

Collaboration between the national tuberculosis programme and a non governmental organisation in TB/HIV care at a district level: experience from Tanzania

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ABSTRACT

Background: The increase in tuberculosis and HIV/AIDS patients in many countries in Africa including Tanzania, is outstripping the ability of public health services to cope. This calls for a closer collaboration between tuberculosis programmes and other stakeholders involved in HIV/AIDS care.

Objective: To determine the feasibility of establishing collaboration between the tuberculosis programme and an NGO in TB/HIV care at a district level in Tanzania.

Methods: Quantitative and qualitative study designs involving TB as well as HIV suspects and patients together with health workers, were conducted between December, 2001 and September, 2002.

Results: A total of 72 patients and 28 key informants were involved. The collaboration was in the following areas; voluntary counselling and testing for HIV, diagnosis and treatment of TB, referral and follow up of patients and suspects, home based care, psychological support and training. Both the tuberculosis programme and NGO benefited from the collaboration. TB case detection among PLWA increased more than three folds and TB treatment was integrated in home based care of NGO. The main barriers identified in this study were; poor communication, poor referral system and lack of knowledge and skills among health staff.

Conclusion: The study has shown that it is possible for a tuberculosis programme and a non governmental organisation to collaborate in TB/HIV care. The study has also identified potential areas of collaboration and barriers that needed to be overcome in order to provide such comprehensive services at a district level.

Keywords: tuberculosis, Human Immunodeficiency Virus, collaboration, non governmental organisation, Tanzania

Running title: Collaboration in TB/HIV care in Tanzania.

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INTRODUCTION

Human Immunodeficiency virus (HIV) infection is fuelling the tuberculosis (TB) epidemic in many countries of sub-Saharan Africa¹. In Tanzania, TB notification among smear positive patients has increased from 38/100,000 to 81/100,000 between 1983 and 2000, mainly due to HIV/AIDS². The increase of TB and HIV/AIDS patients is outstripping the ability of public health services to cope.

The World Health Organisation (WHO) has proposed a number of interventions to deal with

this problem. The interventions aim at providing coherent health response that involves all stakeholders in TB/HIV care. The goal is to exploit synergies between different stakeholders including tuberculosis programmes, HIV/AIDS programmes and Non Governmental Organisations (NGOs) in order to provide comprehensive care to people with TB and HIV/AIDS. Voluntary Counselling and Testing (VCT) for HIV has been regarded as the link and entry point for provision of TB/HIV interventions³

It is estimated that about 90% of People Living With HIV/AIDS (PLWA) in sub-Saharan Africa do not know that they are HIV positive⁴. There is also widespread perception that HIV testing offers little to persons testing positive if is not linked with prevention and care of HIV/AIDS and other related diseases such as tuberculosis. Thus provision of comprehensive services may serve to promote VCT for HIV.

The private sector including Non Governmental Organisations plays a crucial role in provision of health services in Tanzania. A study conducted in Dar es Salaam

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revealed that about 40% of people used private health services⁵. NGOs are particularly important in provision of care for People Living With HIV/AIDS (PLWA) and VCT services to the general population. However, the link between services provided by NGOs and the tuberculosis programme is weak.

There is increasing recognition of establishing a closer and practical collaboration between tuberculosis and AIDS programme together with NGOs to fight the dual TB/HIV epidemic. Although some joint TB/HIV activities are undertaken at the national level and in a few districts in Tanzania, in most districts the activities are implemented separately. We were unaware of any NGO in Tanzania which is formally collaborating with the National Tuberculosis and Leprosy Programme (NTLP) in TB care. We therefore conducted a study to determine the feasibility of establishing collaboration between tuberculosis programme and an NGO in TB/HIV care at district level in Tanzania.

METHODS

Study area

The study was conducted in Temeke district in Dar es Salaam. Temeke is one of the three districts of Dar es Salaam region with a population of about 700,000 people and is heavily affected by the TB/HIV dual epidemic. In the year 2000, the HIV prevalence among blood donors was 25.9% and tuberculosis case notification was 571 per 100000 compared to 11% and 170 per 100000, respectively

Table 1: Key themes of qualitative interviews

Themes

1. What are the strengths of collaboration?
 2. What are the weaknesses of collaboration?
 3. What are the barriers for effective collaboration?
 4. What are the opportunities and mechanisms to overcome such barriers?
 5. What are the barriers for provision of services?
 6. What are the opportunities and mechanisms to overcome the barriers?
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Patients were recruited in the study prospectively as they were reporting to TB clinic and PASADA respectively. Since no any objective criteria of identify patients and suspects who were TB/HIV co-infected was employed, health workers

for the country^{6,7}. A survey conducted among tuberculosis patients in Dar es Salaam between 1994 and 1998 showed that about 49% of them are also co-infected with HIV⁸. The district has about 120 health facilities and tuberculosis services are provided in 18 health facilities.

