

**COMMUNITY CARE WORKERS IN TB CARE: IDENTIFYING AND
MEETING THEIR INFORMATION NEEDS**

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IDA OKEYO

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ABSTRACT

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.

I would like to dedicate this thesis to ...

***Community care workers for their ongoing
and tireless efforts to improve the health of residents
in their communities***

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LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
BCG	Bacillus Calmette-Guerin
CCW	Community Care Worker
CHW	Community Health Worker
DOTS	Directly Observed Therapy Short Course Strategy
FGDs	Focus Group Discussions
HCPs	Healthcare Professionals
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
LMICs	Low and Middle Income Countries
MDGs	Millennium Development Goals
MDR-TB	Multidrug-resistant TB
NGOs	Non Governmental Organisations
NPOs	Non Profit Organisations
NVS	Newest Vital Signs
NVS-SA	Newest Vital Signs South Africa
PILs	Patient Information Leaflets
PHC	Primary Healthcare
REALM	Rapid Estimate of Adult Literacy in Medicine
SSIs	Semi-structured Interviews
STIs	Sexually Transmitted Infections
S-TOFHLA	Test of Functional Health Literacy in Adults, shortened version
TB	Tuberculosis
TOFHLA	Test of Functional Health Literacy in Adults
UNAIDS	United Nations Programme on HIV/AIDS
USA	United States of America
WHA	World Health Assembly
WHO	World Health Organisation
XDR-TB	Extensively Drug-resistant TB

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CHAPTER 1

INTRODUCTION

1.1 Background to research

Tuberculosis (TB) is an ancient disease that has been a public health concern for more than 4,000 years (1). Since being declared a health emergency by the World Health Organisation (WHO) in 1993 there has been a slow decline in TB rates, however in 2014 WHO reported an estimate of 9.0 million new TB cases and 1.5 million people who died from the disease (2). The WHO has identified 22 high burden countries responsible for 83% of the TB incidence globally (2). South Africa is one of these high TB burden countries, with the epidemic being fuelled by HIV/AIDS and a growing resistance to therapy, making TB a major health problem (2–4).

The Directly Observed Treatment Short Course (DOTS) strategy advocated by the WHO in 1994 was one of the earliest global efforts to reduce TB by ensuring adherence through direct observation of patients on therapy (5). This strategy was incorporated into the South African National TB Programme established in 1994 (6). The National TB Programme in South Africa faced the challenge of trying to implement DOTS in previously disadvantaged primary healthcare systems, and the lack of adequate human resources to cope with the increasing workload (4,7). To address these challenges, innovations in the DOTS strategy led to the involvement of community participation in TB service delivery (8–10).

From early years, community-based healthcare workers have played a role in the provision of healthcare services to communities in need. The WHO conference at Alma-Ata recognised the contribution of community-based healthcare workers to primary healthcare (PHC) as a way of ensuring healthcare for all (11). Community care workers (CCWs), who share a common language, culture and living environment with patients, were to contribute to PHC by meeting the demand for essential services (11–13). CCWs are defined as lay community members given a limited amount of training to provide specific basic health services to members of their surrounding communities. Their training does not form part of a professional tertiary health degree and they either receive a stipend or work voluntarily (14–16).

CCW programmes in South Africa have demonstrated success not only in targeting adherence for chronic diseases such as TB, hypertension, diabetes, epilepsy and HIV/AIDS; this cadre of healthcare workers has also had an impact on social development by assisting their local communities with water and sanitation, processing of welfare grants, and food security (19–21). CCWs have been particularly valuable in high TB and HIV settings where they assist in reducing the patient load on formal healthcare workers by taking over supervision and support of patients (8,18). Additionally, they contribute to the decentralisation of TB services by doing home visits and supervising patients at home. Their knowledge of their communities has also resulted in CCWs being able to refer TB suspects to clinics, tracing treatment defaulters and increasing community awareness of TB (20–22).

In recognition of the positive impact of CCW programmes, recent policy reforms in South Africa have prioritised the revitalisation of PHC and community-based healthcare services (23). The renewed focus on PHC has highlighted several issues facing the effectiveness of CCWs (24). Employment of CCWs by either Non Profit Organisations (NPOs) working with healthcare centres or the national Department of Health has resulted in a number of different types of CCWs who provide the same services without reference to each other (24,25). Due to this fragmentation of roles, CCWs often lack the skills to deal with healthcare issues that are outside the range of their training (24). Concern about the quality of training offered to the CCWs has been noted, with a lack of co-operation as well as varying curricula between the community-based NPOs and the Department of Health, resulting in non-standardised training (24). Lastly, because CCWs are employed by different organisations and have different roles, there is also inconsistent support and supervision offered to CCWs in different programmes (24,25).

Most TB patients in South Africa are managed in local PHC facilities by CCWs who supervise and support patients on treatment. CCWs are therefore placed in a unique position where they are often the only medical personnel with whom patients have contact, thereby being responsible for facilitating education and counselling about the disease and its treatment. The effectiveness of CCWs in their role as information providers therefore depends on the quality of their initial and ongoing training in developing a good knowledge base, adequate supervision by professionally trained healthcare workers and access to health information resources to supplement their training (26).

Recent literature has shown some improvement in the performance of CCWs through the use of simple information materials supported by images which provide instructions and information to assist them in performing their tasks; however these materials are rarely available or accessible (27–29). During patient education and counselling sessions, well designed, user-friendly information materials can serve as educational tools, as well as improve communication with patients.

1.2 Study aim and objectives

The aim of this research is to identify the information needs of CCWs, develop information materials to meet these needs and evaluate their impact on knowledge and practice.

The objectives are:

- To explore the roles and TB information needs of CCWs working with TB patients.
- To evaluate baseline TB knowledge and health literacy levels of CCWs.
- To develop simple, illustrated information materials to address CCW TB information needs.
- To assess the influence of the information materials on TB knowledge and practice of CCWs.

1.3 Significance of the research

This study will contribute to an understanding of the contribution of CCWs to TB care, as well as their TB information needs. Considering the challenges facing CCW programmes in South Africa, this study can provide insight into the manner in which CCWs perceive their roles, information which could be useful to regulators, programme managers and other stakeholders when strategizing to improve productivity. The information materials developed in response to CCW needs and desires could, if well designed, increase their TB knowledge and inform future research on ways to design appropriate intervention materials.

Although much is known about the potential impact of CCWs on encouraging the uptake of health behaviours, most studies have focused only on strategies to integrate them within the healthcare system. In contrast to this, minimal research has been reported on information

materials designed for CCWs that are intended to improve their role of patient education. This study therefore contributes to this knowledge by seeking to understand the impact of well-designed information materials during counselling of patients. From the perspective of CCW practices, this study is relevant and timely for the healthcare sector which is currently moving towards a more patient-centred approach (30–34). Understanding the impact of information materials on patient communication and patient-CCW interactions is thus a significant issue for the healthcare system.

1.4 Conceptual framework

The increasing complexity of the healthcare system, the emphasis on patient-centred care and the growing expectations of patients have driven the need for quality improvement in healthcare (35). The problem of inadequate healthcare worker performance has further highlighted the importance of improving healthcare practices to ensure quality (36). Several factors have reportedly influenced the practices of healthcare workers. Some of these are:

- Healthcare system factors such as their knowledge and skills
- Educational environment
- Socioeconomic environment
- Attributes of the work
- Patient factors
- The healthcare facility environment

This study aimed to address the healthcare system factor of knowledge of CCWs by designing TB information material for CCWs after identifying their information needs and any gaps in their TB knowledge. As well as contributing to their own knowledge, the information material was also intended to be appropriate for sharing with patients, with the potential of acting as a suitable tool for patient education and communication, thereby empowering CCWs in their practice.

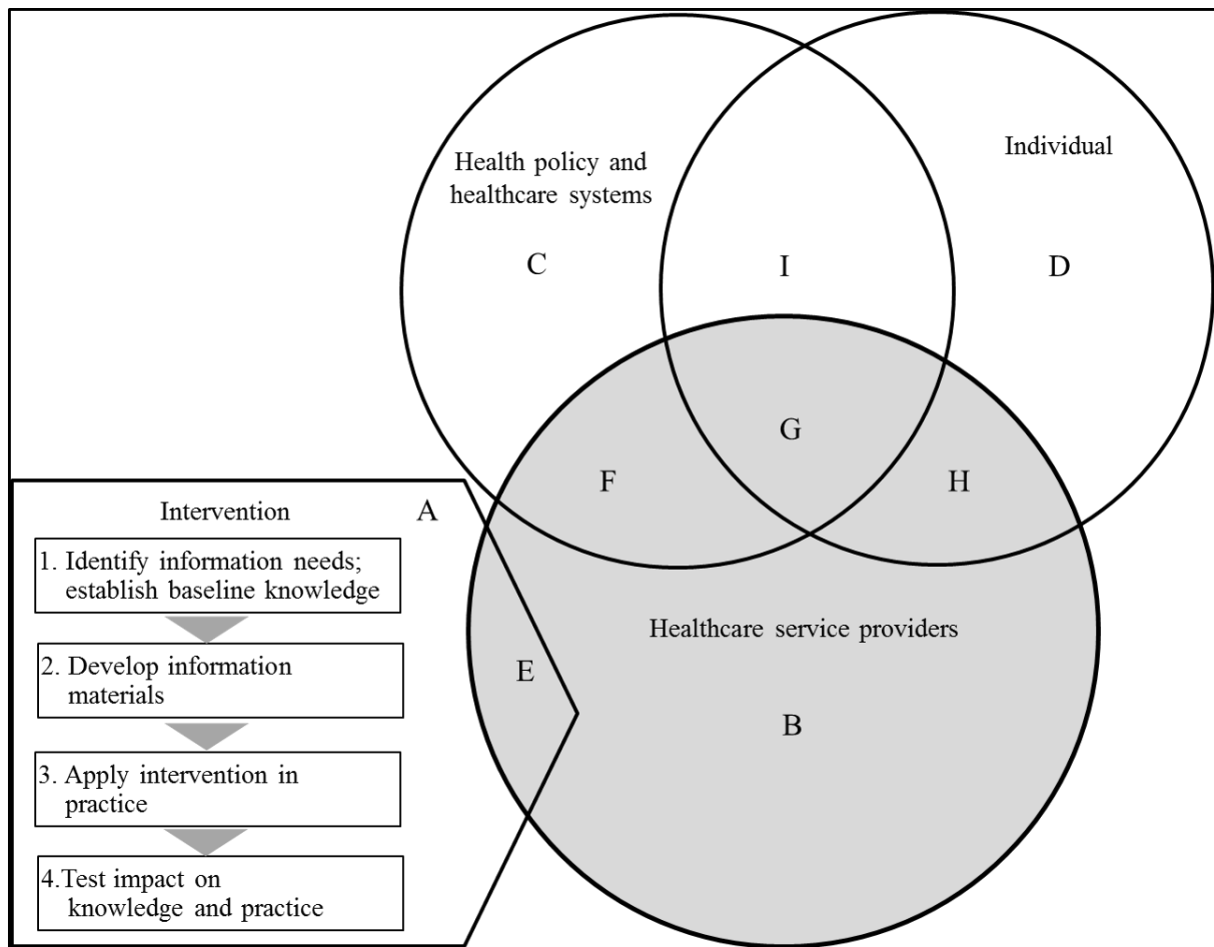


Figure 1.1: Conceptual framework for the design and development of an intervention for CCWs

The conceptual framework for this study is based on two models: the quality improvement process model by Massoud *et al* (35), and Menon’s description of psychological empowerment in the health field (37). The quality improvement process model (35) is based on three questions aimed at improving performance: what are we trying to accomplish, how will we know that the change will result in an improvement, and lastly, what changes can we make that will result in an improvement? Based on these questions, the quality improvement process follows a four-step sequence: 1. Identify what needs improving, 2. Analyse the problem, 3. Develop a proposed change that aims to address the problem, 4. Implement and test the proposed solution. Previous studies have used this process to address factors affecting performance both in healthcare quality and other organisational settings (35,38–41).

Menon’s approach to psychological empowerment was first designed in an organizational setting to address the empowerment of employees and was later extended to the health field to describe psychological empowerment. Menon describes three main elements within each

healthcare setting which is situated within a larger system such as provincial and national health settings (B, C, D in Figure 1.1). Area B includes all healthcare providers (HCPs). Health policy and healthcare systems (area C) describe the broader policies and regulations that govern HCPs. Area D involves individuals from the local community who may come into contact with HCPs. Although his original description of the model was from the perspective of individuals (37), this study has examined it from the perspective of health care providers.

These three elements (B, C, D) influence each other, as shown by the overlaps (F, G, H, I). Health policies affect how HCPs operate and which services they can offer (area F). They can also impact on the individual by making healthcare services available, affordable and accessible (area I). Interaction of HCPs with individuals (area H) can be influenced by their practices, attitudes and performance. Area G describes the obligation of the government to determine health policy for governing the provision of healthcare services, affecting both the individual and the HCPs.

Each element also has its unique area of concern and influence. In area D, concerns of individuals relate to their health, and their adoption of positive health behaviours is often influenced by their socioeconomic background. In the same way HCPs may also have concerns that are unique to their profession such as employment opportunities (area B). Although health policies may often affect the other two elements directly, it (health policies) can have issues that may not immediately concern the other elements such as new requirements for HCPs, or the development of new policies (area C).

The hypothesis for this study is 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. The models by Menon and Massoud *et al* were integrated and the quality improvement process model modified to incorporate the intervention (area A) in order to test the study hypothesis (Figure 1.1). It should be noted that this study was not aimed at improving the quality of healthcare offered by CCWs, but rather adopted the quality improvement process model to guide the development of an intervention based on their identified information needs using the following four steps:

- Step 1 - identify gaps in CCW knowledge and explore information needs. This involves both quantitative and qualitative inquiry through a TB knowledge test (quantitative) as well as discussions and interviews (qualitative).

- Step 2 - develop information materials to meet needs and knowledge gaps.
- Step 3 - implement the intervention (information material) in practice.
- Step 4 – investigate the impact of the information material on practice (qualitative) and knowledge (quantitative) to determine whether it is a viable tool for improving CCW practice.

This four-step process guided the methodology that was chosen for the study, with each step corresponding to a phase in the study (Chapter 3).

Menon's description of empowerment in the health field (37) was employed to assist in understanding the context of the CCW role within the broader healthcare system, and to track the influence of the intervention on CCW interactions within this system. The three elements in the original model were retained in the framework with CCWs included as HCPs in area B. The fourth element (area A) interacts directly only with the CCWs, the target group for the intervention, although indirect influence is possible on the other elements in this framework.

1.5 Overview of chapters

Chapter 2 is a literature review that begins with a description of the burden of TB and describes strategies that have been implemented to control the disease both globally and in South Africa. The concept of CCWs is then introduced, with literature on their historical development and context in the healthcare system, level of TB knowledge in CCWs and their information needs. Health literacy, its definitions, measurement and impact on the healthcare system are presented. The chapter ends with a focus on health information materials for both patients and CCWs, as well as the design and use of pictograms.

Chapter 3 describes the study setting and the methodology used. It provides details of ethical considerations, study population, data collection and analysis. The development of the questionnaire as the main research tool is also described, as well as the information materials designed and used in the study.

Chapter 4 reports both the qualitative and quantitative results associated with the three phases of the study, starting with CCW perceptions of their roles in TB care and their information needs. The impact of the booklet on TB knowledge is presented, and the chapter ends with CCW perceptions of the usefulness of the booklet.

Chapter 5 discusses the study findings and contextualizes them within the literature. Lastly, the limitations of the study are described.

Chapter 6 concludes the thesis by reflecting on the study aims and objectives in relation to the findings, explores practical application of the findings, and provides recommendations for future research.

CHAPTER 2

LITERATURE REVIEW

2.1 Tuberculosis and its treatment

2.1.1 Tuberculosis - an infectious disease

Tuberculosis is caused by the bacterium *Mycobacterium tuberculosis*. People infected with this bacterium may not necessarily develop the disease as some people are able to control the infection and the bacterium remains in an inactive or 'latent' state described as a latent TB infection (42). TB mostly affects the lungs, which is known as pulmonary TB and often presents with a productive, prolonged cough of more than three weeks, coughing blood, chest pain, fever, chills, night sweats, loss of appetite and weight loss. When the infection affects other areas of the body it is known as extrapulmonary TB. This type of TB can involve infection the pleura, the central nervous system, lymphatic system, the urogenital system and bones and joints (42).

TB is spread via air droplets containing the bacteria that are produced when a person with pulmonary TB coughs or sneezes, therefore close contact with an infectious person and prolonged exposure increases the risk of transmission (43). People with latent TB are not infectious due to the lack of replicating bacteria, which prevents them from transmitting the disease (42). The current TB vaccine which is usually administered to neonates and infants is the Bacillus Calmette-Guerin (BCG) vaccine, that protects against meningitis and disseminated TB in children (44).

TB is mostly diagnosed by sputum smear microscopy, which is known as acid-fast bacilli testing (45). This involves observation of the bacteria under a microscope from sputum samples. A diagnosis of 'smear positive' is made after two sputum samples tested on consecutive days show evidence of bacteria (46).

TB is commonly treated with antibiotics that include isoniazid, rifampicin, ethambutol and pyrazinamide for six months or longer (47). If the course of treatment is taken incorrectly, or if the medicines are of poor quality, the bacteria may become resistant to one or more of the antibiotics. Multidrug-resistant TB (MDR-TB) is resistant to both isoniazid and rifampicin.

Treating this type of TB requires a more extensive course of second-line antibiotics usually for a period of 20 months or longer and the treatment success rate is usually lower (47). In some cases, more severe drug resistance can occur where MDR-TB becomes resistant to second-line antibiotics. This is known as extensively drug-resistant TB (XDR-TB) which responds to a limited number of second-line antibiotics (47). It was estimated that globally in 2014 there were 480,000 new cases of MDR-TB with 9.7% of these having XDR-TB (2).

2.1.2 Medicines used to treat TB

Effectiveness in preventing the spread of TB and successful treatment relies on starting the treatment as soon as diagnosis is confirmed, prescription of the correct medicines, adherence of at least 90% and use of medicines for the correct time period (48). Pulmonary TB and extra-pulmonary TB are both treated with the same medicines, but the treatment duration is extended for the latter. All patients diagnosed with drug-susceptible TB are started on TB treatment within two days, while patients suspected of drug-resistant TB are started on treatment within five days of suspicion (49). Treatment of TB occurs in two phases: the initial phase involves the administration of four antibiotics for two months or more and this is followed by the continuous phase of treatment after the patient tests negative for two sputum samples. The continuous phase is managed by administering two antibiotics for the next four months or longer.

The initial phase serves to rapidly kill the bacteria, which improves the health of the patient, while the continuous phase ensures the remaining bacteria are eliminated and prevents relapse (50). Directly observed therapy is recommended for both the initial and continuous phases of treatment for all patients. Patients living close to a health facility are encouraged to take treatment from the health facility, while others can be observed by a treatment supporter at home (49).

The first line TB agents include:

- Isoniazid: A bactericidal agent that works both intracellularly and extracellularly. It kills rapid- and intermediate- growing bacilli by interfering with mycolic acid synthesis.

- Rifampicin: Bactericidal for intra- and extra-cellular bacteria. It is the most effective sterilising agent and kills both growing and dormant bacilli by inhibiting ribonucleic acid synthesis.
- Pyrazinamide: Only targets slow growing intracellular bacilli and achieves its sterilising action within two to three months. It is highly specific for *Mycobacterium tuberculosis* and is the most useful agent in the initial phase of treatment.
- Ethambutol: Exerts its bacteriostatic mode of action by inhibiting the formation of the mycobacterial cell wall and targets both intra- and extracellular bacteria.
- Streptomycin: Bactericidal and targets extracellular rapidly growing bacilli by inhibiting protein synthesis (50).

Second line agents are used to treat drug-resistant TB. They include: rifabutin, ethionamide, flouroquinolones, aminoglycosides, terizidone, capreomycin, para-aminosalicylic acid, cycloserine, clofazimine and linezolid (49,50).

Side effects are unwanted and often harmful effects of a medicine that occur with the desired effect (48). TB medicines may cause major and minor side effects. Minor side effects include anorexia, nausea, abdominal pain, joint pains, orange coloured urine and peripheral neuropathy which are usually treated symptomatically and the patient is reassured. Major side effects include severe rash over the whole body, vomiting and confusion, deafness, jaundice and visual impairment (43,50). They require referral to higher levels of care and health facilities and the medicine responsible may need to be stopped or changed (43). Side effects are magnified in patients taking TB medicines and antiretroviral therapy concomitantly and in those being treated with second-line agents. Patients and families should be educated on how to recognise side effects and are encouraged to report them when they occur (43).

2.2 Global strategies to improve healthcare delivery

2.2.1 Development of primary healthcare in global health

The vision of primary healthcare (PHC) was introduced in 1978 at the declaration of Alma-Ata which adopted PHC as a means of delivering health for all by the year 2000 (11). PHC is a model that recognises health as the state of complete physical, mental and social wellbeing and not primarily the absence of disease (13). PHC is essential community-based healthcare that is made universally accessible to populations, communities, families and individuals at a cost that

both the community and the country can afford. It forms part of the country's health system and is the first level of contact of the community with the healthcare system therefore bringing health services as close as possible to where people live and work (11,12). The Alma-Ata declaration introduced the concept of community-based healthcare workers who shared a common language, culture and living environment as the patients and who were to contribute to PHC by meeting the demand for essential health services (11–13,51,52).

A further focus of the Alma-Ata included the relationship between social and economic development and an emphasis on social determinants as a health concern (51). Social determinants of health include the conditions in which people grow, learn, live, work, age and the systems in place to deal with illness (53). These conditions contribute to health inequalities as a person's social and economic status will determine their risk of illness, preventative actions to avoid illness and the treatment of illness (52).

After the initial enthusiasm of Alma-Ata, the adoption of PHC in healthcare systems in the 1970s and 1980s was hindered by factors such as lack of political commitment, and PHC became a slogan without the necessary changes and reforms needed for its implementation (12,13). This was exacerbated by political instability, civil wars and the emergence of the HIV epidemic which made it difficult to maintain PHC, especially in many sub-Saharan countries (13). As a result PHC became associated with limited resources, erratic medicine supply, shortages of staff and equipment. People formed the opinion that PHC was a cheap form of healthcare and therefore bypassed it, instead attending secondary and tertiary health centres. This defeated the vision of PHC acting as the first point of healthcare services (12).

Despite failing to achieve the goal of health for all by 2000, PHC managed to improve access to water, sanitation and antenatal care (54). Currently, health inequalities continue to affect health outcomes, with high rates of teenage pregnancy, 99% of annual maternal deaths and high under-five mortality rates occurring in low and middle income countries (LMICs) (55). Attention has been given to social determinants of health as important links to global health and the WHO has called for a renewed focus on PHC as a way to address health inequalities. Furthermore, as societies become more modernised, they expect more from healthcare systems and hence there is increasing support for PHC as a way of promoting health equity in order to ensure that healthcare services are centred on people's needs and expectations (54,56).

2.2.2 Global burden of disease caused by TB

According to the WHO, the burden of disease caused by TB can be measured in terms of incidence, prevalence and mortality, where incidence refers to the number of new and relapse TB cases that occur in a year, prevalence refers to the number of cases at a given point in time and mortality refers to the number of deaths caused by TB in a given time period, which is usually reported as a year (45). In 2014, there were an estimated 9 million incident TB cases, 13 million prevalent TB cases and 1.5 million TB deaths worldwide (2). Although Africa accounts for only 11% of the world's population, it was responsible for 28% of the global burden of TB cases and 30% of TB-related deaths (2).

TB is the most common co-existing condition with HIV/AIDS, a disease that exacerbates the high rates of TB in Africa (57). By the end of 2014, 1.2 million of the 9.6 million infected people globally were HIV-positive and 74% of these HIV-positive TB cases were in the African region (2). HIV infection and TB co-exist for two reasons: firstly HIV/AIDS increases the chance of reactivating a latent TB infection and secondly immunosuppression, which is common in HIV/AIDS patients, increases the risk of rapid progression to the disease after infection with TB. The increasing burden of HIV-associated TB patients may then increase the possibility of TB infection as patients with active TB interact with HIV patients in clinics, hospitals and the community, worsening the cycle of infection and disease (4,7,57). As a result TB is the leading cause of mortality in patients with HIV/AIDS and this is worse in countries with high rates of HIV/AIDS as is the case in most African countries (45).

There are 22 high TB burden countries, accounting for 83% of the estimated TB incident cases in 2014 (2). South Africa is one of the high burden countries, and in 2014 had 155,473 new TB cases, of which 4,700 had MDR-TB and 61% were HIV positive (2).

2.2.3 Development of strategies to control TB

In the late 1990s there was rising concern due to the increasing epidemic of TB. During this time TB was declared a global health problem and as a result the World Health Assembly (WHA), which is the decision making body of the WHO (58), aimed to control TB by setting two goals: the first was to detect 70% of new smear-positive cases and the second was to achieve a cure rate of 85% of these cases by the year 2000 (5,59). In 1994 the internationally recommended control strategy, later known as the Directly Observed Treatment Short Course (DOTS) strategy, was launched in order to achieve the targets set by the WHA (Figure 2.1) (5).

The DOTS strategy consists of five main elements, which include;

- Political commitment by national governments to the TB control programme.
- Quality diagnosis using sputum smear microscopy.
- Standardised short course chemotherapy medicines supplied to sputum positive patients.
- Direct supervision of medicine regimens administered. This was the vital part of the DOTS strategy whereby a health worker would observe medicine intake by the patient. One reason why the name DOTS was chosen was to place emphasis on direct observation of therapy.
- Systematic monitoring and evaluation, where the TB cure rate was to be used as the main indicator of programme success (59,60)

This strategy was adopted and implemented in 182 countries, where it acted as a guide for the development of national TB control programmes and assisted in making progress towards TB control targets (59). By 2004, more than 20 million patients had been treated in DOTS programmes worldwide and more than 16 million had been cured. The DOTS strategy managed to reduce TB mortality and incidence in many world regions, apart from sub-Saharan Africa and parts of Eastern Europe, where the epidemic worsened. There was a need to improve DOTS as TB control deteriorated in areas with a high HIV prevalence. DOTS did not take into account the HIV-TB co-epidemic, with similar strategies being advocated for areas of both high and low HIV prevalence (60). A new strategy was thus needed for the remaining constraints that DOTS could not address (59).

In 1998 it was clear that the targets set by the WHA to be achieved by the year 2000 would not be met, and in 2000, the deadline was postponed to 2005. To ensure that these goals would be met, TB was included as one of the targets in the Millennium Development Goals (MDGs). The MDGs were established by the United Nations in 2001 to provide a framework for international co-operation to ensure human well-being by reducing poverty, hunger, child and maternal mortality, ensuring education for all, as well as controlling and managing diseases such as TB (61).

TB was also included in the MDGs as it is fostered by low socio-economic standards, particularly poverty, and hence controlling this disease is dependent on development. MDG goal 6 aims to combat HIV/AIDS, malaria and other diseases, with the specific target for TB stating that TB incidence should halt and begin to reverse by 2015. The indicator for this target was TB prevalence and mortality rates, and the number of TB cases detected and cured under DOTS (61).

In addition to including TB in the MDGs, the WHA also endorsed the establishment of a global partnership and plan to stop TB through the 2001-2005 period (62). Later in 2006, the WHA developed the second plan to stop TB between 2006-2015 (63) which was launched in the same year as the Stop TB strategy. The Stop TB strategy dictates the steps that national TB programmes need to take in order to control the burden of TB and underpins the goals of the global plan to stop TB (59,63).

The Stop TB Strategy was designed to build on the DOTS strategy with the aim of reducing the burden of TB. It consists of six components:

- High quality DOTS expansion and enhancement.
- Addressing TB/HIV, MDR-TB and the needs of the poor and vulnerable populations. This involves scaling up of collaborative HIV and TB activities, focusing on the prevention and management of MDR-TB and TB contacts as well as the needs of vulnerable groups.
- Contributing to health system strengthening based on primary healthcare by improving health policies, health service delivery and strengthening infection control in health centres as well as focusing on social determinants of health.

- Engaging all health care providers which includes public, voluntary and private services and promoting the use of international standards of TB care.
- Empowering people with TB and communities by engaging the participation of communities in TB care, promoting the use of patients' charter for TB care and ensuring communication and social mobilisation.
- Enabling and promoting research to develop new medicines, diagnostics and vaccines and to monitor the success of TB programmes (59).

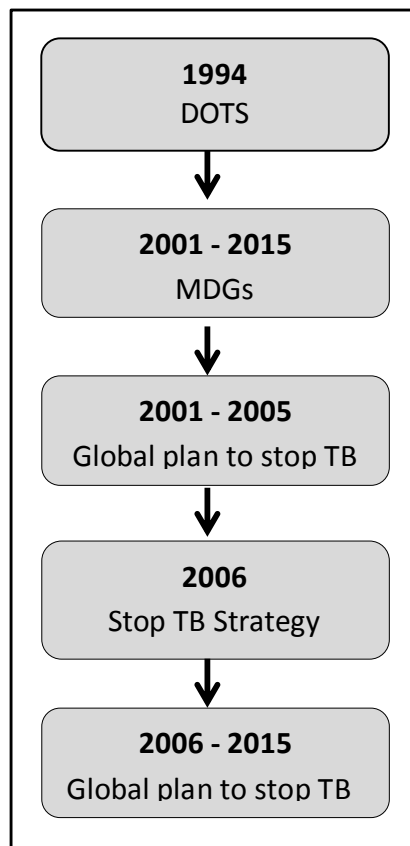


Figure 2.1: Efforts to control TB globally

The year 2015 marked the deadline for the targets set by the MDGs and the Stop TB Strategy. MDGs will now shift to the post-2015 Sustainable Development Goals, while the Stop TB strategy will move to the End TB strategy (2). Major advances that have been achieved include the reduction of TB mortality by 47% since 1990. The MDG target to halt and reverse TB incidence has also been achieved in 16 of the 22 high burden countries (2). From 2016 onwards, the End TB Strategy linked to the Sustainable Development Goals aims to have a 95% reduction in TB deaths and 90% reduction in TB incidence compared to the 2015 TB levels, and to have no family burdened with catastrophic costs due to TB by 2035 (64).

