



USAID
FROM THE AMERICAN PEOPLE

OPERATIONS RESEARCH RESULTS THE EFFECTIVENESS OF TB DOTS SUPPORTERS IN SOUTH AFRICA

QUALITY
ASSURANCE
PROJECT

APRIL 2005

This publication was produced for review by the United States Agency for International Development. It was prepared by the Quality Assurance Project and authored by Judy Dick, Emma Murray, and Elsabe Botha, University Research Co., LLC, Quality Assurance Project/South Africa.



OPERATIONS RESEARCH RESULTS

THE EFFECTIVENESS OF TB DOTS SUPPORTERS IN SOUTH AFRICA

April 2005

Judy Dick

Emma Murray

Elsabe Botha

DISCLAIMER

The authors' views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

The Quality Assurance Project (QAP) is funded by the U.S. Agency for International Development (USAID) under Contract Number GPH-C-00-02-0004-00. The project serves developing countries eligible for USAID assistance, USAID Missions and Bureaus, and other agencies and nongovernmental organizations that cooperate with USAID. QAP offers technical assistance in the management of quality assurance and workforce development in healthcare, helping develop feasible, affordable approaches to comprehensive change in health service delivery. The project team includes prime contractor University Research Co., LLC (URC), Initiatives Inc., and Joint Commission Resources, Inc.

Recommended citation: Dick J, Murray E, and Botha E. 2005. The Effectiveness of TB DOTS Supporters in South Africa. *Operations Research Results*. Bethesda, MD: Published for the U.S. Agency for International Development (USAID) by the Quality Assurance Project (QAP).

About this series: The *Operations Research Results* series presents the results of country or area research that the Quality Assurance Project (QAP) is circulating to encourage discussion and comment within the international development community. Please visit www.qaproject.org for more information on other QAP operations research studies.

ABSTRACT

This report presents reflections on South African supporters of DOTS, the internationally recommended strategy for tuberculosis (TB) control. The DOTS strategy has been implemented on a national level in South Africa's fight against TB, and DOTS supporters are lay health workers who provide some of the services called for by the strategy. The report draws on qualitative data from the Western Cape metropolitan area and the Nyandeni district of the Eastern Cape.

While the DOTS strategy has been widely implemented, still little understood are factors such as: the extent to which TB patients value it, the experiences of supporters in providing support, the necessary conditions for ensuring a successful support program, and the likelihood of successful integration of an HIV/AIDS program into a successful TB DOTS program. The research discussed in this report focused on exploring, from the providers' and consumers' perspectives, a range of organizational factors that are perceived to be necessary to facilitate the function of the DOTS supporters.

The report concludes with recommendations to health providers and policy makers to improve the delivery of care to patients with TB. It asserts that before DOTS supporter programs are implemented in a community, the formal health facilities in the area need to be fully functional. It also concludes that for DOTS supporters to be effective, some sustainable form of incentives needs to be provided.

Acknowledgements: We would like to thank the University Research Co., LLC (URC) for commissioning us to conduct a study on the effectiveness of supporters of DOTS, the strategy promoted by the World Health Organization (WHO) for treating tuberculosis (TB). Much appreciation must be extended to the two nongovernmental organizations, TB CARE and the TB Alliance DOTS Support Association (TADSA), for sharing their extensive understanding of their field of expertise. Without their help in arranging focus groups and appropriate facilitators, this study would have been much more difficult to organize. We are equally grateful to Ria Grant, Lisa-Marie Smith, and Ashley Arosi for their generous assistance and to the Nyandeni district TB coordinator who welcomed us to the district and helped arrange focus groups.

We acknowledge those who took time from their schedules to facilitate focus groups and to the staff at Nolitha clinic, Nyanga clinic, Uluntu Centre, Manenberg's Peoples Centre, and Hanover Park library for allowing us to use these venues for focus groups.

To all the key informants, DOTS area coordinators, DOTS treatment supporters, and TB patients who patiently shared time to speak of their experiences, feelings, and understandings, thank you for entrusting us with this information. We are very grateful for all the input that we received and that made this report possible

A thank you must also be extended to the staff at the centre for TB Research and Education at Stellenbosch University for the support and advice they provided

TABLE OF CONTENTS

I. INTRODUCTION	1
II. METHODOLOGY.....	1
A. RESEARCH METHODS	2
B. RESEARCH SETTING	3
C. ETHICAL CONSIDERATIONS	4
D. STUDY LIMITATIONS	4
III. FINDINGS.....	5
A. WHERE DO DOTS SUPPORTERS FIT IN THE DOTS SYSTEM?.....	5
B. WHAT EFFECT CAN DOTS SUPPORTERS HAVE IN CASE FINDING AND CASE HOLDING?	5
C. HOW DOTS SUPPORTERS ARE SELECTED	6
D. HOW DOTS SUPPORTERS ARE TRAINED	7
E. HOW DOTS SUPPORTERS EXPERIENCE EDUCATION	7
F. WHAT DO DOTS SUPPORTERS DO?	8
G. PERCEIVED QUALITIES AND SKILLS DOTS SUPPORTERS NEED.....	9
H. HOW DO PATIENTS SELECT CLINIC-, WORK-, OR COMMUNITY-BASED CARE?.....	9
I. WHAT SHOULD BE CONSIDERED BEFORE IMPLEMENTING DOTS SUPPORTERS?10	
J. IS IT POSSIBLE TO INTEGRATE DOTS SUPPORTERS WITH AN HIV/AIDS PROGRAM?	11
K. COMPENSATION AND ITS EFFECT ON MOTIVATION	11
IV. DISCUSSION AND RECOMMENDATIONS	12
REFERENCES	13
APPENDIX 1: INFORMED CONSENT FORM FOR INTERVIEWS.....	15
APPENDIX 2: INFORMED CONSENT FORM FOR FOCUS GROUPS.....	16