PASADA (Pastoral Activities and Services for people with AIDS in Dar Es Salaam Archdiocese) is a faith based NGO providing care for PLWA. It is located in Temeke district, about 1 km from the main TB clinic at the district hospital. The NGO offers VCT for HIV, home based care services and psychosocial support to PLWA. The NGO provides medical care for PLWA on an outpatient basis cares for over 1600 orphans and provides community education on HIV /AIDS.

Study design

The study was conducted between December, 2001 and September, 2002. Data was collected using both using quantitative and qualitative study methods.

Quantitative data on TB/HIV patients and suspects were collected from hospital files and cards, referral forms and laboratory registers. On the other hand, qualitative information was obtained from in depth interview of health workers from the tuberculosis programme and PASADA to get an insight view of the opportunities and barriers encountered in establishing an effective collaboration in TB/HIV care. The interviews revolved around the themes outlined in Table 1. The interviews were carried out by two public health specialists and a social scientist who were familiar with TB/HIV issues.

selected eligible study participants by screening them based on presenting symptoms and signs. The purpose of the study was explained and those who consented were enrolled.

Major areas of collaboration between TB programme and PASADA

Intervention	Responsible organisation
Voluntary counselling and Testing for HIV	PASADA
Diagnosis and treatment of TB	TB programme*
Referral of patients and suspects	TB programme/PASADA
Home based care	PASADA
Follow up of patients	TB programme/PASADA**
Psychosocial support	PASADA
Joint meetings	TB programme/PASADA
Training	TB programme

*This activity was later carried out by PASADA

** A nurse was later employed by the project to follow up patients

Description of collaboration

The collaboration was between the tuberculosis programme in the district and PASADA. Before starting collaboration, there were no established mechanisms and organisational structure of handling TB and HIV/AIDS suspects from PASADA and the TB clinic respectively. Neither the tuberculosis programme nor PASADA had the skills and knowledge of providing care to people who were dually infected with TB/HIV.

The collaboration focused on eight major areas as shown in Table 2. TB patients with symptoms and signs of AIDS were referred to PASADA for counselling and HIV testing. Those found HIV positive were offered home based care services including directly observed treatment (DOT) of TB, and psychosocial support through the PASADA network of volunteers.

On the other hand, PLWA from PASADA suspected of having TB, were referred to the TB clinic. If diagnosed with TB, patients were allowed to follow their TB treatment through PASADA's home based care services.

Ethical clearance to carry out the study was obtained from the Ministry of Health in Tanzania and informed consent was obtained from the patients.

RESULTS

A total of 72 patients were followed up in the quantitative study. Twenty four TB patients were referred to PASADA for voluntary counselling and testing for HIV, and forty eight PLWA were referred to the TB clinic for diagnosis. Among TB patients, four refused HIV testing because of insufficient information on the purpose of referral. TB patients

declined to be tested for HIV because the referring clinician did not discuss the need for VCT for HIV, the reason given for referral was 'further management' and not HIV testing.

There was a two months slow start of implementation of collaboration. During this period many patients were 'lost' when referred to and from the TB clinic. An average of only five patients out of fourteen referred either to the TB clinic or PASADA, reported. When looking into the reasons for slow implementation of collaboration and apparent loss of the patients, the following were identified; weak referral system, poor follow up of the patients, poor communication between collaborating partners, and distance between TB clinic and PASADA. The following measures were put in place to rectify the situation; strengthening the referral system by establishing special forms and assign responsibilities to individual clinicians, conducting joint meetings between collaborating partners, advising patients to go directly to the TB clinic and home based care department at PASADA instead of Out Patients Department (OPD) and employing a nurse who was responsible for the follow up of the patients and suspects.

Thereafter, there was a marked reduction in number of the patients who were 'lost' during the referral process. The number of patients who reported to the TB clinic and PASADA increased to an average of twelve per month.