2.3 South African strategies for the delivery of healthcare

2.3.1 Healthcare system in South Africa

The health burden in South Africa is characterised by the simultaneous occurrence of communicable diseases, mainly HIV/AIDS and TB, a rise in chronic non-communicable diseases, a high burden of maternal and child disorders and deaths from injuries and violence (65). Shaped by its history, the South African economy remains unequal with the richest 10% of the population accounting for 51% of the income while the poorest 10% account for just 0.2% of the income (66). Wealth disparities reflect in the health profile as most of the disease burden is normally carried by people residing in lower socioeconomic conditions (67).

Two healthcare systems exist in South Africa. The first is the public healthcare system which is made up of government health facilities that provide for the lower socio-economic population, while the second is the private health system comprised of profit medical aid organisations and caters for the wealthier population. Although the public healthcare system is responsible for 80% of the population, it only accounts for 40% of the health expenditure while the private system, catering for 20% of the population, uses 60% of the health expenditure (68,69).

The public healthcare system is organised by the national Department of Health and nine provincial departments of health. The national department is responsible for the co-ordination and development of health policies nationwide, while the provincial departments are responsible for ensuring the implementation of policies and delivery of health services. Each province consists of health districts which co-ordinate the provision of PHC (70). The origins of PHC in South Africa were motivated by the Pholela Health Centre Model in the province of KwaZulu-Natal which gave rise to the development of a national PHC strategy in the 1980s (11,68,71). This strategy was later incorporated into the National Health Plan in 1994 that aimed to improve the healthcare system by making community-based healthcare accessible through establishing PHC centres (11,63). Currently, the district health system continues to be the vehicle responsible for the delivery of PHC (67).

Hospital care in South Africa is divided into three levels of care comprising of tertiary, secondary and primary care facilities. These three levels allow for PHC to be provided in

clinics, with secondary and tertiary care being provided in hospitals and specialist hospitals respectively (36). The under-resourced and overused public healthcare system has been criticised as lacking in meeting the demand for healthcare services (68). Despite the availability of the three-tier hospital services, the system still remains inefficient, largely because of the inability of the local clinics to deal with heavy patient caseloads, making healthcare services inconsistent (69,72). Although the overfunded private healthcare system is often praised for good provision of healthcare services and well-maintained healthcare facilities, it also faces a crisis of affordability and sustainability with increasing prices and a lack of consistency between healthcare services and costs (68,72,73).

Another component of the South African healthcare system is NPOs which include a number of non-governmental organisations (NGOs), faith-based organisations, community-based organisations and other role players such as research institutions which are categorised under the private sector (74). The HIV/AIDS and TB epidemics have prompted a demand for health and welfare services which has increased the involvement of NPOs in the health sector. In 2012, there were an estimated 60,000 to 80,000 NPOs in South Africa, 6.9% of which were health related NPOs (75). These organisations make an essential contribution to HIV/AIDS, TB, mental health, maternal and child health, palliative care, health promotion and community developments projects. NPOs have also played an additional role in supporting public healthcare institutions through the formation of private-public partnerships (74,76).

In 2013, 8.9% of the gross domestic product was spent on healthcare, which was higher than the 5% recommended by the World Health Organisation (77). However, despite this higher expenditure, the healthcare system struggles to cope with a quadruple burden of diseases and the health outcomes remain unsatisfactory when compared to similar Low or Middle Income Countries (LMICs) (76). Poor health outcomes have been attributed to the skewed allocation of resources, weakly developed primary healthcare systems, human resource crisis and deficiencies in management of different aspects of the healthcare system (65,67,78).

Unequal distribution of healthcare professionals (HCPs) between rural and urban areas, as well as between the private and public healthcare systems, contributes to the inadequately resourced public health sector. This leads to an unequal distribution of the health workforce as the majority of the population only has access to a limited number of HCPs. This is worsened in rural South Africa which comprises 43.6% of the national population, but only has access to

the available 12% of doctors and 19% of nurses. There are fewer HCPs in rural areas due to poor infrastructure, working conditions, lack of employment for spouses of health workers and a lack of schooling opportunities for children of health workers. In addition, the pool of HCPs nationwide is further decreased by the migration of health workers internationally due to more favourable working conditions abroad (79).

The combined problems of inadequate public healthcare services, increasing costs of private healthcare and health inequalities have led to the development of health sector reforms and initiatives such as the implementation of PHC re-engineering, National Health Insurance and the National Quality Health Programme (67). The human resource challenge has also led to innovations in health service delivery especially for HIV/AIDS and TB programmes. One of these innovations is task shifting, whereby tasks usually performed by a higher qualified HCP are delegated to those with less training and fewer qualifications (7,80). This has been useful in decentralising TB services through the use of community health workers, defaulter tracers and treatment supporters who have taken up roles to reduce the burden of patients on professional HCPs (7).

2.3.2 South African strategies to control TB and manage patient load

The prevailing social and economic conditions during apartheid such as poor working conditions, silica dust exposure, overcrowded settlements, poor nutrition and migration of manual labourers facilitated the spread of TB through the poor and native communities, and this was worsened by the deliberate underdevelopment of health centres for the majority of the population (4,7). After the election of the democratic government in 1994, the first effort to control TB in South Africa was the establishment of the National TB Programme in the same year which was strengthened by the implementation of the DOTS strategy as shown in Figure 2.2.

Although the implementation of DOTS made progress in terms of TB control, the major challenges of the National TB Programme lay in implementing the policies within previously weakened healthcare systems, with the HIV/AIDS epidemic fuelling an increase in TB cases (7). After South Africa was declared one of the 22 high burden countries, the government declared TB to be a national crisis and the National TB Control Programme launched a TB

crisis plan in 2006 and introduced electronic TB registers to manage and monitor the treatment of TB patients (4).

In 2005, cases of XDR-TB were found in the province of KwaZulu-Natal, and this prompted the launch of the Tuberculosis Strategic Plan for South Africa (2007-2011) to address issues of antibiotic resistance (81). To respond to the dual link of HIV and TB, the next strategic plan developed was the National Strategic Plan for HIV, Sexually Transmitted Infections (STIs) and TB (2012-2016). The targets specific to TB were to halve TB incidence and mortality by 2016 and to have no new TB infections, deaths or stigma by 2032 (82). South Africa has met the 2015 MDG target for TB control related to reduction in incidence rates, but has not met the 50% reduction in prevalence rates, nor has it met the 50% decrease in mortality rates compared with 1990 (2).

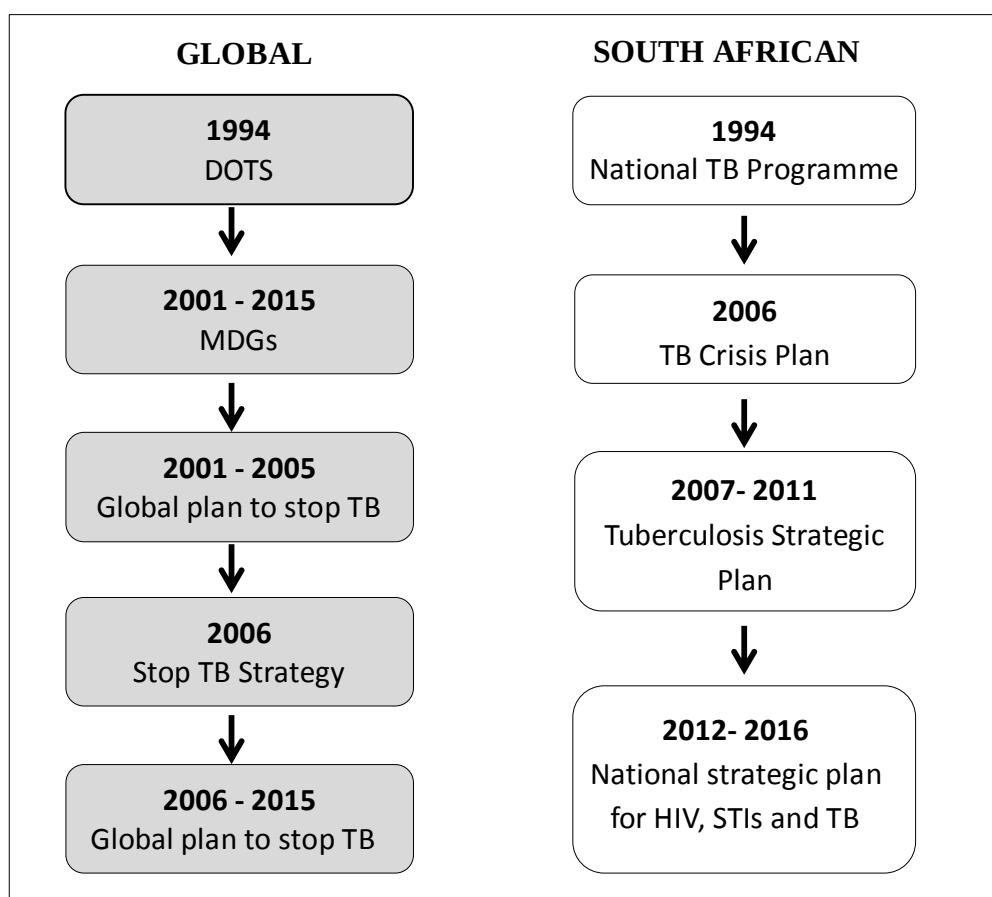


Figure 2.2: Comparative efforts to control TB in South Africa

2.3.2.1 Management of TB patients in South Africa

The objective of the 1994 National TB Control Programme in South Africa was to reduce the mortality and morbidity of TB, reduce the development of resistance and ensure accurate measurement and evaluation of the programme (6). This programme consists of three levels incorporated within the healthcare system: the national level, which works with the national Department of Health to facilitate TB services nationwide, the provincial level which is responsible for budgeting and the implementation of services advocated by the Department of Health, and lastly the district level which facilitates the delivery of primary healthcare through rural hospitals, clinics and community health centres (6,43).

In South Africa TB patients are managed according to the National TB Management Guidelines, which is a component of the National TB Control Programme. These guidelines advocate for the diagnosis of TB by screening persons who present to the health facility with symptoms indicative of TB or who are contacts of pulmonary TB patients (43). Contacts are defined as people living in the same household or who are in contact for a prolonged period of time with known pulmonary TB patients (83). TB suspects identified after symptom screening undergo further investigation with sputum smear microscopy or radiography.

The diagnosis of drug-resistant TB is made in primary healthcare clinics, community health centres or tertiary hospitals. On confirmation of drug-resistant TB, patients are referred to provincial or decentralised MDR-TB centres for assessment and treatment initiation (49). Management of MDR-TB is only done at specialised centres equipped to monitor for safety and tolerability of second-line TB medicines and management of severely ill MDR-TB patients. Hospitalisation occurs only if patients are nonadherent to therapy or if they have any complicated medical problems that threaten the health of the public. The hospitalisation period is usually eight weeks or until patients become smear-negative. After patients are discharged they can receive treatment at local clinics (49).

As soon as MDR-TB is confirmed, patients are tested for resistance to second-line TB medicines and are started on MDR-TB treatment while awaiting the drug-resistance results. If XDR-TB is confirmed, patients are managed via an individualised approach to treatment based on their history and results of susceptibility tests. The stay of XDR-TB patients in hospital varies from patient to patient but is usually six months. Discharged patients are then managed at the local clinic or at home and assessed monthly at the MDR-TB facilities (43,49).

A paper-based TB register is used in healthcare facilities to summarise information about TB patients which includes demographics, disease classification, treatment regimen, monitoring and evaluation. This register is updated daily to weekly and provides an overview of all registered patients, thus acting as the programme management tool at the facility level. The TB register is sent to the sub-district office weekly for electronic data capturing and validation of the data. Feedback is then provided to facilities and the sub-district register report is sent to the district. The district register is updated quarterly and sent to the provincial Department of Health where registers are compiled to provide national registers. This information flow allows for monitoring, evaluation and surveillance of the National TB Control Programme (43).

Although these national TB programmes and treatment guidelines have been adopted in healthcare systems, effective control of TB depends on case finding and case holding (45). The self-presentation of patients to health facilities has been linked to socio-economic factors such as low access to health facilities, transport cost of accessing healthcare, low income, low education level and low awareness of TB, all of which may contribute to health seeking delays (84–86). Similarly, beliefs, attitudes and perceptions toward the disease can determine whether health services are utilised by community members (86,87). Beliefs and perceptions regarding the causes of TB can also cause stigma which may discourage patients from seeking health services when symptoms of TB present (84).

Another objective of TB control besides diagnosis and initiation of treatment is ensuring that the medication is taken regularly for the desired period of time (88). The longer duration of treatment in TB makes nonadherence a major factor hindering TB control (86,89). Defaulting from treatment can have serious consequences such as relapse, drug resistance, prolonged infectiousness and death. Some of the factors influencing adherence include poor socio-economic conditions (86,90,91). Although patients may be willing to adhere to the treatment, their ability to consistently take their medicines may be affected by poorly accessible and poorly equipped health facilities as well as the long distance needed to access TB services (86).

Patient-related factors such as patient beliefs, knowledge, perceptions and attitudes about and experience with the disease and treatment (89,90) might influence how patients accept information given and medication taking. Community and family members can influence patients' knowledge, attitudes and beliefs, possibly resulting in a patient's decision to stop or

continue with treatment. Lastly, health system-related factors can affect adherence. These include long waiting times and queues in health facilities, lack of privacy, inconvenience of DOT at health facilities and communication between HCPs and patients (92,93).

2.3.2.2 Palliative care in TB

Palliative care is defined as care aimed at improving the quality of life of patients and their family members with life threatening conditions (94). Although TB is curable, palliative care is provided for patients with both HIV and TB, drug-resistant TB or those with an advanced form of TB. Palliative care ensures that patients are cared for with attention to distressing symptoms and are provided with emotional support (95). The South African Hospice Palliative Care Association is part of a national organisation consisting of a number of accredited hospices nationwide funded by the private sector. It assists member hospices and home-based care organisations to implement palliative care. Palliative care is provided in three ways: home-based care provided to patients who are home-bound, in-patient units which provide 24 hour services with specific criteria for admission of patients, and lastly community centres where patients who are reasonably well and mobile meet with the palliative care staff who assist them. Community centres initiate projects to generate income and they teach patients and community members a variety of skills (96). TB patients in palliative care are managed according to palliative care guidelines (95) which were developed from the contribution of the Stop TB Strategy (59) and the National TB Management Guidelines (43).

2.4 Community health workers

2.4.1 Definition and history

Community health workers (CHWs) are defined as lay members of the community with no professional health degree who work with the local healthcare system at the community level and are usually members of the community in which they work (15,97). Early CHW programmes were implemented in China, Tanzania, Mozambique and Latin America (14,98,99). Most other CHW programmes were introduced after the 1978 Alma-Ata declaration on PHC (17,100). Efforts to address PHC after the call of Alma-Ata focused on improving health facilities and developing highly skilled HCPs. However, implementing these efforts proved difficult in resource-poor areas where there was a shortage of skilled HCPs. To

address this shortage, PHC systems have shifted in the last ten years towards community-based auxiliary HCPs such as CHWs (24).

CHWs are known by a number of different titles including lay health workers, health promoters, village health workers, village health helpers, community care workers, community health agents, community health advisors and lay health advocates, among others (17). For the purpose of this thesis, the term community care worker (CCW) will be used. CCWs are usually employed by a number of organisations ranging from community-based NPOs, public health institutions and national organisations. CCWs receive some training related to their roles, but the formality, length and type of training varies considerably. Training can be formal or informal and may occur as a pre-employment requirement or on-the-job training (24). This training is recognised by health systems and national certification authorities but is not part of the formal tertiary education system (99,101).

Although the basic role of CCWs is improving access of the community to PHC, their specific roles and tasks differ between regions (98). A distinction has been made between general and specialist CCWs: general CCWs are associated with tasks that include home visits, first aid, health promotion, control of communicable diseases, maternal and child health and family planning, referrals and community development activities (101,102). Specialist CCWs are mostly used by NPOs to target specific health issues including community rehabilitation facilitators, community-based DOTS supporters for TB and traditional birth attendants (99,102,103).

2.4.2 History of community care workers in South Africa

During the 1970s CCW programmes grew, facilitated by NPOs and international donors, to address the inadequate health provision to certain communities during the apartheid era. After the election of a democratic government in 1994, the National Health Plan that was developed (104) focused only on doctors and nurses, avoiding any attention on CCWs due to lack of support by the national Department of Health, which appeared hesitant to support national CCW programmes. This led to a decline in CCW programmes in all provinces apart from KwaZulu-Natal, which retained support of the provincial government (17,25,105). As the HIV/AIDS epidemic overburdened health facilities in the late 1990s, support for CCWs increased as they allowed for the provision of home- and community-based care of HIV/AIDS

patients. In 1999, the Cabinet allowed the Department of Health, working together with social development, to begin the implementation of the CCW programme (105).

The CHW policy was approved by the Cabinet in 2001 resulting in the implementation of a National CHW Policy framework which was released in 2004 (105,106). During this period, the term CHW included all community and lay health workers. Provincial health departments were encouraged to implement CHW programmes and the CHWs were to be paid monthly stipends of R500 to R1000 (US \$ 42.35 – 84.72). In 2006, the Department of Health registered CHW qualifications with the National Qualifications Framework setting the platform for the standardisation of their training. The CHW policy framework was revised in 2008 and released as a draft in 2009 (107). To produce a framework that was unifying for both health and social development, the concept of CHW was changed to CCW to include social development strategies (105).

2.4.3 Current context of community care workers in South Africa

Experiences of CCW programmes in South Africa have demonstrated success in targeting adherence for diseases such as TB, hypertension, diabetes, epilepsy and HIV/AIDS (96,100). CCWs have played a role in reducing child mortality through their involvement in the promotion of breastfeeding, immunisation, contraception and oral rehydration (18,19,24,105). Apart from health-related outcomes, CCWs have made an impact on social development by helping community members with water and sanitation, processing of welfare grants, and food security (18,98,108) .

Despite the success of CCWs in facilitating positive health outcomes, the organisation of CCW programmes has experienced various challenges.

Inadequate supervision

According to the proposed policy, CCWs are required to perform their tasks under the supervision of a qualified manager or a supervisor (107). However due to the lack of formal instructions, training and adequate resources, supervision of CCWs is often inadequate. Health professionals required to supervise CCWs may be unfamiliar with the scope of their practice as there has been lack of clarity relating to the range of tasks in which CCWs should be involved. Supervisors are also often unable to guide CCWs due to the lack of time as clinics are usually overburdened by patients waiting to be attended to (105,109).

Training of CCWs

The varied quality of training offered to different groups of CCWs is concerning as no co-operative initiative in working towards a common curriculum is apparent. Teaching materials for CCWs are often unavailable and, if available, are not adequately disseminated, used and adapted. Lack of compliance with the standards for training of CCWs presented in the National Qualifications Framework contributes to the variability in training methods. This lack of standardised training may be a factor in the reported lack of respect afforded to CCWs by health professionals, and for the poor sustainability of CCW programmes (24,98).

Poor co-ordination of community-based health services

There is poor collaboration of community-based services offered by NPOs and those offered by the public health sector (24,108,110). An audit by the Department of Health between 2010 and 2011 (108) found a total of 2,800 NPOs and 73,839 people providing community-based healthcare services nationwide. Additionally, a total of 72,000 CCWs were divided into lay counsellors, adherence counsellors, DOT supporters, peer educators, TB defaulter tracers, high transmission area workers, hospice workers and mentors. Across the nine provinces, the number of care providers, range of healthcare services provided, employment and remuneration conditions varied (105,108).

Fragmented roles of CCWs

The fragmented roles of many different kinds of CCWs has been a cause of concern, as the roles of these health workers are often different depending on the employer institution, leading to CCWs offering the same services in the same area (105,108,110). This also contributes to inadequate linkages with the district health systems as most of the districts are unable to integrate all the different roles of CCWs with PHC at their clinics (24).

Remuneration of CCWs

The current CCW policy stipulates that CCWs should be paid by NPOs who are funded by the government (107). Despite this requirement, the healthcare system has been relying on volunteer CCWs who are not paid by NPOs. This creates tension between those working for NPOs who receive a stipend versus those who do not. Exacerbating this situation is the inconsistent payment in stipends which has resulted in CCWs feeling that the amount is not commensurate with the number of hours worked (105). Employment by NPOs while working for government facilities also creates an environment where there is misunderstanding as CCWs are unsure of whether to report to their NPO employers or the public healthcare staff. The end result is lack of accountability and inadequate incorporation of CCWs into formal health systems (24,105).

As an effort to address these shortcomings, the Minister of Health launched an initiative in 2010 to re-engineer PHC motivated by the Brazilian model (111). The Brazilian healthcare system has been able to improve health outcomes by including CCWs in teams working together with health professionals (112). One of the goals of this initiative was to improve the performance and access of PHC via the use of ward-based outreach teams that would consist of generalist CCWs employed by the state who were to be supervised by a professional nurse. The main role of CCWs would include community profiling, risk identification, health promotion, education, referral to appropriate health facilities and encouraging adherence (108,111).

2.5 Community care workers in TB

The use of community members in efforts to control TB is not a new approach, the WHO Expert Committee on Tuberculosis Report in 1974 (113) recognised the advantage of community involvement in national TB programmes. This report discussed the importance of involving community leaders such as village elders, lay persons, tribal chiefs and other influential people including voluntary agencies in efforts to control TB (113). Community contribution to TB is not advocated as a substitute for the National Tuberculosis Programme but should be part of the programme where community members can contribute through the following ways. Firstly, community members are in the best position to offer support to patients and act as DOT supporters. In high TB and HIV/AIDS settings, the increased workload impacts the quality of health service being delivered as HCPs may be unable to supervise TB patients adequately. In these settings, CCWs can reduce the load of health workers by supervising TB patients to whom they are able to offer the support and encouragement needed to enhance adherence (18).

Alternatively, in most centres, limited resources and high patient loads may overwhelm health facilities, hence using community-based DOT can contribute to a more rational use of limited resources (43) as well as seeing patients at home, thus decentralising TB services and integrating TB control measures into PHC (21). Most national TB programmes have included community-based TB-treatment delivery which allows for patients to be supervised by CCWs at home while taking their medication (16,20,21,114).

Secondly, as CCWs have good knowledge and understanding of their communities, they may improve case detection by referring TB suspects for diagnosis and can trace treatment defaulters during home visits (21,99). This was evident in Bangladesh where CCWs from the NGO Bangladesh Rural Advancement Committee working in their own villages for the detection and treatment of TB improved case detection and cure rates in their rural communities (115).

Thirdly, indigenous knowledge of their communities and the ability to bridge cultural, linguistic and literacy differences with patients, places CCWs at an advantage when compared with professionally trained HCPs (116,117). CCWs are able to combine their indigenous relationship with patients and their medical knowledge to positively impact on patient communication and health outcomes (116). This can be through increasing community TB awareness by educating the community on the signs and symptoms of TB, availability of TB treatment and the importance of adherence. In addition, they can advise and counsel TB patients with regard to length of treatment and the potential for side effects, as well as what to do when side effects are encountered (21). In Hlabisa health district in South Africa, CCWs have been successfully used in the delivery of a community-based DOT service, showing that community-based contribution to TB care is possible, sustainable and cost effective even in high burden settings (85,118).

2.5.1 Knowledge, attitudes, beliefs and practices of community care workers

Although much has been documented on TB knowledge, attitudes, perceptions and beliefs of TB patients and lay community members and how these factors affect presentation to healthcare facilities and adherence to medication (84,85,87,93,119), little is known about TB knowledge, beliefs and attitudes of HCPs who interact with TB patients, especially CCWs (120). Knowledge, attitudes and beliefs of HCPs at all levels impacts on the delivery of healthcare to patients, and these factors are usually influenced by ethnic backgrounds, culture, training and information sources (16).

A knowledgeable and educated workforce is able to positively contribute to TB control, especially front-line HCPs such as CCWs (118,121). CCWs are in the best position to provide TB patients with accurate TB information, educate patients, correct inaccurate beliefs and encourage positive attitudes to healthcare. Because of their close interaction with patients,

CCW misconceptions and inadequate knowledge may impact their effectiveness in educating and counselling patients (122). Lack of sufficient TB knowledge can also result in low self-confidence among CCWs, resulting in errors in daily tasks which may impact the overall running and management in clinics (26). Working in TB care is a high risk environment and therefore CCWs need adequate knowledge about TB and infection control in order to minimise risk of infection (118).

A Malawian study conducted to evaluate the needs of TB CCWs acknowledged that the lack of TB knowledge was one of the major barriers affecting their role as patient advisors and supporters (26). This included general knowledge about TB, information regarding TB medication as well as job-specific tasks such as the completion of treatment forms. This was similar to a study in Peru in which researchers identified that although CCWs interacted more with TB patients, they had less knowledge of TB than professional HCPs (26,120).

CCW attitudes and practices influence the manner in which they care for patients. Stigma can be defined as shame or disgrace attached to a character that is regarded as socially unacceptable and is a social determinant of health influenced by personal attitudes and community norms (86). Stigma and discrimination by HCPs towards patients have been previously reported (123,124), where attitudes associated with fear of transmission can lead to discriminatory acts such as inappropriate comments, breaching patient confidentiality and refusing to provide basic care to patients (123). Stigmatisation may be linked to incorrect beliefs about TB and has been linked to TB knowledge (124). A study investigating the characteristics of CCWs involved in DOTS in Taiwan found that the lack of knowledge of TB was linked to negative attitudes of CCWs towards patients and stigmatisation of these front line workers towards patients (125).

2.5.2 Information needs of community care workers

As the responsibilities of CCWs in healthcare systems increase, their health information needs are becoming more important, especially in high TB burden areas such as South Africa (110,126). Attention to the health information needs and timeous communication with CCWs enables them to remain well informed, which positively influences their impact in patient education (127). The major information challenges facing CCWs and other HCPs are the lack of routine systems for seeking and sharing information, the lack of quality and current health information on relevant issues and the lack of locally relevant materials and tools (128). These

may lead to many HCPs resorting to sharing information and knowledge amongst themselves and using their experiences to inform their practice rather than referring to evidence-based practices (129). Oral communication has been noted as the most common way information is shared, with communication normally occurring in a hierarchical fashion, which places CCWs as the last to receive information, despite being the first point of contact with the patient (128,130).

Previous studies have assessed TB information needs of professional health workers such as doctors and nurses and have included CCWs as part of general healthcare workers (26,118,120,121,128,130). Studies from Zambia and Uganda, which evaluated the types of information materials that meet HCPs' needs, reported that information sources and materials should cater for both professional and personal use and the different levels of HCPs (doctors, nurses, CCWs, paramedics), should be in print format, be brief and easy to read, and be relevant to their local context and daily lives (126,131).

Identifying the TB information needs of CCWs involves assessing their knowledge and their perception of their own knowledge deficits, specifically targeting information topics that they feel will improve their practice. This process then informs the development and provision of appropriate health-related materials (132). Expressed needs, however, may not equate to actual needs, as needs are often influenced by professional, institutional, social and cultural factors. Hence meeting information needs requires an understanding of the relationship between these factors. Additionally it is recommended that information needs should be assessed within the context of local diseases and available healthcare services (128).

A relationship exists between availability of healthcare information and the quality of healthcare services, as the availability of relevant and reliable information is a prerequisite for effective care. However, it is only one of a complex range of factors that determine effective care and there is a need to look closely at the related area of training needs (117,128). For CCWs, the availability of health information can contribute to confidence in decision making, improve hands-on skills and attitudes to healthcare service provision, and may also reduce their professional isolation (131,133). At the community level, CCWs need information that is context specific, practical, and tailored to health promotion (128,130).

There is often a disparity between recommended guidelines for care and the reality of practice (128,133). This supports the need for topic-specific information materials which, for CCWs, should have high usability, ensuring their clarity, ease of use, availability in the local language(s) and visual appeal. The information materials should be developed in collaboration with CCWs and should meet the health information needs of CCWs, with cognisance of end users who are patients (134).

2.6 Health literacy

2.6.1 Definitions

The ability to obtain, understand and use health information to make appropriate health-related decisions is known as health literacy (135,136). Health literacy is dependent on the general level of literacy. Literacy is the process whereby reading and learning conveys meaning of speech and thought, and this has been linked to health outcomes (136). Patients with limited literacy face difficulties in attempting to navigate the healthcare system, require reinforcement of oral information from HCPs and have problems accessing, using and understanding written health information (135). All these contribute to poorer health status (137,138). Functional health literacy involves the ability to apply reading and numerical skills to healthcare settings, which includes reading medicine labels and comprehending written and oral information (135).

Health-literate patients possess the skills that allow them to interpret health information and use it for self-care and self-management, whereas patients with limited health literacy are often unable to understand their health conditions and are less likely to seek health information (136,138,139). Inadequate health literacy has also been associated with the lack of understanding of medical instructions needed for adherence to prescribed medication. Nonadherence may be due to the failure of patients to understand verbal instructions regarding taking of the medication as well as the inability to read and comprehend medicine labels (140,141).

2.6.2 Health literacy and the healthcare system

There is growing recognition of the importance of addressing patients' health literacy to improve the quality of healthcare (139,140,142). The problems of low health literacy are

exacerbated by those HCPs who expect patients to assume more responsibility in a healthcare system which is becoming more specialised, technological and complex (143). Some of the proposed methods of dealing with health literacy require that HCPs tailor their communication and other interventions to suit the literacy of individual patients. To do this, HCPs need to know the literacy levels of patients, which can prove difficult when dealing with a high load of patients and the shame that many people feel towards their level of literacy (142,144,145).