I. INTRODUCTION

Lay health workers (LHWs) have played an integral role in promoting community participation in many health systems in the developing world, including South Africa (Walt 1988). An LHW is defined as “any health worker carrying out functions related to healthcare delivery, trained in some way in the context of the intervention, and having no formal professional or certified tertiary education” (Lewin et al. forthcoming). Depending on the focus of the intervention they support, LHWs’ role may cover health-related activities or extend beyond health to issues associated with community development (Friedman 2003).

Adherence to treatment regimens is pivotal to TB control, and a cadre of LHWs known as “DOTS supporters” has evolved to assist TB control programs in low-income countries and those with high TB prevalence. It has been argued that community participation and peer group education is relevant in long courses of treatment where culturally sensitive support in or near a patient's home is necessary to maintain adherence to treatment regimens (Friedman 2003; Maher et al 1999; Hadley and Maher 2000).

Despite widespread implementation of DOTS, little is known of how this strategy is valued by patients. Anecdotal information implies that the quality of support provided by DOTS supporters varies significantly. There is wide variation on how DOTS supporters are selected, trained, and managed within their communities. These variations suggest that questions like the following could be addressed to help the South African TB Control Program develop strategies to strengthen the community-based LHWs’ role in treatment supervision: How may the health system facilitate DOTS supporters’ input and prevent attrition? Should they be paid for their contribution or should they work as community volunteers? What sort of organizational factors enhance the effectiveness of these LHWs?

II. METHODOLOGY

The aim of the research was to identify factors that contribute to successful or unsuccessful delivery of care by lay health workers called “DOTS supporters” in the South African TB Control Program. The research also explored, from the providers’ and the consumers’ perspectives, a range of organizational factors that were perceived to be necessary to facilitate the supporters’ function. The research’s pragmatic approach was intended to provide useful information to health providers and policy makers to improve the delivery of care to patients with TB.

Four specific research objectives unfolded from the aim and the approach taken:

- To investigate the experiences of TB patients who are receiving directly observed treatment from DOTS supporters;
- To describe the perceptions and experiences of the various stakeholders, including DOTS supporters, of these programs;
- To describe processes by which DOTS supporters are selected, trained, and monitored; and

Abbreviations

DOTS	Directly observed tuberculosis treatment strategy promoted by the World Health Organization
FGD	Focus group discussion
LHW	Lay health worker
NGO	Nongovernmental organization
STD	Sexually transmitted disease
URC	University Research Co., LLC
TADSA	TB Alliance DOTS Support Association
TB	Tuberculosis
VCT	Voluntary counseling and testing
WHO	World Health Organization

- To collate data associated with the effectiveness of DOTS supporters in TB case detection and in successful treatment completion.

A. RESEARCH METHODS

Three qualitative research methods were used to explore the patients’ and caregivers’ experiences with DOTS supporters: key informant interviews, focus group discussions (FGDs), and participant observation. A purposive sampling technique was used to make contact with potential respondents. A literature review was conducted of published and gray material that included minutes of meetings, reports, articles, and records. This review included reports and organizational literature on LHW programs in primary healthcare that assisted researchers in understanding the process of the development of the various strategies adopted.

In-depth key informant interviews were conducted with four personnel involved with the implementation of the DOTS strategy. These respondents were from two NGOs: TB Alliance DOTS Support Association (TADSA) and TB CARE. The interviews were open-ended.

With the assistance of the two NGOs and the relevant clinics at the study sites, FGDs were conducted with patients on treatment for TB. Key informant interviews guided decisions on where and how to organize the groups. As one informant who had previously organized an FGD explained, “The difficulty was to find a time to get the group together and a venue, and very often it was after hours, and then they’d say they’d pitch in, but then we would rifle the cupboards and if we had caps or pens, we’d give them anything to come. . . .”

Two focus groups were held in the Nyandeni district of the Eastern Cape and four in the Cape Town metropolitan area. In the Eastern Cape, one of the FGDs was held with three treatment supporters, three area coordinators, and the district TB coordinator. The composition of the other five is shown in Table 1.

Table 1: Composition of Five Focus Groups

Focus Group Number	Province	Patients Receiving Treatment from Supporter		Patients Receiving Treatment at Clinic		Total
		Male	Female	Male	Female	
2	Eastern Cape	1			1	2
3	Western Cape	7	4			11
4	Western Cape			6	5	11
5	Western Cape			5	2	7
6	Western Cape	3	3			6

The respondents who participated in the FGDs were approached while attending the primary healthcare facilities. After each FGD, participants were given a small food hamper as a token of appreciation. The respondents were not aware of this gift prior to their participation.

Before each FGD, the researchers explained the session guidelines with the facilitators. Both the interviews and discussions were preceded by a culturally appropriate introduction of the researchers’ professional background and reasons for collecting the data. Persons other than the researchers facilitated all focus group sessions; facilitators spoke the local language and understood local norms but were unknown to the group members. All recordings were transcribed and translated. A preliminary analysis of the data from the interviews and discussions resulted in the development of a series of probes used in

subsequent interviews. Analysis involved the collation of data into categories, themes, and context. The reliability of the process of analysis was enhanced by having three researchers review categories and context independently.

