

A FORMATIVE EVALUATION OF INTEGRATED COMMUNITY-BASED TREATMENT AND ADHERENCE SUPPORT MODELS FOR TB AND HIV CLIENTS

CONDUCTED BY
Health Systems Research Unit, Medical Research Council
TB/HIV Care Association



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A formative evaluation of integrated community-based treatment and adherence support models for TB and HIV clients implemented in the Cape Metropole

Key messages

1. The study confirms the feasibility of integrating community-based care for clients living with TB and HIV. Evaluation of the health outcomes of integrated models that are implemented at scale, and outside of research settings, is needed to confirm the effectiveness of these approaches.
2. Providing support to co-infected clients using one care worker appears to be less intrusive and disruptive than having different carers support these clients, and is an important benefit of integrating community-based services.
3. Clients were very positive about their experiences of services rendered by community care workers (CCWs). The majority of clients on directly observed treatment for TB would prefer self-administered treatment at home, however a notable proportion of these clients indicated a preference for care worker-support during self-administration.
4. Community care workers often become intimately involved in the psycho-social realities of clients and they noted that working with individuals with serious, and often stigmatised, diseases is emotionally stressful. It is therefore important that:
 - CCW training include both the bio-medical aspects of TB and HIV and the psycho-social aspects of living with these diseases.
 - 'Caring for the Carer' programmes be put in place to help CCWs manage these stresses.
5. Identifying clients at-risk of non-adherence and who need intensified CCW care and support, and using this information to prioritise CCWs' work, is an effective way to manage the caseload of care workers.
6. Establishing and maintaining high morale among CCWs is an important component of ensuring the delivery of quality services. Providing non-monetary incentives in recognition of their work is as important to CCWs as increased stipends.
7. The monitoring and evaluation tools used in the study sites strengthened the delivery of CCW services. These tools should be included in programmes that employ CCWs to provide treatment and adherence support to individuals living with TB and HIV.

Executive summary

Introduction

Health authorities in the Western Cape are supporting different models of integrating community-based services to clients co-infected with TB and HIV. There is some evidence that such models may lead to favourable treatment outcomes. However, there is less evidence on how these models are being implemented across different settings. This report details the findings of such a formative evaluation this was conducted during 2010.

Study aim and Sites

This study aimed to evaluate how community care workers (CCWs) provide treatment and adherence support to TB, HIV and co-infected clients, in order to strengthen the integration of services to these clients. The evaluation was conducted in three health care facilities and their surrounding neighbourhoods. The CCWs were employed by TB/HIV Care Association (THCA).

Methods

This comprised the following:

- A time and motion study was conducted with 51% of the CCWs across the sites. This detailed CCW activities and the time spent on these activities.
- A survey assessing various components of CCW and facility services was administered to 226 clients.
- The content and nature of CCW - client interactions during support visits were observed.
- Five clients were recruited to keep visual and/or audio diaries of their treatment experiences to explore the enablers of, and barriers to, treatment adherence.
- Formal and informal interviews were conducted with CCWs, clients, and representatives of the health authorities as well as THCA to explore their experiences and perceptions on how services are delivered to TB and HIV clients.

Key findings

1. Community care workers are often the health care providers with the most intimate knowledge of clients' circumstances and how these impact on treatment and adherence. Clinical staff solicit and respect their input.
2. Appropriate structures and human resources policies for the care workers are in place and function well, and the appointment of community team leaders is an effective way to manage CCWs. Line-management procedures are established to guide the interaction between THCA and facility staff in managing the CCWs.
3. THCA implements a range of measures to account for the services they provide. However, CCWs often feel overburdened with these administrative tasks.

4. Most care workers feel that their managers are not fully acquainted with the challenging conditions of their work, and feel they often have to take on tasks not included in their job description.
5. CCWs would like to share in non-monetary recognition as a token of appreciation for their contribution to cure rates and other improved health outcomes of clients.

Key recommendations

1. Integrated community-based care to co-infected clients, i.e. one care worker to serve these individuals, should be implemented to scale.
2. The system by which clinical staff identify at-risk clients should be considered for wider implementation. This identification should happen in consultation with the CCWs.
3. Local estimates of walking, waiting and client visiting times should be taken into consideration in determining the optimal caseload for care workers.
4. Training on the bio-medical aspects of these diseases should be balanced with information on the psycho-social meaning of being infected, and practical hints to deal with clients who are not able to adhere to treatment.
5. Employing agencies of CCWs should acknowledge the emotional stresses involved in caring for TB and HIV clients, and have systems in place to address this.
6. Non-monetary recognition and shows of appreciation can play an important role in ensuring high morale among care workers.
7. Sustained monitoring and evaluation of CCWs' performance, and attention to their training needs, are needed to ensure that clients receive quality care.
8. Any CCW who is appointed to a leadership and/or management position should receive training and support in the skills needed.
9. A clear understanding of their respective roles and responsibilities should guide collaboration between non-governmental organisations and health authorities in the management of CCWs.

Abbreviations and Definitions

ART/ARV clients: It is interchangeably used to refer to clients who are on antiretroviral therapy.

CBS: Community-based services.

CCW: Community care worker; interchangeably referred to as care worker, who provide treatment and adherence support to clients.

CDoH: City of Cape Town Department of Health.

Clinical staff: Doctors and nurses with professional training at health care facilities.

Co-infected clients: Individuals co-infected with TB and HIV.

Coordinator: THCA's district coordinator that oversees one or more CTLs and CCW teams.

CTL: Community team leader that oversees CCW team(s), and reports to the coordinator.

DOT: Directly observed therapy for TB clients.

Facility: Clinic, community health centre or hospital that provides services to TB and/or HIV clients.

HCT: HIV counseling and testing.

M&E: Monitoring and evaluation system.

NGO: Non-governmental organisation.

THCA: TB/HIV Care Association.

WCDoH: Western Cape Provincial Department of Health.

Introduction

The need to better integrate services, in particular at primary care level, to address the needs of people with TB and HIV infections in South Africa, has resulted in the piloting of different models of care. In the Cape Metropole, at least three such models have been implemented, including: (i) the Enhanced TB Adherence programme, referred to as the ETA model (TB treatment is modeled on the antiretroviral therapy (ART) programme at some non-ART sites in which weekly adherence support is provided rather than DOT), (ii) the integration model in Clinic 2, which served as a pilot for integration (similar to the ETA, but Clinic 2 serves both TB and HIV clients), and (iii) in selected sites, a model of care delivered where co-infected clients receive adherence support from one community care worker (CCW), though directly observed therapy (DOT) to TB clients and weekly support to ART clients. All of these models are supported by the City of Cape Town Department of Health (CDoH) and the Western Cape Provincial Department of Health (WCDoH), in collaboration with TB/HIV Care Association (THCA) that employs the CCWs.

Evidence of effectiveness of these models is critical for policy decisions. However, it is equally important to document and evaluate implementation processes, particularly during the piloting of these models, as such evaluation provides the context for analysing and understanding the outcomes of the different models, and for exploring where improvements are needed. This report details the results of such a formative evaluation of integrated community-based services to TB, HIV and co-infected clients in three communities in the Cape Metropole, that was conducted in 2010.

Study

1. Aim and Objectives

The study aimed to inform further development of treatment and care delivery strategies provided by CCWs to TB, HIV and co-infected clients. In order to achieve this, the following objectives were set:

- a. To describe and evaluate the implementation processes of integrated community care worker models for TB, HIV and co-infected clients in the Cape Metropole;
- b. To explore the experiences and receptivity of clients, CCWs, health authorities and NGO management regarding the integrated programme; and
- c. To develop process indicators¹ for a successfully integrated TB and HIV treatment support programme.

2. Sites

The three primary health care facilities in which the study was conducted were purposively selected by the CDoH, WCDoH and THCA (as employing NGO for the CCWs), on the basis of

¹ Process indicators are measures of the successful implementation of a programme rather than of its outcomes. Such indicators would include components such as the supervision of CCWs, their case load, retention of clients and CCWs, and the collaboration between facility staff and CCWs.

variation in the types of integration models implemented. Whilst ART and TB treatment are provided at Clinic 1 and 2, Clinic 3 only offers TB services, hence the local hospital was included as it is the ART facility that serves the community of Clinic 3. Clients from Clinic 3 and the supporting ART clinic are supported by the same team of CCWs.

3. Methods

A range of quantitative and qualitative methods were used. Some methods were implemented across all sites and others only in specific sites, due to resource and time constraints. The two tables below detail the methods used in each site and how these methods relate to the study objectives. This is followed by a description of how these methods were applied.