One of the ways that health programmes can assist patients with limited health literacy to navigate the healthcare system is through the involvement of CCWs. This group of healthcare workers has traditionally been involved in improving access to healthcare for vulnerable groups and influencing patients' knowledge, and this advantage can be harnessed by the healthcare system. Two studies that found improved patient health literacy with the involvement of CCWs concluded that they were able to provide practical, consistently available assistance to patients, whereas this relationship would be difficult to find in regular healthcare settings (143,145).

To accomplish the above-mentioned roles, CCWs would have to be involved in tasks that require adequate health literacy such as interpreting blood glucose readings and recording clinical data, and have reasonable quality listening and speaking skills, as well as numeracy skills. Having good health literacy could positively influence their confidence and their ability to conduct certain tasks, instead of avoiding certain tasks or duties for fear of making mistakes (146). There is currently no study that has focused on the literacy and health literacy of CCWs and whether this has an impact on their knowledge and communication with patients. However, there has been a call for employers of care workers to address low literacy levels of these workers with training, and to include hands-on training methods that are task-oriented (146).

2.6.3 Measuring health literacy

Many instruments have been developed to measure health literacy in various contexts. Some tools are developed as screening tests while others require more comprehensive assessments (147). One of the most widely used tools is the Test of Functional Health Literacy in Adults (TOFHLA) which measures print literacy and numeracy. In the first section participants are required to read a comprehension section containing medical information on a prescription label or diagnosis procedure and then answer related questions. The second section uses the Cloze procedure and consists of short passages of medical topics containing blank spaces that

have to be filled in with words from a multiple choice list. A short version of the TOFHLA (S-TOFHLA) is also available. A limitation of this test is that it takes 18- 22 minutes for the TOFHLA and 8 – 12 minutes for the short version which restricts its use during consultations for busy healthcare centres (135,136,148).

The Rapid Estimate of Adult Literacy in Medicine (REALM) is quicker than the TOFHLA taking less than five minutes to administer. This is a word recognition and pronunciation test that consists of a list of medical words that the participant reads out loud. Each word that is pronounced correctly is one point and the sum of points is calculated. Both the REALM and TOFHLA have been criticised as they only measure print literacy using health related words, whereas health literacy is far more complex than the ability to recognise and pronounce certain words (135,148).

The Newest Vital Signs (NVS) is a quick screening tool consisting of a nutrition label, with participants being required to answer questions by accessing and applying information from the label. The questions require both reading comprehension and numeracy, similar to what is needed in order to understand and manage basic health information (135,149).

These existing tools have been assessed and developed mostly in developed countries and hence have been criticised for their lack of cultural sensitivity and of being more applicable to only selected groups.(150). There is a need for more research in the development of these tools in LMICs which usually have higher illiteracy rates. Currently no health literacy tools have been developed and validated for the South African context.

2.7 Provider-patient communication and the need for an informed patient

The recent call for more patient participation in the healthcare process may alienate patients with low health literacy who have lower disease-related knowledge, need a more in-depth explanation of health conditions and ask fewer questions (139). As the relationship between patients and HCPs is progressing towards a partnership based on shared decision-making, several studies have reported that patients would like more health information than they currently receive from HCPs, and often this need is underestimated (30–32). There is increasing pressure on HCPs to improve the quality of their healthcare service and to adopt a more patient-

centred approach. One of the aspects that determines healthcare quality is the extent to which health information needs of patients and their family members are met (31,32).

Patients are limited in their ability to make informed decisions about their health unless they have access to appropriate, useful health information that will assist them in understanding their condition and its management. This is essential in empowering patients to participate more actively in decisions about their treatment (33,34). Shortcomings in information provision affects the quality and outcomes of healthcare and may negatively influence patient satisfaction with healthcare services, adherence to treatment instructions and the relationship with HCPs (141).

TB patients on treatment under DOTS are in contact with HCPs from their diagnosis to everyday monitoring and observation (43). DOTS positions HCPs centrally in the demand for high treatment adherence as they are in frequent contact with the patient. HCPs are the main source of TB information for the patient and they play a key role in ensuring adequate counselling and education to both patients and their families regarding the disease, its treatment and the importance of adherence. This complex relationship between the patient and the HCP relies on adequate communication between the two parties. Quality communication enables a patient-provider relationship to develop and trust to be earned, which in turn impacts positively on patient satisfaction and adherence (90,151,152). The success of this interaction is affected by the knowledge of HCPs on the disease and treatment, their communication skills, the quality of their patient counselling and education and their attitudes towards patients (151,153).

In a Nepalese study, poor communication was identified by TB patients as one of the factors contributing to nonadherence. Most of the nonadherent patients mentioned side effects of TB medicines as a reason for defaulting therapy as they had not been informed by HCPs about what to do and where to go if these were experienced (119). HCPs in a study in Bali linked nonadherence to poor communication with patients and acknowledged that specific training which would enable them to deliver treatment in a patient-centred approach, can increase the level of patient involvement, thus improving adherence (154). Additionally, research previously done in South Africa showed that the combined strategy of a patient-centred interview and issuing a patient education booklet had a significant effect on the regularity and the amount of medication taken by TB patients (152). Although not measured by the study, the motivation of the clinic staff to engage with patients due to the availability of education

resources was highlighted as an additional factor that may have contributed to the improved outcomes (152). In TB care, a trusting, open relationship with HCPs is essential, as this can support adherence over the long duration of treatment and contribute to better health outcomes (155,156).

2.8 Health information materials

2.8.1 Information materials for patients

Communication barriers are common in interactions between formal HCPs and patients. The frequent use of medical jargon contributes to patient difficulty in understanding (141,157), often resulting in patients having to rely on other, possibly less reliable, sources of information. Most patients have difficulty remembering verbal information from HCPs and in this case written health information materials may assist in acting as a memory aid. (141,158). Written materials can be useful if they convey clear and understandable information which reinforces verbal information provided by HCPs, and may also assist in reducing HCP-patient communication barriers (157).

The design of written health information materials for patients has been comprehensively discussed in the literature (158–162). These authors agree that the success of written materials in communicating the desired information to patients relies on involving the target audience in the development and design of the materials (158), paying attention to the content which should be both easily understood and culturally appropriate (159), ensuring easy navigation of the information by using legible text that is easy to read and addition of illustrations and graphics to enhance the appeal of these materials (34).

2.8.2 Information materials for community care workers

The focus of written materials developed for HCPs mainly addresses competencies of professional standards (prescribing patterns, evidence-based clinical practices, compliance to treatment guidelines). Given the lack of a professional health qualification and the unique role of CCWs in patient care, materials for informing and training CCWs should be developed to address the specific needs of this cadre of healthcare workers. (163–167). The few studies that have assessed the impact of written materials designed for CCWs have included training

manuals, pamphlets and booklets (27–29,168). These materials have been developed for various reasons, including to serve as training tools and reference guides for CCWs during their daily work, to facilitate task-shifting, conduct health promotion activities in the community, educate patients and facilitate implementation of community-based health programmes. The majority of these materials are developed by organisations such as the WHO, United Nations Programme on HIV/AIDS (UNAIDS), Centres for Disease Control and Prevention and the International Medical Services for Health (169–172). These organisations and studies suggest that the designers of materials for CCWs and other HCPs should pay attention to certain factors.

Meeting priority health needs

Information materials should be relevant to the HCPs that need them, paying attention to specific information needs for improving understanding, knowledge or practice. Information materials that meet perceived information needs are more likely to be used than unsolicited information that is given to the end users. Each level of health staff and their own educational background must be considered (128,129,173).

Content

The content needs to be relevant to the local situation and should include only information that HCPs need to have in order to perform their tasks properly, especially at the primary care level, where CCWs need instructions on when to refer patients to the next level of care (27,169,173).

Adaptation

Instead of developing new written materials for HCPs, consideration should be given to existing materials which can be adapted to meet priority information needs (173).

Intelligibility

Similar to the development of patient information materials, the language used should correspond to the reading abilities of the users. Including a list of contents is crucial for HCPs who need a quick guide of the topics available. To enhance the understanding of the text, short sentences and simple words should be used. The presence of flow-charts, questions and answers, illustrations and tables can also assist the understanding of the text. (28,173,174).

Testing of draft versions

The first versions of information materials can be tested using a group of the intended audience who read them and identify sections or concepts that are unclear. Feedback from testing should then be used as a guide to make changes. Readability tests can also be used to

measure the readability level, but the results from these tests should not replace direct field testing with the intended users (173).

Evaluation

This is an important step in the design of information materials where the usefulness to the intended audience is evaluated. The content of the materials should also be regularly updated as healthcare is always changing (170,173).

2.8.3 Pictograms in health communication

Pictograms are symbols that represent a concept, object, place or event by illustration. It has been noted that humans prefer pictures to text-based information (157). Evidence shows that when pictograms are used together with written or spoken text, they enhance health communication interactions (32). Pictograms are useful in promoting patient understanding of complex medical instructions such as information regarding the medicine indication, dosing schedule, special instructions for administration, side effects and the importance of completing the full course of therapy (32,137,141,157).

Pictograms and other visual aids draw attention to health messages, making information user-friendly as well as more accessible and interesting, thereby increasing the likelihood that it will be read (34). In addition, pictograms which are simple and clear enhance understanding of medical instructions and facilitate recall of information, which may enhance adherence particularly for low literate patients who may derive greater benefit from pictorial based medical instructions (33). A study conducted in a low-literate population compared the influence of text-only versus text-plus-pictogram medicine labels for prescribed antibiotics. Pictograms were found to enhance comprehension and promote understanding of medicine instructions, timing of doses, and the importance of completing the drug therapy (32,137).

Apart from their use in enhancing patient communication, pictorial-aided information materials have been used successfully to aid practices of nurses and to improve the knowledge, skills, training and practice of CCWs (27–29,164,168,174,175). Job aids consisting of written information or instructions supplemented with images and pictograms, have been found to improve the performance of minimally trained CCWs when combined with training and supervision (29,164). They were seen as an innovative tool, particularly in low-resource

settings, to improve the performance of HCPs and therefore improve the quality of healthcare in malaria, infant-feeding and family planning (27–29,168,174).

Pictorial-aided written information enhances understanding of information, minimises dependence on memory, allows for clear and simple illustrated instructions which reduces common errors and, when used in counselling patients, strengthens patient communication by offering HCPs a tool to encourage patient participation (27,29,29,175). A study that used job aids to improve maternal knowledge of eclampsia found that although job aids increased knowledge of the mothers, it also had an unexpected benefit of providing HCPs with a structure on which to base their advice and it increased their knowledge of the disease (175).

2.8.3.1 Design of pictograms

Although pictograms have been shown to aid in health communication, their effectiveness depends both on their design and on their appropriate use (32,34,137). The recommendations for using pictograms in health education include using simple pictograms that are realistic and provide a single clear meaning to allow for understanding, without the distraction of unnecessary details (32,34). Similarly, pictograms should also be designed to include symbols or objects which are familiar to the target audience as this may enhance acceptability of information materials. Familiar images also help in drawing the attention of the target audience (141). The use of simple text that accompanies the pictogram assists in interpretation of the image and in clarifying the intended message (32,34,158).

The design of pictograms should involve the intended audience, as picture preferences differ depending on cultural factors and personal characteristics (141). Differences in culture and language may present barriers to communication between patients and HCPs, and therefore visual aids should be adapted to the local culture of the target audience (34,141,162). Before pictograms can be used as a tool to facilitate communication with patients, they should be pre-tested using the target audience and modified for an improved, more acceptable version (32,137,162).

To ensure the correct interpretation of pictograms, it is advocated that verbal instructions should always accompany the use of pictograms in order to clarify concepts to the viewer. This

is especially important for low literate patients who are unable to read the accompanying text (34,137).

2.9 Conclusion

The purpose of this review was to investigate evidence showing the impact of CCWs in general efforts to control TB, and to see how the lack of both knowledge and information needs reportedly influenced their performance. Research indicates that healthcare systems benefit from the inclusion of CCWs in treating and managing TB patients, as CCWs not only address the challenge of shortages of healthcare workers, but also contribute to the socioeconomic development of their communities as a whole. The support of CCWs by the healthcare system through adequate supervision, training and paying attention to their needs has been shown to affect their performance. Although there is a scarcity of research that has explored the possibility of whether empowering CCWs with information materials can assist their roles in patient education, it has shown that supporting CCWs using information materials that cater to their needs may be one of the cost-effective measures that can improve performance, especially in the field of TB.

CHAPTER 3

METHODOLOGY

This chapter describes the mixed-method study design employed to identify and meet TB information needs of CCWs in Grahamstown. It outlines the overall plan for conducting the study, including study setting, study design, study population, ethical considerations, data collection and analysis.

3.1 Study setting

The Eastern Cape province, one of nine provinces in South Africa, is home to 12.7% of the South African population, making it the third most populated province after Gauteng and Kwa-Zulu Natal. Ranked as one of the poorest provinces in South Africa, poverty in the Eastern Cape is widespread, with 57% of its population living in poverty and 13% of households having no education (176,177). Eighty nine percent of the Eastern Cape population relies on the public health sector while 11% have private medical aid (178). TB is a public health problem in this province, which had the third highest incidence of TB-related deaths in 2011 (178).

Provinces are divided into districts, municipalities and wards. Of the seven districts in the Eastern Cape, the Cacadu district is the largest and includes the Makana Municipality with Grahamstown, the study setting, as the main town. Grahamstown has a population of 50,217 and is the largest town in the municipality (179,180). It consists of three wards (Tantyi, Raglan Road, Joza) with each ward marking a regional area. To distinguish the parameters of each ward, a community map outlining the residential areas and addresses, schools, churches, public service facilities, schools and crèches is present in each of the clinics. Ward-based PHC outreach teams under the PHC re-engineering strategy are linked to three PHC clinics (Tantyi, Raglan Road and Extension 7) and are supported by the District Health Office.

The Grahamstown public health sector is served by six PHC clinics (Raglan Road, Tantyi Clinic, Extension 7 Clinic, Town Clinic, Middle Terrace Clinic, Settler's Day Hospital) and three hospitals (Themba TB Hospital, Fort England Hospital, Settler's Hospital). TB patients are managed according to the National TB Management Guidelines, which is a part of the National TB Control Programme (6). Under this programme, PHC clinics are responsible for

TB symptom screening and testing, diagnosis of both drug-sensitive and drug-resistant TB, treatment of drug-sensitive patients, contact tracing, adherence monitoring, counselling after diagnosis and referral of drug-resistant patients to provincial or decentralised MDR-TB centres located nearby in Port Alfred and Port Elizabeth (6,82).

Each clinic is staffed by nurses, pharmacist's assistants, CCWs and support staff. CCWs are classified into three categories, including home-based carers who are part of the outreach team where they perform home assessments and referrals to the clinic if needed, lay counselors involved in HIV testing and counseling at the clinic, and DOT supporters who provide medication and support to TB patients. Once a patient is diagnosed with TB, medication and counseling are provided by CCWs who are DOT supporters under the supervision of a nurse. Patients continue with DOTS at the clinic for six months supported by the DOT supporter under the supervision of the nurse (181). DOT support can either be done at patients' homes for those unable to walk to the clinic or in the clinics either daily or weekly depending on the clinic.

The TB Care Society also contributes to TB care in Grahamstown. It trains CCWs who work as DOT supporters in PHC clinics and provides nutritional support for TB patients by assisting PHC clinics with food items which are given to patients on treatment.

The Hospice Palliative Care Association of South Africa (HPCA) is a national organisation that aims to improve the quality of life of patients and their families facing life threatening illnesses. HPCA gives palliative care through home care and general inpatient care for end-stage diseases including TB. The Grahamstown and Sunshine Coast Hospice is one of the members of the HPCA and it serves two municipalities in the Cacadu district. It consists of an interdisciplinary team which includes nurses, doctors, social workers, CCWs and counsellors. CCWs in the team provide home-based palliative care under the supervision of a nurse.

3.2 Pre-study activities

3.2.1 Meetings with key stakeholders

After conceptualising the project, the research team (researcher and research supervisor) met with a team from the Makana municipality District Health Office, that included the district pharmacist, the manager of PHC outreach teams and the TB programme manager. The aim of

these meetings was to explore the context of CCWs in Grahamstown and establish whether the proposed study would be supported by the District Health Office. Discussions included the new PHC re-engineering strategy, classification of CCWs in the public sector, CCW training and a basic overview of their role in the TB care team. A similar meeting was held with the clinical skills manager of Grahamstown Hospice to inform her of the project and investigate the possibility of recruiting CCWs to the study.

Discussions in both meetings 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 who agreed to allow us access to their CCWs.

3.2.2 PHC outreach teams in Grahamstown

Each of the three wards in Grahamstown has one PHC outreach team consisting of a professional nurse as the team leader, a health promoter who is responsible for support and assistance pertaining to health promotion activities, an environmental health officer who monitors environmental health and safety, and six home-based CCWs employed at the PHC clinics. They meet at the clinic on Mondays and Fridays to discuss progress and share ideas. A monthly report is submitted to the District Health Office detailing their progress and activities.

The researcher shadowed a PHC outreach team on a day visit to one ward (Tantyi), with the objective being to gain some insight and better understand the organisation and context in which CCWs work, the interactions of CCWs with their patients and with other health professionals, and their roles and activities in the healthcare team. Spending time with the outreach team and meeting key stakeholders prior to data collection enabled a relationship to be established between the research team and participating organisations. This was done to desensitize the participants to the researcher as a way of reducing research bias, as often the participants may reveal themselves in the best possible light or distort information (182).

These outreach teams contribute to the healthcare system mainly by decreasing the patient load on the health facilities through the provision of basic health services at patients' homes. The Tantyi clinic also has a support group run by the outreach team that offers health promotion

activities, encourages patients to talk about their experiences and provides food and vegetables to patients.

3.3 Ethical considerations and obligations

Prior to commencing the study, ethical approval was obtained from the Rhodes University Faculty of Pharmacy Ethics Committee (PHARM 2014 – 10) (Appendix 1), and the Eastern Cape Department of Health (Appendix 2). Permission was also obtained from the District Health Office, the nurses in charge of each clinic and the manager at Hospice prior to approaching participants.

Informed consent was obtained before involving CCWs in the study. Participation in the study was voluntary and participants were fully informed about the aims and objectives of the study. They were also advised that they could withdraw from the study at any time during the research process. Interviews and discussions were scheduled at the convenience of the participants prior to each interaction with the researcher. Confidentiality was ensured throughout the study by using participant numbers instead of names in the research report and collecting only relevant details during the study.

3.4 Study design

Based on the conceptual framework defined in Chapter 1, a mixed-method design was chosen for this study. The mixed-method design refers to a method that intentionally combines both quantitative and qualitative research methods to investigate a research problem, and guide the data collection and data analysis processes (183). Qualitative research describes a type of research where the researcher relies on the views of participants to gain an understanding of their underlying reasons, experiences, opinions and motivations. The voices of the participants are emphasised through quotes. Quantitative research is used to quantify the research problem by generating numerical data that can be used to examine relationships between variables (183,184).

Investigating the health information needs of CCWs required firstly a deeper understanding of how they fit into the healthcare system based on their own reported experiences and perceptions, followed by an analysis of their current TB knowledge levels. This demanded a

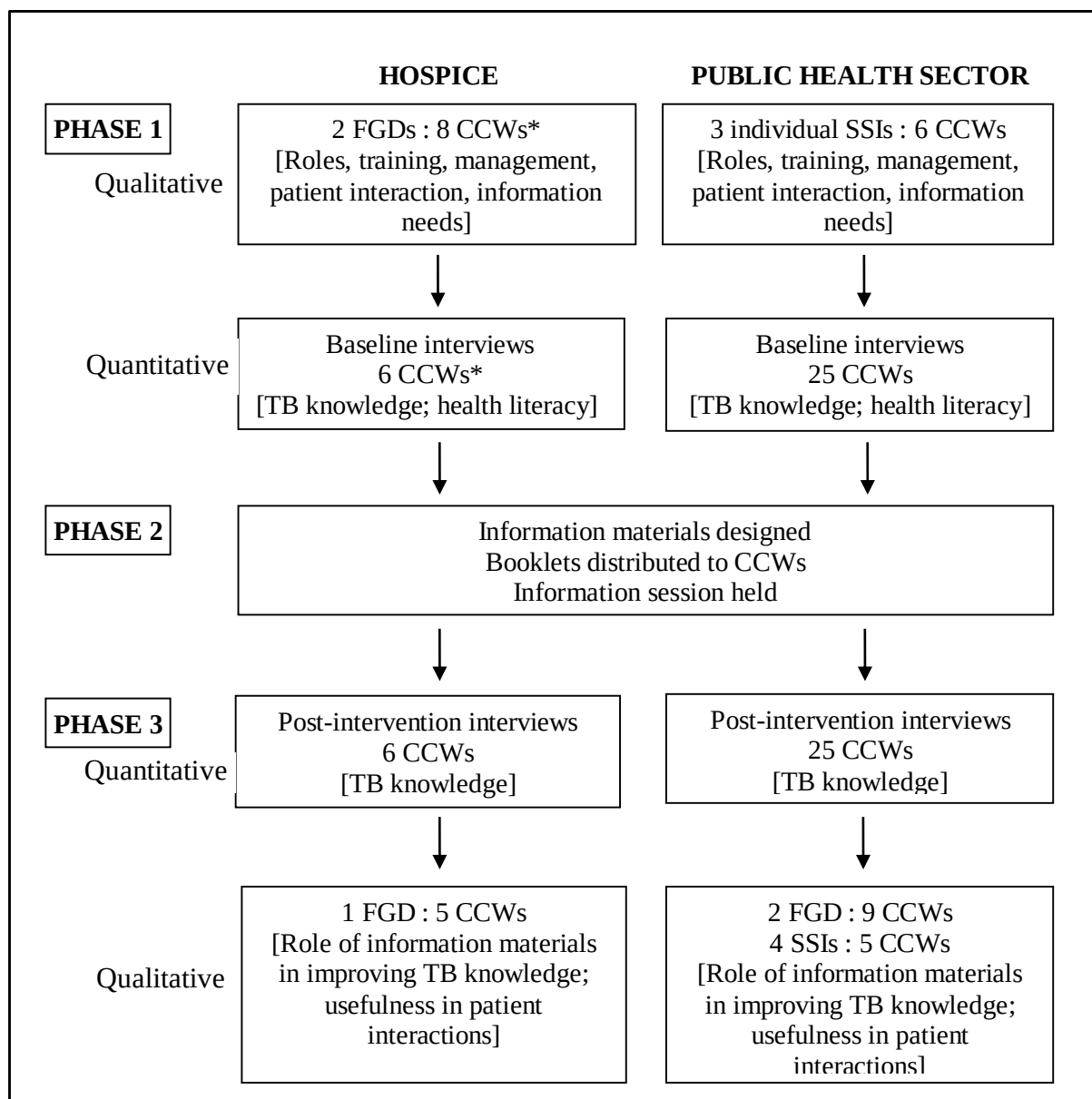
combination of methods, with the qualitative method being used to understand the work context of the CCWs and gain insight into their experiences and perceptions of their information needs. The quantitative method served to measure TB knowledge levels and to compare knowledge levels before and after the intervention. Combining both methods also ensured validity of the study through triangulation (185) as the different research methods compensated for their individual limitations.

Qualitative data were collected using focus group discussions (FGDs) and semi-structured interviews (SSIs). A FGD is a group discussion including between five and ten participants based on a specific topic initiated by the researcher (184,186), and it allows participants to talk to one another, ask questions and comment on each other's responses, thus facilitating an interaction that uses communication between participants to collect data (184). SSIs consist of predetermined open-ended questions based on the topic to be covered (184) and are conducted with individual participants. For this project, SSIs were used in settings where a group could not be gathered for a joint discussion. Quantitative data were collected during individual interviews using a structured questionnaire.

Each of the 4 steps of the intervention presented in the conceptual framework (Chapter 1, Figure 1.1, Area A) corresponded with phases in the study. The aims of the three phases were as follows:

- **Phase 1 (Step 1):** To explore the perceptions of CCWs regarding their functions, training, management, interactions with patients and information needs, and to assess the baseline TB knowledge level.
- **Phase 2 (Steps 2 and 3):** To design and distribute information materials.
- **Phase 3 (Step 4):** To measure post-intervention TB knowledge and investigate the role and influence of the information materials in everyday CCW practice.

A flow diagram describing the phases of the study and their associated activities is presented in Figure 3.1.



* Eight CCWs were initially recruited from Hospice but two of them were lost prior to the baseline knowledge interviews due to retrenchment.

Figure 3.1: Flowchart describing phases of study

3.5 Study population and recruitment

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 (187). The researcher carefully selected CCWs based on the aim of the study with the expectation that each participant will provide unique and rich information of value to the study. Inclusion criteria for the CCW recruited included employment as a CCW by either Grahamstown

Hospice or the provincial Department of Health as a CCW (either TB-specific or generalist) and involvement in the routine care of TB patients. All CCWs from Grahamstown Hospice and from the six PHC clinics working with TB patients in Grahamstown were eligible for inclusion in the study. Using CCWs from two different organisations ensured site triangulation (182) in order to avoid having findings of local factors that only affect one institution. Facility managers of the PHC clinics and the Grahamstown Hospice manager informed their CCWs about the study during one of their routine meetings. The researcher then met with CCWs for an information session, and those willing to participate proceeded to sign the consent form (Section 3.8.1). Although CCWs were encouraged to participate in the study, they were made aware of their option to decline. A total of 31 CCWs were recruited for participation in the study and at the time of recruitment they had the following roles: four were lay counsellors, eight were DOT supporters, six were general care workers and 13 were home-based carers.

3.6 Data collection instruments

Data collection, both quantitative and qualitative, occurred in Phases 1 and 3 of the study (Figure 3.1).

3.6.1 Qualitative: Interview guides

The availability of only minimal literature sources and policies documenting the CCW programmes in the Eastern Cape prompted the need to more fully understand the context of CCWs in Grahamstown. The Phase 1 question guide (Appendix 3) was also informed by previous studies (15,24,98) that have described CCW programmes to help establish a profile of CCWs. It consisted of categories to be addressed, each with three to four questions.

The question guide for Phase 3 (Appendix 4) was designed to explore CCW perceptions regarding the usefulness of the booklet in their daily work, especially when interacting with patients. The relatively loose structure of both question guides allowed space for probing and for additional questions that emerged during the interview. Both of the interview guides were in English.

3.6.2 Quantitative: Questionnaires

A structured questionnaire was developed for the assessment of knowledge and health literacy. The questionnaire was modified from two questionnaires which had been used previously to assess TB knowledge, attitudes and perceptions in Grahamstown in a patient population (188) and in lay community members (189). The questionnaire was also informed by previous studies (117,120,190–192) that have assessed TB knowledge, attitudes and practices of healthcare workers, patients and community members, as well as recommendations on how to conduct TB surveys by the WHO Stop TB partnership (193). The questionnaire was in English and was administered by the researcher in English.

Health literacy was assessed using a locally modified version of the Newest Vital Signs (NVS) health literacy test developed in the USA (149). The South African version replaced the ice cream nutritional label with a nutritional label from a can of pilchards, a commonly eaten food by the majority of the local population. The Newest Vital Signs – South Africa (NVS-SA) consists of six questions that assess numeracy and comprehension skills. This test has been piloted but has not yet been validated in a South African population (194).

The participants were asked to read a prompt card that contained an enlarged image of a nutritional label from a tin of pilchards (Appendix 5) and were required to answer the six questions by referring to the label. Each correct response was allocated one mark, giving a total score of six. Health literacy was classified as inadequate (<2), marginal (3-4) or adequate (5-6).

3.7 Piloting of instruments

A pilot study is described as the pre-testing of data collection instruments on a small group of people similar to the intended study population. Its purpose is to assess whether the participants are able to understand the questions in order to rectify any sources of confusion or problems of comprehension which improves the success and effectiveness of the data collection tools to be used in the main study (195).

A pilot study to assess the developed questionnaire was conducted with a sample of six participants: two support staff employees of Rhodes University, two students at Rhodes

University and two nurses working at Settler's Day Hospital. Due to the limited number of locally available CCWs, the pilot study could not be conducted in the same target population of CCWs as defined for the main study. However the pilot study population did mimic, in part, the target population by including local participants from the same language and culture as the CCWs.

The pilot interviews were conducted by the researcher at Rhodes University and Settler's Day Hospital with the aid of an interpreter. The duration of the interview was noted, with interviews lasting between 30 and 45 minutes. During the interviews, the researcher was particularly vigilant in noting participant reactions, any difficulties in responding and other logistics. All this feedback was used to modify the questionnaire prior to use in the main study.

3.7.1 Piloting of instruments: Modification of the questionnaire

The following modifications to the questionnaire were implemented.

Questions 1.3 and 1.4

Pilot version:

How well do you understand your home language/English? Can you listen or speak or read?

1 = Listen (verbal understanding); 2 = Speak; 3 = Read

The third option for these two questions was changed to include one that was "listen, speak and read" as most participants could do all three.

Final version:

How well do you understand your home language/English? Can you listen or speak or read?

1 = Listen (verbal understanding); 2 = Listen and speak; 3 = Listen, speak and read

Question 2: Medicines Literacy Test

This test was removed due to time constraints and the NVS-SA health literacy test was retained as the only tool used to measure health literacy.

Question 3: Newest Vital Signs – South Africa (NVS-SA)

A reminder was included for the interviewer to note the time taken for the test.

Question 4.3

Pilot version:

If you are with a person who has TB can you get TB if you: shake his hand; eat from his plate; breathe in the air after he coughs; share his clothes; use the same toilet; use the same towel; have sex with him/her?

0 = Incorrect; 1 = Correct

These seven transmission options had been previously investigated in lay members of the same community as the CCWs and several misconceptions were revealed regarding transmission of TB (189). However, it was felt that this question, with a total of seven marks, was too heavily weighted. The question was modified to include only three options, each worth one mark that contributed to the final knowledge score, reducing the total score to 35. It should be noted that all seven options were still asked in order to compare with results of the study in lay community members.