Participant observation at designated research sites provided an opportunity for rich contextual information to be collected and recorded in the form of field notes: Where appropriate, actual quotations are provided herein. The findings are reported as themes as is customary in qualitative research.

B. RESEARCH SETTING

“As the biscuit box emptied, the group discussion drew to a close, one of the participants came up towards me asking for money to help him buy some gas with which to cook his food.” Field notes: August 26, 2004

The research was conducted in the urban suburbs of Manenberg, Hanover Park, and Nyanga in Cape Town, and in the rural district of Nyandeni in the Eastern Cape. These areas are characterized by high unemployment, overcrowding, and a high TB prevalence rate. The respondents from Manenberg and Hanover Park were Afrikaans-speaking, “coloured” South Africans; respondents from Nyanga and Nyandeni in the Eastern Cape are Xhosa-speaking “blacks.”*

The following vignettes were selected from field notes to illustrate contextual variations within the field. Extracts 1 and 2 are taken from the research process in the Western Cape while extract 3 reflects the setting in the rural Eastern Cape. The innuendos of these comments suggest that Manenberg is stark, Nyanga a busy urban area, and Nyandeni in the Eastern Cape more peaceful and serene.

***Extract 1:** “By the end of the focus group, the unreachable window in the corner was still clanging, the noise quite deafening to me in the large and bare room. It seemed to be a noise that no-one but Elsabe and myself had been distracted by. As we walked out of the “People’s Centre,” I took note of the metal grills on the lower windows just as I had done when we arrived. It was midday on a Friday and music was beginning to pump from the surrounding blocks of flats that were all draped in drying laundry. The vibrant colours of the clothes and the sound of music made a feeble attempt at swaying the initial sense of bleakness I had felt upon arriving in Manenberg.”* (Field notes: August 20, 2004)

***Extract 2:** “We stopped at the Shell™ garage to ask for directions to Nyanga clinic. The big and purple advertisement for “dark and lovely hair” caught my eye. We passed the bustling taxi rank, alongside of which there were several vendors selling raw and cooked meat, braaied sausages, what I assumed to be home-made beer in barrels, clothing and accessories. The clinic was opposite these stalls. We walked in past the two security guards and then through a rabbit warren of rooms to find where the TB patients we had arranged to meet were waiting. The clinic*

*In 1950 South Africa’s population was officially separated into for racial categories— “African” or “black,” “white,” “Asian,” and “coloured”—by the now-defunct Population Registration Act. Use of these categories herein does not imply endorsement of the ideology underlying racial classification but rather presents identity labels used by those who define themselves with this classification.

was lined with patients, some seated and some standing outside closed doors.” (Field notes: August 26, 2004)

Extract 3: “We drove amongst the pale green hills, scattered with houses and several roaming goats. The district coordinator led the way in the white 4x4 bakkie, and shortly after the tar road had turned to dirt, we arrived at Nolitha clinic. There was a group of patients sitting outside in the winter sun next to a small table from which some bags of naartjies were being sold. I climbed out of our car to hear the music from the white bakkie softly filter through the still warm air. The clinic was small and the walls were covered in informative posters covering various topics from nutrition, STDs, and immunization against measles to human rights and responsibilities. There was also one Xhosa poster that I didn’t understand. Benches were arranged for us to sit on and the one light in the room flickered on and off.” (Field notes: August 12, 2004)

The importance of demographic and social landscape became especially evident when respondents began speaking about the problems they experience through the practical implementation of DOTS:

“And most of the patients are unemployed, so they are using the mornings to maybe look for some work to do or something to eat at night, so that’s why they don’t attend support groups.”

“[I]n some areas [Manenberg and Hanover Park] it’s also a matter of territory, because of the gangsterism. This family can’t enter this territory, so they can’t go to that supporter for treatment, so rather than go to the clinic or whatever situation they are in, they rather prefer to go there. And on the other hand there is also the matter of Christians towards Muslims. You won’t find a Muslim who easily goes to a Christian treatment supporter.”

“It’s not easy for them [the DOTS supporters] because it happens sometimes that they can’t even attend a meeting because there was a fight and their son or whoever is involved, and they can’t enter the other gang’s territory.”

“[O]ne of my patients lives far away from me on the banks of the Umtata river. Sometimes he cannot walk so far to see me, so he’ll send a relative to collect his pills or I will have to walk to him.”

C. ETHICAL CONSIDERATIONS

Informed consent was obtained from each respondent for the interviews and participation in focus group discussions. In instances where interviews or FGDs were recorded, consent was obtained to record responses on audio-tape or digital recorder. All literate respondents were asked to sign a consent form that had been translated into their language (Appendix 1). All audio-tapes and digital recordings were stored in a secure place.

Approval to conduct this study was obtained from the Committee for Human Research at Stellenbosch University, Western Cape, South Africa. The project reference number is N04/08/128.

