Assessment of health-care seeking behaviour:

The case of co-infection of TB and HIV/AIDS in Temeke, Tanzania

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List of Acronyms

ART	Antiretroviral therapy / treatment
CBHC	Community based health care
CPT	Cotrimoxazole Preventive Therapy
CTC	Care and Treatment Centre
DCT	Diagnostic Counselling and Testing
DTLC	District Tuberculosis and Leprosy Coordinator
FTB	Former TB Patients
LHL	The Norwegian Association of Heart and Lung Patients
MUKIKUTE	Mapambano ya Ugonjwa ya Kifua Kikuu na Ukimwi Temeke (NGO formed by former TB patients).
NGO	Non Governmental Organisation
NORAD	Norwegian Agency for Development Cooperation
NTLP	National TB and Leprosy Programme
PASADA	Pastoral Activities and Services for People Living with HIV/AIDS
RTLC	Regional TB and Leprosy Coordinator
TB	Tuberculosis
TZS	Tanzanian Shilling
USD	US Dollar
VCT	Voluntary Counselling and Testing

EXECUTIVE SUMMARY:

Main objectives

1) to assess to what extent peoples' health-care seeking behaviour and their disease aetiology (i.e. causal explanation) influences a decline in case finding / a possible increase in diagnostic delay and low ART uptake

2) to assess the potential for collaboration between traditional / religious healing and modern health care facilities in Temeke District.

Methodology:

This study was a rapid assessment (14 days duration) and utilised multiple methods for data collection; household study, life-career and illness narratives, interviews with individuals and groups on focused topics, participant observation of hospital- and clinic procedures and community sensitisation, and a local documents and literature studies.

Temeke district and people's livelihood:

Due to urban-rural migration, poverty, increasing socio-economic differentiation and individualisation of the family unit, health networks are relatively small and socially and economically vulnerable. Care and economic support of a family member with disease, is considered a 'family issue'.

Recommendations: Carry out an in-depth study of the 'family unit' focusing on: Who makes up the urban/modern extended family in contemporary Temeke; Who are counted as reliable family members in times of need, that is, long-term illness, fatal illness, death and dying; To what extent are other people and institutions drawn upon for help in times of long-term illness and economic crisis; Are any institutions playing a crucial role in the socio-economic and emotional care of the sick and dying (NGOs, or such as church congregation, etc.)?

Peoples' health care seeking practices within a plural medical culture

Temeke district is characterised by a plurality of complex and co-existing medical systems and cultures, 1) Traditional African/ Islam medical practices, 2) Religious faith healing which is practiced by the various charismatic church congregations, and 3) government/modern biomedicine – including the private institutions and practitioners. These systems are more or less overlapping and the TB/HIV patient shuttles between the various systems. In addition, there is a rapidly growing commercialisation of 'traditional' medicine and these new forms of treatment alternatives are drawn upon by TB and HIV/AIDS patients.

The most common health-cares-seeking-behaviour pattern among the TB and TB/HIV infected informants is in the following order: 1) Self-treatment; 2) Governmental hospital/clinic; 3) Private health facility; 4) Local (including religious) healers; 5) Returning to the Governmental hospital/clinic.

The pathway to correct diagnosis and treatment is long and costly. It is not uncommon that the delay in correct treatment takes up to 2-3 months even if the patient turns to the modern health sector as the first treatment option. The cost of multiple consultations, examinations, laboratory tests, and repetitive ineffective medication, is high and puts significant economic strain on the household's economy.

Recommendations: 1) More efforts must be put into early diagnosis in the formal / governmental health sector in order to reduce the diagnostic delay; 2) Patient-doctor dialogue has room for significant improvement. Patients in this study fear being criticized by health personnel and are at times (incorrectly) blamed for coming too late to the clinic/hospital. 3) The social worker's position and capacity in supporting the poorest patients should be looked into and possibly strengthened to facilitate assistance to more patients.