Final version:

If you are with a person who has TB can you get TB if you: eat from his/her plate; breathe in the air after he/she coughs; have sex with him/her?

Answer options: 0 = Incorrect; 1 = Correct

Additional options asked but not included in the final score: shake his/her hand; share his/her clothes; use the same toilet; use the same towel.

Question 4.18

If the new patient is a woman of child-bearing age, what should she tell the doctor in addition to the above?

0 = Incorrect; 1 = Correct

This question was removed as it was ambiguous and was interpreted only as “if a woman is pregnant...” instead of including a broader perspective that included the potential for women of a certain age to fall pregnant.

Questions 4.20 and 4.21

Pilot version:

4.20 What do the names MDR-TB and XDR-TB mean?

0 = Incorrect; 1 = Correct

These two questions were separated into individual questions in order to avoid asking two questions in one.

Final version:

4.20 What does the name MDR-TB mean?

4.21 What does the name XDR-TB mean?

After the changes were made to the questionnaire, the final version (Appendix 6) used in the main study consisted of five sections:

Baseline:

Section 1: Demographics - nine questions.

Section 2: NVS-SA to measure health literacy level of CCWs.

Section 3: Baseline TB knowledge tested with 33 questions covering causes of TB, transmission, prevention, diagnosis, association with HIV/AIDS and treatment. Each question had one mark for a correct response apart from one question which had three marks allocated, leading to a total score of 35.

Follow-up:

Section 4: Duplicate of section 3 for measuring follow-up TB knowledge.

The final questionnaire consisted of both open-ended and close-ended questions, with the latter having pre-determined correct responses. The order in which the questions were asked was an important part of the questionnaire design and hence to allow for a logical order, all questions relating to a specific topic, e.g. transmission, were grouped together.

Due to the lack of information regarding the length and depth of training provided to the CCWs in Grahamstown, as well as the reported lack of adequate training that emerged in the initial discussions, all CCWs were asked about specific TB-training or any other related training they had received before they started working as CCWs as part of section 1 in the questionnaire.

The questions determining TB knowledge were organised in the following way: Questions 3.1 - 3.5 focused on the cause of TB, transmission and prevention. Questions 3.6, 3.11 and 3.12 were aimed at addressing the stigma surrounding HIV/AIDS and TB. Signs and symptoms as well as the diagnosis of TB were tested by Questions 3.8 - 3.10. The remaining 20 questions focused on TB medication, advice for patients in treatment, MDR and XDR-TB and side effects. CCWs were also asked to mention the percentage cure rate of TB in the Eastern Cape to investigate whether they had an understanding of the level of TB control in the province where they worked.

3.8 Phase 1: Qualitative and quantitative baseline data collection

3.8.1 Qualitative: CCW perceptions of their roles in TB care and their information needs

Discussions and interviews were conducted over a period of five months (July-November 2014) at Grahamstown Hospice and three PHC clinics (Middle Terrace, Tentyi, Extension 7). Two focus group discussions (FGDs) were conducted at Grahamstown Hospice, with four CCWs in each group. Semi-structured interviews were conducted at the PHC clinics, with two CCWs in each interview. All sessions were conducted in a private room at each facility

The research team consisted of the researcher (IO) and her project supervisor (RD) who acted as an observer. The researcher introduced herself and presented an overview of the study. Invitation letters (Appendix 7), 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 to explore the following areas: motivation for becoming CCWs, personal perception of CCW role(s) and training, and TB information needs which 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. The researcher also ensured that CCWs knew that there was no right or wrong answers to help encourage honesty in responses. The sessions started with everyone introducing themselves. This was followed by an ice-breaker activity to encourage the CCWs to relax, feel comfortable and share information about themselves. They were asked to: "Please write down one word to describe how you feel about being a CCW" and 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) to the CCWs. 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 observations during the interviews. All sessions were audiotaped to ensure verbatim accounts of information provided by the CCWs. The FGDs and individual interviews lasted between 45 minutes and one hour. The sessions continued until data saturation, and this was deemed to have occurred after five sessions that included a total of 14 CCWs.

3.8.2 Quantitative: Baseline TB knowledge

After the FGDs and SSIs were completed, individual interviews with 31 CCWs were conducted to assess baseline TB knowledge using the modified questionnaire (Appendix 6). The interviews were conducted at Grahamstown Hospice and all six PHC clinics. For the 14 CCWs involved in the qualitative sessions, baseline TB knowledge was assessed immediately after the sessions. For the remaining 17 CCWs, TB knowledge was assessed on subsequent days determined by the availability of both parties. All interviews were conducted in English with an interpreter who was present to assist in translation to isiXhosa when required. The questionnaires were administered by the researcher in individual sessions with each CCW, and these lasted between 20 and 30 minutes. All data were captured by the researcher and the sessions were audio recorded.

3.9 Phase 2: Development of information materials

3.9.1 Content

The design of the booklet was informed by Phase 1 findings that afforded insight into the context of CCWs in the healthcare system and their stated information needs. CCWs highlighted knowledge areas that they felt should be included in the booklet, both to increase their knowledge and to assist in patient education. These topics included the following: cough hygiene, general hygiene, signs and symptoms of TB, side effects of medication, treatment duration, management of MDR and XDR-TB and advice regarding the importance of adherence.

The above-mentioned topics were supplemented with additional input from a meeting held between the district pharmacist, responsible pharmacists in the public sector facilities, the district TB manager, nurses in charge of the public sector clinics, and health programme managers who identified key areas that they wanted the booklets to address. These key areas included: advice for patients to have regular check-ups after completing therapy, alcohol consumption, collection of sputum samples, advice regarding colouring of urine, ventilation of rooms in the houses, testing of contacts, masks for prevention of TB for patients and CCWs and HIV testing for TB patients.

To find reliable TB information for inclusion in the booklet relevant to the South African context, the National TB Management Guidelines (43), South African Medicines Formulary (50), Essentials Drugs List (196), as well as education guides and CCW training manuals developed by the South African Hospice Palliative Care Association, were consulted. This was supplemented with previously developed TB leaflets and booklets from organisations such as the UNAIDS, the United Nations Children Fund, Treatment Action Campaign, Médecins Sans Frontières and the Ministries of Health of other countries.

A previously designed patient information leaflet for TB patients from the same community that was successful in improving patient knowledge was also used to inform presentation of booklet content (188). Opinions of the booklet were sought from the CCWs via informal discussions once the first draft of the booklet had been developed. Immediately following administration of the knowledge questionnaire, the researcher showed the CCWs a draft version of the booklet and requested feedback on both textual content and the design of the pictograms. This informal feedback session took less than ten minutes and the feedback led to subsequent modifications of the booklet.

The final booklet consisted of the following key knowledge areas:

- **Title:** Indicates that the booklet is about TB prevention, disease and medicines for CCWs.
- **TB in South Africa:** Shows the incidence of TB in South Africa and in the Eastern Cape Province.
- **Cause of TB:** Transmission of TB and addresses misconceptions about how it is not spread.

- **Prevention of TB:** Highlights the three main ways to prevent TB.
- **People more likely to get TB:** Addresses how anyone can get TB.
- **Signs and symptoms of TB:** Includes the common signs and symptoms of TB and what to do when they present.
- **Diagnosis of TB:** How TB is commonly diagnosed and advice for sputum collection.
- **TB treatment:** Medication used to treat TB, advice for patients on TB treatment and consequences of defaulting treatment.
- **Side effects of TB medicines:** Shows the common side effects of TB medicines and those that require medical attention.
- **MDR and XDR- TB:** Defines drug-resistant TB, how it develops and its treatment.
- **HIV/AIDS and TB:** Includes information on the link between HIV/AIDS and TB as CCWs often encountered patients with both of these conditions.
- **Support for TB patients:** Advice for care takers of TB patients.

3.9.2 Design of the pictograms

A total of 43 pictograms were included in the booklet to aid the understanding of the text. Seventeen of these pictograms shown in Table 3.1 had been designed by our research group for previous studies (188,197,198).

The remaining 26 pictograms were newly designed or modified from previously developed pictograms using the original design process described in detail by Dowse et al (199). After identifying pictograms that needed to be newly designed or modified, initial ideas and designs were generated using sketches, posed photographs or images sourced from the internet. In consultation with an expert graphic artist who works with our research group, the initial sketches were modified several times in an iterative process which resulted in the final pictogram (Table 3.2). Visuals generated at each stage were scrutinised by the researcher and her supervisor who is experienced in pictogram design. These suggested modifications were communicated to the graphic artist and changes were made until a final version of the pictogram was created which was deemed acceptable.

Table 3.1: Previously developed pictograms included in the booklet

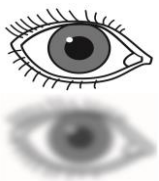
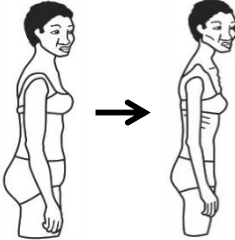
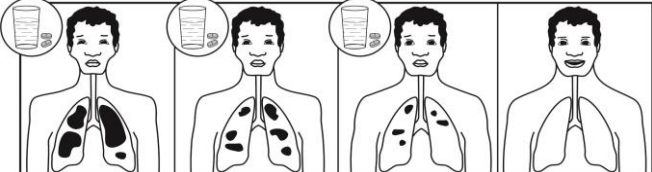
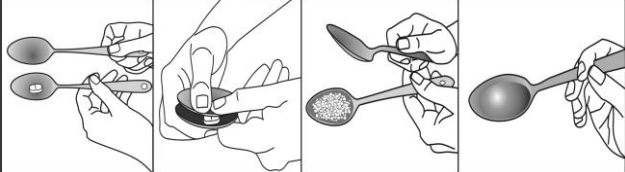
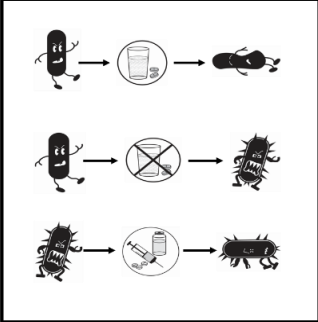
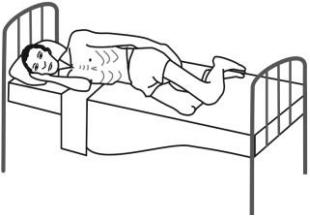
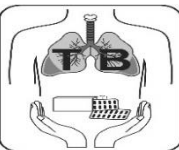
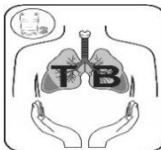
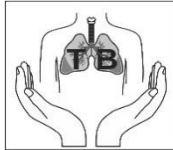
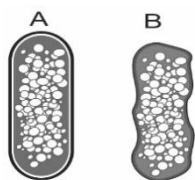
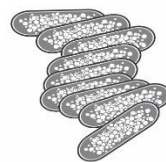
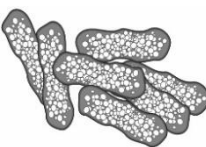
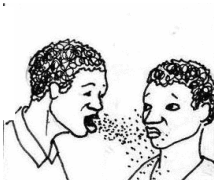
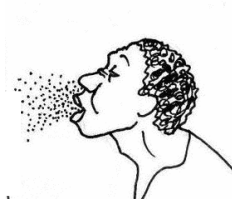
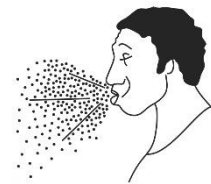
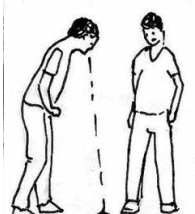
			
Blurred vision	Coughing	Night sweats	Tiredness
			
Fever	Vomiting	Dizziness	Weight loss
			
Muscle weakness	Time to take treatment	Severe rash all over the body	Stomach pain, nausea and vomiting
			
Lung sequence showing gradual clearing		Tablet crushing and mixing sequence	
			
Drug-resistant TB sequence		Consequence of defaulting	TB medicines

Table 3.2: Pictogram development process for new pictograms

Pictograms	Development and final versions				
1. TB logo	Version 1a	Version 1b	Version 1c	Version 1d	Final version
					
2. CCW and patient	Version 2a	Final version			
					
3. Bacteria	Version 3a	Final version			
					
4. Coughing with droplet spread	Final version				
					
5. Sneezing	Version 5a	Final version			
					
6. Spitting	Version 6a	Version 6b	Final version		
					

7. Hugging

Final version



8. Handshake

Final version



9. Sharing the toilet

Final version



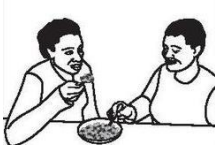
10. Sharing food

Version 10a

Version 10b

Version 10c

Final version



11. Safe cough

Final version

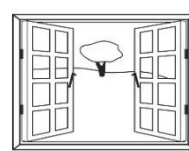
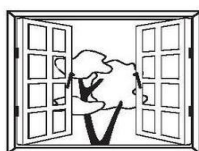
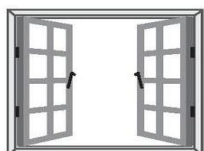
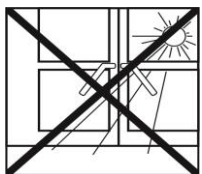


12. Open windows

Version 12a

Version 12b

Final version



13. Wearing a mask

Final version



14. Anyone can get TB

Version 13

Final version



15. Coughing for two weeks

Version 14a

Final version



16. Sweating at night

Version 15a

Final version



17. Lack of appetite

Version 16a

Version 16b

Version 16c

Final version

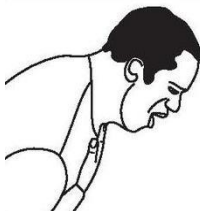
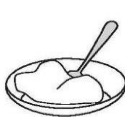
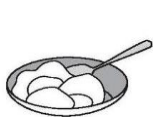


18. Coughing up blood

Version 17a

Final version



19. Nausea	Version 18a	Final version			
					
20. Sputum bottle	Version 19a	Version 19b	Final versions		
			Empty sputum bottle	Sputum bottle with patient name	
					
21. Sputum collection sequence	Version 20a	Final version			
					
					
					
22. With or without food	Version 22a	Version 22b	Version 22c	Final version	
				With food	Without food
					

23. Orange urine

Version 22a

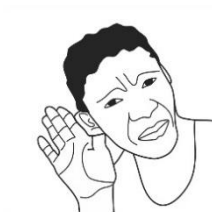
Version 23b

Final version



24. Hearing problems

Final version



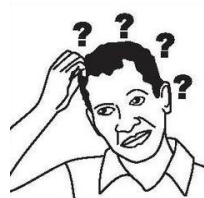
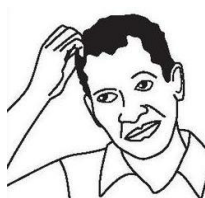
25. Confusion

Version 25a

Version 25b

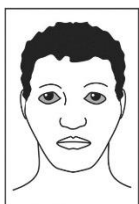
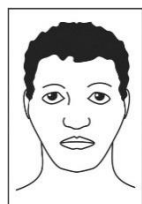
Version 25c

Final version



26. Yellowing of the eyes

Final version



Pictogram 1: TB logo

A TB logo was designed for the cover page of the booklet and for use on the posters. The first version contained only the lungs with the letters 'TB' inside. Later versions tried to include TB medicines either in the form of a box of tablets or a glass of water with a tablet, but this made the pictogram appear too crowded. The body outline was deemed unnecessary and hence the final version settled on depicting only the lungs with the hands underneath.

Pictogram 2: CCW and patient

In order to have an image that captures the role of CCWs, an illustration showing a care giver counselling a patient on how to use medication was developed.

Pictogram 3: Bacteria

In an effort to promote the understanding of the causative agent of TB, a pictogram showing an enlarged group of bacteria was designed. A choice had to be made between depicting bacteria with a smooth, uniform cell wall versus a more irregular outline. The latter was selected as it more closely represented the actual shape of a TB bacterium.

Pictogram 4: Coughing with droplet spread

This pictogram illustrates droplet spread to nearby people when coughing.

Pictogram 5: Sneezing

The act of sneezing also results in the dispersion of droplets. The first version, showing an upwards extended neck while sneezing, was modified by having the neck in a more normal position and emphasising directionality of the droplets using lines.

Pictogram 6: Spitting

Spitting is one of the factors that was commonly mentioned by CCWs to be a concern in the spread of TB. Earlier versions of this pictogram tried to demonstrate how spitting can cause droplet spread; hence another person was placed near the spitting man. This latter image was removed to avoid the pictogram being interpreted as coughing or vomiting on the other person. The image of sputum content was also modified by using projected lines to show it being deposited on the ground.

Pictogram 7-10: Hugging, handshake, sharing the toilet and sharing food

These four pictograms were designed to address the misconceptions surrounding the spread of TB. For pictograms 7, 8 and 10, photographs were used as a template for pictogram design. The food content on the plate in pictogram 10 was altered several times to reflect a more realistic representation. Pictogram 9 was designed from a sketch to show a number of people lining up to use the same toilet.

Pictogram 11: Safe cough

In the past, HCPs often advised TB patients when coughing to use a hand or a tissue to reduce the spread of TB. However, using the arm or elbow is now widely recommended as a much safer way to reduce droplet spread of TB when coughing. Safe cough practice is illustrated by the pictogram.

Pictogram 12: Open windows

CCWs stressed that opening windows to prevent TB was one of things they advised patients to do, especially those living in overcrowded houses. This pictogram was designed to emphasise the importance of this practice. A tree was added outside the window in the second version to suggest the window opening to the outdoors and fresh air. A landscape view was later added outside the window to make it more realistic.

Pictogram 13: Wearing a mask

Feedback from key HCPs involved in TB management stressed the need for CCWs to wear masks when interacting with TB patients to protect themselves from getting TB. This pictogram was designed from a posed photograph. .

Pictogram 14: Anyone can get TB

TB is a stigmatised condition and it is often perceived that ‘certain’ groups of people normally get TB (189). CCWs advised us to stress the idea that anyone can get TB, and this pictogram attempts to illustrate this.

Pictogram 15: Coughing for two weeks or longer

The passage of a specific period of time is a challenging concept to communicate to limited literacy patients. This was addressed by using a previously designed ‘cough’ pictogram and including a calendar highlighting a two week period.

Pictogram 16: Sweating at night

This symptom of TB was shown using a man wiping his sweat with a cloth. The upper body image reflected an emaciated state, with the final version including the droplets of sweat for additional clarity.

Pictogram 17: Lack of appetite

This is a difficult concept to communicate visually. The approach taken was to try to illustrate a dislike for and subsequent rejection of food. A photograph guided the design of body positioning. The food content of the plate was modified as for pictogram 10.

Pictogram 18: Coughing up blood

To demonstrate this symptom of TB, the first version showed an individual coughing into a bowl, with the bowl contents shaded to indicate blood. However this was assumed to reflect vomiting. Large, shaded droplets were included in the final version to try to emphasise the presence of blood.

Pictogram 19: Nausea

Nausea was illustrated from a photograph. The width of the neck seen in the first version was reduced in the final version.

Pictogram 20: Sputum bottle

A photograph of a locally used sputum bottle informed the design of the image. The final version shows a clear bottle with a label on which the patient's name is recorded.

Pictogram 21: Sputum collection sequence

We were asked by the CCWs to illustrate the correct way of collecting a sputum sample, as they often encountered problems with this process. This was conceptualised as a three step process showing the main steps involved in collecting a sputum sample. Adjustments to body position and body shape were made, with the final pictograms clearly showing the sample of sputum entering the bottle.

Pictogram 22: With or without food

Patients are usually told to only take TB medicines with food, despite the fact that they can be taken with or without food. This pictogram was designed to address this issue. A bowl of food

with a spoon was modified a number of times. The final version shows the same type of food as pictograms 10 and 18.

Pictogram 23: Orange urine

This side effect is almost impossible to illustrate without the use of colour. The approach taken was to show a man urinating into a container. It took a few versions to capture an acceptable body position and trajectory of the urine. The urine in the bowl was shaded to suggest a darker colour than normal.

Pictogram 24: Hearing problems

Difficulty with hearing is difficult to communicate visually. To indicate impaired hearing, it was decided to show a person adopting a common posture when wanting others to speak louder i.e. cupping the ear with the hand.

Pictogram 25: Confusion

The presence of confusion is an extremely abstract and difficult concept to represent with an image intended for limited literacy viewers. We eventually integrated two ideas: scratching the head and including question marks. The first version was interpreted as a man having an itchy head, hence the question marks were added in the second version. The positioning, number and design of the question marks altered until a satisfactory version was achieved.

Pictogram 26: Yellowing of the eyes

Yellowing of the eyes was another challenging side effect to illustrate. A comparative before-after strategy was adopted to visually show a contrast between clear eyes and yellow eyes by shading the affected eyes with grey shading.

3.9.3 Format and layout of the booklet

The booklet was A5 in size and double-sided in accordance with CCW choices. It consisted of 17 pages with the title page followed by a contents page to allow for easier navigation of the booklet. Pages all had a heading for each section which was highlighted in bold. Each section had minimal text which made it easy to read, with some of the sections using bullets to present a number of points. Important information was emphasised by placing text in a shaded text box which made it clearly visible. The text was simple and avoided the use of medical jargon to

ensure words would be understood. The booklet was translated into isiXhosa and Afrikaans using professional translators, and back-translated by a different language expert.

3.9.4. Information session with CCWs to distribute booklet

This was conducted in January and February 2015. Once the booklet had been finalised, an information session was held with each of the CCWs interviewed in Phase 1. However, any new CCWs interested in using the booklet were invited to attend the session as observers. The information session began with handing each CCW a booklet in their preferred language (Appendix 8 – Afrikaans and isiXhosa versions available on request). The researcher systematically worked through each section of the booklet, explaining each topic and encouraging comments, questions or feedback. Booklets were also distributed to facility managers. The CCWs were encouraged to use the booklets in their daily practice with TB patients and were reminded about the follow-up interview after three months. The information session took about 20 minutes.

3.10 Phase 3: Qualitative and quantitative follow-up data collection

3.10.1 Quantitative: Follow-up TB knowledge test

Three months after completion of Phase 2, individual follow-up interviews were conducted with all CCWs using the same questionnaire to assess TB knowledge. This was conducted in each of the facilities by the researcher. Each interview was audio recorded and lasted for 20 to 30 minutes.

3.10.2 Qualitative: CCW perception of the usefulness of the booklet

Qualitative discussions were held in each facility with the aid of a question guide (Appendix 4). These sessions were conducted in a closed room in each of the facilities similar to Phase 1. Questions were asked by the researcher, and an observer was present to observe and take notes. Each session lasted between 30 and 45 minutes and was audiotaped. Discussions began with trying to establish the extent to which the CCWs had used the booklet in their interactions with patients. The discussions covered perceptions of the booklet, feedback after using it in practice, how patients or other community members reacted to the booklet, and the overall impression

of the CCWs relating to the research study. Sampling of CCWs who were involved in these sessions was done until data saturation was reached, resulting in a total of 19 CCWs.

After the discussions and interviews were completed, an A3 size poster (Appendix 9) was designed, informed by CCW input on the most important topics to include. These topics were transmission of TB, prevention, signs and symptoms, TB and HIV/AIDS co-infection and misconceptions regarding the spread of TB. The posters were made available in English (Appendix 9A), isiXhosa (Appendix 9B) and Afrikaans (Appendix 9C) and were distributed to all seven facilities for placement in strategic areas where they had high visibility to patients. During the distribution of the posters, CCWs were also thanked for their participation in the study and additional booklets were provided on request.

3.11 Data analysis

3.11.1 Qualitative data analysis

Thematic analysis is defined as a method of identifying, analysing and reporting patterns also known as themes within the data (200). Qualitative data were analysed thematically as follows:

Step 1: Transcription and familiarisation with the data

Data were transcribed verbatim from the audio-taped discussions by the researcher, which helped ensure familiarity with the data. The transcripts were then checked against the audio-recordings to ensure they were accurate and no errors were made. A few phrases and comments made in isiXhosa or Afrikaans by the participants were translated. The transcripts and notes collected during interviews were read up to three times to allow for understanding of the data and initial ideas were noted.

Step 2: Development of codes

Codes were developed and applied to relevant segments of the data based on key words and recurrent issues that arose from the data itself. During this process, some data segments were coded repeatedly, uncoded or sometimes coded once, changed and combined. This step helped organise the data into segments based on the codes generated. NVivo 10[®] software was used to aid this process by organising text in the relevant codes. Coding was done independently by two researchers who later met to compare and discuss any disparities.

Step 3: Identifying themes

Once all the text was coded, themes and sub-themes were identified from the coded data segments. This was done by going through the text segments in each code and extracting common and significant themes.

Step 4: Defining and naming themes

The selected themes were reviewed and refined to ensure that they were both specific enough yet adequately broad to include all ideas contained in the data segments. Afterwards, clear definitions and names were decided for each theme and the names were checked to ensure they were an accurate reflection of the entire data set.

Step 5: Final description

Themes and examples of quotes which captured the points generated were placed within a narrative to provide a rich description of the research findings.

3.11.2 Quantitative data analysis

Data were analysed using the software programme SPSS. Initial data analysis was performed by generating frequency tables for all data and calculating baseline and follow-up percentage scores for the knowledge test both at baseline and follow-up. The difference in the knowledge scores between baseline and follow-up were investigated using the Paired T-Test for comparison of means, Pearson Chi-square test of association and a Z-test of proportions. The relationship of selected variables (age, education, years as a CCW, TB workshop attendance in the last year) with knowledge scores, both at baseline and follow-up, was investigated using T-Tests for equality of means. Statistical significance for all tests was set at 5%.

CHAPTER 4

RESULTS

This chapter reports the findings at each phase of the study, starting with a qualitative description of the information needs of CCWs. Results from the TB knowledge test both at baseline and follow-up are then presented to evaluate the effect of the booklet on CCW knowledge. Finally, findings obtained from discussions and interviews with the CCWs related to their use and acceptability of the booklet, are presented.

4.1 Demographics of all CCWs

A total of 31 CCWs participated in the study.

Table 4.1: Demographic characteristics of CCWs, n = 31

Demographics	Total n (%)
Gender	
Male	3 (9.7)
Female	28 (90.3)
Age (years)	
≤ 35	14 (45.2)
≥ 36	17 (54.8)
Mean ± SD	38 ± 7.71
Years of schooling	
10 - 11	15 (48.4)
12	16 (51.6)
Mean ± SD	11 ± 0.79
Type of CCW	
Lay counsellor	4 (12.9)
DOT supporter	8 (25.8)
Home-based carer	13 (41.9)
General care workers	6 (19.4)
Years as a CCW	
0 - 3	8 (25.8)
≥ 4	23 (74.2)
Language preference in reading	
IsiXhosa	6 (19.4)
English	24 (77.4)
Afrikaans	1 (3.2)
TB workshop in the last 12 months	
Yes	16 (51.6)
No	15 (48.4)

Table 4.1 shows the characteristics of CCWs in the study, all of whom participated in both baseline and follow-up stages. All but three of the participants were female (90.3%) and most have been working as CCWs for more than four years. Home-based carers formed the main group of CCWs (41.9%), with a quarter (25.8%) being DOT supporters. All the CCWs had a good understanding of English with 77.4% reading English in preference to isiXhosa, their home language, or Afrikaans.

The number of CCWs recruited per facility ranged from one to seven (Table 4.2).

Table 4.2: Number of CCWs recruited in Grahamstown Hospice and six PHC clinics

Facility	Number of CCWs
Grahamstown Hospice	6
Raglan Road Clinic	7
Middle Terrace Clinic	6
Tantyi Clinic	4
Extension 7 Clinic	4
Settler's Day Hospital	3
Town Clinic	1

4.2 Phase 1: CCW perceptions of their roles in TB care and their information needs

4.2.1 Demographics

Fourteen CCWs participated in the first phase of the study (Table 4.3). The majority of CCWs were female and between 30 and 50 years of age (mean age = 42±6). Of the 14 CCWs, 10 had completed high school education and 10 had been working as CCWs for five years or more.

Table 4.3: Demographic characteristics of CCWs in Phase 1

Participant number	Gender	Age (years)	Education (years)	CCW experience (years)	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

4.2.2 Themes from findings

Three major themes emerged from qualitative 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.

4.2.2.1 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....” (Participant 7, FGD 1).

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” (Participant 5, FGD 1).

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 volunteer at a clinic” (Participant 3, FGD 1).

Others said 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.

4.2.2.2 Perception of the CCW role as a fulfilling one

CCWs identified their main role in the healthcare system as the link between patients, community members and the healthcare centres that serve them. An additional aspect of their work that emerged was their involvement in activities that uplifted and sustained the community. 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” (Participant 11, SSI 2).

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

“I wrote great. I feel great because I manage to help a lot of people with TB” (Participant 7, FGD 1).

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

4.2.2.3 Identification of needs to improve training and skill

There was a diversity of responses pertaining to the 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” (Participant 14, SSI 3).

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?” (Participant 10, SSI 2).

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” (Participant 9, SSI 1).

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 etc. for TB.... So I need more information to give education, to empower the people outside” (Participant 13, SSI 3).

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 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 [you] show some pictures because when you talking sometimes they [patients] don’t understand what you are talking about” (Participant 8, FGD 1).

4.3 Phases 1 and 3: Training and TB knowledge of CCWs

4.3.1 Training of CCWs

Table 4.4 shows the responses received in terms of sources of training, courses done and training location. The four organisations responsible for training included the Department of Health via the local District Health Office, the NGO TB Care Society, St John's Ambulance, an accredited provider of first aid training, and Grahamstown Hospice. Some of the CCWs were trained with more than one of these institutions depending on where they first started working e.g. some of the Hospice CCWs were first trained by the Department of Health while working in the PHC clinics and were later trained by Hospice when they moved there.