D. STUDY LIMITATIONS

This study was commissioned with short notice (two months). Time constraints limited the study as follows:

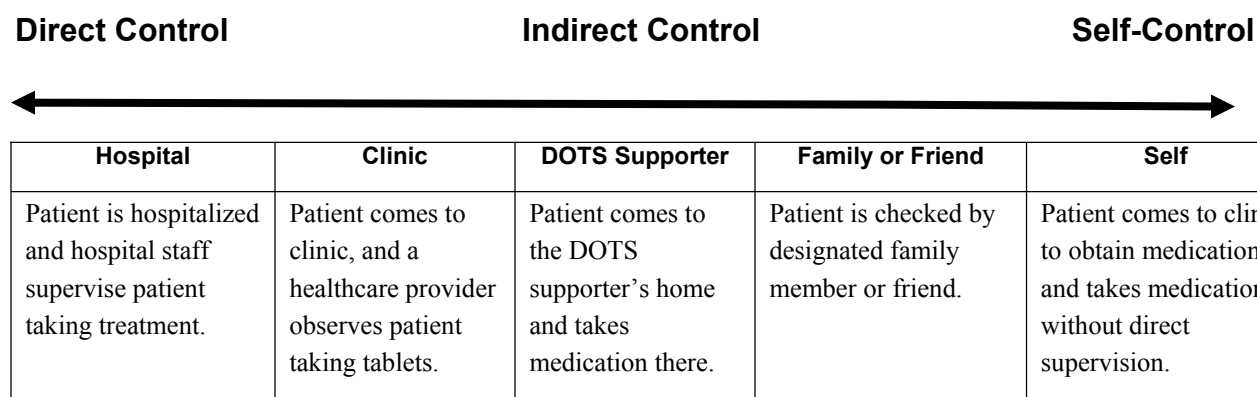
- Only two NGOs involved with the implementation of DOTS supporters were consulted.
- Fieldwork was conducted in two (Eastern and Western Cape) of nine provinces.
- It difficult to solicit the cooperation of non-adherent TB patients within a short timeframe, so the sample was biased in favor of those who were receiving treatment.
- Six focus group discussions were held. The number of respondents per session varied from two to 11. The focus groups were facilitated by different people (male and female) who, although prepared beforehand using the same guidelines, used different group facilitating approaches.
- Having treatment supporters and treatment support coordinators in the same group restrained discussion in that they did not wish to express problems they had with one another or with the patients participating in the FGD.
- Participant observation by the two researchers was limited in that they were not able to follow what was said during the four focus groups that were conducted in isiXhosa.

III. FINDINGS

A. WHERE DO DOTS SUPPORTERS FIT IN THE DOTS SYSTEM?

The establishment of the DOTS strategy has enhanced the management of TB control at an international level. Directly observed therapy (DOT), defined by the WHO as “watching patients take their medication” (WHO 1999) emphasizes the supervision and control of drug swallowing with the rationale that this supervision/controlling would lead to improved case-holding and cure rates. This concept has evolved into a mentoring of the patient congruent with models of chronic care, with the emphasis placed on providing accessible, empathetic care (Marq et al. 2003). See Figure 1.

Figure 1: Continuum of Support Based on the Authority of the Person Ensuring Patient Compliance



Source: Senekal et al. 2001.

B. WHAT EFFECT CAN DOTS SUPPORTERS HAVE IN CASE FINDING AND CASE HOLDING?

Randomized control trials conducted in South Africa have shown that TB patients supported by an LHW can comply as well (Zwarenstein et al. 2000) or significantly better (Clarke et al. Forthcoming) than those supported by other parties. A recent cluster-randomized control trial by Clarke et al. (forthcoming),

designed to measure the effectiveness of LHWs in the agricultural sector, found that the successful treatment completion rate in new smear-positive adult TB patients on farms was 19% higher ($p = 0.042$, 95% CI: 0.9%–36.4%) in the intervention group than in the control group. Case finding for this target group of patients was also 8% higher ($p = 0.2671$) on farms in the intervention group compared to the control group (Clarke et al. forthcoming).

C. HOW DOTS SUPPORTERS ARE SELECTED

Only people living near TB patients are chosen as DOTS supporters, since they must be accessible to patients. LHWs are usually otherwise unemployed and based at their homes. They are recruited from the specific areas where there is a high density of patients.

“Well, there is a process. First of all, the clinic has to do mapping of where the pockets of TB patients are around that facility.”

If the program can provide remuneration for DOTS supporters, there is little difficulty in finding people willing to take on the role. Volunteers approach the clinic staff offering their assistance or come in on the basis of recommendations from existing DOTS supporters in the area. In the project in the agricultural setting, efforts were made to assist the farm laborers select their own candidate to take on the role for the farm.

It is important to select the appropriate type of person as a DOTS supporter. Candidates need to be reasonably mature, as some older patients do not like to be supervised by young people: “They say that they are too impatient.”

“I mean we have had treatment supporters who are 18 or 19 who are very motivated but depending also on the area because, you know, culturally we’ve got to take into consideration that sometimes an elderly male patient might not want to take his treatment from an 18 year old.”

“And it’s also the fact of youngsters versus the other youngsters helping out. Let’s say if the other treatment supporter is a youngster, like 22, they don’t want to go to her because of the same age.”

“Patients from treatment supporter groups prefer an older person to be the supporter: They are more experienced.”

The potential DOTS supporter needs to be functionally literate, as they keep records of their dealings with patients. LHWs often provide important role models in the community and thus must be “of sober habits.” In many township areas, alcohol is sold from private houses, and owners of these businesses are not selected as DOTS supporters.

Most DOTS supporters are women, but a few men have become involved in these interventions.

“I have seven treatment supporters under me: two males and five females. I have problems with one male treatment supporter: He’s got a lot of defaulters; he doesn’t observe the treatment being taken; he gives it to the patient to take home. The other male treatment supporter is good, no problems.”