Table 1a: Data collection methods per site

Sites	Data collection methods				
	Time and Motion	Survey	Client-CCW observation	Diary keeping	Interviews
Clinic 1	✓	✓	✓	✓	✓
Clinic 2	✓	✓	X	X	✓
Clinic 3	✓	✓	X	✓	✓

Table 1b: Data collection methods in relation to the study objectives

Study objective	Method (Participants)
To describe the roles of CCWs	Time and Motion , in which the activities and time spent on each activity was recorded (CCWs)
To assess clients' experiences and perceptions of CCWs and of facility services	Survey (Clients)
To understand how CCW support services are delivered	Observation of the content, nature and interactions of CCWs' adherence support visits to clients (Clients and CCWs)
To understand how clients experience their illness and how they manage it with the support of care workers	Diary keeping (Clients)
To understand the perceptions and experiences of clients and service providers (from care worker level to that of management) regarding community-based services	Interviews (Clients, CCWs, clinical staff, health authorities - and THCA management)

Time and Motion study

CCWs in all three sites were asked for their consent to participate. Consenting care workers were shadowed by a researcher, and a stop watch and recording sheet used to record each activity and the time spent on it. No selection criteria were applied to the CCWs as it was understood that their duties were similar across the sites. The community team leaders (CTLs) were observed over more than one day, as were the care workers who undertook community visits and worked in the clinic. The 23 CCWs, including CTLs, that participated, represent 51% of CCWs in the study sites. The data were captured and analysed in Excel.

Client survey

The survey questionnaire comprised the following components:

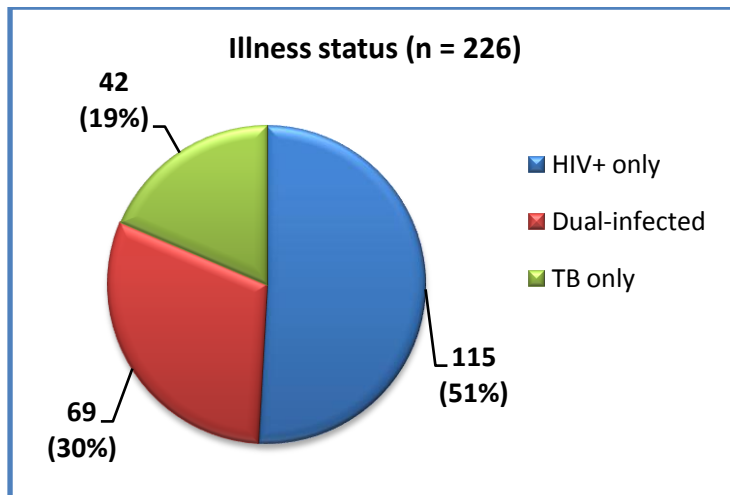
- Clients' assessment of TB and ART counseling, of adherence support visits by CCWs and of services at the facility
- Treatment location preference for TB clients
- General knowledge of HIV and TB among clients

Clinical staff distributed information letters to all clients attending the health facilities in the three sites and referred those interested to the researcher, who obtained consent and administered the survey. Table 2 shows the sample sizes across sites. The survey in Clinic 3 was conducted at three sites: Clinic 3 (TB services only), the local hospital (ART services only), and a community centre (DOT service only) which serves an informal settlement near Clinic 3. Chart 1 provides a breakdown of respondents by illness status, collated for all sites (See Appendices 1a and 1b for more detail). The data were captured and analysed in Excel.

Table 2: Survey sample size across sites

Sites	N (%)
Clinic 1	71 (31%)
Clinic 2	70 (31%)
Clinic 3	85 (38%)
Total	226

Chart 1: Survey participants' illness status: all sites



Observations of Client-CCW interactions

These observations differed from those of the Time and Motion study as they aimed to document the details of interactions between client and care worker during adherence support visits. The researcher identified two CCWs that had clients with a range of problems, including poor adherence to treatment, and with whom the researcher had established rapport during the Time and Motion study. Informed consent was obtained from clients, and five CCW support visits to clients (in total seven clients, as two of these visits were to couples) were observed (see Appendix 2 for the observation guide). The visits were audio-recorded and analysed thematically.

Diary keeping on illness experiences

Because diary keeping is an intensive and experimental method, only five participants were recruited through the CCWs in Clinic 1 and 3. These individuals were living with HIV and/or TB, and either on treatment, or in preparation for treatment for their illnesses. Participants received a disposable camera and/or digital audio recorder, and were requested to share through photos and/or audio recordings (seen as diary entries), their everyday experiences related to: (i) their treatment itinerary (i.e. their interactions with the health services), (ii) barriers and enablers to treatment adherence, and (iii) events and issues impacting on their quality of life. After the researcher had received their photos and audio recordings, research conversations were conducted about these data. Participants were followed for between four and eight months. The demographic profile of participants and fieldwork details are presented in Appendices 3a and 3b.

Formal and informal interviews

Interviews were conducted with CCWs, CTLs, clinical - and management staff from the delivery organisations and one academic working in the field. Interviews with CCWs and CTLs focused on their challenges, their interactions with THCA management, and the factors motivating them to

become CCWs. Some of these interviews were conducted informally during the Time and Motion study fieldwork. Clients responded to questions on adherence and their views on the care provided by CCWs. Formal interviews were conducted with clinical staff, officials from CDoH, WCDoh and THCA management. These interviews focused on the strengths and challenges of the current management systems for CCWs. Table 3 summarises the range of participants who participated in formal interviews.

Table 3: Formal interview participants

Position	Number of participants
CCW	7
CTL	4
Clinical staff: ARV doctor, TB sisters	3
THCA management	3
Health authority management	3
Academic	1
Total	21

Results

The results begin with a description of the implementation of the different care integration models, followed by (i) clients' views and experiences of services, (ii) CCWs' experiences and perceptions of being a care worker, and (iii) the views and experiences of managers on managing community care workers². Each section begins with a summary of the key findings followed by a detailed description of the data.

1. Implementation processes across the study sites

This section outlines THCA's management structure for CCWs and provides a summary of the main demographic characteristics of the CCWs. A detailed description of how the services are delivered is then presented. This is based on informal observations of practise, the Time and Motion fieldwork, interviews, and a review of programmatic documentation from THCA and the health authorities.

1.1 Key findings

- a. THCA has a well developed a structure for the management of CCWs, of which the appointment of community team leaders is a good practice to manage the care workers.
- b. Community-based care generally was provided in accordance with existing guidelines from the health authorities and THCA management. However, there is currently no

² Referencing participants in quotes or paraphrases is done in brackets at the end of a quote or paraphrase.

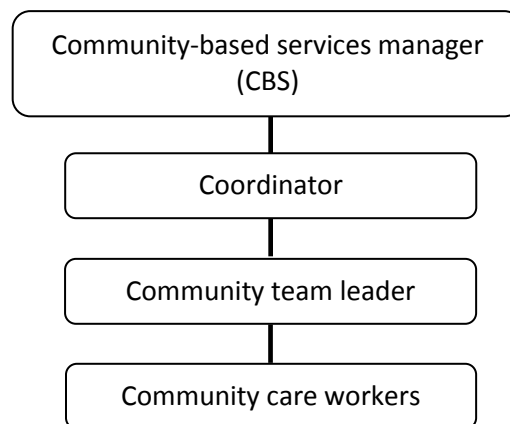
written protocol that could serve as checklist to structure the sequence and content of care workers' support visits to clients.

- c. The models across the sites mainly differ on how treatment is provided to clients infected with TB.
- d. Two practices were observed that help to streamline and support CCWs' work:
 - Identifying ART clients at-risk of non-adherence that need intensified care and support, and using this information to prioritise CCWs' work.
 - Improving how care workers are introduced to ART clients so as to build stronger rapport between the client and her/his care worker.
- e. In the absence of guidelines on ART client-caseloads for CCWs it is not possible to assess whether current practice aligns with what is expected in this regard.

1.2 CCWs: management structure, demographics and caseload

TB/HIV Care Association has a well established line-management system, depicted below, within which the CCWs function.

Flowchart 1: THCA's line-management structure



The CBS manager assumes overall responsibility for the community-based services, whereas the coordinators (not recruited from the community) are the first line of reporting for the team leaders and are responsible for managing the care workers through the CTLs. All community team leaders are, like the care workers, recruited from the community. The CTLs are the first line of management for the CCWs, and also serve as link between the clinical staff and CCWs.

All care workers must have prior lay health worker experience within the field of TB and HIV. The Clinic 3 team is unique in that the majority of them are also experienced home-based carers, and some still provide home-based care services in their own time.

Table 4 summarises the demographic profile and caseloads of CCWs across the study sites. The average number of clients supported by CCWs in Clinic 1 is considerably higher

than for Clinic 2 and Clinic 3. Differences across the sites were also observed regarding educational level and average age.