Table 4.4: Details of CCW training, n = 31

CCW Training	Total n (%)
Training facility	
Department of Health	14 (45.1)
TB Care Society	6 (19.4)
St John's Ambulance	9 (29.0)
Grahamstown Hospice	5 (16.1)
Courses	
Home-based care	12 (38.7)
First Aid course	4 (12.9)
TB	10 (32.3)
HIV training	2 (6.5)
Palliative care	2 (6.5)
Nutrition	3 (9.7)
Counselling	4 (12.9)
Breastfeeding	1 (3.2)
Training location	
Themba TB hospital	3 (9.7)
Grahamstown Hospice	5 (16.1)
Settler's Hospital	2 (6.5)
Fort England hospital	1 (3.2)

The hospitals based in Grahamstown and the District Health Office seemed to be the location of most of the training. Considering that the majority of the CCWs were home-based carers, this was the course that most of them had attended. Each CCW seemed to have experienced different courses, and it proved almost impossible to identify a standardised course for CCWs.

4.3.2 Health literacy assessment

Table 4.5 displays the frequency of correct responses to all questions from the NVS-SA.

Table 4.5: Frequency of correct responses to NVS-SA, n = 31

NVS-SA questions	Total n (%)
1. Are the pilchards plain or is there a flavour?	21 (67.7)
2. If you eat 200 g how much of the tin will you eat?	18 (58.1)
3. Which will give you more protein: eating the 3 slices of bread (6 g protein) or eating some pilchards?	27 (87.1)
4. Pretend that you are allergic to the following substances: penicillin, milk and gluten. Is it safe for you to eat this food?	16 (51.6)
5. If you eat the whole can of pilchards, how many grams of carbohydrate will you eat?	4 (12.9)
6. Pretend that you have a problem with your blood pressure or heart. According to the label how would you know if this food is good for you?	5 (16.1)

Questions 1, 4 and 5 required participants to locate information on the label in order to correctly answer the questions. Although question 1 and 4 were well answered, CCWs had difficulty locating the information pertaining to the Heart and Stroke Foundation, making question 6 one of the most poorly answered questions. Questions 2, 3 and 5, which required some form of calculation, varied widely in correct responses, with question 5 being the most poorly answered of all six questions (12.9%).

Most CCWs achieved marginal health literacy scores (58.1%). Only three managed to achieve a rating indicating adequate health literacy (Table 4.6). The mean literacy score was 2.94 out of a total of 6.

Table 4.6: Mean literacy score for NVS-SA and medicine literacy categories, n = 31

	Total n (%)
Medicine literacy categories	
Inadequate health literacy (0-2)	10 (32.3)
Marginal health literacy (3-4)	18 (58.1)
Adequate health literacy (5-6)	3 (9.7)
Literacy Scores	
Mean $\pm$ SD	2.94 $\pm$ 1.34
Total % score	48.9%

4.3.3 TB Knowledge at baseline and follow-up

The 35 knowledge questions were divided into five knowledge areas: disease, TB and HIV co-infection, TB treatment, MDR and XDR-TB and side effects of TB medicines. Of the 35 questions, significant increases in the knowledge score between baseline and follow-up were observed for eight questions. The range of correct responses for the individual questions was from 3.2% to 100%.

4.3.3.1 Disease

At baseline, 17 CCWs (54.8%) identified a bacterium as the causative organism of TB, whereas at follow-up only two CCWs were unable to respond (Table 4.7). The two who did not get the correct answer offered responses that included TB being caused by the sputum, smoking, the air, the cold or they were not sure. All the respondents knew that TB was infectious and only one did not know that transmission was via airborne droplets containing the TB bacilli.

Knowledge of preventative measures increased significantly from 71.0% at baseline to 96.8% at follow-up ($p=0.008$). Poor knowledge of the availability of a BCG vaccine did not change from baseline to follow-up, possibly due to this information not being included in the booklet. After using the booklet, all CCWs were able to correctly state that TB mostly affects lungs and could indicate at least three or more signs and symptoms of TB, with only one not knowing that sputum testing is used to diagnose TB.

Table 4.7: Frequency of correct responses to individual knowledge questions, n = 31

Questions	Baseline (n = 31)	Follow-up (n =31)	p-value
Disease			
Cause of TB	17 (54.8)	29 (93.5)	0.000 ^a
Mode of transmission	31 (100)	31 (100)	-
Transmission occurs via air droplets	30 (96.8)	30 (96.8)	1.000
Transmission occurs via sharing food	27 (87.1)	29 (93.5)	0.687
Transmission via breathing in air after a TB-infected person coughs	31 (100)	31 (100)	-
Transmission can occur sexually	28 (90.3)	30 (96.8)	0.500
Prevention of TB	22 (71.0)	30 (96.8)	0.008 ^a
Availability of a vaccine	20 (64.5)	20 (64.5)	1.000
Lungs mostly affected by TB	30 (96.8)	31 (100)	0.396
Signs and symptoms of TB	29 (93.5)	31 (100)	0.236
Diagnosis of TB	28 (90.3)	30 (96.8)	0.500
TB and HIV/AIDS			
HIV/AIDS patients more easily infected with TB	31 (100)	31 (100)	-
All HIV/AIDS patients have TB	27 (87.1)	31 (100)	0.075
TB can be cured in HIV/AIDS patients	31 (100)	31 (100)	-
Treatment			
TB is curable	31 (100)	31 (100)	-
Not all patients with TB get cured	17 (54.8)	27 (87.1)	0.002 ^a
Cure rate of TB in Eastern Cape	2 (6.4)	1 (3.2)	1.000
Duration of treatment	31 (100)	31 (100)	-
Information that patients should tell the doctor	2 (6.5)	1 (3.2)	1.000
Advice for taking TB medicines and other medication	5 (16.1)	8 (25.8)	0.508
TB medicines and food	19 (61.3)	25 (80.6)	0.031 ^a
Avoiding alcohol and smoking while on TB meds	26 (83.9)	27 (87.1)	1.000
Advice for patients with difficulty swallowing tablets	28 (90.3)	30 (96.8)	0.500
Forgetting treatment	22 (71.0)	29 (93.5)	0.039 ^a
Stopping treatment	31 (100)	31 (100)	-
MDR- and XDR-TB			
Meaning of MDR-TB	25 (80.6)	25 (80.6)	1.000
Meaning of XDR-TB	11 (35.5)	12 (38.7)	1.000
Cause of MDR or XDR-TB	28 (90.3)	30 (96.8)	0.500
MDR-TB is curable	30 (96.8)	30 (96.8)	1.000
XDR-TB is curable	25 (80.6)	25 (80.6)	1.000
Same treatment for TB and drug-resistant TB	23 (74.2)	30 (96.8)	0.016 ^a
Treatment duration for MDR or XDR-TB	17 (54.8)	23 (74.2)	0.109
Side effects			
Meaning of side effects	19 (61.3)	26 (83.9)	0.016 ^a
Side effects of TB medicines	15 (48.4)	19 (61.3)	0.424
Advice for patients experiencing side effects	25 (80.6)	31 (100)	0.015 ^a

^aSignificant difference between baseline and follow-up

Based on an earlier TB knowledge project conducted in lay people from the same community as the CCWs (189), it was decided to replicate the seven questions on possible modes of transmission to test CCW knowledge. However, when calculating the total knowledge score, only three options were included. Responses to all seven questions on transmission of TB are shown in Table 4.8. Knowledge improved at follow up for all but one question, although these increases were not significant. The incorrect belief that TB can be transmitted by shaking hands with someone who has TB was the only question that did not improve on follow-up and was due to the idea that coughing into a hand and then shaking hands without washing could spread TB.

Table 4.8: Correct responses about transmission of TB, n = 31

Modes of transmission	Baseline (n=31)	Follow-up (n=31)	p-value^a
Shaking hands	26 (83.9)	25 (80.6)	1.000
Sharing food ^b	27 (87.1)	29 (93.5)	0.687
Breathing the air ^b	31 (100)	31 (100)	-
Sharing clothes	28 (90.3)	30 (96.8)	0.500
Using the same toilet	29 (93.5)	31 (100)	0.236
Using the same towel	26 (83.9)	30 (96.8)	0.125
Having sex ^b	28 (90.3)	30 (100)	0.500

^aSignificance of difference (p<0.05) between baseline and follow-up

^bQuestions contributing to total knowledge score.

4.3.3.2 TB and HIV/AIDS

Questions in this knowledge area were well answered, with all CCWs correctly identifying lowered immunity in HIV/AIDS patients as enhancing susceptibility to TB infection, and that TB can be cured in HIV/AIDS patients. Only 4 (12.9%) incorrectly stated at baseline that all who have TB also have HIV/AIDS, although none reported this at follow-up.

4.3.3.3 Treatment

Three questions in this knowledge area were answered correctly by all CCWs; whether TB can be cured, duration of treatment of first-line TB medication and when patients can stop taking TB medicines (Table 4.7).

At baseline, just over half (54.8%) acknowledged that not all patients who had TB would be cured, mainly due to non-adherence, whereas at follow-up this improved significantly to 87.1% (p=0.002). Only one CCW knew that the cure rate in the Eastern Cape was 65%, with some thinking it was as high as 95% or as low as 5%, and many simply did not know.

One of the most poorly answered questions addressed important information that patients should ideally mention to their HCPs, e.g. allergies, HIV status or medication history. Only one CCW was able to identify more than two of these aspects. Suggestions included telling HCPs about their contacts or people they lived with, and whether these contacts had been tested and treated.

A similarly poor response was received when asking what patients should do if taking other medicines; only five at baseline and eight at follow-up responded that patients should tell their HCPs if taking other medicines. TB medication and food was a controversial topic as CCWs from different facilities advised patients differently. At baseline 12 (38.7%) of the CCWs incorrectly mentioned that TB medication could not be taken on an empty stomach. After addressing this in the booklet, the number answering correctly significantly increased from 19 to 25 CCWs ($p=0.031$).

At follow-up most CCWs (87.1%) knew that TB patients should avoid alcohol and smoking while on treatment, and all but one CCW could correctly advise patients who were experiencing problems swallowing the large TB tablets. Just below three quarters (71.0%) were able to advise patients on what to do if they forgot to take their treatment, which significantly improved at follow-up ($p=0.039$).

4.3.3.4 MDR and XDR-TB

This was one of the knowledge areas that CCWs particularly requested for inclusion in the booklet. The meaning of the MDR-TB acronym was much more commonly known (80.6%) than that of XDR-TB (35.5%), with the latter only increasing by one CCW at follow-up. Although knowledge relating to the curability of drug-resistant TB did not change from baseline to follow-up, more CCWs knew the cause of drug-resistant TB at follow-up.

Differences in the medicines used to treat drug-resistant TB versus those for first-line TB were acknowledged by 74.2% at baseline, increasing significantly to 96.8% after the intervention ($p=0.016$). Slightly over half (54.8%) knew that the duration of treatment of drug-resistant TB was longer than six months, but this improved to 74.2% at follow-up.

4.3.3.5 Side effects

Baseline knowledge revealed that 19 (61.3%) CCWs knew what a side effect was. This improved significantly at follow-up to 83.9% ($p=0.016$). Less than half of the participants (48.4%) could mention at least three side effects caused by TB medicines, and this appeared to be based only on what they had encountered when interacting with patients. After the intervention, a higher number of CCWs (61.3%) could list the side effects of TB medicines.

The last question in this knowledge area was designed to determine whether CCWs could correctly advise patients about what to do if they encountered any side effects. At baseline, the majority (80.6%) were able to answer correctly, with this significantly increasing to include all CCWs at follow-up ($p=0.015$).

4.3.3.6 Overall knowledge scores

The mean knowledge score for all 33 questions, as well as scores for each of the five knowledge areas, are shown in Table 4.9. At baseline, the overall mean percentage knowledge was 76.1% which increased significantly at follow-up to 85.4% ($p=0.048$). Knowledge was highest on TB and HIV/AIDS co-infection whereas TB medication knowledge was the most poorly answered for both phases.

Each of these knowledge areas, apart from side effects, showed a significant improvement at follow-up. The side effects category showed an 18.3% increase in the score, however the statistical significance could not be assessed due to the similarity in the standard deviation value at baseline and follow-up (Table 4.9).

Table 4.9: Mean percentage score for knowledge areas, $n = 31$

Category	Baseline	Follow-up	p-value
Disease	85.9	94.4	0.001 ^a
HIV/AIDS and TB	95.7	100.0	0.043 ^a
Treatment	62.2	70.4	<0.001 ^a
MDR and XDR-TB	73.3	80.6	0.040 ^a
Side effects	63.4	81.7	- - ^b
Overall % knowledge score	76.1	85.4	0.048 ^a
Overall knowledge score (mean $\pm$ SD)	26.3 $\pm$ 3.0	29.2 $\pm$ 2.0	

^aSignificant difference ($p<0.05$) between baseline and follow-up

^bSignificance of the scores between baseline and follow-up could not be assessed as the standard deviation values were the same.

The total individual knowledge scores of the CCWs were grouped into four categories (Table 4.10). The three who achieved a ‘poor’ knowledge score at baseline improved at follow-up. A large increase occurred in the number of CCWs who achieved a ‘good’ score from baseline (48.4%) to follow-up (83.9%). Although only five of the 31 CCWs did not achieve a ‘good’ score at follow-up, three CCWs managed to achieve an ‘excellent’ score ($\geq 90\%$) after the intervention.

Table 4.10: Categories of knowledge score at baseline and follow-up, n = 31

Knowledge score	Baseline	Follow-up
Excellent ($\geq 90\%$)	0	3 (9.7)
Good (76 - 89%)	15 (48.4)	23 (74.1)
Moderate (61 - 75%)	13 (41.9)	5 (16.1)
Poor ($\leq 60\%$)	3 (9.7)	0

4.3.3.7 Effect of variables on knowledge

As there were only three male CCWs, gender effect was not investigated. The knowledge score was not affected by age or education at both baseline and follow-up (Table 4.11).

Table 4.11: Effect of variables on mean knowledge score, n = 31

Variables	Baseline	Follow-up
Age group (years)		
≤ 35	25.4 $\pm$ 2.2	29.0 $\pm$ 2.2
≥ 36	26.9 $\pm$ 3.5	29.3 $\pm$ 1.8
	p=0.147 ^a	p=0.695 ^a
Education		
Grade 10 - 11	26.5 $\pm$ 2.6	28.9 $\pm$ 2.2
Grade 12	26.1 $\pm$ 3.4	29.4 $\pm$ 1.8
	p=0.711 ^a	p=0.436 ^a
TB training in the last year		
Yes	26.7 $\pm$ 3.2	29.4 $\pm$ 1.5
No	25.8 $\pm$ 2.7	28.9 $\pm$ 2.4
	p=0.415 ^a	p=0.441 ^a
Years as a CCW		
0 - 3	25.3 $\pm$ 3.5	29.3 $\pm$ 1.5
≥ 4	26.6 $\pm$ 2.8	29.1 $\pm$ 2.2
	p=0.343 ^a	p=0.865 ^a

^aSignificance of difference (p<0.05)

Attendance of training courses over the past year had no significant effect on the knowledge score, and neither did the length of time working as a CCW in the healthcare system (Table 4.11).

4.4 Phase 3: CCW perception of the usefulness of the booklet

4.4.1 Demographics

The numbers of CCWs involved in either a FGD or a SSI are shown in Table 4.12.

Table 4.12: Post-intervention FGDs and SSIs held at Grahamstown Hospice and PHC clinics

Facility	FGD or SSI	Number of CCWs
Grahamstown Hospice	FGD	5
Raglan Road Clinic	FGD	5
Extension 7 Clinic	FGD	4
Tantyi Clinic	SSI	1
Middle Terrace Clinic	SSI	2
Town Clinic	SSI	1
Settler's Day Hospital	SSI	1

Nineteen of the 31 CCWs participated in the Phase 3 FGDs (3) and SSIs (4). Apart from Participants 4 and 14, all had participated in Phase 1 and Phase 2. These two CCWs had not been involved in either phase of the knowledge test, but because they had been present when the booklet was distributed after the baseline interview, they had used it in their practice for the entire three month period and were therefore included (Table 4.13).

Table 4.13: Characteristics of CCWs in Phase 3

Participant number	Gender	Age (years)	Education (years)	CCW experience (years)	Institution
1	F	43	11	13	Public sector
2	F	46	11	22	Public sector
3	M	34	12	1	Public sector
4	M	23	12	5 months	Public sector
5	F	40	12	10	Public sector
6	F	42	12	14	Public sector
7	F	35	11	10	Public sector
8	F	54	10	11	Public sector
9	F	33	11	8	Public sector
10	F	31	10	11	Public sector
11	F	28	10	1	Public sector
12	F	49	12	11	Hospice
13	F	40	12	5	Hospice
14	F	32	12	1	Hospice
15	F	47	11	19	Hospice
16	F	41	12	3	Hospice
17	F	34	10	13	Public sector
18	F	35	12	10	Public sector
19	F	45	12	8	Public sector

4.4.2 Themes from findings

Discussions with CCWs revealed four themes: the impact of the booklet on CCW practice, limited use of the booklet, acceptability and understandability of the booklet and the benefit of additional information materials.

4.4.2.1 Impact of the booklet on CCW practice

CCWs attested to using the booklet in different ways for facilitating patient counselling and education. Some preferred reading the booklet themselves and then using the information as a guide during counselling, especially for new TB patients who require more guidance.

“When I talk to the patients....I use that point I get....from the booklet and then I go to do education and then some of the things I took from the booklet for the patient...that booklet guides you to what you can tell the new patients ...some new patient[s] doesn't understand TB.”

(Participant 18, SSI 3)

Others would have the booklet close by while educating patients so that they could refer to it if they needed to verify information and to assist in answering any questions.

“It is rather when you are doing the education.....I like to open this book and then peruse and then give them the information that I have forgotten.” (Participant 6, FGD 2)

Other CCWs mentioned showing the booklet to the individuals they were educating, especially if it was in a setting such as house visits or support groups where everyone would have a chance to see the book. Once the CCWs had read and were familiar with booklet, they would explain the topic areas in the booklet to patients.

“The first time ...I took it and I read, I read and then I was so interested then I show the clients here in front [patients sitting in the waiting areas of the clinic] what we have when I educate them about TB.” (Participant 19, SSI 4)

CCWs such as lay counsellors or home-based carers who were not as involved in TB as the DOT supporters, reported that the topics which had the most impact included the different ways of spreading TB, and safe coughing practice, as they appreciated how safe coughing practice was clearly illustrated in the booklet. They also valued the reminder that they as healthcare workers would also need to protect themselves when in contact with TB patients.

“When I read this book it actually taught me a lot of things...that you need to cover your mouth in order for the germs not to go out. If you are a person with TB you don’t just spit wherever you may please.” (Participant 4, FGD 1)

CCWs found the booklet extremely useful as a screening tool to remember which signs and symptoms to look out for, and to refer those in need of testing to the clinic.

“I am not visiting the patient all the time but for me it’s easy now to see the signs, like if I’ve noticed that the child is coughing a lot and losing weight. I write a letter to the mother or the granny to take the child for TB screening.” (Participant 16, FGD 3)

The pictograms included in the booklet assisted CCWs in reinforcing the importance of adherence. They reported that showing pictures of someone who appeared to be emaciated and frail as a result of non-adherence would be useful in encouraging adherence to avoid a similar outcome. Not only did the pictograms assist in counselling patients, but they also facilitated memory recall.

“I told him [patient] he will become like this [pictogram of ailing patient on the bed] if you don’t take your medicine....you will be skinny like that person ... just for the defaulter. I want to scare him.” (Participant 12, FGD 3)

“It helped because I like the pictures, I read then I see in the pictures and I remember.” (Participant 17, SSI 2)

Because CCWs are required to give daily health education talks at the clinic, they reported that patients often complained of being tired of listening to health talks when they were feeling ill. CCWs therefore appreciated the booklet which could be handed to patients to read at their own pace. It also relieved them of the pressure of talking for long periods and allowed them more time to spend on other tasks.

“Every morning you supposed to do talks [health talks at the clinic]. Sometimes they say you are talking too much, I am sick.” (Participant 1, FGD 1)

“Yeah, it give me a short timeBecause I gave them while they were waiting [rather] than talk and talk and talkthey read and read. Then when I have the time I go there and ask some questions from the booklet...they raise their hands and answer without looking.” (Participant 19, SSI 4)

4.4.2.2 Limited use of the booklet

Some CCWs reported that the booklet did not improve their knowledge or impact on their practice as it was similar to what they were already telling patients, resulting in limited use of the booklet. This was mostly echoed by the DOT supporters in the study.

“I haven’t been using it very much because the knowledge that I’ve got is the same knowledge that is being given from the booklet.” (Participant 3, FGD 1)

During the three month period during which CCWs were requested to use the booklet in practice, new CCWs were employed in all the facilities. The District Health Office was also in the process of an extensive training programme for both new and existing CCWs. Limited use of the booklet was therefore also attributed to their absence from patient care. However they acknowledged that the booklet was a useful information source.

“There is another [training] programme that we are dealing with. That is why we didn’t get a chance to read it but it’s not a waste to us... Then when you’ve got a chance you going to take it and go further with it.” (Participant 5, FGD 2)

4.4.2.3 Acceptability and understandability of the booklet

CCWs reported that the booklet information was simple and easy to understand, which benefitted both them and the patients. During educating and counselling, patients and community members were able to understand the information and liked it to such an extent that they wanted to keep the booklet for themselves.

“They [patients] got a good understanding of what is happening there..... They said, ‘we going to keep this [booklet]’ ” (Participant 12, FGD 3)

CCWs acknowledged that the illustrated booklet with its attractive images made the educating process more meaningful, with patients displaying more interest and eagerness to hear what was being said. This resulted in improved interactions between patients and CCWs.

“It actually shows pictures in which people can prevent the spread of TB so with the pictures and us explaining to them the actual way of doing it, it’s very easy to interact with people in that way.” (Participant 4, FGD 1)

One of the CCWs in charge of a children’s support group mentioned that the illustrations made it easy for children to follow what was happening and thus promoted understanding.

“I use this book in a support group, children support group and it’s easy for them to understand because there are pictures. For some of them they can’t read, so while I’m reading they can see what I am talking about. So it was easy for them to understand.” (Participant 16, FGD 3)

The availability of the booklet in different languages further improved understanding of information as patients could be shown the booklet in their home language and could easily follow what was being said.

“You can actually give them the booklet and there is an English booklet and a Xhosa booklet, so if a person can’t read English you can give them the Xhosa booklet so they canknow what we are actually saying to them.” (Participant 16, FGD 3)

One of the issues the CCWs mentioned was the lack of patient trust of the information relayed to them. Patients seemed to trust the written text which they could see as opposed to verbal information from the CCWs. The booklet was thus useful as a means of validating and ensuring a better reception of what the CCW had to say.

“When you are talking to people you must show...what you are talking about I am talking about TB, this is the booklet. What I am saying is written here so that they can agree. Sometimes they don't trust us as CCWs they want to see the realness.” (Participant 19, SSI 4)

Because of the improvement in patient counselling, CCWs felt that using the booklet was exciting and they enjoyed the experience. They appreciated the fact that it had been designed specifically for them, taking into account their needs and opinions, and they felt that it inspired them in their role as educators. They also acknowledged that they would like to keep using the information materials for future practice.

“ Well so far you have done a great job, you have actually inspired us in a way we haven't expected and we would actually like to thank you for coming up with something like this and it was brave of you and it was generous of you and we would like to keep it going not just for now.” (Participant 11, SSI 1)

4.4.2.4 Benefit of additional information materials

As TB patients lack adequate TB knowledge, CCWs felt it would be beneficial for patients to have information materials of a similar design for personal use. This, they felt, would prompt patients to read the information and increase TB knowledge and awareness.

“It can be useful for the patients if you print it because ...we are giving pamphlets to the patients. And they don't have enough information about TB but this book has got enough information.” (Participant 7, FGD 2)

“Sometimes if there are people that are seeing....something in front of them maybe they will read it.” (Participant 5, FGD 2)

CCWs also identified other community groups who would benefit from having information materials such as the booklet. These included teachers in schools and crèches who would find the simple illustrated nature of the booklet beneficial when teaching children.

“It can be useful if you are going to schools. You can leave this booklet to the teachers so the teachers can read it and they can use it.” (Participant 7, FGD 2)

The booklet was recommended as a useful tool for educating the elderly in old age support groups within their communities which are run by supervisors.

“We have got also the old age support groups. How about to give the supervisor there when sometimes they are sitting together and doing sowing then he can give the education of TB also.” (Participant 6, FGD 2)

Few in this community have access to a computer for internet-based searching for information. Therefore the booklet was considered to be a valuable resource for children who receive assignments or any homework focused on researching TB, as it was considered simple enough for them to understand.

“I have noticed that my son was being given task about TB, homework so I have given him this so that he can read then he managed to read. It’s easy to understand even for the children.” (Participant 8, FGD 2)

In the clinic setting, the CCWs suggested that posters containing selected written TB information and pictograms be placed in the patient waiting area. This was advocated as a good idea to assist in patient education, particularly for those patients who missed the health education talks. The poster could also be used during the TB health talk as a useful tool for reference and to help patients visualise what was being said. Specific topics they wanted in the poster included prevention, signs and symptoms, and TB and HIV/AIDS co-infection.

“When we educate the client about TB you need to show the client that there is a poster. If you are still waiting then you can just go around to look while we are doing education.” (Participant 1, FGD 1).

CHAPTER 5

DISCUSSION

The WHO estimates that countries with fewer than 23 healthcare workers per 10,000 population will be unlikely to achieve adequate coverage rates for key PHC interventions (201). Although South African density ratios for healthcare workers (doctors, nurses and midwives) were above this minimal level, maldistribution in favour of urban areas and the private health sector results in a severe deficiency in human health resources within the public health sector that serves 80% of the population. The shortage of resources is particularly apparent in rural areas (79,202). Due to the increasing burden of disease and the under-resourced public health system, CCWs have been seen as a practical solution for strengthening healthcare systems. Insight into personal perceptions by CCWs of their own practice has been lacking, hindering the integration of CCWs into the formal healthcare system at the community level (203).

My study, conducted during the implementation of the PHC re-engineering strategy (2011-2015) in South Africa, contributes to this knowledge and highlights a number of challenges and opportunities to further strengthen the support for these healthcare workers for the benefit of TB patients under the care of CCWs. The study findings support the hypothesis that user-friendly, simple, illustrated information can enhance TB knowledge of CCWs and serve as a tool in facilitating communication and education of patients.

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.

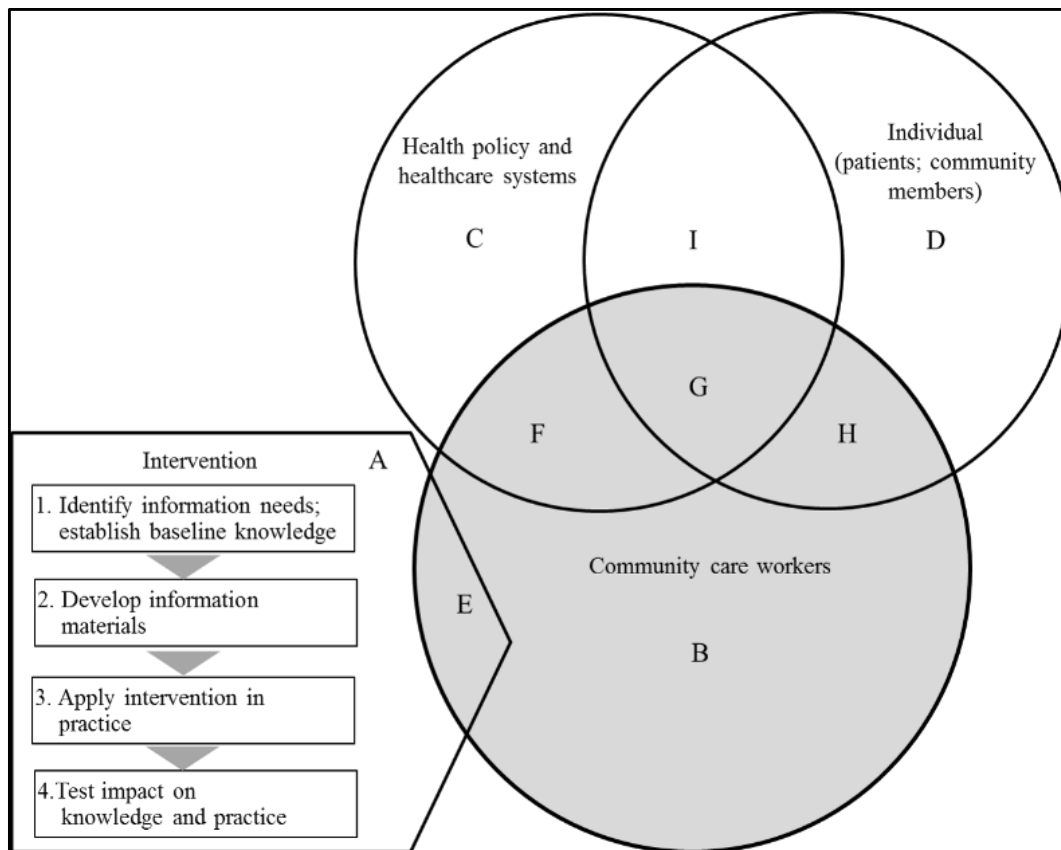


Figure 5.1: Modified conceptual framework for the design and development of an intervention for CCWs

Minor modifications were made to the framework after the study (Figure 5.1). Area B, which in the original model included all healthcare providers, was modified to include CCWs only, the target group for the intervention. In keeping with this alteration, health policy and healthcare systems (area C) refers to broader policies and regulations that regulate the CCW profession. Area D was specified to define individuals who may either be patients or community members coming into contact with CCWs. Patients in the framework are TB patients who regularly interact with CCWs while ‘community members’ describes recipients of health promotion activities provided by CCWs. Findings of my study will therefore be discussed according to the different elements and their interacting areas affected by the intervention.