It is suggested that it is important that the supporter’s spouse be agreeable that the spouse take on the role of DOTS supporter, preventing problems regarding clients of another gender coming to the house. Some

husbands have been reported to become antagonistic to other men visiting their homes while they are not present.

“Very often a woman would offer, would come forward and say that she would like to do it, but then just our TB NGO district coordinator would have to go visit the home and make sure that the husband is aware of this as well; and once or twice, I mean it really is very, very seldom, a husband has said “No,” that he wouldn’t want these men to come and take the treatment from his wife while he is not at home.”

“I used to take my treatment at a supporter, but her husband didn’t like my coming to her house, so I stopped and now come to the clinic.”

D. HOW DOTS SUPPORTERS ARE TRAINED

The introductory training of the selected DOTS supporters varied according to the different sites and ranged from five days to five weeks. Training covered the principles of becoming a DOTS supporter, details about TB as an illness, HIV/AIDS, and health aspects of hygiene and nutrition. Usually there is some emphasis on self-care, dealing with conflict, and issues associated with communication. An interactive, experiential learning approach is used to encourage the DOTS supporters to reflect on their own experiences.

Training continues as the DOTS supporter is supervised and supported in his or her role by the person coordinating the intervention. The contact is monthly and generally occurs when the DOTS supporter obtains the supply of medication.

E. HOW DOTS SUPPORTERS EXPERIENCE EDUCATION

Education is perceived to be one of the incentives for becoming a DOTS supporter.

“They love it. They absolutely love it.”

“Well, I think the training is another carrot because of the benefit they get from the training.”

For many DOTS supporters, especially those coming from rural areas, exposure to any kind of training was a completely new experience. Many had little formal education, with only a few having completed secondary school. They entered the training hesitantly, anxious about being in an unfamiliar learning environment. Through the teaching style, these feelings were soon overcome and replaced by feelings of gratitude for the opportunity. For some respondents, exposure to this training meant gaining something invaluable, and it was often reported to lead to forms personal growth.

“In this course I gained knowledge; I gained something that no one can take away.”
(Daniels et al. forthcoming)

“One of our district coordinators, her husband said to me the other day, “You know, before she came to work here, she was very meek and mild, and she now keeps answering me back—she’s become very assertive.”

“We have some [DOTS supporters] moving on to better opportunities because of the extra, the little certificate that they’ve got.”

F. WHAT DO DOTS SUPPORTERS DO?

“A treatment supporter is a person who works hand in hand with the nurses by giving TB patients their treatment.” (DOTS supporter, Western Cape)

The main focus of the DOTS supporter programs has been in assisting the patient with TB to take their medication as prescribed. This frequently means collecting the medication each month from the clinic nurse and waiting for the patient to come to their house each day so that they can check that the patient has taken the medication. When this has been done, the dose is recorded on a card. If the patient does not come to the house, it is the function of the DOTS supporter to go and find that patient and encourage him or her to adhere to the treatment program. DOTS supporters also cooperate with the formal health sector by reminding patients to attend doctor’s appointments and ensure that they go to the clinic to provide two- and five-month follow-up sputum specimens.

Inherent in the role of DOTS supporters is that they will raise community awareness of TB and TB treatment, and be a resource within the community to assist in case detection and referral for diagnosis. Whether this actually happens or not seems to vary. A DOTS supporter in Nyanga responded,

“I enjoy being a treatment supporter, to help patients and refer them. When they default, I will go to the house, talk to the patient, and explain what’s going to happen. I explain that the TB will come back and will need more treatment.”

Although treatment supporters were supposed to provide patients with education about TB, some patients felt that DOTS supporters did not really do this. As one respondent put it,

“They just give you your treatment and tell you that if you finish your treatment, you will be cured. . . . You only get to know about TB in the group session in the clinic.”

In the Eastern Cape, when respondents were probed about what DOTS supporters do, TB health education did not appear prioritized. Emphasis was placed rather on counseling and nutritional advice.

“We encourage them to grow vegetables so that they can be able to eat healthy food, and we also counsel them if necessary. . . . We do it for the whole community.”

It was clear only in the program implemented within the agricultural sector that LHWs saw case detection as one of their priorities. In this project, the DOTS supporters were encouraged to provide a facility for weighing people on a monthly basis and for screening their peers for clinical signs of TB. In this project there is evidence that they were effective in increasing case detection of new smear-positive cases of TB (Clarke et al. forthcoming).

In some programs, the DOTS supporters come to the clinic and assist the nurses with their caseload of patients with TB. This has proven to be an effective way of making contact with potential clients.

“In many of the clinics, we have also put the treatment supporter in the treatment room with the nurse for an hour or two every morning to help manage the huge flow—especially in big clinics where there are 300 patients. And there they also connect with the treatment supporter and they see that this is a community person who is working with the nurse and is part of the clinic, and then they more readily go out into the community.”

G. PERCEIVED QUALITIES AND SKILLS DOTS SUPPORTERS NEED

DOTS supporters reported assuming an advocacy role, speaking on behalf of the patient and sometimes accompanying patients to clinics on a first visit. Some assisted in dealing with referral letters and reminding patients of follow-up appointments at the clinics. They felt they had gained some expertise in working with people.