Table 4: CCW demographics and caseloads across sites

Site	Average Age	Educational level	Average client caseload of CCWs
Clinic 1	31	Gr. 10 and lower: 9 Gr. 11 and higher: 4	62
Clinic 2	38	Gr. 10 and lower: 4 Gr. 11 and higher: 10	17
Clinic 3¹	48	Gr. 10 and lower: 9 Gr. 11 and higher: 5	TB Clinic and ART clinic: 10 Community DOT centre: 38

¹ TB services are provided at the clinic and a community centre, and ART at the local hospital in the community.

1.3 Care by CCWs to clients on ART

Assigning clients to a CCW and treatment counseling

- At weekly clinic-based case management meetings, a CCW is assigned to each client, based on geographical proximity between client and CCW. The client’s preference for a specific CCW overrides geographic proximity.
- The client is expected to recruit a treatment buddy, usually a confidant such as a friend or family member, to provide additional, informal treatment support.
- The assigned CCW should conduct a home assessment before treatment commences, to record the social and housing conditions of the client and assess potential non-adherence risks.
- Treatment counseling is provided by lay counselors using flipcharts and other materials. Clients must attend three to four sessions before treatment commences.

Adherence support visits and visit frequency

- The care worker provides both medical (pill counts and checking for side-effects) and social (help with non-disclosure and social problems) support to clients during visits.
- During weeks 1 and 2 following assignment, clients should be visited daily, but in practice the frequency is 2-3 times per week; if it is found that the client is not managing well, the CCW may visit more frequently. Thereafter, visits tail off to weekly for the remainder of month 1. Once the client is coping with the adherence routine, the CCW will conduct one or two visits per month.

1.4 Care by CCWs to clients on TB treatment

Assigning clients to a CCW and treatment counseling

- Following diagnosis, DOT is administered at the clinic for two to four weeks to monitor adherence and side effects, after which adherent clients are placed out for community-DOT (Clinic 3 and partly in Clinic 1). In Clinic 1 and 2, identified adherent clients, self-administer their treatment with weekly CCW support visits after the clinic-DOT period. The CTL will assign the CCW who stays nearest to the client as their supporter.
- The procedure for home assessments is the same as for ART clients.
- TB treatment counseling is provided using flipcharts and other materials, but is not required before treatment commences, and often happens during the period of clinic-based DOT. The counseling is conducted by the clinical staff, sometimes assisted by the CTL.

Community-based DOT

- In Clinic 1 and 3, DOT is administered either at the CCW's house, a community centre, or at the client's home when he/she is bedridden.
- Non-adherent clients are referred back to clinic-based DOT.

Adherence support visits

- Visits to clients' homes are conducted only in Clinic 2 where TB treatment is self-administered: the care worker does a pill count and monitors side effects. In Clinic 1 and 3, CCWs will immediately do recall visits for clients that do not attend for DOT.

1.5 Care by CCWs to co-infected clients

Variations in the integration of care

Though all sites assign one CCW to co-infected clients, there are important differences in this regard:

- In Clinic 1, TB treatment is self-administered with CCW support visits, but only after the client has been on DOT with a care worker for between two to four weeks. If the client is adherent during this period, the CCW will recommend self-administration to the clinical staff. Clients not recommended for self-administration, remain CCW-DOT clients.
- In Clinic 2, TB treatment follows the same strategy as for ART: after two weeks of clinic-based treatment, monthly medication is supplied to identified adherent clients, and these clients self-administer their treatment with weekly CCW support visits. Non-adherent clients or those suffering from side-effects remain clinic-DOT clients.
- DOT is still administered to all TB clients in Clinic 3.

1.6 Education, awareness and referral services

- In all sites, CCWs are expected to participate in education and awareness campaigns in the community, which include TB and STI screening, promoting HIV counseling and testing (HCT) and sharing health information related to TB, STIs and HIV/AIDS.
- CCWs are encouraged to refer clients and others in their household to the primary health care clinic for specific health issues. For each referral, the care worker completes two cards: one goes onto the clinic's folder system, and the other is collected by the CTL. This allows the CTL to record the number of referrals from each CCW.



Photo 1: A care workers writes a referral for TB services

1.7 Site specific practices

Client classification system: Clinic 2 and Clinic 1

ART clients at Clinic 2 are categorised as 'green' or 'red' based on their treatment adherence, and on whether they have experienced any side-effects. The 'red' category indicates a client who has been noted to have poor management of treatment, non-adherence and/or side-effects, and so needs more intensive CCW support and supervision. As one CCW noted: *"This is a green patient, according to the clinic. If you take your medication regularly and correctly, then you become green. You become red when there is something wrong in what you are doing."*

The same prioritising of clients that need regular support visits was observed in Clinic 1, though without being formalised in 'green' and 'red' clients. CCWs may therefore have a high number of clients assigned to them (see Table 4), but not all ART clients require weekly or bi-weekly visits.

Client-held card for CCW home visits: Clinic 2

Clients keep a card that the CCW has to sign as proof that she/he has conducted an adherence support visit. Clients hand this card in during their monthly clinic visits.

Assigning of ARV clients: Clinic 3

The CCW is formally introduced by the clinical staff to the client before treatment commences. The CCW then joins the client for the last two counseling sessions and is also present during the visit to the doctor when treatment is initiated.

Door-to-door visits: Clinic 3

Each CCW is expected to do six door-to-door visits per day to households in the community, during which the same activities described in *Point 1.6* happen. This may be possible in this area because of lower client caseloads than in the other sites.

2. The roles of community care workers: Clients' views and experiences of services

This section presents findings from the survey of 226 clients, diary keeping and informal interviews with clients.

2.1 Key findings

- a. Most clients have positive reports of: (i) the value of the adherence visit, counseling and facility services; and (ii) how they are treated by CCWs and counselors.
- b. CCWs not only provide treatment and adherence support, but are called-upon by clients to assist with a range of social problems, and become intimately involved in the personal lives of their clients.
- c. 67% of TB clients on DOT would prefer self-administered treatment, and 44% of them would prefer for their self-administration to be supported by a CCW.
- d. Of the clients who have received TB and/or HIV counseling, 69% indicated that they would like to have received information materials that they could have taken home after completion of treatment counseling.
- e. The survey findings suggest that not all clients received a visit at start of treatment, and there is variation across sites in the frequency of visits to clients.
- f. Some misconceptions around TB, HIV, and its treatment, still prevail among clients.

2.2 Clients views and experiences of CCW services: Survey data

Visits at the start of treatment

61% of ART only clients that responded to this question (n = 97) indicated that they received a visit from a CCW at start of treatment. There were differences across sites in the proportion of clients receiving such visits, with 74%, 65% and 44% reported in Clinic 1, 2 and 3 respectively.

The wording of the question didn't specify '*baseline home assessment*', and could be the reason for the low percentages reported. These home assessments are more rigorously done, since commencement of ART requires the filing of the home assessment form on

the client’s folder (see *Point 1.3*). It is therefore reasonable to conclude that the responses are under-reporting the situation of the home assessment visits. It may also be due to the fact that the survey sampled all clients regardless of whether an individual received community-based adherence support.

Adherence support visits to ART and co-infected clients

Only 24 clients (44%) on ART or on ART and TB treatment, and listed as in care of a CCW (n = 55), reported that they received adherence support visits at the time of the survey: 42%, 38% and 53% respectively in Clinic 1, 2 and 3. Two issues might explain this: firstly, the high client load in both Clinic 1 and 2 has resulted in CCWs prioritising visits to non-adherent clients; and secondly, CCWs reported that when they take clients over from another CCW, is it difficult to find these clients’ homes.

These 51 clients also reported differences between the sites regarding the frequency of these visits (see Table 5).

Table 5: CCW adherence support visit frequency

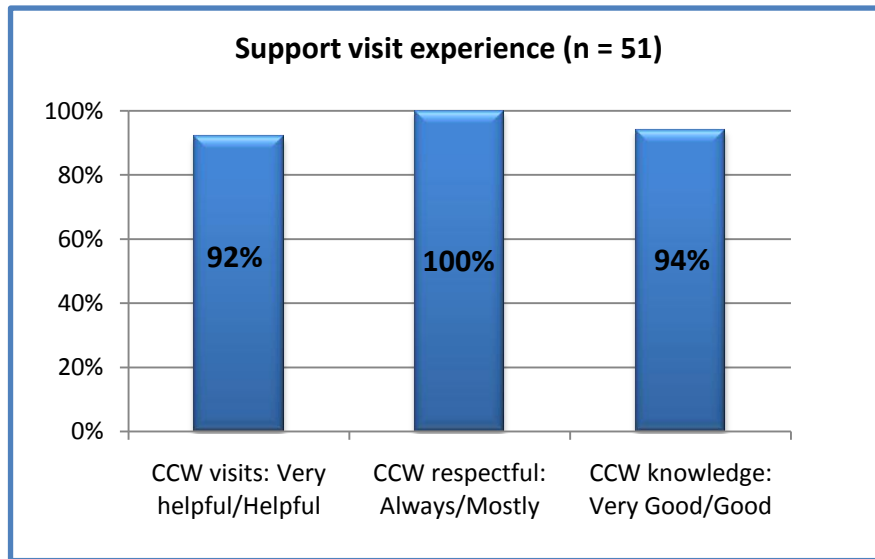
Site	Proportions of clients reporting frequencies of visits			
	Weekly/> once a week/ bi-weekly (%)	3-4 weekly (%)	No routine (%)	When the client calls the CCW (%)
Clinic 1	92	8	-	-
Clinic 2	36	19	45	-
Clinic 3	52	10	26	12

The majority of clients (69%) who received visits, was satisfied with the current frequency of CCW visits; 21% would have liked to receive more visits and 10% were unsure.