"Patient flow" at the clinic often turns into a time consuming queue. Too many forms are currently filled out by overburdened staff.

Recommendations: If the system allows, the measuring of the CD4-level in HIV positive patients should be undertaken whether the patient has agreed to initiate ART or not. TB/HIV patients' knowledge about their CD4-count may be motivating for the initiation of ART and thus reduce the number of defaulters or those who refuse ART. The anglicised term 'CD4' is currently a relatively meaningless term for the patient - local/ Swahili term should be used.

Information about ART (including side-effects) and the importance of proper nutrition is much needed as there is a lack of knowledge and also misconceptions. Many patients are too poor to get a sufficiently nutritious diet.

"AIDS is the end of me". The fact that ART is available and can prolong life and delay death does not seem to make any difference among the complicated / defaulters-cases in their health care seeking behaviour. People perceive that their body is too fragile to cope with ART in addition to the TB-treatment when sick, and believe that the two therapies together will overdose and overburden the body.

The issue of stigma and stigmatisation

Most informants, patients and their caregivers were well-informed about stigma and referred to both 'kunyanyapaa' (disgust) and 'kutenga' (to isolate, separate)

However, none of the patients in this study had personal experience of being stigmatised by their community or by those closest to them upon disclosing their diagnosis. This could be due to the small sample size in this study or poor interview techniques. But other explanations might be that perceptions of stigma may be related to lack of knowledge of ways of transmission, so that people distance themselves out of fear of infection, or poverty resulting in lack of ability to help.

Community Sensitisation – The case of Mukikute

1) Mukikute (TB patient organisation) should be gradually strengthened; 2) FTB should be encouraged to continue their important work in community interventions as well as their work as guardians; 3) members need more training in communication skills; 4) the content of the community sensitisation-programme must be grounded in people's actual life-situation; members must learn how to utilise and build on their own experience both as FTB and as HIV/AIDS patients; 5) They must be encouraged to integrate the experience they continuously get through their work in the community as caretakers of TB and HIV/AIDS patients. Mukikute members are uniquely situated locally and thus are well positioned to enable a close communication between health personnel at Temeke TB/AIDS Clinic and the community.

Potential for collaboration between the health cultures / systems

All parties expressed positive attitudes towards collaboration –'for the benefit of the patient'. Due to the wide difference in medical cultures, training and practices – including their very different disease aetiology (causal explanations), collaborating efforts have however, varied in success and often proven difficult. Representatives of the modern sector must be conscious about what they see as 'cooperation'. Does their intended cooperation mean only encouraging the traditional and religious healers to distribute condoms, adopt hygienic practices, educate their patients, and refer TB and Aids cases to modern medical institutions? To exercise collaboration on equal terms is difficult, but the danger is that a fictive collaboration quickly turns to confrontation or silence between the involved partners. Traditional / local healers could potentially play a role in promoting primary health care, educate communities, and bring about behavioural change, and reduce stigma or ill-behaviour due to blame. If approached in the most appropriate way, through a locally situated approach, this could play a significant role.

Recommendations: 1) Any collaboration between modern and traditional medicine should take place between the two independent partners based on mutual respect, open-mindedness, and interest in learning and a sharing of knowledge. 2) A locally designed strategy should be developed addressing the means and goals in efficient collaboration between the parties which will sustain continuous engagement by the healers 3) Health community strategies must be adapted to the particular local realities of peoples' livelihood in Temeke, and include Mukikute recommendations (see above).

THE ASSESSMENT:

Aims and objectives of the assessment

Main objectives of the assessment

To assess to what extent peoples' health-care seeking behaviour and their disease aetiology (i.e. causal explanation) influence a decline in case finding/ a possible increase in diagnostic delay and low ART (anti retroviral therapy) uptake.

To assess the potential for collaboration between traditional/religious and modern health care facilities in Temeke district.