5.1 Impact of the booklet on CCW knowledge

It is important for front-line CCWs to have adequate TB knowledge corresponding to National TB Management Guidelines to facilitate case finding and appropriate case management, the

two foundations of TB prevention and control (84). CCWs in my study had relatively good TB-related baseline knowledge of 76%. Although this score is higher than those reported in other studies (121,190,204), a direct comparison is limited due to the different measures used to assess knowledge.

CCWs supervising TB patients are often exposed to the risk of infection. It was encouraging that most had good knowledge regarding modes of transmission of TB, as well as its signs and symptoms in order to ensure their own protection, and to present for testing if any symptoms are apparent. However, their misconceptions relating to the cause of TB were concerning, given the integral role that these front-line workers play in communicating information about the disease throughout the community. If these incorrect perceptions mirror those within the local community, they could be a reason for delayed healthcare seeking (121). After use of the booklet, knowledge of the cause of TB significantly improved from 54% to 93%. It was interesting to note the common perception among some of the CCWs that shaking hands could transmit TB due to the lack of hand washing; this did not change at follow up. Although hand washing is generally good practice for infection control, it has limited relevance to TB prevention. CCWs therefore need to be informed on this point (205).

Although TB treatment-related knowledge significantly improved from 62% to 70%, shortcomings in this knowledge area were identified. Given that TB healthcare delivery in South Africa is moving towards task shifting to CCWs, a cadre of workers with limited training and access to evidence-based resources, their low TB treatment-related knowledge may negatively affect their ability to fulfil their roles as patient educators and adherence supporters. It was concerning that in a healthcare system often overwhelmed by patients with multiple conditions (65,70), CCWs were not aware of the valuable advice they could offer to patients taking TB medicines concomitantly with other medication. This has serious implications on their ability to correctly advise such patients.

Knowledge of the cure rate of TB in their own province is essential in helping CCWs contextualise the seriousness of the disease and the potential for a cure. Even after the intervention, CCWs were still unsure of the cure rate. Contextualising the impact of the disease within the goals of the National TB Control Programme helps all healthcare workers understand how crucial their role is in the national effort to control TB. Some CCWs were also unaware that certain TB patients do not get cured. Understanding that TB can only be cured

through adherence to TB medication as prescribed may serve as a motivating factor for CCWs to monitor patient adherence more closely and to focus on encouraging patients to keep taking their medication. Statistics on TB indicators is essential to include in CCW training and may improve their understanding of the burden of disease both locally and internationally.

The two areas of low baseline knowledge in drug-resistant TB were the meaning of XDR-TB (36%) and its treatment duration (55%). Given the increasing incidence of drug-resistant TB (2), inadequate CCW knowledge can have severe consequences. For example, if CCWs fail to identify patients who may have drug-resistant TB and do not refer the patient to the higher levels of healthcare, transmission of drug-resistant TB may increase. As such, XDR-TB knowledge, which only increased to 39% at follow up, and treatment duration, which increased to 74%, should be highlighted as key areas for training and intervention.

Equally, CCWs only achieved a baseline score of 63% of side effects knowledge, with less than half being able to identify side effects that can present with TB medication. Although the intervention did improve understanding of side effects to over 80%, additional education on the identification of side effects is needed, as this only increased to 61%. TB patients want information regarding side effects as they feel it improves their understanding of the medication and reduces the chances of defaulting if they are aware of what to expect when taking the medicines (85,86,90). CCWs therefore require adequate knowledge to fulfil this need.

The booklet developed was successful in improving CCW knowledge about the disease, TB medication, MDR and XDR-TB and HIV/AIDS and TB co-infection. The significant difference in the mean knowledge score shows that the use of the booklet had a positive impact on TB knowledge. Addressing TB-related topics in the booklet consequently can have an impact beyond that of increasing the knowledge of CCWs but can also correct misconceptions in the broader community.

5.2 Design of the booklet

The booklet was designed with careful consideration to readability of textual content, font type and size, page layout and visual content. This is one of the few studies that has developed and tested the impact of pictorial-based booklets on CCW practice. Earlier studies designed materials for malaria and for maternal and child health (29,175) whereas mine is the first study

that has developed materials for TB. My study found that a pictorial-based, simple booklet tailored for CCWs can improve knowledge, enhance confidence in decision making and improve communication with patients, findings which are supported by previous research (27–29,175). However, a key distinguishing aspect of this study is that the information materials were not combined with lengthy training or supervision, but included only a short session of about 20 minutes during which the topics in the booklet were explained to the CCWs.

Although the use of simple text has been advocated for the design of patient information materials (159), study CCWs were also appreciative of the simplicity of the text. This confirms the recommendations of Dowling that designers of information materials for any healthcare worker should consider the use of simple terms to enhance understanding (173). It should be noted that a few of the CCWs in this study reported knowing most of the information in the booklet and thus were of the opinion that the booklet did not offer anything new or impact on their practice. These CCWs had expected the text in the booklet to be pitched at a higher level as opposed to being simple and easy to read. However, incorporating more advanced information would have isolated the majority of the CCWs who were deficient in certain areas. This approach may also have had less of an impact on patient acceptance and understanding.

Paying attention to the information needs of CCWs contributed to the success of the booklet. Including topics that were requested by CCWs and involving them in the design process of the booklet made the end-product more appreciated. Involving CCWs in interventions that affect their practice is crucial to gain their perspective on how interventions can best improve their productivity (206).

Translation of the booklet into isiXhosa and Afrikaans, two of the most commonly used languages in Grahamstown, increased its acceptability and gained favour with patients, CCWs and officers from the District Health Office. Likewise this has been advocated as a way to improve understanding of text for those with limited literacy (188).

The advantages of including pictograms with text has been widely reported (33,34,137,141). CCWs in this study were enthusiastic about the pictograms and felt that they enhanced recall of TB information, an advantage that has been previously described (28,33). Pictograms also made it easier to communicate certain concepts about which study CCWs were uncertain, such as nonadherence and its negative health outcomes. This supports research showing that

pictograms can be useful in promoting patient understanding of complex instructions and concepts (141,157).

Enhanced understanding of text through using pictograms was regarded by participant CCWs as particularly important when communicating with lower literate groups such as children, an opinion supported by other studies (137,199). This was felt by study CCWs to be such an important aspect that they recommended the use of the booklet in early childhood development, schools, elderly homes and in patient education.

Similar to other studies, the reported success of pictograms in this study could be attributed to their design and development (32,34,137). This study employed a rigorous design process involving several modifications before a final version was produced. Attention to local culture, lifestyle and eating habits, as well as ensuring simplicity of pictograms, were all key features in their design. CCWs were canvassed for their opinions prior to finalising the booklet.

5.3 CCWs in the healthcare system

High attrition rates of CCWs in TB programmes have resulted in an increasing call for a better understanding of what motivates individuals to become and remain CCWs (22). Study CCWs were motivated by a genuine concern for others, revealing moving personal experiences which stimulated a drive to help those in need of healthcare. Earlier 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 (207).

Although monetary incentives have been previously noted, and financial support of CCWs advocated (22,207,208), these were not mentioned by the study CCWs as a motivating factor. Instead, responses from study participants revealed intense engagement with and enjoyment in their work. This 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. Other non-monetary incentives such as personal growth and responsibility are linked to job satisfaction (203). Understanding these non-monetary incentives can provide ideas as to which factors, if influenced, will result in greater job satisfaction. It should be noted that the present study did not investigate factors motivating CCWs to remain in the system, but rather focused on their reason for becoming CCWs. Hence,

financial incentives may promote retention as CCWs, but were not a factor for entry into this healthcare role.

Women comprise the majority of care workers in South Africa, which was similar to the profile of CCWs in this study. It has been reported that women face difficult working conditions as they can potentially become victims of violence when moving around households in the community (78,106). It was for this reason that female CCWs in my study reported working in pairs when visiting areas in the community for security purposes. Recent research has moved for the involvement of men in this field which could challenge males' misconceptions regarding gender stereotypes and encourage a change in their health behaviours (106).

5.4 Interaction of the healthcare system and CCW practice

Despite the importance of adequate training of CCWs having long been recognised (24,117), findings in this study revealed a distinct weakness in CCW training, which is supported by other studies (26,117). Inadequate basic training with unacceptable variability in course content and duration stated by participant CCWs have been linked to the lack of co-operation between different training organisations (24). Moreover, the lack of continuous refresher training emphasised by study CCWs, was identified as a crucial component that reportedly results in loss of skills and knowledge (17,26,98,117). The findings were supported by key stakeholders from the District Health Office who confirmed training shortcomings of these healthcare workers. This can result in CCWs being unable to fulfil the changing needs and expectations of patients in an evolving healthcare system. Training and skill development of these workers is crucial to ensure sustainability and relevance of this cadre of healthcare workers in the future (209).

CCWs in this study reported their inability to clarify certain concepts to patients such as difficulty in dealing with excuses given for defaulting, and advising patients about the correct method of sputum collection. CCWs who are trained in certain disease-related aspects may still be confronted with aspects unrelated to the disease, which can challenge their scope of practice (210). This mainly occurs when CCWs act in their additional roles such as advisors, counsellors or health educators as was the case in this study. For this reason, experiential training, possibly in the form of role plays, may familiarise CCWs in dealing with difficult patient scenarios (117). Although not investigated in my study, CCWs, with their limited formal education, are

likely to have information needs differing from those of other healthcare professionals (130), typically requiring materials that contain simpler language with more pictograms to cater for their lower educational status (211).

A determinant of the success of CCW programmes is the availability of regular and reliable support and supervision (98,206). In this study, supervision of CCWs in the outreach team by an experienced professional nurse was well structured. However, facility-based CCWs reported consulting their supervising HCPs only to report challenging cases and for questions they could not answer. A more participatory approach in supervision would help CCWs to identify their challenges, implement solutions and create a good flow of information and communication (206). This was lacking in facility-based CCWs, possibly due to the lack of available time in overburdened facilities for the supervising HCPs to adequately train and support these CCWs.

TB policy and treatment guidelines are constantly being updated, but can be implemented only if all levels of healthcare workers are informed of updates. This was identified as a deficiency by CCWs in this study. Top to bottom verbal communication that occurs in a hierarchical fashion, with CCWs at the lowest level, leaves them either uninformed of new updates or the last health worker to know about new information. Overreliance on oral communication means that information can easily be forgotten; verbal discussions should be supported by follow up printed materials or other tools that support the message (130).

CCWs cited limited sources of available information, identifying a lack of appropriate written materials to support their work. Various authors have identified this deficiency, especially in low-resource healthcare settings (126,128–131). The availability of ‘booklets’ or simply relying on information from training sessions by study CCWs further revealed the lack of tailored materials for this cadre of workers. This fits into the description of other findings that have noted information materials for HCPs as being unavailable, variable in quality, and not well organised (128,212).

The lack of support and supervision, deficiencies in training and lack of information materials indicate a negative interaction between CCWs with health policy and its impact on CCW practice. This may explain the lack of a CCW ‘voice’ and their relative disempowerment within the system, which is often stated as a barrier to CCW programmes (106).

Although empowerment of CCWs was not an objective of this study, the constructs of psychological empowerment as defined from Menon (37) were evident after the intervention. Psychological empowerment is defined as the internal urge of an individual to gain control over their lives as well as being able to influence others or external events. A psychologically empowered individual is one who has a sense of perceived control over their work context, who feels they have the competence to do their work, and who are personally energised by the goals of the health institution (37). The self-reported change in the awareness of TB and confidence in performing their tasks due to the booklet, revealed that CCWs had a sense of perceived competence which is one of the constructs of psychological empowerment. Supporting CCWs with information materials can therefore be explored further as a means of empowering this cadre of healthcare workers.

5.5 Impact of the intervention on CCW interaction with patients

The availability of a simple well-designed booklet as a patient educational tool had a positive effect on the interpersonal relationship CCWs enjoyed with patients due to improved communication within the dyad. HCPs, including CCWs, need to be adequately trained to improve their communication skills when interacting with patients (85,86,90). My findings highlight the potential value of having a well-designed educational tool to improve interaction between CCWs and patients. The improved patient-HCP communication not only satisfied the patients in this study, who understood more about the disease, and who participated more during the interaction with their providers, but also had a positive impact on the CCWs who found patient education easier and more exciting. This dual effect of patient education tools is an additional benefit that has been previously noted (175).

Study CCWs commented that patients did not always trust information that was verbally communicated. This finding can potentially compromise the role of CCWs in patient education, as verbal communication is usually the only mode by which information is communicated. For health information to be accepted and internalised, it needs to be adequate, trustworthy and easily comprehended (213). A previous study noted a lack of trust by community members of verbal information given by CCWs, and this is often linked to the lack of healthcare resources such as availability of medicines. The authors reported that the community may perceive the CCWs' knowledge, skills and overall abilities as being inferior, leading to a general distrust in information from this group (206). The availability of written information materials can

therefore be utilised as a tool to overcome this trust barrier, as the materials serve to validate verbal information, as was the case with CCW practice in my study.

HCPs often cite the lack of time as a barrier to using patient education tools during consultations (28), but this was not identified as a problem by study CCWs. Contrary to this finding, CCWs in this study found that the inclusion of pictograms made it easier to explain certain concepts which resulted in saved time. CCWs tend to have fewer time constraints than other HCPs such as nurses or doctors and so can communicate with the patient in a more relaxed manner.

5.6 Interaction of CCWs with patients and community members

The good patient relationships 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 endorses the rationale behind the development of CCW programmes of improving healthcare services in local communities. Similar to other studies (78,208,210), their main role in this study was seen to be the link between patients and the healthcare system, ideally situating them to create a voice for patients and to improve TB knowledge and awareness. Likewise, they can also encourage community participation in the healthcare system which can be an advantage in TB control.

Poor TB knowledge in patients may affect health-seeking and adherence behaviours, impacting on TB control (214). CCWs in my study reported confidence in their ability to identify poor TB knowledge in their patients which could affect patient self-management. Likewise, with their insider perspective, CCWs have been noted to be more equipped to identify cultural and social factors that influence health in their communities (215). They also noted the lack of information materials tailored for patients, an issue comprehensively discussed by Patel (188). This highlights the need for simple, understandable information materials for TB patients.

5.7 Health literacy of CCWs

This is the first study that has assessed the health literacy of CCWs (136,144,147,148). Although the modified South African version of the NVS used to assess health literacy in this study has not yet been validated in South Africa, it was previously used in an exploratory study

to evaluate health literacy in lay people in the same community from which the CCWs were recruited (194). Numeracy-based questions were poorly answered compared to comprehension questions, a finding that has been associated with other numeracy-related tests (149,216,217). This finding implies that CCWs may have lower comprehension when interpreting number-based health and medicines information and, importantly, in explaining this type of information to patients.

Comprehension-related questions were better answered as some answers were easily located and identified from the test food label. However, those questions requiring greater cognitive efforts led to poorer performance. The question on whether the tinned food contents were healthy to eat, relied on reading auxiliary information at the bottom of the label. This was not well answered as CCWs tended to ignore the information and image at the bottom of the label.

According to the test, the majority of CCWs had marginal health literacy. Written health information can disadvantage those classified as having limited health literacy, therefore there is a need to tailor training materials and other information materials to cater for that reader's level of education and literacy. Improvement of understanding can also be ensured through the use of local language when developing information materials for CCWs. The original NVS test has been described as being more sensitive in identifying individuals with poor health literacy and hence can overestimate the percentage with limited health literacy (149,216). Despite this, it can be a valuable tool in alerting programme managers to CCWs who may need more support in comprehending disease- and medicine-related information.

No association between educational background and health literacy was found in this study, differing from previous studies (149,216,218). This could be due to the relatively low numbers of CCWs and the limited range of educational levels in this group. However, it is established that the education level does not always predict health literacy, as it reflects only the number of years that an individual has attended school, rather than the actual skills that have been developed.

5.8 Reflections of the intervention design and impact

Study findings confirm that designing a study based on the four step process shown in Figure 5.1, area A, can be used to improve certain aspects that affect the practices of healthcare

workers. It was also clear that any research intending to design an intervention should always involve the participants in every stage of the project. Most people are apprehensive about change, often resisting it (41). Involving CCWs throughout the development stages assisted in reducing possible apprehension and resistance to the intervention as they were responsible for suggesting topics to be addressed, and provided their opinion on how the intervention should be structured and its time frame. Another interesting observation was that, despite the fact that the intervention was designed to impact on CCWs mainly in Area E, it had a positive knock-on effect on patients, and it may improve the interaction that CCWs have with the healthcare system by making them feel more secure in the significant position they occupy in the healthcare system.

5.9 Limitations of the study

The CCWs were all from one district in South Africa, thus the findings of this study (both qualitative and quantitative) may not be more widely generalisable nationally or within sub-Saharan Africa.

Not all CCWs in the district could be recruited despite this being the intention, and this adversely affected final numbers. Reasons for this included absence from the district due to training in a nearby city and the employment of new CCWs during the course of the study who could not be included. Although the relatively small sample size of CCWs may not have affected the qualitative results, the small size reduced the possibility of identifying statistically significant relationships from the data, such as the effect of education on knowledge and health literacy. The modified tool used to measure health literacy was not a validated one and therefore this did not allow direct comparison with the health literacy skills of other healthcare workers.

This study included the views of CCWs; however, feedback from TB patients and other community members who interact with these healthcare workers on a daily basis could have facilitated a deeper understanding of the impact of the booklet on counselling and communication. Views of other healthcare workers in PHC clinics who work with CCWs were also not explored, although future research could explore whether they could also benefit from the booklet during patient interactions. Additionally the effect of the roles of various CCWs which could have affected the aspects related to TB (knowledge and counselling of TB

patients) which was not explored in this study due to the limited numbers of CCWs and can form the basis of further research.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

The aim of this study was to determine whether user-friendly, simple, illustrated information would enhance TB knowledge of CCWs, as well as serve as a practice tool in facilitating their counselling and education of patients. The booklet designed for this study was found to improve TB knowledge and to have a positive impact on the practice of CCWs. A conceptual framework was developed to inform study design and to present the various interacting elements in the health system through which study findings were described and contextualised.

At the core of the conceptual framework are CCWs, whose main roles in this study were generally found to involve the social development of their communities and improving access to healthcare services and health promotion. CCWs identified closely with and were fulfilled in their roles, taking great pride in improving health outcomes. In addition to their role in patient care, this study also provided additional insight into the two-way interaction between CCWs and community members, with CCWs experiencing the rewards for their work through personal recognition by their communities. These insights show that a greater investment is needed in defining the context in which CCWs work, as well as their roles and their relationship with the institutions that recruit them. This process needs to be informed by the perceptions of the CCWs themselves; acknowledging their voice in the health system hierarchy is necessary to provide the basis for developing any interventions or policies that may affect their practice.

An association was identified between lack of adequate support by the healthcare system in the form of training, supervision and communication with other HCPs, and the unmet information needs of CCWs. Having CCWs who are not well supported by the system within which they work limits their effectiveness and contributes to the perception that the nature of CCW contribution is not as important as that of other HCPs who have professionally recognised qualifications. Greater effort is therefore needed to apply the stated intentions of both the South African CCW policy and PHC reengineering towards greater support of CCWs. This would maximise the benefits of CCWs in the TB programme and could facilitate better integration of their work into the healthcare system.

In an era of high TB incidence rates, the findings of poor knowledge areas, specifically TB medication-related knowledge, XDR-TB and side effects of medication, support the need to

include CCWs as one of the target groups for continuous TB education activities. Targeted educational interventions will not only improve the capacity of CCWs to manage TB patients and provide correct and appropriate counselling, but can also benefit their communities with whom they share their knowledge regarding TB, and particularly its prevention and detection.

These key members of the healthcare team performed relatively poorly on the health literacy test, and only three managed an 'excellent' score for the TB knowledge test at follow up. Knowing CCW health literacy levels can help identify their ability to understand and apply health information. These findings underline the need for intensive CCW education, which pays attention to their level of health literacy.

Careful consideration paid to the design of information materials emerged as a reliable predictor of its ease of use, which heavily affects its acceptability. It was also shown that access to information materials developed according to the needs of CCWs, increased their knowledge and improved their confidence in carrying out their roles. Having appropriate materials readily available also reduced their uncertainty when confronted with scenarios that were difficult to negotiate. This does not imply that simply providing, for example, books from training activities will be beneficial for CCWs; they require well designed information materials that are tailored to their needs and their literacy levels.

One of the more significant findings to emerge from this study was the confirmation by CCWs of the deficiency in patient knowledge of TB as well as the lack of adequate information materials to cater for patients' needs. CCWs reported the important benefit of the booklet in improving the quality of their communication with patients, as well as their patient counselling and education activities. This has implications for other HCPs who may also appreciate access to a well-designed, patient-friendly booklet to use during their own interactions with patients. Equally important, this could encourage a more active participation of patients during communication with HCPs, a prerequisite to improving their disease - and medication-related knowledge and adherence to treatment.

The importance of using pictograms together with text in information materials is clearly supported by the study findings. The presence of pictograms and the quality and appropriateness of these visual images were positively regarded by both patients and CCWs. CCWs reported the benefit of pictograms in enhancing recall of information and facilitating

communication with low literate patients, and commented that patients had found that the pictograms made the information easy to understand and appealing. This confirms previous findings that support the inclusion of pictograms in patient education tools and contributes additional evidence that suggest their advantage in information materials for CCWs.

Recommendations for future research:

- 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. 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.
- Unmet information needs and inadequate TB knowledge are factors that influence the quality of TB care. These should be researched in other HCP groups, particularly nurses who, in South Africa, form the largest HCP group caring for patients.
- This research has shown that the majority of CCWs found the booklet useful to their practice, although a few differed in their opinion. More research could investigate reasons why the latter group of CCWs reported a different experience with the booklet. This may assist in establishing other factors to consider when designing information materials for CCWs.
- CCWs accepted the intervention despite the fact that it was only accompanied with a short information session. This challenges the idea behind lengthy training for better uptake of new interventions. Further research may investigate the type of training required for acceptance and introduction of new interventions.
- Further work could establish whether the booklet would have a similar impact in other CCWs in the different provinces of South Africa. National CCW opinion could then provide additional opinion on booklet content, and form the basis for a widespread rollout of the booklet in other regions.
- The current absence of documented research on CCWs limits the effectiveness of combined action between different stakeholders and also leads to repeated interventions that are not co-ordinated. Future research can therefore investigate the development of a data collection system which collates documented research projects involving CCWs. This data base can be used by researchers, policy-makers, NGOs and other key

stakeholders to have access to a continuously updated reference source on CCW research and which can form the basis for the design of new interventions.

Practical application of the findings and implications for practice:

- The research team discussed the findings and outcomes of the study with key stakeholders at the District Health Office who were highly impressed by the quality, textual content and high user appeal of both the poster and the booklet, as well as their availability in three different languages. At their request, posters and booklets have been placed in all public health facilities in the District, and booklets have been distributed to all CCWs.
- Pictorial-based information materials can be an effective strategy for improving provider-patient communication and should be integrated into routine TB healthcare delivery strategies. In addition, the design, content and format, as well as cultural and language considerations should be taken into account when developing information and training materials for CCWs.
- The managers of CCW programmes and training facilitators should be mindful of the knowledge levels of CCWs depending on their scope of practice. More attention can be placed on including knowledge assessment tests for these healthcare workers. This can be beneficial after training activities to assess the impact of any educational intervention received. Knowing CCW health literacy and knowledge levels may assist the design of information material and training materials in a format that best suits their needs.

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APPENDICES

APPENDIX 1

Rhodes University Faculty of Pharmacy Ethics Approval



RHODES UNIVERSITY

Grahamstown • 6140 • South Africa

FACULTY OF PHARMACY

Tel: +27 (0)46 603 8381 • Fax: +27 (0)46 603 7506 • E-mail: dean.pharmacy@ru.ac.za • PO Box 94, Grahamstown, 6140, South Africa

2 June 2014

Dear Ida Okeyo

RE: Ethical approval by the Faculty of Pharmacy's Ethics Committee
(Tracking number PHARM 2014 - 10)

As a registered student in the Faculty of Pharmacy, with student number 10o2811, I am pleased to inform you that the Faculty of Pharmacy's Ethics Committee grants you ethical approval for your research entitled:

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

Please ensure that the Faculty of Pharmacy's Ethics Committee is notified should any substantive change(s) be made, for whatever reason, during the research process.

Sincerely

Carmen Oltmann, PhD
Chairperson

APPENDIX 2

Eastern Cape Department of Health Ethics Approval



Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 31st July 2014

Fax No: 043 642 1409

e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Dear Ms I. Okeyo 0466037506

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

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



APPENDIX 3: Qualitative Interview Guide (Phase 1)

Welcome everyone

I would like to start by introducing myself, my name is Ida Okeyo and this is my supervisor Ros Dowse, and the interpreter who will be here with us today is Bulelwa.

Introductions

Let us do a quick round introductions, so we all know each other. We will start with everyone mentioning their name and where they are from and how they feel today.

Thank you to all of you for agreeing to participate in this study. In this discussion, we will be discussing how you feel about being CCWs, training that you receive, your tasks and how you interact with patients

The information you give us is completely confidential, and we will not associate your name with anything you say in this session.

We would like to tape the discussion so that we can make sure we capture the thoughts, opinions, and ideas we hear from everyone.

Ground rules

To make the discussion proceed smoothly some ground rules such as;

There are no right or wrong answers to the questions being discussed so all the ideas, experiences and opinions are valuable.

Only one person should talk at a time so we all get to listen to what they are saying.

You don't need to agree with what anyone is saying but you should listen respectfully to what they say.

We ask that you keep your cell phones off. If you can't and you need to respond to a call please do so quietly and rejoin us.

Ice breaker activity

Before we start the discussion, I would like us to do an activity. I will give each of you a piece of paper and on this paper you have to write one word that describes what you feel about being a CCW.

I will give you some time to think about it for a minute and then you can write the word down on the piece of paper. After everyone has written down their word, you will have to share with the group the word that you have chosen and why.

After the activity

Now that we know how everyone feels about being a CCW, I would like know why you chose to become a CCW.

Warm up questions

- People are motivated by various reasons to work as CCWs, let us start this discussion by talking about some of the reasons why you decided to become CCWs?
- If you could describe your experience of working as a CCW, what would you say? (Is it fulfilling?)

Roles, tasks, training

- As CCWs, apart from being DOT supporters, what other tasks do you normally do? (Once a week/everyday, is it full time?)
- How are you trained to help with TB patients?
- How do you feel about the training (Is it enough to perform the tasks you are involved in?)
- If you could change anything about the training you receive what would it be?

When talking to TB patients or counselling them:

- How do you feel about the information you have, is it enough for you to use when you talk to patients? (gap about knowledge of TB medicines)
- Where do you get the information about TB and TB medicines that you use while working with patients?
- How do you feel about improving information you give to patients?
- What sort of information materials would you like to have in order to learn more about TB and the medicines? (Format, layout, length). Note: Show example of a poster, pages/leaflet containing only text, one with text and illustration.

Summary

- Is there anything else you would like to add to what we have discussed?

APPENDIX 4: Qualitative Interview Guide (Phase 3)

Welcome

Thank you to all of you for agreeing to participate in this study. To make the discussion proceed smoothly some ground rules such as; there are no right or wrong answers to the questions being discussed so all the ideas, experiences and opinions are valuable. Only one person should talk at a time so we all get to listen to what they are saying. You don't need to agree with what anyone is saying but you should listen respectfully to what they say.

Questions

- Ever since I gave you the booklet, how have you been using it? [clinic, community, personal e.t.c]
Probe: Can you give me an example from your own experience?
Probe: Can you tell me more on that?
- What do you think about the booklets after using them?
Probe: Why do you think that/ say that?
Probe: Can you give me an example from your own experience?
- Tell me about how patients have reacted to the booklet?
Probe: Why do you think that/ say that?
Probe: Can you give me an example from your own experience?
- Is there any way that you think I could improve the booklet or is there anything you did not like about the booklet?
Probe: If I understand correctly you mean?
Probe: Format in terms of size of the booklet, words/text simplicity, inclusion of pictograms, ease of use?
- How does it feel like when you use the booklet when talking to patients?
Probe: Why do you think that/ say that?
Probe: Can you give me an example from your own experience/ can you explain more about what you mean by that?
- Has the booklet helped you in any way?
Probe: Your knowledge of TB and practice?
- What do you think about having other information materials that are the same as the booklet?
Probe: Other booklets? Different size of materials? Posters?
- How do you feel about the study since we started last year?
Probe: How has it helped you?

Summary

- Anything you would like to ask me?
- Anything you would like to add to what we have discussed?