The content of adherence support visits varied across sites. In Clinic 3 it was observed that more attention was given to social support than to conducting pill counts, whilst the reverse was true in Clinic 2. In addition, the Time and Motion study indicated that the visits in Clinic 2 were more structured than in Clinic 3. This may reflect the more intensive CDoH training and support received by care workers in this site.

Those clients who received visits viewed these very positively (Graph 1). However, clients reported that only 44% of CCWs in Clinic 2, and 62% in Clinic 3, mostly or always kept their appointments, which is in sharp contrast with the 100% reported in Clinic 1.

Graph 1: Clients' perceptions of CCW support visits



Of the 51 clients on ART, including co-infected clients on TB treatment, who reported receiving visits at the time of the survey, 69% (35 clients) indicated that the CCW conducted a pill count during the visit (81%, 67% and 39% in Clinic 1, 2 and 3 respectively). All of these clients said that the CCW gave feedback on the pill count.

Finally, the survey revealed that 67% (n = 69) of DOT clients would prefer to take their treatment at their home. 44% of these clients indicated that they would still prefer to do so with support from a care worker, providing further evidence (see Graph 1) that clients' experiences of CCWs are very positive.

2.3 Clients' views and experiences of facility services: Survey data

In brief, clients from all three sites had very positive views on their experiences of facility services and on the counseling (for ART and TB treatment) received (see Appendix 4a and 4b). 95% of clients indicated that they were very satisfied or satisfied with the TB and ART services at the facilities. With respect to the counseling, 72% and 65% of clients who received ART and TB counseling respectively, indicated that they would have preferred to have received materials to take home after their counseling.

2.4 Clients' knowledge regarding TB and HIV: Survey data

The last section of the survey focused on clients' general knowledge regarding TB and HIV. Table 6 highlights several indicators for which the level of knowledge could be improved.

Table 6: Clients’ general knowledge of TB and HIV

Survey question	Yes/Don’t know (%)
Can TB treatment be stopped when you start to feel better?	8
Can ARV treatment be stopped when you start to feel better?	10
When the CD4 is < than 200, the body is strong enough to fight the virus.	29
When someone is infected with TB, does it automatically mean that he/she is also HIV+ ?	33

2.5 The role of the CCWs in the day-to-day lives of clients: Interviews and Diary keeping data

The interview and diary data indicate that care workers not only play an important role in clients’ health care, but often go beyond what is expected of them in providing care to clients.

Helping people to cope with their illness

Many clients noted that the presence of a community care worker helps them to deal with their illness. This ranges from alleviating their fears: *“I was so scared, really scared to start with ARVs, and Sister [CCW] helped me to deal with it.” (Client)*; to being the only source of support to clients: *“Because every time she [CCW] comes, she makes sure that everything is going well. So it’s better than to sit here alone.” (Client)*. CCWs are often called after hours to provide support to their clients. For example, a diary participant related how her supporter had to visit her on a Friday night because she was experiencing severe ART side-effects. Clients appreciated not only the medical care that they received, but also the caring attitude of CCWs. This was particularly the case for those clients who were bedridden and terminally ill. Clients also commented that patience and good communication skills are characteristics that a care worker must have: *“... she [CCW] talks in the right way to me.” (Client)*.

Taking on additional roles and tasks

Many instances were cited by clients, and also observed, of care workers taking on tasks and roles in addition to treatment and adherence support. This included: visiting a client after he appeared in court to make sure that he was coping; helping a client to access government aid to start a food garden; and accompanying a client to the police station or welfare offices.

3. Being a community care worker: CCWs’ activities, experiences and perceptions

The findings presented here are drawn from the Time and Motion fieldwork, in-field observations, informal and formal interviews, as well as from client-CCW observations. The scope of practice and experiences of team leaders, and the activities and experiences of care workers are presented. For both cadres, the results refer to clinic duties and

adherence support visits only, as no education and awareness campaigns (see *Point 1.6*) were attended by the researchers during the study period.

3.1 Key findings

- a. CCWs spent a substantial proportion of their time in the community (36 to 73%) either walking between clients' houses or waiting for clients.
- b. During adherence support visits care workers have to deal with a range of psychosocial issues related to living with TB and HIV. At times, they feel that they are not equipped to deal with such matters.
- c. CCWs experienced many aspects of their work as stressful and need regular debriefing opportunities.
- d. Care workers want non-monetary recognition and appreciation for their work.
- e. When CCWs are also clinic-based, in addition to conducting adherence visits, they spend a considerable proportion of their time doing nothing while waiting for clients to arrive. This reduces the time available for adherence support visits in the community.
- f. Community team leaders experience the managing of CCWs as stressful, and would prefer more support and training in management skills; current initiatives in this regard are a step in the right direction.

3.2 Community team leaders: roles and activities

In addition to managing the care workers (Flowchart 1), CTLs undertake a number of clinic- and community-based tasks. The data presented below provides a detailed account of what each of these activities entail.

Managing CCWs

CTLs' responsibilities include human resources issues regarding the CCWs, such as assistance with recruitment and appointment, their leave, and travel claims. While they saw their role as generally strenuous, they found the following tasks to be particularly stressful: ensuring that care workers submit their monitoring and evaluation reports on time; maintaining high morale among the team; and addressing service delivery problems raised by either facility staff or THCA management. In this, all of them requested more support from their coordinators, and felt that sufficient support was not always forthcoming: "... but sometimes it feels as if you are talking to a wall." (CTL).

Activities and time spent at the clinic

Table 7 provides a summary of the data from the Time and Motion study on the key activities undertaken by CTLs and the time spent on these. In Clinic 1, the total time spent observing the team leader was nearly 12 hours, in Clinic 2, almost six hours, and for Clinic 3 approximately eight hours. Each category of activities is expressed as the percentage of the total observed time.

Table 7: CTL activities¹ in the clinic

Site	Contact with clients	M&E admin	Managing CCWs and other admin	Break	Case management meeting ²
Clinic 1	11%	28%	32%	3%	26%
Clinic 2	not observed ³	not observed	100% ⁴	not observed	not observed
Clinic 3	13%	28%	39%	20% ⁵	not observed

¹ The activities included in each category are as follows:

Contact with clients: Weighing; screening and counseling; administering DOT (on average 3 minutes per client); doing pill counts.

M&E administration: Completing THCA's monitoring and evaluation forms.

Managing CCWs and other administration: Managing CCWs, either through meetings or phone calls; labeling sputum jars; cleaning the workspace; updating client folders; interaction with clinical staff; attending clinic staff meetings.

Case management meetings: Joint meeting between clinical staff and CCWs during which clients are assigned to CCWs, and clients' problems regarding their illness are discussed.

² The duration of case management meetings varies across sites: in Clinic 1 between 86 and 94 minutes, Clinic 2 between 90 and 120 minutes, and Clinic 3 between 45 and 60 minutes.

³ The *not observed* only indicates that these activities did not happen during the observation days.

⁴ The Clinic 2 team leader was recently appointed and had to attend to the backlog on her administrative duties. The proportion of time she spent on activities during the observation, was as follows:

- CCW admin and managing CCWs: 70%
- Updating clients' folders: 13%
- Collecting and replacing folders: 17%

⁵ The team leaders reported that they haven't taken lunch on the previous day because of their workload, and hence the longer break during the time of the observation.

Team leaders reported often being asked to assist with facility services that are not part of their job description. In all sites they do so with enthusiasm, however they were wary of the legal implications of becoming involved in tasks such as preparing, and in some cases writing, prescriptions for TB medication that are then signed-off by clinical staff.

Community activities

Although these activities were informally observed in Clinic 3 only, the CTLs in the other sites confirmed that they have similar duties:

- Conducting quality assurance assessment visits with care workers as part of their support and supervision duties.
- Conducting client recall visits on request from clinical staff.
- Accompanying CCWs when they encounter problems with difficult clients.