“To be a lay health worker means that others share their health problems with you. You therefore hear for example that one has AIDS and so on. You learn also to keep secret what they share with you.” (Daniels et al. forthcoming)

“[S]o that if there is an emergency, they can come to me and tell me this and this: “My child is sick, what do you think I should do?”” (Daniels et al. forthcoming)

Patients with TB may have definite ideas on the characteristics of DOTS supporters.

“Nomakhaya [Xhosa term for treatment supporter] is the kind of person that looks after people; she cares about the well-being of people. She also encourages cleanliness.”

“They are playing a big role, because TB is now controllable, and those people who are staying far from the clinics are now able to get their treatments from nomakhayas in the community.”

Patients expressed frustration when the DOTS supporter was not at home when they came for their medication. This meant that their card would not be signed, and the clinic staff would assume they had missed a dose of their medication. Respondents did not like it when the DOTS supporter delegated their duties to his or her spouse or child. Respondents were uneasy about DOTS supporters who run a “house shop” from home, as it often meant that they had to wait to take their treatment.

H. HOW DO PATIENTS SELECT CLINIC-, WORK-, OR COMMUNITY-BASED CARE?

Usually the clinic sister in charge of the TB program counsels the TB patients as to what alternatives there are regarding TB support and directly observed therapy. Sometimes there is some coercion in the choices the patient makes, and it is reported that clinic nurses are reluctant to delegate the task of mentoring what they perceive to be problem adherence cases to community-based care.

Patients reported that some clinics provided food with the medication, and this was a strong incentive for them to make the extra effort to choose clinic-based DOTS. Hunger is one of the main reasons why patients fail to take their TB medication and often determines whether or not the TB patient chooses to use the clinic or a DOTS supporter, depending on where they could get food. In some focus groups, patients also made reference to the need for social support, which could only be secured by consultation with the clinic staff.

Also mentioned was how social status can affect whether a TB patient is happy to use a treatment supporter or not.

“There are the zones and there are the co-houses, the subsidy houses, those nice ones unlike the hostels. . . . So, those from the co-houses didn’t want to go to the supporter

“Those from the nice houses didn’t want to have supporters around because of the stigma. . . . As a result, now, there were supporters in the area of co-houses but they

didn't get any patients, but there are patients in the area. They don't receive patients because patients don't want to go to them, so the patients were flocking in the clinic, so as a result those two ladies are no longer active."

I. WHAT SHOULD BE CONSIDERED BEFORE IMPLEMENTING DOTS SUPPORTERS?

Stakeholders knew from experience that a system of DOTS supporters providing community-based care could not fix a poorly performing TB control program. In addition, the TB control program at the district and health unit level would have to promise management commitment to the program with technical competence in ensuring an efficient system of drug supply and laboratory service. The clinic must be competent in diagnostic processes and a reliable reporting system on case management would have to be in place before community-based DOTS could be considered. In essence, a network of DOTS supporters should complement a TB control program at the clinic and district level.

"This has also been a lesson, that community-based DOTS shouldn't be implemented to solve the TB problem if there isn't functional TB control at the clinic level. In other words, the health services need to do at least the minimum that they should do, then the community becomes an extension of the service; it's not the provision of the service, it's an extension of a service that's already been provided."

Lisa-Marie Smith, the Executive Director of the TB Alliance DOTS Support Association (TADSA), discussed how the organization responsible for facilitating community-based DOTS nationally had begun to emphasize a quality assurance process before contracting with the formal health sector.

"We go through a readiness process before we can implement community-based DOTS. . . . So, we have a situation where there will be 15 clinics in a district: six will be ready to introduce community-based DOTS. . . . [W]e rather spend a lot of time on readiness and then we work with the sites that are ready and then we do very basic stuff, just to have a pre-intervention profile and then we go about sitting with the sites that are ready."

She noted that much depends on selecting people with the personality and enthusiasm for the task:

"It's people and then systems. There are lots of theories about this, but you can't create a system first: You first have to know whom you're working with and then you create a system to suit them. If so, chances are a little bit stronger that it will succeed. So, even with the system that we created, it's quite individualized, in terms of the different clinics."

The system has basic principles, but it's adapted to the context and the people:

"We look at who's your best person to be a DOTS coordinator, the person who will look after the treatment supporters? Who's your best person to be your DOTS trainer? The DOTS trainer learns to train treatment supporters on an ongoing basis. Trainers can serve more than one clinic, but every clinic must have its own DOTS coordinator, whether it's a TB sister, whether it's the clinic manager, whether it's the cleaner, whether it's the health promoter."

One of the barriers to sustaining an efficient system of community-based DOTS is the policy of frequent rotation of staff within the formal healthcare system.

“We need to have commitment from a person for a year, at least.”

J. IS IT POSSIBLE TO INTEGRATE DOTS SUPPORTERS WITH AN HIV/AIDS PROGRAM?

Stakeholders responsible for coordinating community-based DOTS consider it important to educate DOTS supporters in all aspects of HIV/AIDS. LHWs need basic HIV information in order to counter any AIDS myths in the community and to support their TB patients.

“Patients don’t want to go to [the supporter] because . . . she might think that having TB would mean that he is also HIV positive. They are running away from those things.”

“As one treatment supporter put it, ‘More education on TB and HIV is needed.’ A common misconception is ‘This TB brings me AIDS.’ The supporter explains the difference to the TB patients, but the families of the patients neglect them because they think if you have TB, you have HIV.”