APPENDIX 5: NVS-SA Nutritional label

INGREDIENTS	
Pilchards (fish), water, tomato paste, salt, maize starch, guar gum	
TYPICAL NUTRITIONAL INFORMATION	
Per 100g serving	
Energy	438 kj
Protein	17 g
Carbohydrate	2 g
of which total sugar	1.0 g
Total fat	5.1 g
Cholesterol	68 mg
Dietary fibre	2.3 g
Sodium	270 mg
Calcium	267 mg
ALLERGY INFORMATION	
Free from: gluten	
Contains: fish	
Contents: 400 g	
 APPROVED AS PART OF THE HEART AND STROKE FOUNDATION EATING PLAN	

APPENDIX 6

TB Knowledge Questionnaire

QUESTIONNAIRE
TB KNOWLEDGE OF COMMUNITY CARE WORKERS (CCWs)
Ida Okeyo : MPharm : 2014-15

Date: _____	Interview site: _____
Interviewer: _____	Interpreter: _____
Participant: _____	Participant number _____
Participant contact number _____	

1. DEMOGRAPHICS

I would first like to ask you some questions about yourself		
1.1	Gender	1 = Male 2 = Female
1.2	Age	Write number of yrs
1.3	How well do you understand your home language? Can you listen or speak or read?	1 = Listen (verbal understanding) 2 = Listen and speak 3 = Listen, speak and read
1.4	How well do you understand English? Can you listen or speak or read?	1 = Listen (verbal understanding) 2 = Listen and speak 3 = Listen, speak and read
1.5	What grade or standard did you finish at school?	Grade: Write number of yrs
1.6	Do you prefer reading things like newspapers, medicine labels or health information in English or IsiXhosa/Afrikaans?	1 = isiXhosa 2 = English 3 = Afrikaans
1.7	How many years have you worked as a Community Care Worker?	Write number of yrs
1.8	Have you participated in any TB training/workshop/seminar in the last 12 months?	1 = Yes 2 = No
1.9	How were you trained to be a CCW? (where was the training?, who did the training?, what areas where you trained in?)	Answer:

2. NEWEST VITAL SIGNS – SOUTH AFRICA (NVS-SA)

Show prompt card (image of tin of pilchards) and read: Do you know what this is? Have you and your family ever eaten this food before and if so do you like it? There is a label on the tin that is quite small, so we have made the label bigger so that it is easier to read. Please could you read the label and then I will ask you some questions. You can look at the label for the answers. . (NB: Note time taken for the test)			Score
2.1	Are the pilchards (the fish) plain or is there a flavour that has been added? <i>The pilchards are in a tomato sauce</i>	0 = Incorrect 1 = Correct	
2.2	If you eat 200g from this tin, how much of the tin will you eat? <i>Half the tin (ensure the answer is a proportion of the tin)</i>	0 = Incorrect 1 = Correct	
2.3	If 3 slices of bread contains about 6g of protein, which will give you more protein: eating the 3 slices of bread or eating some pilchards? <i>Pilchards has 17g protein/100 g (i.e. in ¼ tin) and this is much more than the 6g of protein in the 3 slices of bread (Subject must indicate label info of 17g protein/100g. Subject not require to specify the amount of pilchards eaten)</i>	0 = Incorrect 1 = Correct	
2.4	Pretend that you are allergic to the following substances: penicillin, milk and gluten. Is it safe for you to eat this food? <i>Yes</i>	0 = Incorrect 1 = Correct	
2.5	If you eat the whole can of pilchards, how many grams of carbohydrate will you eat? <i>2 x 4 = 8 g</i>	0 = Incorrect 1 = Correct	
2.6	Pretend that you have a problem with your blood pressure or heart. According to the label how would you know if this food is good for you? <i>Because it is approved as part of the Heart and Stroke Foundation eating plan (subject must indicate text and image)</i>	0 = Incorrect 1 = Correct	
Total Score (out of 6) Interpretation 0 - 2: Inadequate health literacy 3 - 4: Marginal health literacy 5 - 6: Adequate health literacy			
Time taken for NVS-SA (mins)			

INGREDIENTS	
Pilchards (fish), water, tomato paste, salt, maize starch, guar gum	
TYPICAL NUTRITIONAL INFORMATION	
Per 100g serving	
Energy	438 kJ
Protein	17 g
Carbohydrate	2 g
of which total sugar	1.0 g
Total fat	5.1 g
Cholesterol	68 mg
Dietary fibre	2.3 g
Sodium	270 mg
Calcium	267 mg
ALLERGY INFORMATION	
Free from: gluten	
Contains: fish	
Contents: 400 g	
 APPROVED AS PART OF THE HEART AND STROKE FOUNDATION EATING PLAN	

3. TB KNOWLEDGE

CAUSE, TRANSMISSION, PREVENTION, DIAGNOSIS, HIV			
3.1	If someone has TB, can they infect someone else? Yes	0 = No 1 = Yes	
3.2	How is TB passed from one person to another? <i>Droplet transmission, via the air when a person with TB coughs etc</i>	0 = Incorrect 1 = Correct	
3.3	If you are with a person who has TB can you get TB if you: (read option and ask if correct or not) 0 = Incorrect 1 = Correct <i>(Only 3.3.1 – 3.3.3 assessed in knowledge test to give a total of 3 marks if the three options are answered correctly.)</i>	Shake his hand	
		3.3.1 Eat from his plate	
		3.3.2 Breathe in the air after he coughs	
		Share his clothes	
		Use the same toilet	
		Use the same towel	
		3.3.3 Have sex with him/her	
3.4	What is the main cause of TB? <i>Bacteria</i>	0 = Incorrect 1 = Correct	
3.5	How can a person try to avoid getting TB? <i>Cough hygiene</i>	0 = Incorrect 1 = Correct	
3.6	If someone has HIV/AIDS, is it easier for them to get TB? Yes	0 = No 1 = Yes	
3.7	Is there a vaccine against TB? Yes	0 = No 1 = Yes	
3.8	What part of the body does TB usually affect? <i>Must mention lungs or chest</i>	0 = Incorrect 1 = Correct	
3.9	What are the signs and symptoms of TB? – <i>Do not offer options, tick all mentioned</i> Cough - ask how it is different from other coughs e.g because of asthma, or a with cold or flu Note: mark correct only if 3 or more signs and symptoms are identified 0 = Incorrect 1 = Correct	Cough (see note)	
		Severe headache	
		Losing weight	
		Coughing up blood	
		Chest pain	
		Shortness of breath	
		Fever and/or chills	
		Nausea	
		Coughing for 3 weeks or longer	
		Not eating a lot	
		Sweating at night	
		Feeling tired and weak	
3.10	How is TB of the lungs mostly diagnosed? <i>Sputum tests</i>	0 = Incorrect 1 = Correct	
3.11	Does everyone who has TB also have AIDS? No	0 = Yes 1 = No	
3.12	Can TB be cured if you have HIV? Yes	0 = Incorrect 1 = Correct	

TREATMENT			
3.13	Is it possible to cure TB? <i>Yes</i>	0 = No 1 = Yes	
3.14	Are all patients with TB cured? <i>No</i>	0 = Incorrect 1 = Correct	
3.15	What is the approximate cure rate for TB in Eastern cape? <i>C = 65%</i>	A = 10% B = 50% C = 65% D = 95%	0 = Incorrect 1 = Correct
3.16	How long does the standard TB treatment last? <i>At least 6 months</i>	0 = Incorrect 1 = Correct	
3.17	If someone is starting to take TB medicines for the first time, what should they tell the doctor? <i>Note: mark correct only if 2 of the options below are mentioned</i> <i>For example the nurse/doctor needs to know whether they are diabetic or hypertensive so what should the patient tell the nurse/doctor before they start treatment?</i> <i>-are HIV positive</i> <i>-are taking any other medicines</i> <i>-have any allergies</i>	0 = Incorrect 1 = Correct	
3.18	If a TB patient is about to start taking TB medicines but is also taking other medicines what should they do? <i>Inform their healthcare provider</i>	0 = Incorrect 1 = Correct	
3.19	What does the name MDR-TB mean? <i>Multi-drug resistant TB</i>	0 = Incorrect 1 = Correct	
3.20	What does the name XDR-TB mean? <i>Extreme-drug resistant TB</i>	0 = Incorrect 1 = Correct	
3.21	What causes a patient to get MDR- or XDR-TB? <i>Not taking meds correctly</i>	0 = Incorrect 1 = Correct	
3.22	Can MDR be cured? <i>Yes</i>	0 = Incorrect 1 = Correct	
3.23	Can XDR be cured? <i>Yes</i>	0 = Incorrect 1 = Correct	
3.24	Are the medicines to treat MDR- and XDR-TB the same as those used for standard TB? <i>No</i>	0 = Incorrect 1 = Correct	
3.25	How long does it take to cure MDR- or XDR-TB? <i>18 months / 1½ years/ more than a year</i>	0 = Incorrect 1 = Correct	
3.26	Should TB medicines only be taken with food / on a full stomach? <i>No, they can also be taken without food</i> <i>If yes, then why?</i>	0 = Incorrect 1 = Correct Answer:	
3.27	When a patient is taking TB medicines, is there anything they shouldn't eat, drink or do? <i>- smoke</i> <i>- drink alcohol excessively</i>	0 = Incorrect 1 = Correct	
3.28	If patients have problems swallowing the large TB tablets, what can they do?	0 = Incorrect 1 = Correct	

	<i>Crush them and take them with small amount of water or food</i>		
3.29	Explain what is meant by a side effect of a medicine <i>A bad reaction because of a particular medicine</i>	0 = Incorrect 1 = Correct	
3.30	What are some side-effects of TB medicines? Tell me as many as you know. <i>Tick correct side-effects named</i> Note: Mark correct only if 3 or more side effects are identified 0 = Incorrect 1 = Correct	Blurry Vision Dizziness Fever Joint pain Muscle weakness Nausea/ vomiting Orange urine, sweats and tears Skin rash Severe rash on body Stomach pain Tingling, burning, numbness, pain in hands and feet (pins and needles) Tiredness / fatigue Yellow eyes or skin Number of side effects named	
3.31	What should a patient do if he/she experiences one or more side-effects? <i>Tell CCW or health professional at the clinic</i>	0 = Incorrect 1 = Correct	
3.32	What should a patient do if they forget to take their TB medicines? <i>Take it as soon as they remember on that day. If they don't remember until the following day, they should leave out the missed dose and take the next dose as usual.</i>	0 = Incorrect 1 = Correct	
3.33	When should a patient stop taking their TB medicines? <i>When a health professional at the clinic says they have finished the complete course of 6 months and after sputum tests are negative.</i>	0 = Incorrect 1 = Correct	
	TOTAL KNOWLEDGE SCORE (out of 35)		

END OF BASELINE INTERVIEW

POST-BASELINE TEST

4. TB KNOWLEDGE

CAUSE, TRANSMISSION, PREVENTION, DIAGNOSIS, HIV			
4.1	If someone has TB, can they infect someone else? Yes	0 = No 1 = Yes	
4.2	How is TB passed from one person to another? <i>Droplet transmission, via the air when a person with TB coughs etc</i>	0 = Incorrect 1 = Correct	
4.3	If you are with a person who has TB can you get TB if you: (read option and ask if correct or not) 0 = Incorrect 1 = Correct <i>(Only 4.3.1 – 4.3.3 assessed in knowledge test to give a total of 3 marks if the three options are answered correctly.)</i>	Shake his hand	
		4.3.1 Eat from his plate	
		4.3.2 Breathe in the air after he coughs	
		Share his clothes	
		Use the same toilet	
		Use the same towel	
		4.3.3 Have sex with him/her	
4.4	What is the main cause of TB? <i>Bacteria</i>	0 = Incorrect 1 = Correct	
4.5	How can a person try to avoid getting TB? <i>Cough hygiene</i>	0 = Incorrect 1 = Correct	
4.6	If someone has HIV/AIDS, is it easier for them to get TB? Yes	0 = No 1 = Yes	
4.7	Is there a vaccine against TB? Yes	0 = No 1 = Yes	
4.8	What part of the body does TB usually affect? <i>Must mention lungs or chest</i>	0 = Incorrect 1 = Correct	
4.9	What are the signs and symptoms of TB? – <i>Do not offer options, tick all mentioned</i> Cough - ask how it is different from other coughs <i>e.g because of asthma, or a with cold or flu</i> Note: mark correct only if 3 or more signs and symptoms are identified 0 = Incorrect 1 = Correct	Cough (see note)	
		Severe headache	
		Losing weight	
		Coughing up blood	
		Chest pain	
		Shortness of breath	
		Fever and/or chills	
		Nausea	
		Coughing for 3 weeks or longer	
		Not eating a lot	
		Sweating at night	
		Feeling tired and weak	
4.10	How is TB of the lungs mostly diagnosed? <i>Sputum tests</i>	0 = Incorrect 1 = Correct	
4.11	Does everyone who has TB also have AIDS? No	0 = Yes 1 = No	
4.12	Can TB be cured if you have HIV? Yes	0 = Incorrect 1 = Correct	

TREATMENT			
4.13	Is it possible to cure TB? <i>Yes</i>	0 = No 1 = Yes	
4.14	Are all patients with TB cured? <i>No</i>	0 = Incorrect 1 = Correct	
4.15	What is the approximate cure rate for TB in Eastern cape? <i>C = 65%</i>	A = 10% B = 50% C = 65% D = 95%	0 = Incorrect 1 = Correct
4.16	How long does the standard TB treatment last? <i>At least 6 months</i>	0 = Incorrect 1 = Correct	
4.17	If someone is starting to take TB medicines for the first time, what should they tell the doctor? <i>Note: mark correct only if 2 of the options below are mentioned</i> <i>For example the nurse/doctor needs to know whether they are diabetic or hypertensive so what should the patient tell the nurse/doctor before they start treatment?</i> <i>-are HIV positive</i> <i>-are taking any other medicines</i> <i>-have any allergies</i>	0 = Incorrect 1 = Correct	
4.18	If a TB patient is about to start taking TB medicines but is also taking other medicines what should they do? <i>Inform their healthcare provider</i>	0 = Incorrect 1 = Correct	
4.19	What does the name MDR-TB mean? <i>Multi-drug resistant TB</i>	0 = Incorrect 1 = Correct	
4.20	What does the name XDR-TB mean? <i>Extreme-drug resistant TB</i>	0 = Incorrect 1 = Correct	
4.21	What causes a patient to get MDR- or XDR-TB? <i>Not taking meds correctly</i>	0 = Incorrect 1 = Correct	
4.22	Can MDR be cured? <i>Yes</i>	0 = Incorrect 1 = Correct	
4.23	Can XDR be cured? <i>Yes</i>	0 = Incorrect 1 = Correct	
4.24	Are the medicines to treat MDR- and XDR-TB the same as those used for standard TB? <i>No</i>	0 = Incorrect 1 = Correct	
4.25	How long does it take to cure MDR- or XDR-TB? <i>18 months / 1½ years/ more than a year</i>	0 = Incorrect 1 = Correct	
4.26	Should TB medicines only be taken with food / on a full stomach? <i>No, they can also be taken without food</i> <i>If yes, then why?</i>	0 = Incorrect 1 = Correct Answer:	
4.27	When a patient is taking TB medicines, is there anything they shouldn't eat, drink or do? <i>- smoke</i> <i>- drink alcohol excessively</i>	0 = Incorrect 1 = Correct	
4.28	If patients have problems swallowing the large TB tablets, what can they do?	0 = Incorrect 1 = Correct	

	<i>Crush them and take them with small amount of water or food</i>		
4.29	Explain what is meant by a side effect of a medicine <i>A bad reaction because of a particular medicine</i>	0 = Incorrect 1 = Correct	
4.30	What are some side-effects of TB medicines? Tell me as many as you know. <i>Tick correct side-effects named</i> Note: Mark correct only if 3 or more side effects are identified 0 = Incorrect 1 = Correct	Blurry Vision Dizziness Fever Joint pain Muscle weakness Nausea/ vomiting Orange urine, sweats and tears Skin rash Severe rash on body Stomach pain Tingling, burning, numbness, pain in hands and feet (pins and needles) Tiredness / fatigue Yellow eyes or skin Number of side effects named	
4.31	What should a patient do if he/she experiences one or more side-effects? <i>Tell CCW or health professional at the clinic</i>	0 = Incorrect 1 = Correct	
4.32	What should a patient do if they forget to take their TB medicines? <i>Take it as soon as they remember on that day. If they don't remember until the following day, they should leave out the missed dose and take the next dose as usual.</i>	0 = Incorrect 1 = Correct	
4.33	When should a patient stop taking their TB medicines? <i>When a health professional at the clinic says they have finished the complete course of 6 months and after sputum tests are negative.</i>	0 = Incorrect 1 = Correct	
	TOTAL KNOWLEDGE SCORE (out of 35)		

APPENDIX 7: Participant Invitation Letter and Consent Form



RHODES UNIVERSITY

RHODES UNIVERSITY: FACULTY OF PHARMACY PARTICIPANT INVITATION LETTER

TITLE: Community care workers in TB care: identifying and meeting their information needs.

My name is **Ida Okeyo** from the Pharmacy Faculty at Rhodes University. I am doing a research project on designing information materials for community care workers that I hope will improve TB and TB medicine knowledge and that may be useful when counseling patients. You are kindly invited to take part in this study. This letter will tell you a few things about the study. If there is anything you do not understand in this letter, please let me know so that I can explain. You may ask questions at any time. If you wish to take part in the study, you will be asked to sign this form.

What is the study about?

The aim of this study is to find out what information materials you as a community care worker need to improve your knowledge of TB and the medicines used to treat TB. Once we know this, we will develop the information materials for you to use.

Who can take part in this study?

Community care workers who work with TB patients can take part in this study.

What will we ask you to do?

If you agree to be in the study, you will be asked to do the following:

If you work with Hospice you will be part of a group of community care workers and I will have a discussion with the group. If you work in the public sector clinics, I will talk to you by yourself. There will be an interpreter to help you understand questions in isiXhosa. We will talk about your role in the health system and the type of TB information you need when talking to patients. The discussions and interviews will be audio taped so that we can record all the comments.

After these discussions, the interpreter and I will meet with you by yourself and will ask you questions about TB and the medicines used in TB.

After we have developed the information materials, I will see you again to give them to you and I will briefly tell you about what information they contain. I will ask you to read them and to use them when you meet with TB patients to help the patient to understand more about TB and TB medicines.

About 2-3 months later, I will meet with you by yourself (and with the interpreter) and again ask you some questions about TB and the medicines. If you work with Hospice, I will then meet with you in a group to talk about whether the information materials have helped when you see TB patients. If you work at the clinics, I will do this straight after asking the questions about TB and TB medicines.

Confidentiality

A code will be used instead of your name for the focus group discussions and interviews and on the questionnaires. The answers obtained from the interviews and discussions will be kept confidential, so no-one will know how you answered the questions. Personal information and your name will not be used in any report or results.

Do I have to take part?

You are free to choose whether or not to take part in this study. You may decide to leave the study at any time, even if the discussions and interviews are not finished.

Benefits

After this study is completed, you will receive copies of the information materials which you can use when seeing TB patients.



RHODES UNIVERSITY

**RHODES UNIVERSITY: FACULTY OF PHARMACY
CONSENT FORM: PARTICIPANTS**

Title of the project: Community care workers in TB care: identifying and meeting their information needs.

Researcher: Ida Okeyo.

I have read the information that has been provided or it has been read to me. I have been assured that my identity and personal details will be kept confidential. I consent voluntarily to be a participant in this study

Print name of the participant _____

Signature of the participant _____

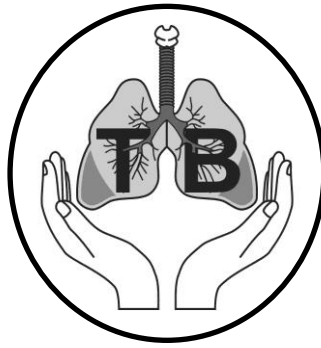
Signature of the researcher _____

Signature of the witness or interpreter _____

Date_____

APPENDIX 8

Booklet for Community Care Workers



TB information: Prevention, disease and medicines

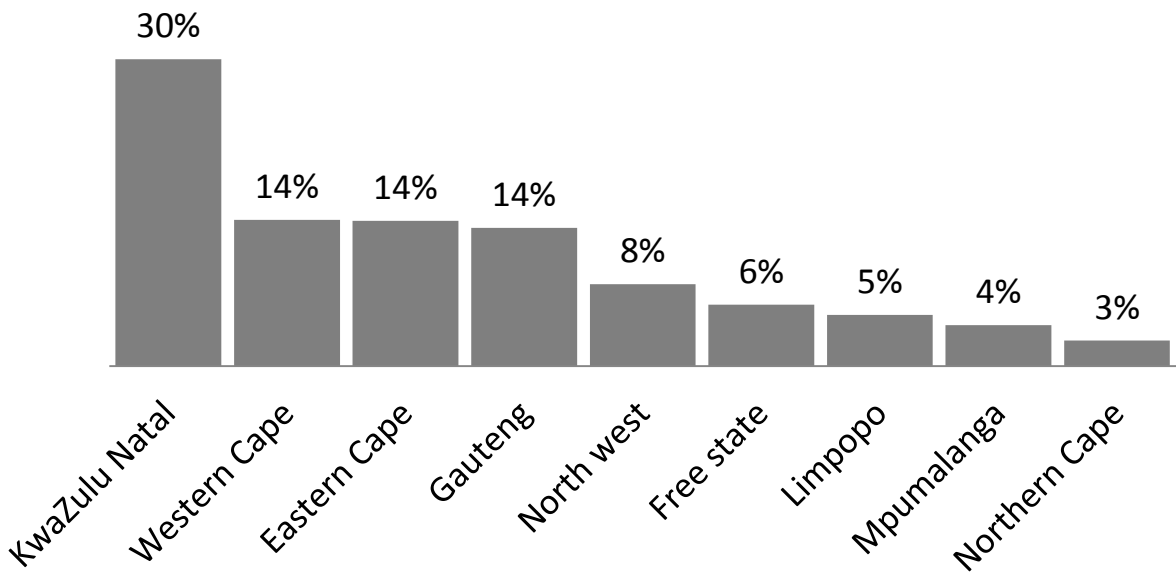


Booklet for Community Care Workers

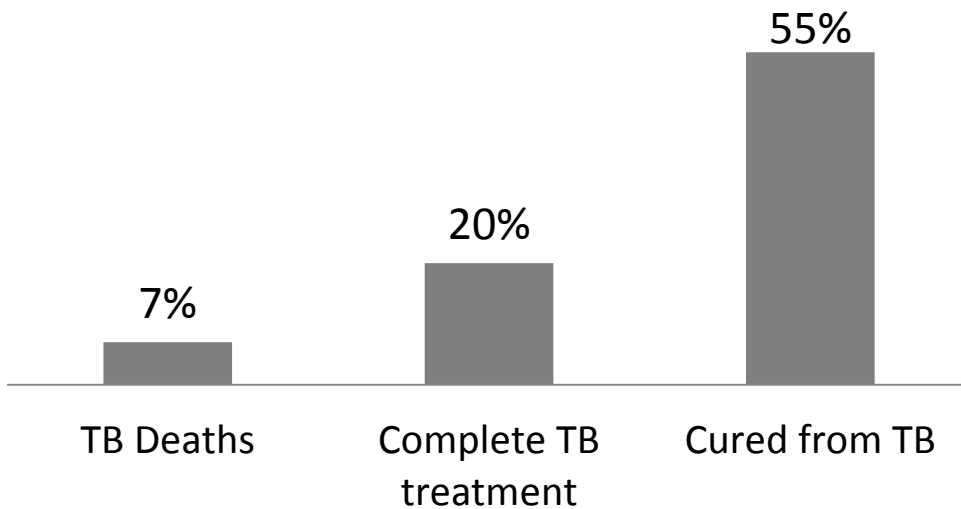
Contents

TB in South Africa	1
Cause and spread of TB	2
TB is not spread by	2
How to prevent the spread of TB	3
People more likely to get TB	4
Signs and symptoms of TB	5
Diagnosis of TB,.....	6
Producing a sputum sample for testing	7
TB treatment	8
Advice for patients on TB treatment	9
Side effects of TB medicines	10
Consequences of defaulting	12
MDR-TB and XDR-TB	13
Treatment of MDR-TB and XDR-TB	15
HIV and TB	16
Support for TB patients	17

TB in South Africa

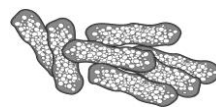


TB in the Eastern Cape

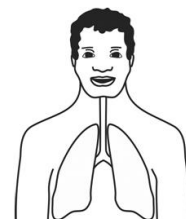


Cause of TB

TB is caused by bacteria (germs).



TB mostly affects the lungs (pulmonary TB).

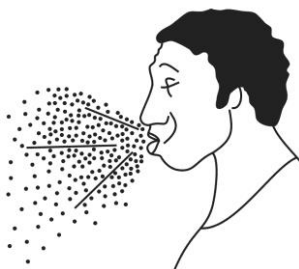


How TB is spread

TB can be spread from person to person when the germs fly through the air if a person with TB...



Coughs



Sneezes



Spits

TB is NOT spread by:



Hugging



Shaking or holding hands



Sharing a toilet



Sharing food or drinks

Preventing the spread of TB

The spread of TB can be reduced with good cough hygiene and ventilation.

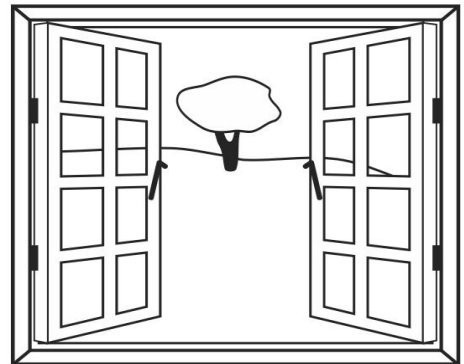
Safe coughing

Use a bent arm to cover the mouth when coughing, or cough into a piece of cloth or a tissue.



Ventilation

TB can spread easily in areas without a lot of fresh air. Always open windows to allow for fresh air especially in crowded rooms and full cars or taxis.



Use of masks

If masks are available, use them while seeing TB patients. TB patients coming into contact with other people can be asked to wear masks.



Groups of people more likely to get TB

- HIV/AIDS patients because they have a weak immune system.
- People who spend a lot of time with TB patients (TB contacts).
- People living in crowded areas e.g. prisoners.
- Healthcare workers who work with TB patients (including community care workers).
- Young children and older people.

IMPORTANT!
Anyone can get TB



Signs and symptoms of TB

Anyone who has some of the following symptoms should go to the clinic to be tested.



MARCH

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Coughing for two weeks or longer



Night sweats



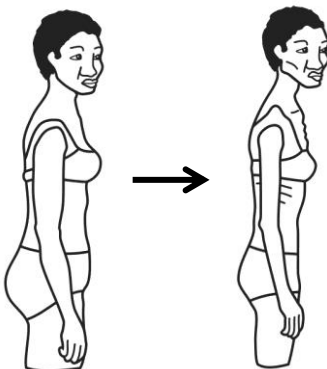
Poor appetite



Coughing up blood



Nausea



Weight loss



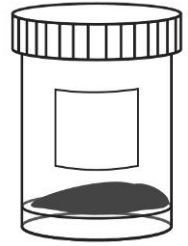
Tiredness



Fever

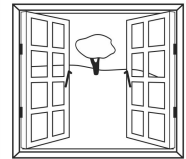
How TB is diagnosed

- TB is diagnosed in a person with symptoms by testing the sputum.
- TB is diagnosed after two positive sputum tests.
- If the sputum test is negative but TB is still suspected, a chest x-ray is done.

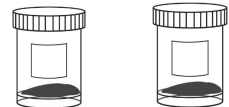


Sputum collection

- Sputum should be collected outdoors or in a well-ventilated area that is away from people.



- Two samples are collected 15 - 20 minutes apart.



- Label the sputum bottle with patient information before collecting sputum.



If the patient is lying on a bed:

- Move the bed until the patient is in front of an open window or door.
- Stand behind the bed.
- Ask patient to turn their head towards the open window or door when they cough and spit into the sputum bottle.

If the patient can't produce sputum, ask him/her to:

- Run or walk around and then try again.
- Inhale from a nebuliser or steam inhalation.

Sputum is collected in the following way

1. Rinse mouth with water to remove any food pieces



2. Breathe deeply from the bottom of the chest



3. Place the sputum bottle underneath the lower lip, cough deeply from the chest and spit into the bottle



Remember

- When you supervise someone collecting sputum, do not stand in front of the patient when they are coughing.
- Ensure the patient produces enough sputum (3 mls).
- Close the bottle tightly by turning the lid three times to ensure it is completely closed.
- Wash hands after closing the sputum bottle.
- Avoid direct sunlight to the sputum bottles.

TB treatment

The medicines work by killing the bacteria that cause TB.

First 2 months (initial phase)

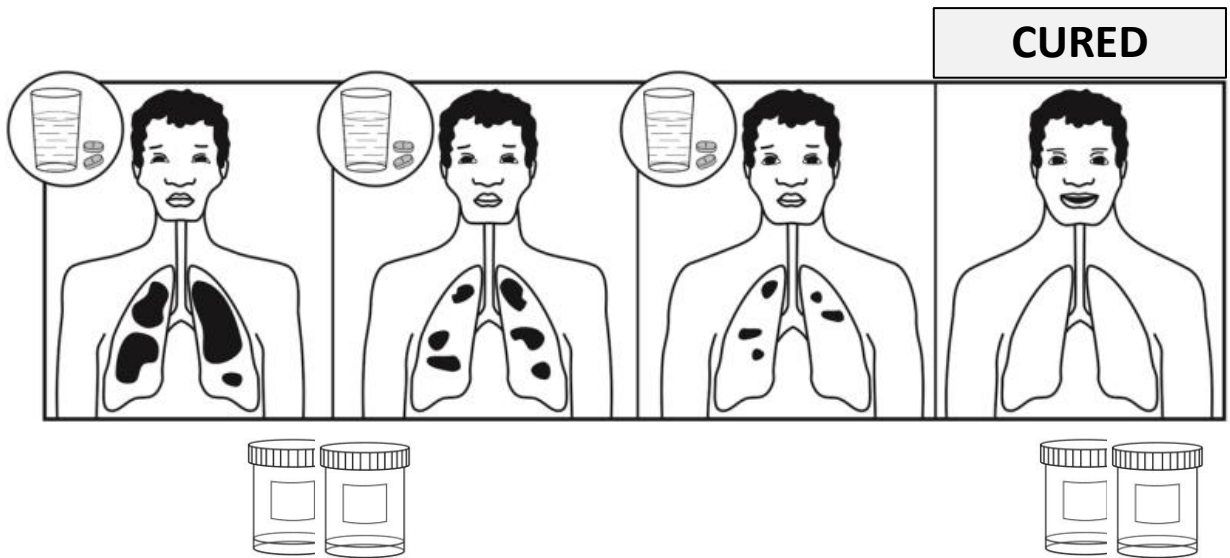
Rifafour®

It contains 4 medicines:
isoniazid, ethambutol
rifampicin, pyrazinamide.

Next 4 months (continuation phase)

Rifinah®

It contains 2 medicines:
rifampicin and isoniazid.