3.3 Community care workers: roles, activities and experiences

Views on self-supervised TB treatment

Care workers who had experience of DOT were ambivalent about the benefits of self-supervised TB treatment. Some felt that “... *taking their own medication per month ... is better because of that sitting and waiting [at the clinic], they were defaulting, now they [clients] are happy.*”, and clients are not necessarily more prone to defaulting: “... *they will not cheat; we encourage them to drink their medication on their own.*” Yet, others favoured DOT because “... *there’s no throwing away [of medication], because by the time you have given it, you are talking to the patient [to make sure the pills were swallowed].*”

Adherence support visits

In Clinic 1, the care workers were observed for nearly 12 hours, and in Clinic 2 and 3, approximately eight and 13 hours respectively. The Time and Motion fieldwork yielded the following data for each site (see Table 8). The percentages reflected for contact time are a proportion of the total observation time. The last column indicates the percentages (of the total of visits made) of clients found at home.

Table 8: Time spent during adherence visits

Site	Average walking time between clients	Average duration of home visit	Number of visits done	Contact time with clients (% of observed time)	% total visits when clients found at home
Clinic 1	6 minutes	8 minutes	2 - 6	27%	64%
Clinic 2	3 minutes	7 minutes	6 - 17	64%	75%
Clinic 3	15 minutes	11 minutes	4 - 10	48%	72%

The information in Box 1 below, recorded in Clinic 3, give more detail on the time spent on various components of the care worker's visits.

Box 1: Clinic 3-specific Time and Motion data

- Home assessment visits (see *Point 1.3*) on average took 19 minutes.
- Screening and referral for TB testing lasted between 3 to 18 minutes.
- Door-to-door visits (see *Point 1.7*) took on average 5 minutes.

Innovative practices introduced by CCWs

Across the sites, CCWs have introduced a number of innovative practices to facilitate the delivery of adherence support. These include:

- Placing visit stationery inside an ordinary magazine in order to not reveal to other members of the community that the CCW is visiting an individual who is on TB and/or HIV treatment, and so reduce the likelihood of inadvertent disclosure of the client's illness status.
- Pretending to be just a friend who is visiting in situations in which the client has not disclosed their HIV or TB status publically.
- Having discussions among themselves regarding which CCWs are less at risk to serve gang-infested areas, and allocating clients accordingly.
- THCA provides CCWs with a number of M&E tools to assist with adherence monitoring. It would appear that some CCWs prefer to use their own tools during home visits and then transcribe the information collected onto the official forms. The photos below show self-initiated M&E tools: Photo 2 shows how the CCW keeps record of her clients that come for DOT at the community centre (Clinic 3), and in Photo 3 the care worker (Clinic 2) calculates the number of pills that the client had left in comparison to how many they should have had. It is interesting to note that the self-initiated tool in Photo 2 has exactly the same data elements as the official tool, but it is in a notebook form for a period of 1 week compared to the official tool which is loose leaf and for a period of 1 month. Further investigation is required to determine why self-initiated tools are developed.

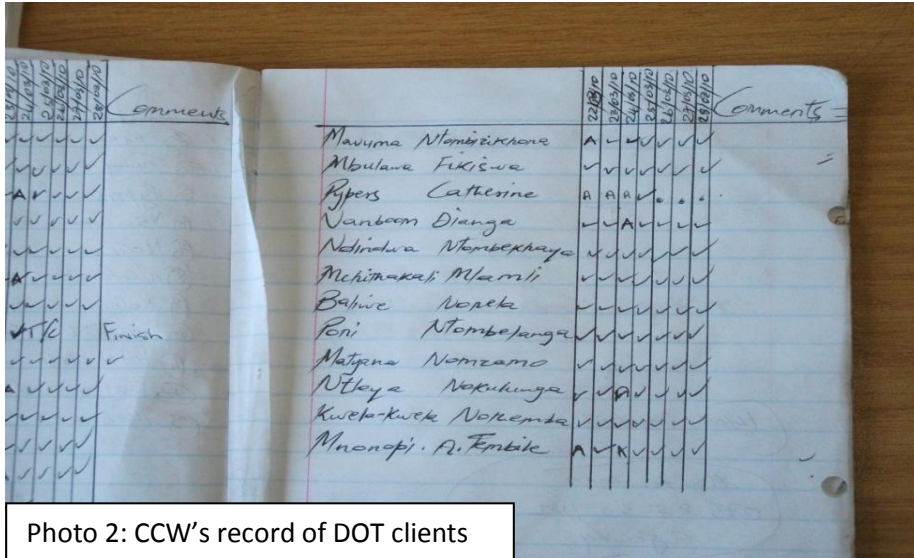


Photo 2: CCW's record of DOT clients

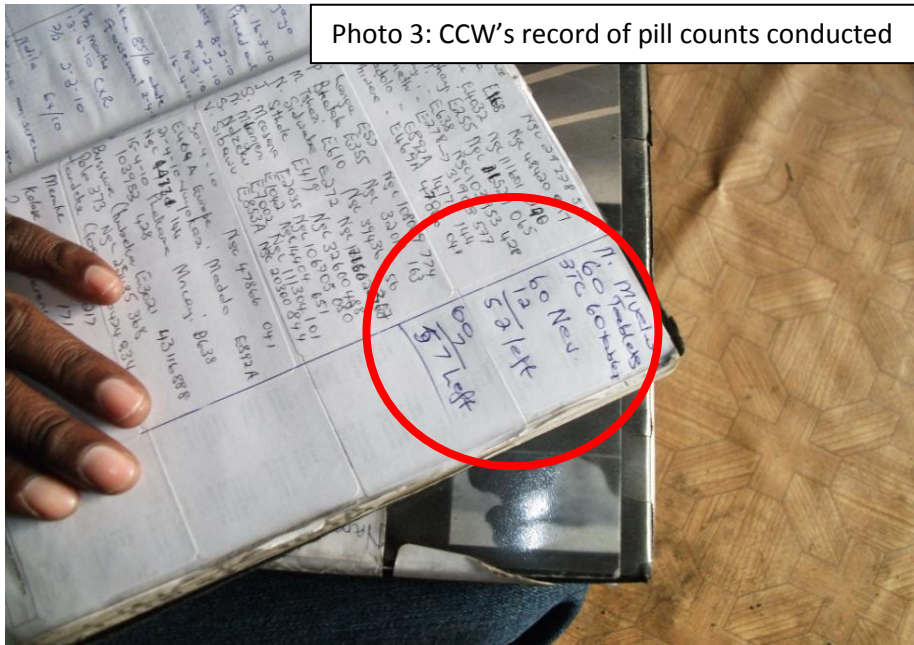


Photo 3: CCW's record of pill counts conducted

Reasons for becoming a CCW

In view of the many challenges to their work, it made sense to explore the reasons for becoming a care worker. CCWs highlighted passion for their community, a caring personality and liking to work with people as important reasons: *“For me, it’s all about that patient.”* (CCW). Their positive attitude towards their clients is stated succinctly in the following comment: *“You must thank your TB clients [when they are cured] because they showed resilience in completing treatment.”*(CCW).

However, less altruistic reasons also played a part, such as (i) recognition and status: *"Sometimes at night, when somebody is sick, they come and call me. I say, 'No, I'm not a doctor' ... [but they say] you must see this child before we call the ambulance so that you can advise us."* (CCW); or (ii) using this opportunity as a means to better employment. The latter applies in particular to younger care workers, according to a THCA management participant. Despite complaints about their stipends, paid employment was also a motivation for the work: *"Many of us are single mothers who need some income to care for our families."* (CCW).

Challenges experienced by community care workers

This study found the following concerns, based on CCWs' reports and in-field observations.

- Changing the behaviour and attitudes of non-adherent clients

The most fundamental challenge reported was people who are ill with TB and/or HIV and who refuse treatment, as one CCW remarked: *"You cannot enforce adherence or a lifestyle change."* The most common risk behaviours reported were clients with drug and alcohol problems: *"Sometimes I have to beg and plead with the people to come and drink their tablets, because wine is first."* (CCW). This results in care workers having often to go to the shebeen or 'smokkel yard' (where illicit drugs are used and sold) to find their clients. There were also reports of clients suffering from emotional problems, such as depression, who require much support to adhere to their treatment.