General assessment tasks

1. What are the main barriers to well-functioning integration of HIV/AIDS and TB activities?

What are the main barriers to well-functioning integration of TB and ART ?

- in the clinic procedures?
- at the community level?

The main goals of this assessment were to:

1) Identify potential causes for delay in correct diagnosis

   a) Identify causes for health sector delay

   b) Assess to what extent treatment and care by traditional/religious/local healers and /or private sector contribute to diagnostic delay for TB?

2) Why do so few HIV/AIDS positive patients identified by DCT (diagnostic counselling and testing) come for ART?

   a) Any factors related to the clinic procedures

   b) Any factors related to the individual patient's experience and reasoning

3) Is there any potential for collaboration between the traditional/religious practitioners and the clinic/ hospital sectors?

THE ASSESSMENT METHODS AND METHODOLOGY

Methods and methodology

This study utilised multiple methods, such as, a household study/survey (random), illness narratives, life-career histories, interviews with individuals and groups on focused topics, participant observation of community sensitisation, observations of hospital- and clinic procedures, as well as peoples' livelihood in their communities and neighbourhoods. The study/ assessment also drew on some local documents and literature studies.

1) TEMEKE household study

Aiming to get an understanding of people's livelihood, a household study among totally 11 households was carried out in the two randomly sampled sub-wards in Mji Mpia in Azimio ward. Azimio ward is one of the 24 wards (administrative units) in Temeke district and is characterised as an urban ward.

These two samples were selected by the researcher in collaboration with the local administration at ward and sub-ward levels.

If in the selected households they had experience with members having suffered from TB and HIV/AIDS, their illness narratives were also collected.

In sample 1, three of five houses had TB and AIDS patients, one of the houses had one patient who was co-infected with TB/AIDS and was under ART.

In sample 2, two of the six houses had patients who were co-infected with TB/AIDS.

2) Illness histories/ illness narratives were collected

a) at the clinic from patients referred to as 'defaulters' and/ or 'complicated' by the health personnel.

b) at Mukikute from FTB who are Mukikute members (see below, point 4)

c) from patients with FTB as treatment supporters or 'guardians' (see below point 4)

Cases referred to as "complicated", "problematic" or as "defaulters" by the health personnel, were interviewed at the clinic. According to the health personnel these patients had neglected their TB and/ or AIDS treatment for longer or shorter periods of time due to a fear of stigma. Others had 'refused' to initiate ART.

The researcher asked the staff at Temeke TB Clinic to select some of those "complicated" cases. These patients had thus not (yet) agreed to begin ART treatment and had therefore not measured their CD4-level and accordingly the health personnel had not yet "opened a file" for them.

A total of 8 such cases (5 females and 3 males) were interviewed and asked to give their illness narratives focusing on any problems they had faced during their illness. Among the issues were why they were hesitant to begin with ART, their family situation, income/ lack of income, the issue of stigma and stigmatisation (*kunyanyapaa*). The informants were chosen by convenience sampling.

These interviews aimed to map:

- the plural medical cultures and practices present in Temeke, i.e. both traditional/ religious and modern – government and private – medical cultures and
- the steps taken by the patients in search for care and treatment.

What are the multiple treatment options drawn upon by patients in a medical plural setting as that of Temeke?

What are the characteristic patterns in people's (TB/HIV) health care seeking behaviour?

3) Observations of and interviews with health personnel at Temeke TB clinic

a) the clinic procedures – focusing on the "patient flow"

b) health education – addressing TB and HIV/AIDS

4) Observations of and interviews with Mukikute leadership and Mukikute FTB

(MUKIKUTE is abbreviated 'Mapambano ya Ukimwi na Kifua Kikuu Temeke' and is a newly established TB / HIV patient NGO in Temeke, the first TB patient organisation in Tanzania).

The team approached twelve of the regular Mukikute members who were present at their office and asked them to participate in the assessment. Based on an open-ended questionnaire with some listed topics (see Appendix 2) we asked them to:

- narrate their own illness history, and
- the illness history of one or two of their patients.