Patients with TB are encouraged to know their HIV status. This is sometimes problematic due to organizational difficulties with the voluntary counseling and testing (VCT) programs run by clinics. DOTS supporters also need to know what is happening in the district in terms of HIV prevalence.

There is a range of controversial issues associated with DOTS supporters’ role in the HIV/AIDS program. One of these is whether or not DOTS supporters would be willing to issue condoms to their patients. Many of the patients with TB being supervised by DOTS supporters are male, and the DOTS supporters are female:

“How is a woman going to talk to a man about sex? He’s not my husband!”

Should DOTS supporters extend their role to becoming “home carers” in the HIV/AIDS program? This category of LHW is trained to support families with a terminally ill AIDS patient and assist them in basic nursing duties such as bathing, feeding, and cleaning. They are expected to work four hours five days a week and are paid a salary of R500 per month for their activities. It is essential that DOTS supporters remain home based and accessible to their clients, and serving as a home carer in the HIV/AIDS program would make this difficult.

One respondent involved with the implementation of DOTS emphasized that while one cannot avoid the fact that DOTS supporters need background training in HIV/AIDS, this should not be done in a way that blurs their role as TB treatment supporters. This, it was felt, would lead to inefficiency within the TB control program.

K. COMPENSATION AND ITS EFFECT ON MOTIVATION

Most DOTS supporters in South Africa are volunteers and receive no monetary incentives for their work. The training they receive in preparation for their role is seen as an incentive and in some cases is thought to improve the possibility of formal employment in the future. The supporters say that they have learned certain skills and become more self-assured during their involvement in the program.

In the program organized by TB CARE in the Western Cape, DOTS supporters are paid ZAR 30 per patient per month. They are encouraged not to supervise more than 10 to 15 clients a month. This monetary incentive has proven to be a strong one as there is widespread unemployment in the area. The

supporters are assisted in opening their own bank accounts into which the money is deposited. Many of the women have never earned any money and were not aware that they could have an account of their own without the supervision of their husbands.

In the Farmworker Intervention 15, the LHWs were employed by farm management. The employers were encouraged to supplement the LHWs' existing salaries with gratuities for performing this extra function on the farm.

In the Nyandeni district, DOTS supporters have not yet received any monetary compensation.

“There are times when you just say to yourself, You know what, I don't even get paid for being nomakhaya, but since we love helping people, we carry on with the good work that we are doing.”

Many of the existing incentives are given in association with transport money to attend meetings or using a taxi to pick up the medication for clients, and the resources are raised by the TB coordinators in fundraising activities.

IV. DISCUSSION AND RECOMMENDATIONS

The DOTS supporter program should not be seen as a “quick fix” for failing TB control programs. If DOTS supporters are introduced in settings where formal health facilities are not functional, it is likely that existing problems will only worsen. DOTS supporters should be incorporated where health facilities are well organized and technically competent in TB management, an extension of an already-functioning service.

Our research also reinforces existing studies indicating that DOTS supporters have the potential to improve the lines of communication between the formal health sector and the community they serve. Although some study respondents chose not to use DOTS supporters, none of our selected respondents showed any antagonism towards the concept of DOTS supporters, implying that different patients in differing circumstances have different needs and should choose different modalities of treatment support. When well trained, DOTS supporters seemed to be as effective as health professionals in providing information on health to their peers; they thus have the potential to positively affect the health and treatment behavior in communities where they live and work. Following this, we assert that the challenge of DOTS supporters is the effective implementation and management of this type of public health intervention, not determining whether it should or should not exist. The next question, then, is How does one ensure quality control?

An important component for successful community-based interventions is sustaining high morale by caring for the caregivers. It appears from the research that where DOTS supporters are well prepared for their role, effectively supervised and monitored, acknowledged in some form (not necessarily monetary) for their contribution, and well integrated into the formal health sector's management process, there is a stronger possibility of sustaining the intervention. This points to how DOTS supporters' motivation is imperative in implementing such a program.

The issue of monetary incentives remains controversial. The concept of voluntarism is associated with altruism, but can one expect people living in poverty to dedicate their energies to assist the health services achieve their objectives without compensation? Rewarding volunteers for their role may occur in a number of ways, and many of these approaches are built into successful community-based programs.

DOTS supporters may be acknowledged for the work they do and receive positive feedback from their clients and the healthcare providers. They may receive compensation for the costs they incur in traveling to the clinic and meetings and in providing food to patients who complain of hunger. In addition or alternatively, they may receive personal benefits as a reward for delivering measurable outcomes, such as being paid for each patient who is successfully supervised for a month. We urge further research to move away from the question of whether to pay and toward that of how to effectively motivate and reward supporters in the most efficient and sustainable way, be it monetary or other.

The debate over incentives was exacerbated by the Minister of Health's announcement in 2003 of the intention that each community health worker will be given a minimum stipend of R1000 per month. This stimulated the Provincial Health Departments to compile a list of LHWs working in the health system, and in the Free State and KwaZulu-Natal. LHWs on this list receive a monthly stipend. There is a danger associated with setting up a system of incentives without an efficient support system in place for DOTS supporters:

“Because otherwise people will be doing it for the money, and then you're losing that humanity aspect of what community-based DOTS is about.”