- Emotional stress

Community workers have to deal on a daily basis with a wide range of stressful and disturbing issues. They noted that the death of a client due to TB/HIV related illness is probably the most difficult: *"Oh, it's very sad [when a client dies] ... if someone dies, you don't feel on top of it."* (CCW). In addition, they are confronted with clients' psycho-social problems, some of which may be serious, such as rape and abuse: *"This client was allegedly gang raped and is suffering with severe depression."* (CCW); and being confronted with family violence and marital problems. Some care workers were quite aware of the legal implications of providing counseling whilst not being qualified to do so. They also reported that often intoxicated clients became very hostile towards the carer: *"When she [client] is drunk she gets abusive and start swearing and yelling at me, and afterwards will apologise."* (CCW). CCWs also noted challenges of support to clients experiencing severe poverty: *"They will knock on my door and ask if Sister [CCW] doesn't have something for them to eat."*

- Stigma

CCWs have a role to play in normalising TB and HIV/AIDS, as reflected in the following advice to a client: *"You [the client] should think of this [HIV] as being the same as when another person has high blood [pressure]."* However, CCWs noted that it is not easy to counter clients' fear of rejection because of their illness which, in turn, leads to a

reluctance to disclose their illness status. Often clients will ask the care worker to facilitate disclosure to their family.

Photo 4: A care worker conducting adherence support visits



- Safety

Care workers had concerns about their physical safety when conducting visits in gang-infested areas: *“They [gangsters] would shout at me: ‘Hi, Sister, get out of the way because we are going to shoot now’, and then they will wait till I’m out of the area.”* (CCW). They were also concerned about health risks during visits: *“Sometimes, there are MDR patients who have defaulted, and then we have to go to those patients, for two weeks he hasn’t used his treatment.”* (CCW). It appeared as if masks were available to the care workers, but only two of those observed wore masks during visits. In another case a care worker was pricked with a needle used during an HCT campaign and was put on ART for post-exposure prophylaxis.

- Finding clients

This was a common problem across the sites, and the following example illustrates how frustrating it can be: The ART clinic requested the recall of eight clients, and the CCW spent 105 minutes on this, finding only four of the addresses, and two clients with whom 18 minutes (17% of the observed time) were spent.

In recognition of the need of debriefing sessions for CCWs, THCA appointed a social worker during the study period, who is to conduct such sessions. Care workers expressed the view that the sessions are more tailored as mentoring opportunities, and did not meet their need to talk to a professional about emotional stresses related to their work.

A need for non-monetary recognition

Care workers across all sites referred to recognition, other than stipends, as a token of appreciation of their work. Some of them felt that: *“We also contribute towards the awards that go to the [TB] clinic because of good cure rates.”*, and would have appreciated sharing in this, because, *“... we work as a team to help support patients; even if we are not invited to the formal ceremony, we would like to celebrate with the clinic.”* Others mentioned more regular visits from THCA’s management, or receiving a birthday card as examples of such recognition.

Clinic activities

Though utilising CCWs for clinic-based tasks in Clinic 1 (in addition to their support for clients in the community) was stopped towards the end of 2010 (allowing them to devote all of their time to their clients), the data in Table 9 provide interesting information on the range of their clinic duties, based on approximately seven full days of observations.

Table 9: CCW clinic-based activities in Clinic 1

Activity	Time spent: % of observed time
First point of care Weigh clients; refer them to the correct consultation room; conduct pill counts	29%
DOT to clients	18%
Group counseling Counsel and educate pre-ART clients and ‘restarts’ (clients who have defaulted) on treatment, healthy lifestyles, and the roles of the treatment buddy and the CCW	7%
Case management meetings	4%
Other Translate for clinical staff; collect client folders and x-rays; collect medication for delivery to clients unable to collect it themselves	12%
Break Doing nothing while waiting for clients to arrive	30%

4. Managing community care workers in TB treatment and ART support programmes: Management’s views and experiences

This section firstly reflects the views of managers (from both THCA and the health authorities) on CCWs and the integration of community-based services. This is followed by a description of how THCA manages their community care workers, which include aspects such as recruitment and training, but also the agency’s supervision and M&E practices

related to community-based services. The section concludes with data on how THCA interacts with the local health authorities regarding community care workers.

4.1 Key findings

- a. The health authorities are appreciative of the role that CCWs play in providing treatment and adherence support to clients.
- b. Both health authority and THCA management see the integration of community-based services to TB and HIV infected clients as the most appropriate strategy to address the diseases, and are in the process of finalising the policy and logistical issues related to implementing this at scale.
- c. THCA has a range of mechanisms in place to ensure effective management, monitoring and evaluation of their CCW programme. The quality assurance measures appear to be an effective way to assess care worker services.
- d. Providing formal training to newly recruited CCWs remains a challenge as this cannot be scheduled each time a new CCW is appointed.
- e. The practice of in-service training on antiretroviral drugs provided by the ART clinic at the hospital (Clinic 3) was found to be a useful way of equipping CCWs with the necessary knowledge.
- f. The interface between the health authorities and THCA regarding the community care workers, was found to be working well and procedures are in place to structure their collaboration.

4.2 Management's views on CCWs

The role of the CCW as an extension of professional health services is recognised by the health authorities, and CCWs generally are praised for their commitment: *"They are always so cheerful and positive, I wish it was true of the professionals who work under better circumstances and with better salaries."* (Health management); and *"... if we level the playing field, then the health outcomes for non-adherent clients who receive supporters are far better than for those who don't receive such service."* (Health management). Likewise THCA management is aware of the importance of their CCWs, and some of the measures to improve their employment conditions are discussed below.

4.3 Management's views on integrating TB and ART services

All those interviewed were supportive of integrated services for TB treatment and ART support, and noted that in the Western Cape, *"There is quite some leeway for trying out different systems."* (Health management). There is a strong drive from the WCDoH and CDoH to move towards full scale implementation of integration in all their facilities, which is not without challenges: *"As we implement everything is changing in particular for the HIV services; not everything has been worked out ..."* (Health management). Apart from this flux in clinical and management policies, there are also differences in opinion on the shape that integrated services should take. One view was that this does not necessarily have to imply that services to TB and HIV clients have to happen in 'one room, by one

practitioner', "... but that it [integration] should rather be the harmonising of services." (Health management).

4.4 CCW - human resources practices at THCA

Recruitment and appointment of CCWs

Vacancies are advertised by word-of-mouth in the community and through advertisements placed at clinics. Applicants submit a 2-page CV and an interview panel uses a scoring sheet during the recruitment interview. The panel comprises THCA management and CTLs, with an open invitation to facility staff to be present.

Induction and training of CCWs

As induction, new CCWs should first be placed at the clinic to work for two weeks in the TB and/or ART room. However, fieldwork reports indicate that this does not always happen due to the priority given to adherence support visits. The new recruit is then placed with an experienced CCW who acts as mentor. Before clients are placed with the new CCW, the mentor will meet with CTL and coordinator to decide if the new CCW is ready to have her/his own clients. Case management meetings are also used as assessment opportunities, and training needs are identified in this way. New care workers also receive a one-day induction on THCA's policies and procedures.

This in-service training is critical since scheduled training may not coincide with the time of the appointment. It was also noted that there is a need to pay more attention to the caring element in providing treatment - an issue that THCA would like to address in their training and support of care workers: "*Part of this [training] should be to do more than paying lip-service to help with poverty alleviation and empowerment of their [CCWs] clients.*" (THCA management).

A very useful practice was found in the ART clinic at the hospital (Clinic 3), where the ART doctor routinely provides informal but structured and intense training to all CCWs and, among other things, provided the CCWs with a leaflet illustrating the different ART medications. CCWs found it useful to have such a guide at hand when doing ART adherence support visits.

Attrition of CCWs

Retaining trained staff is a key consideration for THCA, and part of their initiative to retain them is to provide CCWs with training and in-house promotion opportunities. CCWs are subsidised to enroll for relevant training such as social auxiliary worker training, and THCA offers transport money to attend other training like the Extended Public Works Programme (EPWP). However, a consequence of this is that the better qualified the care workers become, the more likely they are to apply for better-paid employment, as happened with two team leaders during the study period.

The attrition rate during the 11 months of the study was as follows: in Clinic 1, 67% (ten of the 15 care workers, including the CTL), and in Clinic 2, 40% (four of the ten CCWs, including the CTL) of the CCWs left the programme. The attrition rate for Clinic 1 was similar to what was reported for other years, but in Clinic 2 the rate is normally lower. In Clinic 3 none left; remarkably there was no attrition reported for the past three years in this site, “... because they were voluntary community workers before they started with THCA.” (THCA management).

Though three of the CCWs in Clinic 2 were dismissed because of poor performance, THCA management reported that it is seldom that such a large number of care workers are dismissed; trends over the years showed that in almost all cases CCWs resign because of better employment opportunities and a negligible number of them are asked to resign because of misconduct. This was evident in Clinic 1, where all the CCWs left for better paid employment. Of interest is that most often the better employment in Clinic 1 is that of domestic worker.

Supervision and quality assurance measures for CCWs and CTLs

Team leaders meet regularly with their CCW teams to discuss clients and to address the concerns of CCWs. However, supervision and support of CTLs by their coordinators is not as frequent as team leaders would like: “She [the coordinator] does not visit regularly and always tells me I must do what I think is right because she trusts me.” (CTL).