In order to improve patients' compliance and reduce inconveniences, it was decided to open a TB clinic at PASADA premises. PASADA was therefore recognised as a TB diagnostic and treatment centre operating under NTLP guidelines. On job and formal training was given to PASADA health workers on different aspects of TB management and smear microscopy. Since then the number

of TB suspects submitting sputum for diagnosis has increased to an average of 30 per month.

A total of 28 key informants were interviewed in a qualitative study. Twenty one of them were District Tuberculosis and Leprosy Coordinators (DTLC) from different areas of Dar es salaam and seven were health workers from PASADA. The DTLCs are involved in management of TB patients in their areas. Five of them were involved in the study.

Key informants from PASADA came from OPD and home based care department. They included five clinicians and two nurses

The interviews focused on the following themes:

Strength and weakness of collaboration

The majority of informants (23/28) felt that collaboration will help to extend the scope and coverage of services provided to TB and HIV/AIDS patients. The strength of tuberculosis programme was viewed as its network of health facilities providing TB services, good organisational setup and follow-up of patients.

On the other hand, NGOs' were viewed as having good community involvement, being less bureaucratic and providing wide range of services.

The main benefit of collaboration mentioned was provision of comprehensive services and continuum of care to the patients from health facility to the community. Other benefits are increased awareness to health staff about the two diseases, reduced patients inconvenience, increased TB case detection and reduced workload to the staff mainly in public health facilities

The main weakness mentioned were poor communication, lack of trust and poor understanding of each others role.

Although the tuberculosis programme and HIV/AIDS NGOs attend to the same patients, many informants felt that the two organisations work in isolation with no forum to meet and discuss their activities.

The majority of the tuberculosis staff (18/21) felt that NGOs are not transparent in their activities, do not follow national guidelines in management of their patients and often exclude certain types of patients. On the other hand NGOs view general public services as rigid, less efficient and provide low quality services.

Barriers to services

The following were identified as barriers for provision of comprehensive services to TB/HIV patients: lack of knowledge and skills, poor referral system, stigma and cost sharing.

The majority of the tuberculosis staff (20/21) felt that they lacked HIV counselling skills. Many did not talk to their patients about HIV/AIDS despite the facts that about a half are co-infected. On the other hand, PASADA staffs were not conversant with national guidelines on management and control of tuberculosis.

Poor referral system and lack of networking was regarded as one of the barriers on provision of services. This was important because many NGOs and tuberculosis clinics are not located in the same premises.

Other barriers mentioned were stigma towards TB and HIV/AIDS, among both health workers and the general public, and cost sharing especially for VCT and diagnosis of TB in OPD.

Some tuberculosis staff felt that emphasis on VCT among TB patients will deter some patients to continue with TB treatment and have negative impact for tuberculosis control. On the other hand, some PASADA staff feared of being infected with TB and increase workload from TB patients.

Opportunities and mechanisms to overcome the barriers

There was consensus among key informants that there are unexplored opportunities and potentials for provision of comprehensive services to TB/AIDS patients. The services can be delivered by improving collaboration between TB programmes and NGOs. As a starting point, the informants suggested NTLF to take the initiative. This will help to establish trust and understanding among the collaborating partners. It was suggested that, tuberculosis programme should select NGOs with capacity and experience of delivering care to PLWA. The collaboration should start with a few set of activities and gradually increase to include more activities. The following were mentioned as potential areas of collaboration; voluntary counselling and testing for HIV, home based care, diagnosis and treatment of TB, referral and follow up of patients, preventive therapy for TB and Anti retroviral drug provision, health education and prevention, training and psychosocial support.

DISCUSSION

Our study has shown that it is possible for a tuberculosis programme and a non governmental organisation working with PLWA to collaborate in TB/HIV care. The study

has also identified potential areas of collaboration and barriers that needed to be overcome in order to provide such comprehensive services at a district level.

The study has a number of limitations, including those emanating from methodological and logistical difficulties. There might be a selection bias in the qualitative study, since the majority of key informants were from the tuberculosis programme and tended to give more of the 'tuberculosis perspective'. Although a broad range of issues important for both TB and HIV/AIDS care were covered during the interview, it would have been more useful to conduct interviews with more stakeholders from the HIV/AIDS 'community' including participants from the AIDS programme and other NGOs besides PASADA. The qualitative information gathered from interviews did, however, add to the interpretation and understanding of key issues encountered during the quantitative study and implementation of the collaboration.

