWs had only marginal health literacy, indicating the need for wider assessment of health literacy within CCWs, and the need to tailor training and information materials to cater for their health literacy levels. The pictorial-based, simple booklet tailored for CCWs was also found to enhance confidence in decision making, and reduce their uncertainty when confronted with difficult care scenarios. CCWs were enthusiastic about the inclusion of pictograms which were reported to enhance recall of TB information and understanding of text. The booklet also served as a patient educational tool, where it reportedly improved communication and had a positive effect on the CCW-patient interpersonal relationship. The simplicity of the booklet and the inclusion of pictograms resulted in a user-friendly appealing information source for patients. Factors contributing to the success of the booklet can be attributed to paying attention to CCW information needs, involving CCWs in the design process, translating the booklet into local dialect, ensuring simplicity of the text and including pictograms that had undergone a rigorous design process. This study was the first to design TB information materials targeted specifically for CCWs that were also suitable as patient education materials. The study demonstrated that these information materials can have a positive outcome on CCW roles in TB care by improving their knowledge and facilitating patient communication and education.