REFERENCES

- Clarke M, Dick J, Zwarenstein M, Lombard, CJ, and Diwan V. Forthcoming. Lay workers improve TB treatment outcome in commercial farming area of South Africa: Cluster randomized control trial.
- Daniels K, van Zyl H, Clarke M, Dick J, and Johansson E. Forthcoming. Ear to the ground: Listening to farm dwellers talk about the experience of becoming lay health workers.
- Department of Health, South Africa. 1996. The South African TB Control Programme. Practical Guidelines. Pretoria:1–11.
- Friedman I. 2003. Community Based Health Workers in the South African Health Review 2002, Health Systems Trust. Durban.
- Hadley M and Maher D. 2000. Community involvement in TB control: Lessons from other health care programmes. *International Journal of Tuberculosis & Lung Disease* 4(5):401–08.
- Lewin S, Dick J, Pond P, Zwarenstein M, Aja G, van Wyk B, Bosch-Capblanch X, and Patrick M. Forthcoming. Lay health workers in primary care and community health: A systematic review.
- Maher D, Van Gorkom JLC, Gondrie PCFM, and Ravilione M. 1999. Community contribution to TB care in countries with high TB prevalence: Past, present and future. *International Journal of Tuberculosis & Lung Disease* 3(9):762–68.
- Marq JCM, Theobald S, Dick J, and Dembele M. 2003. An exploration of the concept of directly observed treatment (DOT) for tuberculosis patients: From a uniform to a customized approach. *International Journal of Tuberculosis & Lung Disease* 7(2):103–09.
- Rifkin SA. 1986. Health planning and community participation in health programmes. *Health Policy and Planning* 1(3):240–49.
- Senekal I, Schoeman JH, and Ntotina T. 2001. “An Exploration of Community DOTS Models in the Eastern Cape Province.” (Unpublished Report) Cape Town: TADSA.

- Walt G. 1988. *Community Health Workers: Policy and practice in national programmes. A review with selected annotations.* Evaluation and Planning Centre for Health Care. London: Publication Number 16, Spring.
- Walt G, ed. 1990. *Community Health Workers in National Programmes: Just Another Pair of Hands?* Buckingham: Open University Press.
- WHO (World Health Organization). 1998. Status of TB in High-Burden Countries and Global Constraints to TB Control (WHO/TB/98.242). Geneva: p 37.
- . 1999. What is DOTS: A guide to understanding the WHO-recommended TB control strategy known as DOTS. Geneva: WHO/CDS/CPc/tb/99.270.
- . WHO Global TB Control Report 2004. 2004. Geneva: WHO/CDS/TB2004.331.
- Zwarenstein M, Schoeman JH, Vundule C, Lombard C, and Tatley M. 2000. A randomized controlled trial of lay health workers as direct observers for treatment of tuberculosis. *International Journal of Tuberculosis and Lung Disease* 4(6):550–54.

APPENDIX 1: INFORMED CONSENT FORM FOR INTERVIEWS

I, _____, have been contracted by the University of Stellenbosch to conduct research for them. The project seeks to acquire knowledge of “DOTS supporters,” so that they may provide better support to patients with TB. Improving the quality of care to patients with tuberculosis will also assist in controlling the disease in South Africa.

The study is conducted in two sites in South Africa: the Western and Eastern Cape. The information that we get from you will help us to write a report that will be published. However, the information that you give us will be considered confidential, and your name will not be used.

Your participation is voluntary, and if you do not wish to participate in the study you have the right to say no, and that will not jeopardize your relationship with the clinic or any other health services. You may also terminate the interview or your participation in the group discussion whenever you feel that you do not want to talk. You can also choose not to answer some of the questions if you do not feel comfortable answering them.

There are no benefits for participating in the study. However, the information that you give us may help us to make recommendations that will impact on the quality of care you receive in the health system.

Data will be collected in the form of participant observation and interviews. The interviews will be tape recorded so as to capture accurately all the information that you will give us.

I _____ agree to participate in the study; I have read and understood everything, and all my questions have been answered.

Signature _____

Date _____

Witness _____

Date _____

I, _____, agree to be tape recorded in an interview or group discussion.

Signature _____

Date _____

Witness _____

Date _____

APPENDIX 2: INFORMED CONSENT FORM FOR FOCUS GROUPS

I, _____, the undersigned group facilitator, declare that I have informed the patient of the nature and purpose of the research project in his/her own language. The research looks at how effective the DOTS supporters are. Looking after patients with TB better will help to control this disease in South Africa.

The study is done in the Western Cape and Eastern Cape. Data will be collected by observing the members of the group and by audio-recording the discussion to capture accurately all the information that is given. The information that you give to us during a group session will help us to write a report that will be published. We will keep the information that you give to us confidential by not using your name in any reports that may be published.

If you do not wish to participate in this study, you have the right to say no, and that will not influence you or your family's treatment at the clinic or any other health services. You may also stop participating in the group discussion whenever you feel that you do not want to talk. You can also choose not to answer some of the questions if you do not feel comfortable answering them.

There will be no financial rewards for participation in this study. However, the information that you give us may help us make recommendations that will impact on the quality of care you receive in the health system.

I, _____, (name and surname of participant) born/age _____ and living at _____ (address) agree to be part of the study. I understand everything, and all my questions have been answered.

Signature Date

Witness Date

I, _____, (name and surname of participant) agree to be audio-recorded in the group discussion.

Signature Date

Witness Date

(Signature of facilitator) (Date)

(Witness) (Date)

QUALITY ASSURANCE PROJECT

University Research Co., LLC
7200 Wisconsin Avenue, Suite 600
Bethesda, MD 20814

Tel: (301) 654-8338

Fax: (301) 941-8427

www.qaproject.org