This was a pragmatic study involving a faith based NGO and NTLF. Only one NGO was involved in this collaboration, and services provided to the patients were limited to those provided in routine practice. We did not have objective criteria of selecting patients and suspects for referral and we may have missed some patients because of overlap of TB and HIV symptoms and signs. Another limitation is the small number of patients. Nevertheless, this does not belittle the conclusion since the aim was to investigate the feasibility of collaboration in TB/HIV care under routine conditions in the district.

Analysing barriers and weakness encountered during implementation of collaboration in this study, gives some understanding of why it has been difficult to establish and implement TB/HIV collaborative activities, especially at district level in Tanzania and probably in other parts of Africa. The main barriers identified in this study were; poor communication, lack of trust among collaborating partners, poor referral system and lack of knowledge and skills among health staff and. Other lesser barriers were stigma attached to both diseases and costs to access services especially in public health facilities.

These weaknesses may have arisen due to philosophical and cultural differences in the approach to TB and HIV care between tuberculosis programme and NGOs. Conversely, it may also reflect the lack of strategic framework on joint TB

and HIV/AIDS activities not only at district level but also at national and international level. Until recently, there has been little interaction at international level between tuberculosis and HIV/AIDS stakeholders⁹

An important first step to overcome the barriers is to establish open communication between collaborating partners. In our case, the tuberculosis programme took the initiative and later facilitated subsequent joint meetings with PASADA. This provided a platform to discuss weaknesses and barriers encountered during the implementation of collaboration, and restored confidence and trust among partners.

Worth noting in this study is the apparent low level of knowledge and skills among health workers, especially tuberculosis staff on HIV counselling. Some TB patients refused to be tested for HIV when referred from the TB clinic because of insufficient information. Patients were told by TB staff that they were referred for 'further management' and not for HIV testing as requested by VCT staff at PASADA. During the qualitative study, TB staff admitted they lack counselling skills on HIV and do not know how to bring up the issue of HIV testing among their TB patients. Whether to train tuberculosis staff on professional HIV counselling or not remain open for debate. Based on our experience in Temeke we are reluctant to advocate this approach. TB staff who are already overstretched with increasing number of TB patients will be overwhelmed with the demands involved in providing effective and quality HIV counselling. We are rather recommending TB staff to be trained in basic skills of HIV counselling so that they should be able to communicate effectively with their TB patients and refer them to professional counsellors.

The benefits of collaboration to both partners and individual patients are substantial. The collaboration presents a more holistic and coherent response to the dual epidemic.

It maximises synergies between collaborating partners and offer an effective use of resources. Drugs and supplies for TB diagnosis in our study were provided by the NTLF while psychological support, VCT and home based care services were provided by PASADA. The tuberculosis programme benefited by increasing TB case detection more than three folds among PLHW, and PASADA was able to provide TB services to its patients including home based TB care. There was marked increase in TB and HIV/AIDS awareness among staff from both institutions

The findings of this study have been presented to the local and national authorities in Tanzania. Subsequently, the collaboration is now implemented as part and parcel of routine TB and HIV/AIDS activities

in Temeke district. The challenge, however, is to expand this experience beyond Temeke district. There appears to be considerable potential for expansion of scope and scale of collaboration. Future work should include other components of care not covered in this study, and preventive interventions such as joint health education campaigns.

A study conducted in Zambia showed that integration of TB treatment with home based care services for HIV/AIDS can lead to improved TB programme performance¹⁰. Lesson learned from our study are in keeping with experience from other parts of Africa^{11,12}.

These experiences might be useful for district based interventions such as the WHO facilitated proTEST initiative which is piloted in a number of countries including Tanzania to involve all stakeholders in TB/AIDS care

The current conditions provide a good opportunity to promote collaboration between all stakeholders involved in TB and HIV/AIDS care. There is increasing interest and recognition both at international and national level to provide coherent response to TB/HIV epidemics. Establishment of Global fund against AIDS, Tuberculosis and Malaria and WHO proTEST initiatives are just some of these examples. Tuberculosis programmes and NGOs need to capitalise on the current increasing commitments. This can be achieved by establishing joint TB/HIV activities particularly at the district level.

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