During the study period, a quality assurance protocol was developed and implemented. This protocol enables the CTL to score each CCW on how she/he performs her duties, and coordinators to evaluate the performance of their team leaders. Part of the CTL’s assessment of CCWs involves accompanying the care worker on adherence visits, which provides the team leader with a firsthand account of how the services are delivered, thereby facilitating quality improvement. Feedback from both coordinators and team leaders indicated that these measures are useful and improving the quality of care.

Monitoring and evaluation

The fact that there is a monitoring and evaluation (M&E) unit reflects the importance that THCA places on “... being accountable for what we do.” (THCA management). The focus of the M&E differs from the quality assurance measures as it focuses on the scope of services and number of clients supported by these services. Team leaders and CCWs are involved in compiling M&E reports, and complained that some of it is overburdening, and that changes to data collection forms occur too often.

4.5 Interface between health authorities and THCA

That fact that there are both provincial government and municipal health authorities, poses challenges in managing overlapping spheres of responsibilities. Yet, in-field observations found the interactions between the role players to be constructive with a

strong spirit of collaboration between THCA staff and the facility management. The key issues raised were as follows:

- Changing policy and procedures is complicated and slow, and made more so because two health authorities need to deal with these matters; and
- The CTLs are the direct line managers of their community-based care workers (within the framework of the health authorities' policies). This means that clinical staff refer to THCA's CTLs and coordinators in cases of complaints about CCWs. This seemed to work well in one site: *"I do have an open line to THCA managers, and they are very responsive when I raise concerns."* (Clinical staff member). The day to day line manager of CTLs is the facility manager because they work within the health facility and THCA's coordinator cannot visit every facility every day.

Summary of key evaluation findings

The results of this study highlight the following six aspects of community-based service delivery to TB and HIV clients in the study sites:

1. Implementation of support by CCWs

CCWs should provide integrated adherence support for both TB and HIV care and treatment. There is a high level of congruency between what is expected from the CCW, both from the health authorities and THCA management, and how they deliver these services in the community.

2. The work of CCWs is acknowledged as important to care delivery

As a cadre, CCWs have the most detailed knowledge of clients' circumstances that impact on treatment and adherence. Clinical staff are very aware of this and it is evident in the many ways that CCWs' input is solicited and respected.

3. Monitoring, evaluation and quality assurance measures

Managers highlighted the value of ongoing monitoring, evaluation and quality assurance measures, as ways to account for the services that they provide. Community care workers, however, often felt overburdened by the administrative tasks and would also like to see less frequent changes in the forms that they need to complete.

4. Management of the CCW

Community Team Leaders are effective at managing CCWs and provide a crucial link between health facilities and community workers. Proper structures and human resources policies are in place, and function well. Line-management procedures are established to guide the interaction between THCA and facility staff, should performance or disciplinary problems with community care workers need to be addressed.

5. CCWs' perceptions of how their work is valued

Many CCWs feel that higher level management does not fully understand their challenging work conditions, and that the nature of their work with clients often takes more time and effort than their current remuneration covers. Apart from an increased stipend, they would also like to receive non-monetary recognition of their work.

Recommendations

Many of the approaches described in the report serve as good practices for replication. These are summarised below as *Current practice recommendations*. Where applicable, *Additional recommendations* are offered. This is followed by suggestions for future research.

1. Managing community care workers in TB treatment and ART support programmes

Treatment and adherence support to co-infected clients

Current practice recommendation

One community care worker should be assigned to provide treatment and support to clients living with both TB and HIV.

Recruitment and appointment

Current practice recommendation

Team leaders should be involved in the process. Having a formal appointment process with CVs and interviews to which facility staff are invited, helps to both give status to the position of CCWs, and to ensure that competent community members are appointed.

Remuneration

Additional recommendation

Stipends continue to be perceived by CCWs as too low for the amount of work involved. Options should be explored to address this, such as:

- Increase stipends for CCWs to recognise their valuable contribution to health service delivery.
- Monitor work allocation closely, including numbers of tasks and of clients, to ensure that it is manageable within the time available; and
- Reduce the time spent by CCWs on administrative tasks.

Non-monetary recognition

Additional recommendation

Both the health authorities' and THCA's management should consider putting in place mechanisms to promote wider public recognition of CCWs' work. This might include yearly awards by employing agencies to CCW teams who have contributed towards excellent health outcomes for their clients, and annual visits by senior management to CCWs .

Induction and training

Current practice recommendation

At the time of report writing, it was found that the health authorities are standardising CCW training, which will strengthen services delivered by care workers.

Additional recommendations

- a. The mentoring and in-service training (see *Point 4.4*) can be strengthened in the following ways:
 - Develop a checklist to guide team leaders in what should be covered; and
 - Provide elementary source materials (similar to the counseling materials) to new care workers.
- b. More training is needed to help care workers understand the emotional and psychological impact of being ill, and particularly of being co-infected. This may help CCWs to understand resistance to treatment and how to respond to non-adherent clients.
- c. Training should include ‘worst-case client’ scenarios to prepare care workers for the challenges of their work.
- d. CCWs also expressed the need for regular refresher training, which makes sense in light of the ever-evolving treatment regimes.

Managing caseload

Current practice recommendation

The system in which at-risk clients are identified and prioritised for intensive adherence support, should be considered for wider implementation.

Additional recommendations

- a. A ‘once size fits all’ approach to CCW caseloads may not be the best solution, given the geographical differences across settings (e.g., walking time in congested communities, such as informal settlements, will be substantially lower than in formal, urban areas). Local estimates of traveling, waiting and visit times could be used to determine the ideal number of clients per CCW.
- b. Strategies to minimise time spent on travelling and waiting during adherence support need to be explored. These may include matching CCWs and clients based on smaller geographical areas, and providing the care worker with a bigger allowance for the use of cell phones to confirm if clients are at home.

Supervision and support

Current practice recommendations

- a. The appointment of a community-based team leader is an effective way in which to manage and supervise CCWs.
- b. Regular in-house meetings between team leaders and their care workers are seen as an effective way of providing supervision to CCWs.
- c. The health care authorities and THCA have realised the need for up-skilling the management proficiency and supervisory skills of team leaders and, at the time of report writing, were working on ways in which to improve this.

Safety and 'Caring for the carer'

Current practice recommendation

- a. It is THCA policy that CCWs should not conduct adherence support visits during periods of violence in the community.
- b. THCA's employment of a social worker to conduct debriefing sessions with care workers is a way of 'Caring for the carer'. Given the working conditions of CCWs, such initiatives should not be an add-on to their employment conditions, but routinely provided to them.
- c. Top management of the employing agency should meet in person to discuss CCWs' concerns with them, as was observed during the study.
- d. Visiting and supporting TB clients places CCWs at risk, and can be regarded and managed as an occupational hazard, and likewise when participating in HCT campaigns. Employing agencies of care workers could support CCWs who become infected while on duty, by allowing paid sick leave for TB infection, and referring infected care workers to appropriate medical services.

Quality assurance measures

Current practice recommendation

The process of assessing the quality of care provided by CCWs and CTLs (see *Point 4.4*) is recommended as good practice, provided that it is done in a sustainable manner. The approach may need adaptation for specific local contexts.

Monitoring and evaluation

Additional recommendation

CCWs and CTLs are quite innovative in developing M&E tools that meet their needs. The development of M&E tools should be a consultative process in which the overlap between what care workers have developed and what is required by THCA and the health authorities, can be explored and utilised.

2. Future research

- a. The rollout of integrated models of TB and HIV treatment support should be evaluated rigorously, preferably using a controlled study combined with a formative evaluation.
- b. It would be useful to assess whether the quality assurance measures are improving health outcomes.
- c. The Client-CCW observation component of this study was limited in its scope. This should be conducted on a larger scale and across different sites for a better understanding of the dynamics of these interactions.
- d. Innovative ways of minimising CCW walking and waiting times in the community need to be explored.

Acknowledgements

First of all, the research team wishes to thank the National Department of Health for their financial support that made this study possible. We trust that this report will in some way help in structuring integrated community-based services and the employment of our community care worker colleagues.

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Finally we wish to thank all the clients whom we met during the course of the study, for sharing their views and experiences of the care that community care workers provide to them.

Photos

The photos used in the report are with the consent of the participants.