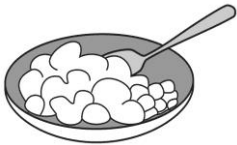


- TB patients stop being infectious after 2 weeks of taking TB medicines.
- TB patients must have two negative sputum tests before starting with the continuous phase of treatment.
- Treatment is only completed if patients test negative for three sputum tests after six months or more of treatment.

TB treatment

Advice you can give to patients on TB treatment

TB medicines can be taken:



With food

OR



Without food

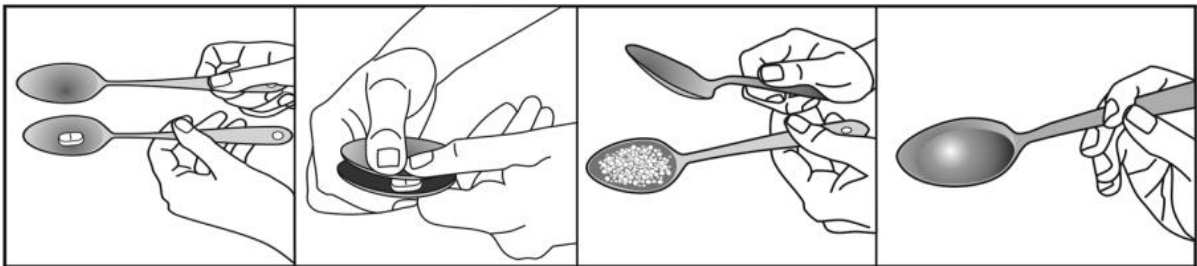
Take the medicine at
the same time every day



If patients forget to take their medicine:

they can take it as soon as they remember as long as it is on
the same day

For patients who find it difficult to swallow their medicines



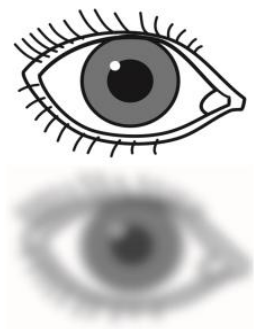
Place tablet
on a spoon

Crush tablet
between the
spoons

Mix crushed tablet with a small
amount of water, juice, jam or
yoghourt before you take it

Side effects of TB treatment

- Side effects are bad reactions from a particular medicine.



Blurred vision



Vomiting



Dizziness



Fever



Muscle weakness



Orange colour
of urine

Always advise patients:

- That new TB patients may experience some of these side effects.
- To report **ALL** side effects experienced.
- That it might take some time to get used to TB medicines but the side effects may go away after they have got used to the TB medicines.

Side effects that need urgent attention

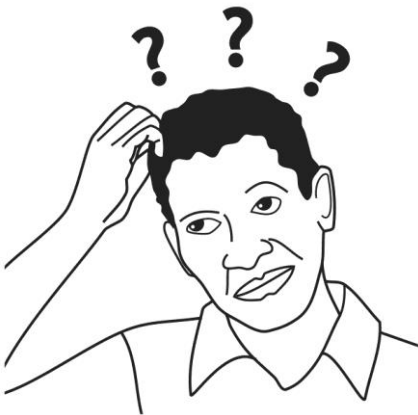
The side effects that need to be urgently referred to the nurse or the clinic include:



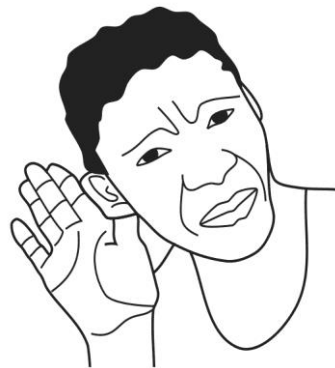
Severe rash all over the body



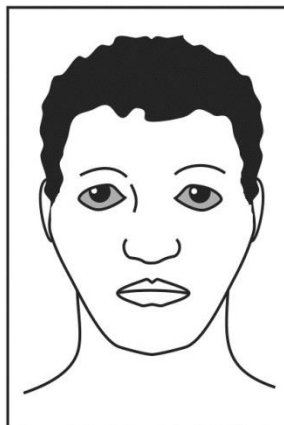
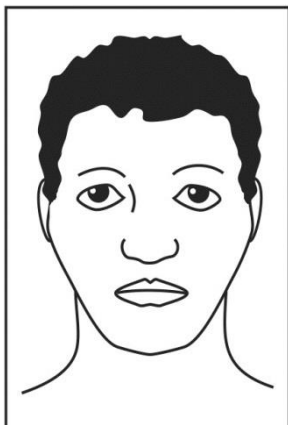
Stomach pain, nausea and vomiting



Confusion



Hearing problems



Yellowing of the eyes

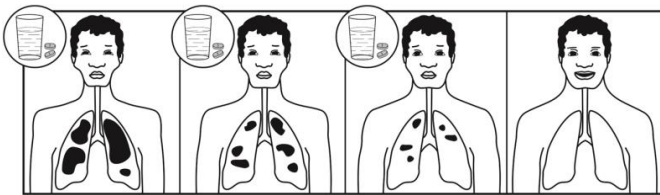
TB treatment

Remind TB patients to return to the clinic:

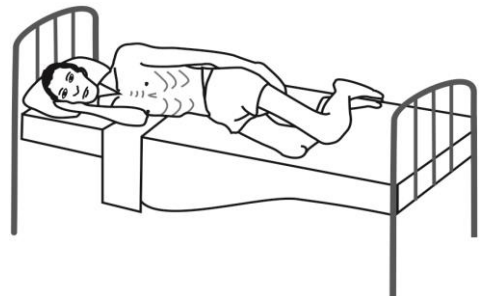
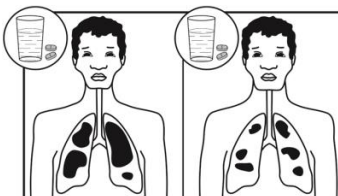
- For follow up sputum test after two months.
- For sputum tests after six months of treatment.

Consequences of defaulting

If patients **complete** their TB treatment



If patients **do not** complete their TB treatment



MDR and XDR TB

MDR-TB - stands for multi-drug resistant TB
- is resistant to rifampicin and isoniazid

XDR-TB - stands for extensively drug-resistant TB
- can be cured with medicines if there is no resistance to the medicines

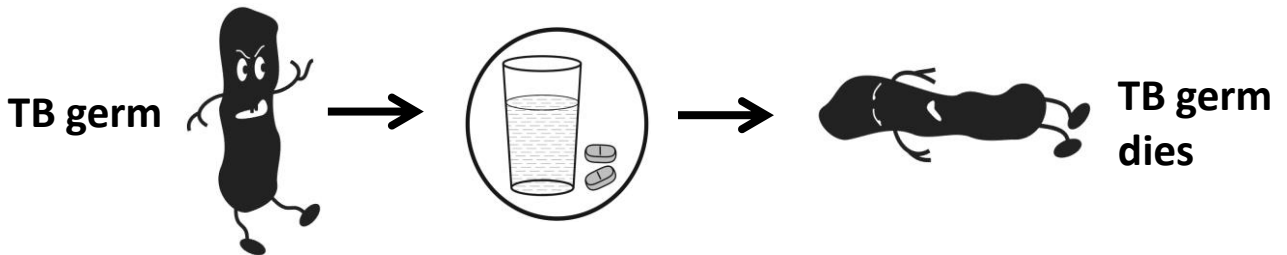
When to suspect MDR-TB:

- TB patients who are not improving while on TB treatment.
- People in contact with MDR-TB or XDR-TB patients.
- When the sputum test remains positive after treatment has been completed.
- If the patient has not finished their treatment.

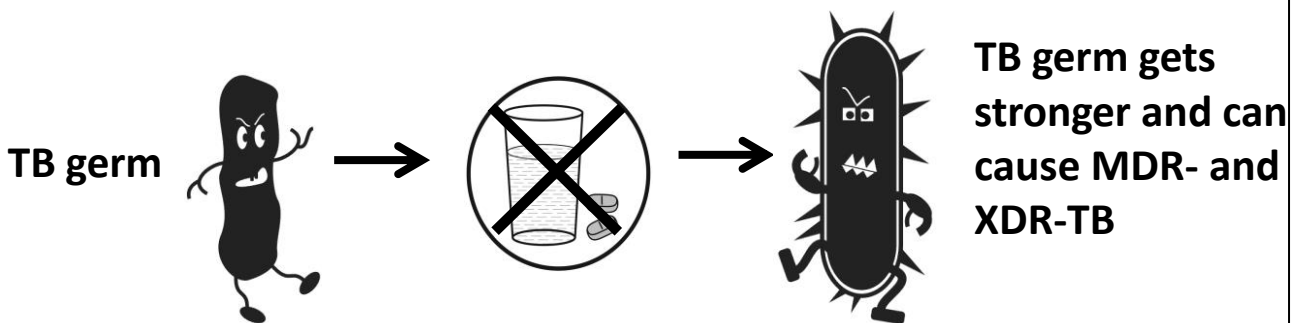
Both MDR-TB and XDR-TB can be spread like regular TB and have the same signs and symptoms as normal TB

Development of MDR and XDR TB

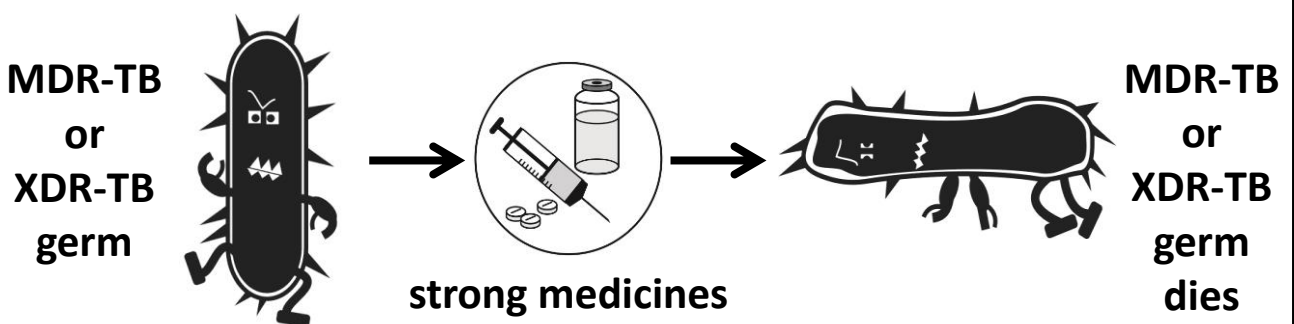
If patient takes medicine correctly



If patient DOES NOT takes medicine correctly



MDR-TB and XDR-TB are resistant to normal TB medicines



MDR-TB or XDR-TB germs can be killed by STRONGER MEDICINES that must be taken for about 18 months

MDR-TB and XDR-TB

Difference between normal TB and drug-resistant TB

Normal TB	MDR-TB or XDR-TB
Tests to confirm normal TB can be completed in a few hours	Tests to confirm MDR-TB take up to 3 months
TB treatment usually lasts for 6 months	Treatment can take up to 2 years
After a few weeks of taking treatment as prescribed, the patient stops being infectious	A patient with MDR-TB is still infectious for a longer period of time even if they are on treatment
Usually does not require hospitalisation	May require admission to hospital for the first 4-6 months

Treatment of MDR and XDR TB

- Drug resistant TB is diagnosed by GeneXpert.
- All patients who are positive should be referred to MDR-TB facilities in Port Alfred or Port Elizabeth.
- Once patients are stable they can be managed by local clinics.

MDR-TB and XDR-TB are treated with second-line medicines

Initial phase Five medicines including an injection 0 – 6 months	Continuous phase Four medicines without the injection 12– 18 months
---	--

HIV and TB in the same patient

- HIV infection weakens the immune system.
- This means that people with HIV are more likely to get sick with TB.
- Always advise HIV-infected patients to regularly get tested for TB disease.
- TB can be cured even for HIV and AIDS patients.
- 66% of people in South Africa have both HIV and TB.



- **Some patients may have HIV only**
- **Some patients may have TB only**
- **Some patients may have both HIV and TB**
- **Some patients may have both HIV and drug resistant TB**



HIV/AIDS patients on TB treatment:

- They may have to take TB medicines for up to 8 months because of a lowered immune system.
- After finishing the TB treatment, HIV/AIDS patients often get TB again.
- Patients taking antiretroviral therapy (ART) and TB medicines together may experience severe side effects.

Support for TB patients

Advice for family members and care givers of patients:

- Provide emotional support and nursing care to patients during treatment.
- Report any problems or changes in patients condition to the care worker or nurse at the clinic.
- Encourage contacts of the TB patient to get tested.

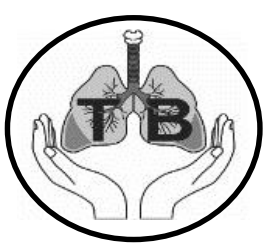


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Faculty of Pharmacy, Rhodes University,
Grahamstown 6139.
Tel : 046 603 8381.

APPENDIX 9

Poster (English, isiXhosa and Afrikaans)



TB (Tuberculosis)



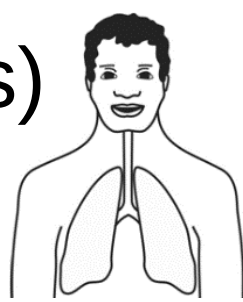
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2015

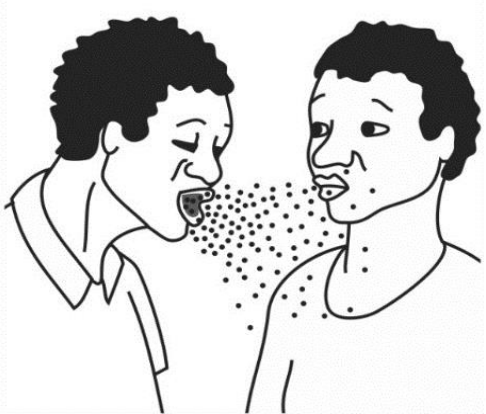
What is TB?

TB is caused by bacteria (germs)
TB mostly affects the lungs

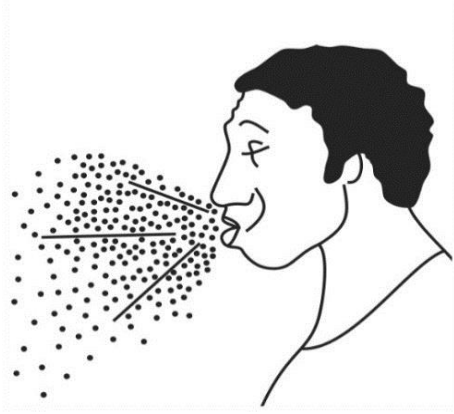


How TB is spread

TB can be spread from person to person when the germs fly through the air if a person with TB coughs, sneezes or spits



Coughs



Sneezes



Spits

Signs and Symptoms

Go to the clinic to get tested if you have any of the following:

Coughing for more than a day



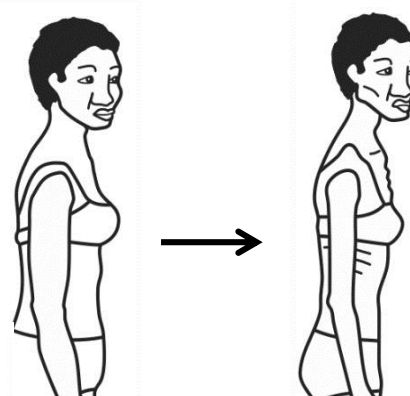
Sweating at night



Coughing up some blood



Lost a lot of weight



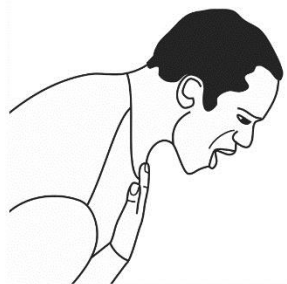
Have a fever



Don't feel like eating

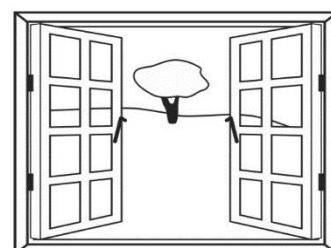


Nausea



Prevent the spread of TB

Use a bent arm to cover the mouth when coughing

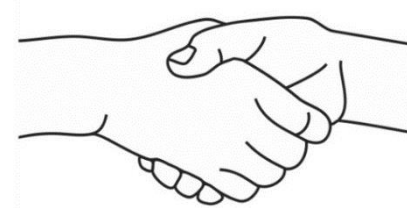


Always open windows to allow for fresh air

How TB is NOT spread



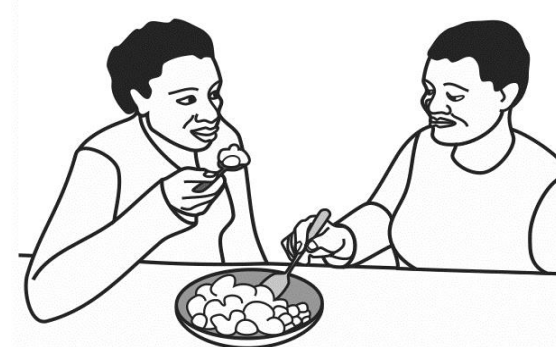
Hugging



Shaking / holding hands



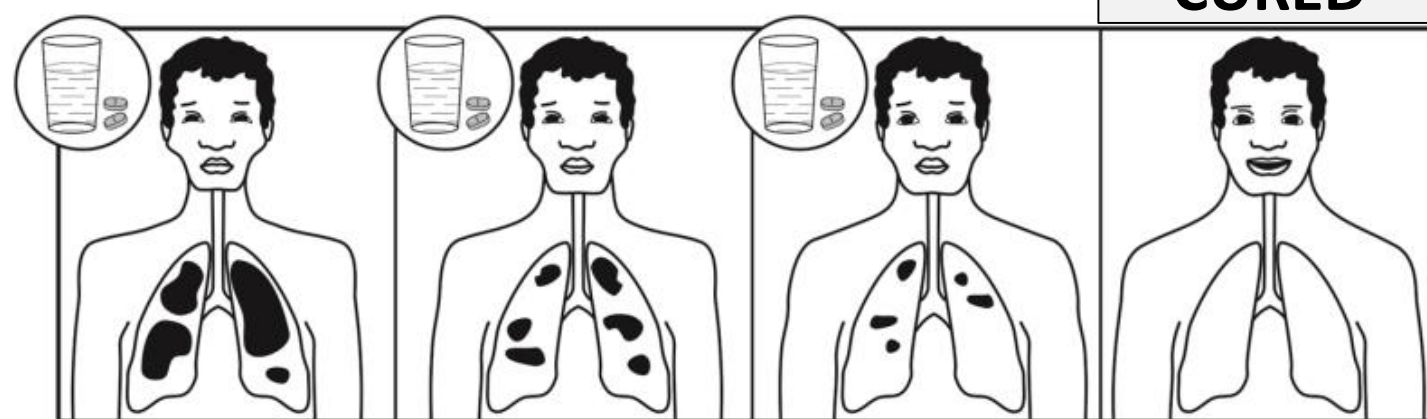
Sharing a toilet



Sharing food / drinks

TB can be cured

TB can be cured by taking TB medicine correctly



HIV / AIDS and TB

A person with HIV:

- should regularly get tested for TB
- is more likely to get sick with TB
- can be cured of TB

IMPORTANT!
Anyone can get TB



I-TB (Sisifo Sephepha)



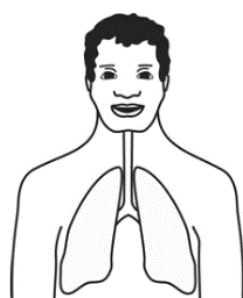
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Yintoni i-TB?

I-TB ibangwa ziintsholongwane
I-TB ikakhulu ihlasela imiphunga

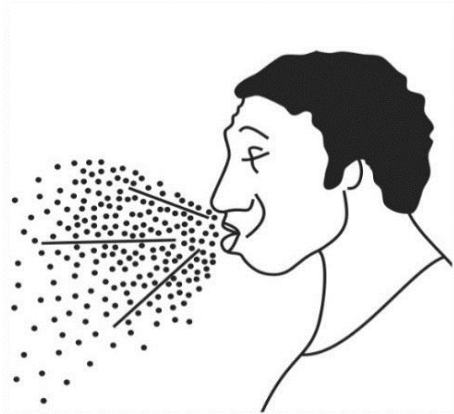


Isasazeka njani i-TB?

I-TB ingasasaseka, isuke komnye umuntu iye komnye xa iintsholongwane zibhabha emoyeni xa umntu one-TB ekhohlela, ethima okanye etshica



ekhohlela



ethimla



etshica

Imiqondiso neempawu

Yiya ekliniki uvavanywe ukuba ufumanise ezizinto zilandelayo

Xa ukhohlela ngaphezu kosukuolunye



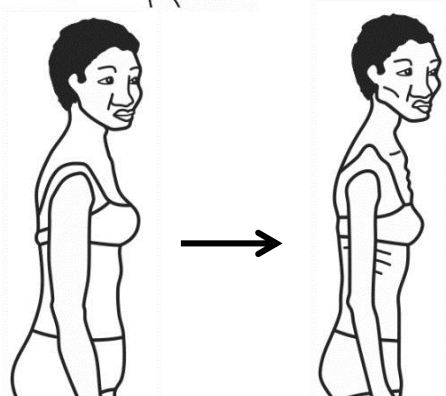
Ukubila ebusuku



Ukukhohlela igazi



Ukuhla ubunzima



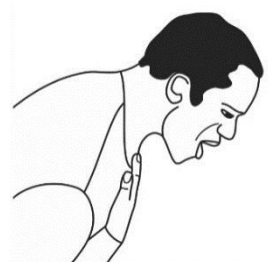
Xa umntu ene fever



Angakhanuki kutya

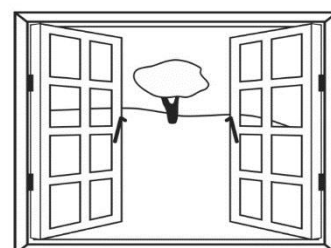


Isicaphu-caphu



Thintela ukunwenwa kwe-TB

Goba ingalo yakho ugqume umlomo wako xa ukhohlela



Hlala uzivulile iifestile ngalo lonke ixesha ukuze kungene umoya

I-TB ayisasazeki:



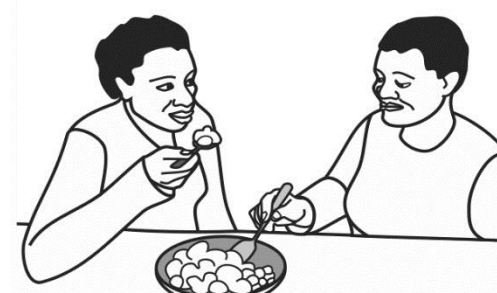
Ngokugonana



Ngokubambana ngezandla



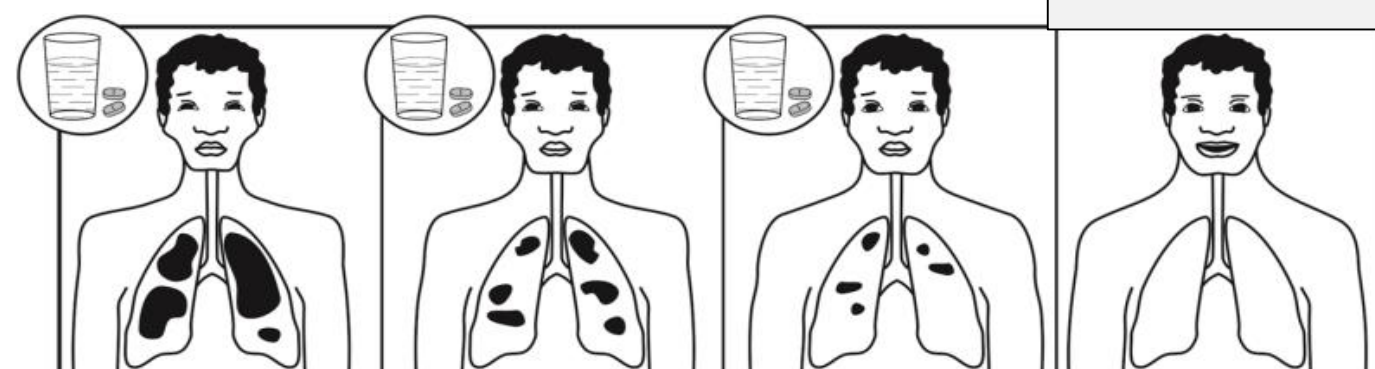
Ngokusebenzisa ithoyilethini enye



Ngokwabelana ngokutya

I-TB inako ukunyangeka

TB inganyangeka ngokuthi usebenzise iyeza layo ngendlela eyiyo

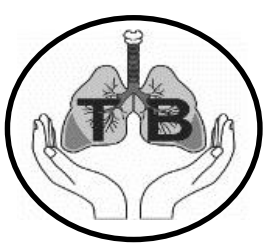


I-HIV ne TB

Umntu one-HIV:

- makavavanywe rhoqo i-TB
- kulula ukuba agule yi-TB
- anganyangeka i-TB

OKUBALULEKILEYO!
Nabani na angayifumana i-TB



TB (Tuberkulose)



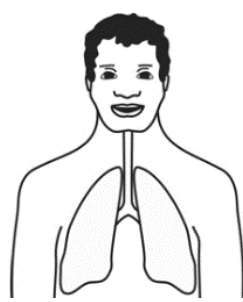
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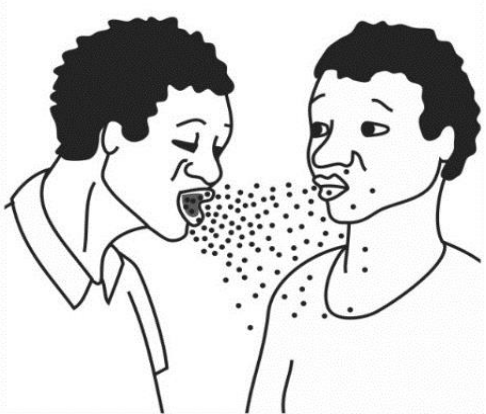
Wat is TB?

TB word veroorsaak deur
bakterieë (kieme)
TB tas meestal die longe aan

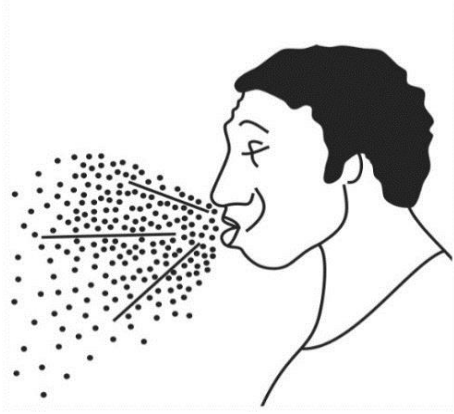


Hoe TB is versprei

TB kan versprei word tussen persone
wanneer geïnfekteerde persone die
kieme in die lug vrystel deur te hoes,
te nies, te spoeg ens.



Te hoes



Te nies



Te spoeg

Tekens en simptome

Gaan na die kliniek om getoets te
word indien u enige van die volgende
ervaar:

'n Hoes vir langermore meer as 'n
dag



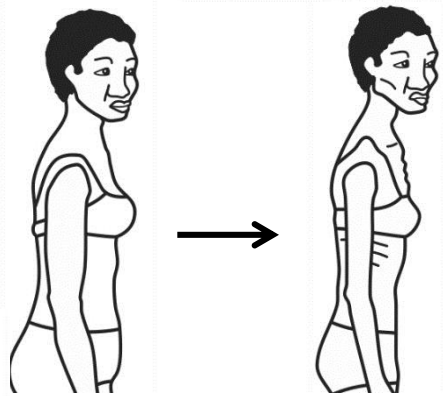
Nagswete



Die ophoes van bloed



Verloor baie gewig



Koorstig is



Swak eetlus het

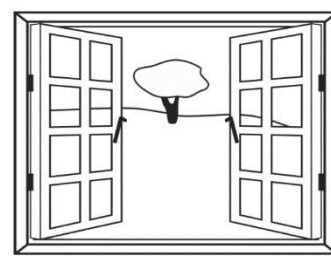


Naarheid



Om verspreiding van TB te voorkom

Bedek die mond wanneer
daar gehoes word



Maak altyd die vensters
oop vir vars lug

Hoe word TB nie versprei nie



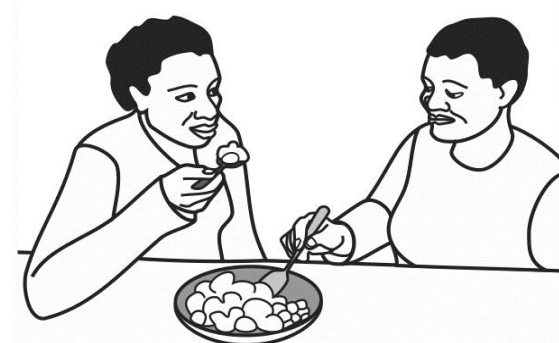
Drukkies nie



Handrukke nie



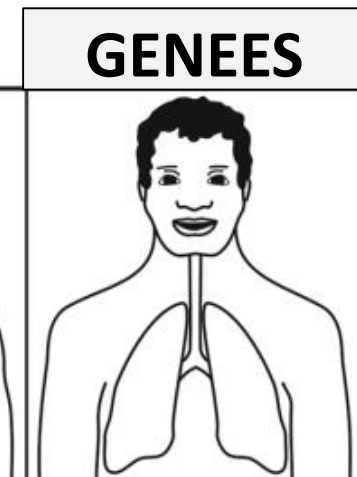
Toilette te deel
nie



Kos en drinkgoed te
deel nie

TB kan genees word

TB kan genees word deur die
inname van TB medisyne



HIV / VIGS en TB

'n Persoon met HIV:

- moet gereeld getoets vir TB
- is meer geneig om siek te word met TB
- kan genees word van TB

BELANGRIK!
Enige iemand kan TB kry