APPENDICES

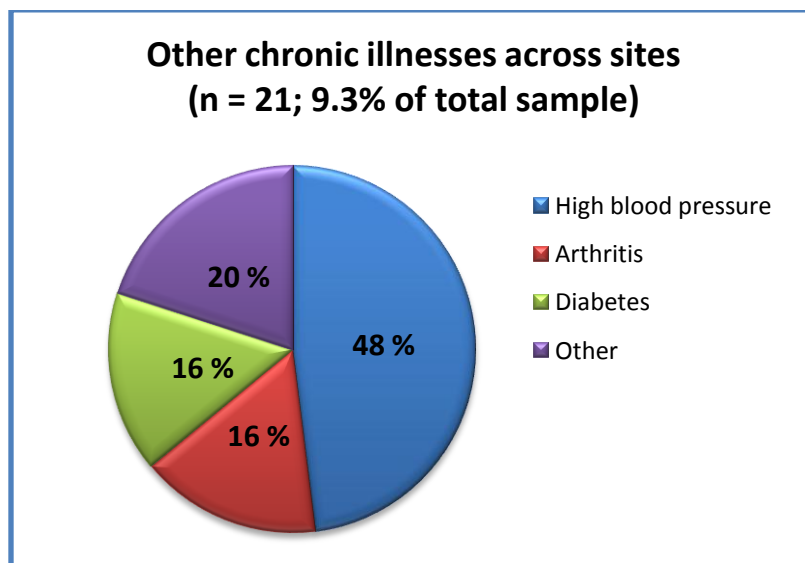
Appendix 1a: Summary of illness per site

Table 10: Survey - all illnesses per site

	ART only	Prepared ART only	Referred ART only	TB & ART	TB & prepared ART	TB & referred ART	TB only	TOTAL
Clinic 1	43	-	-	9	3	2	14	71
Clinic 2	17	2	1	18	10	3	19	70
Clinic 3 (TB only)	-	-	-	3	1	-	8	12
Clinic 3 (ART clinic at hospital)	33	12	3	7	3	2		60
Clinic 3 (DOT community centre)	4	-	-	8	-	-	1	13
TOTAL	97 (43%)	14 (6%)	4 (2%)	45 (20%)	17 (7%)	7 (3%)	42 (19%)	226

Appendix 1b: Summary of other chronic illnesses collated across sites

Chart 2: Survey – chronic illnesses across sites



Appendix 2: Client-CCW observation guide

Demographic information <ul style="list-style-type: none"> • CCW • Client 	
Venue and Time <ul style="list-style-type: none"> • Venue details • Time of the day and duration of the interaction 	
Mood when entering the house:	People <ul style="list-style-type: none"> • How many and who present? • How many/who left? • Seating and seating changes during the interaction
Conversation <ul style="list-style-type: none"> • Who started the conversation? • Content • Language: list things to clarify with CCW • Details on barriers/enablers • Non-verbal communication 	Conversation flow: <ul style="list-style-type: none"> • Who talks more, any silences? • Mood between CCW and client (distant, warm, suspicious) • Role of others present
Researcher reflection <ul style="list-style-type: none"> • Solicited participation • Did my presence/reactions impacted on the interaction? 	

Appendix 3a: Diary keeping participants and diary method

Pseudonym	Demographics	Status at recruitment	Diary method
Joan	Unemployed	ART (5 years) TB cured (3 years)	Audio and Visual
Paul	Unemployed and homeless; alleged drug addiction	TB treatment (5 months) HIV+ (5 months) Referred for ART (5 months ago)	Visual
Jane	Part-time employment	TB treatment (4 months) ART (3 months)	Audio
Peter	Unemployed; alcohol abuse	TB treatment (4 months) HIV+ (8 years) ART (4 years)	Audio and Visual
Tom	Unemployed; drug addiction and alcohol abuse	TB cured (9 years) HIV+ (10 years) Referred for ART (3 months ago)	Audio and Visual

Appendix 3b: Diary keeping data collection

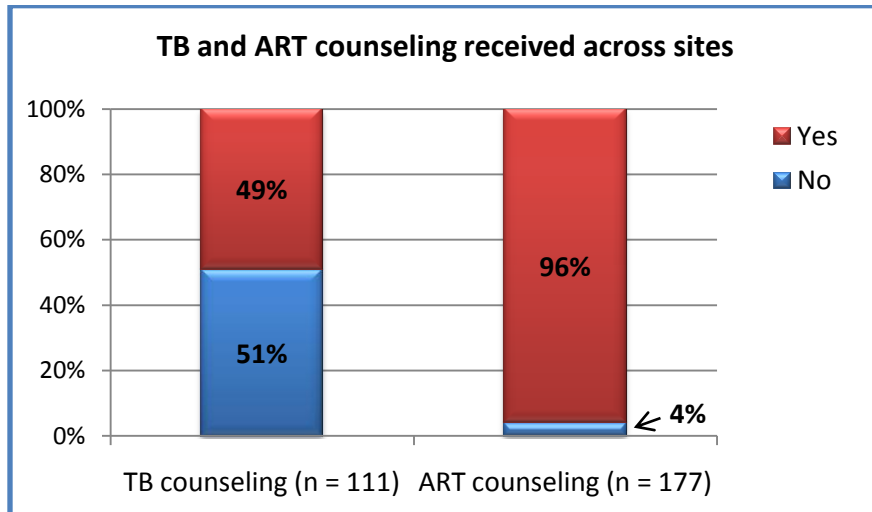
Pseudonym	Audio recordings ¹	Photos	Data collection period
Joan	31	20	29 weeks
Paul	n/a	48	19 weeks
Jane	23	n/a	26 weeks (in progress)
Peter	81	28	23 weeks
Tom	196	97	20 weeks (in progress)
Total	331	193	

¹ The average length of audio recordings was 4 minutes.

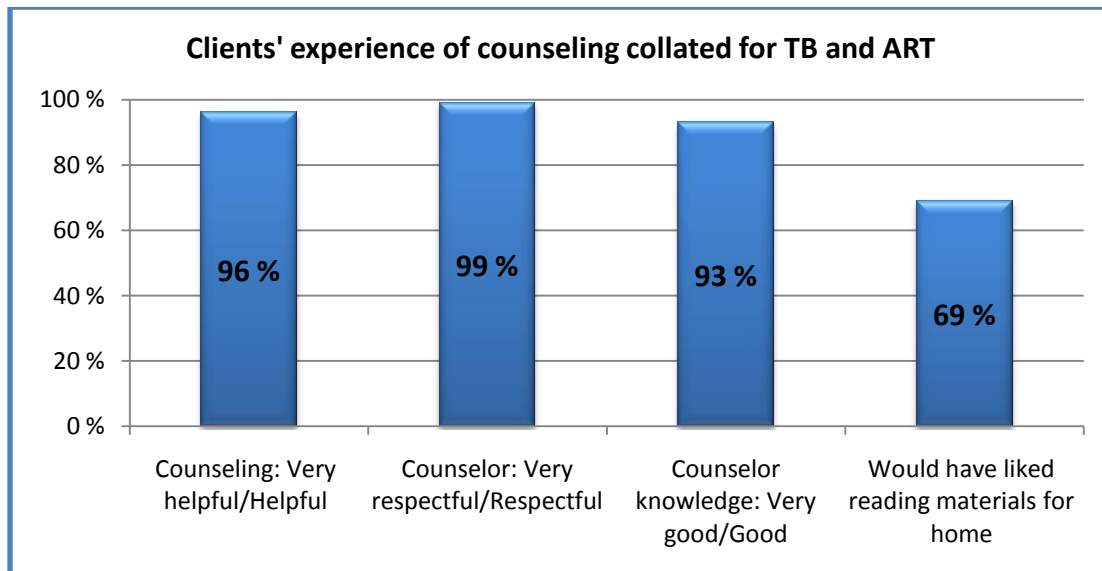
Appendix 4a: Survey results - Counseling services

The graphs below reflect the counseling received for all TB and all ART clients respectively, and how the clients experienced the counseling. Although 51% of TB clients (see Graph 2) indicated that they had not received TB counseling, this does not mean that they received no information on treatment, but rather that this information was provided less formally. Responses on how clients experienced TB and ARV the counseling were very positive and similar for both illnesses and across sites, and are therefore collated in Graph 3 below.

Graph 2: TB and ART counseling received collated across the sites



Graph 3: Clients' views across sites on counseling: collated for TB and ART counseling



Appendix 4b: Survey results - Facility services

Across all sites, 95% of clients were very satisfied or satisfied with the TB and ART services that they had received at the facility. This was despite the fact that waiting times were reported to be quite long. In Clinic 1, 44% of the clients reported waiting three hours or longer before being attended to, and in Clinic 2, 77% of clients reported similar waiting times. In contrast, all clients were reported as being seen in less than an hour in Clinic 3, and, at the ART clinic (Clinic 3), only 25% of clients said that the waiting time was three hours or longer. This reflects the different client load across these sites. In addition, facility staff pointed out that many clients arrive before the clinic opening time, and this contributes to long waiting periods.