The team first discussed the questionnaire and the listed topics with the informants. All informants were given paper, pencil, and a copy of the questionnaire (in Swahili) and they were asked to write as detailed as possible – but no more than 5 pages – about their own and their patient's illness history.

A few days later their written narratives were collected by the team, read, and discussed with each one of them separately. All except two returned their written narratives before the team left. On an average each wrote roughly 2-3 handwritten pages. The narratives were not very elaborate in its narrating style, so all informants were consequently individually interviewed to get a fuller understanding of their illness narratives as well as their experience as guardians of patient.

5) Approaching traditional and religious healers

To get knowledge about the various categories of local healers working in Temeke district, we interviewed six conveniently chosen healers (assisted by Mukikute members) about their:

- professional career,
- medical knowledge and treatment practices, and
- experiences and attitudes towards collaboration with governmental / modern health sector.

6) Participant observation of Community Sensitisation (about TB, AIDS and ART)

During this assessment, a "community sensitisation"-meeting was organised by Mukikute and supported by staff from Temeke hospital – including some employees from the TB-Clinic. The researcher and field assistant were present during the whole meeting. The session was recorded.

7) The use of assistant and interpreter

The interviews and the informal discussions with people were conducted in Swahili, the *lingua franca* and local language of Tanzania (the local language of most people in the study area). A few interviews were conducted in English. Close to all interviews were recorded and transcribed from Swahili to English. Almost all were transcribed by the research assistant, a few by a secretary, and still a few by the principle researcher herself.

All of those who were approached during the assessment, accepted to participate voluntarily.

Whenever the researcher and research assistant approached people outside the clinic setting – i.e. in their homes, neighbourhood at all administrative levels (ward and sub ward and the sub-sub ward) / communities – we worked through the well-organised administrative system.

This is a very efficient way to approach people in their community, but it is very time-consuming. Accompanied with an introduction-letter from Temeke district Council, we introduced ourselves at all administrative levels (ward and sub ward and the sub-sub ward) and informed community leaders about the purpose of the study.

Challenges and Obstacles:
Considering the time limit, the planned assessment and its objectives were too ambitious for all parties involved.

The transcriptions of interviews (from Swahili to English) were returned late and parts of it were not directly transcribed and the English was poor. This was partly compensated by the research assistant who spent some extra days in transcribing some of the interviews. This, in turn, reduced the time to collect data, and delayed the first part of data compilations and analyses.

Members of the team:

Dr. Liv Haram, Team leader.

Mr. Jehovaroy Kaaya, Research/ field assistant.

Local Temeke facilitators:

Dr. Eliud Wandwalo (NTLP, Ministry of Health and Social Welfare).

Dr. Neema E. Kapalata (RTLC Temeke) facilitated the assessment.

BACKGROUND

Over the last several years, tuberculosis (TB) has been increasing in many sub-Saharan countries. One main reason is the association of TB with Human Immunodeficiency Virus (HIV) seropositivity. This is also the case of Tanzania and particularly that of Temeke district (Wandwalo 2005). Temeke district is one of three districts of Dar-es-Salaam and the locus of this study/ assessment. Dar-es-Salaam is the business capital of Tanzania. It is located in the east coast of the country, along the Indian Ocean, and according to the 2002 consensus had a population of 3.5 million in 2005. The city is divided into three municipals namely; Temeke, Kinondoni and Ilala.

Temeke district and people's livelihood

Temeke district (municipality) is situated in the southern part of the Dar-es-Salaam Region. As noted, the region consists of three districts and Temeke is the largest one with a population growth rate of 7.8 percent/year.

Temeke district has an estimated population of 886,529 in 2007. Temeke is a typical urban city and compared to the two other districts (Kinondoni and Ilala) has poor social economic indicators. Kinondoni and Ilala are centres for government and commercial offices and residential areas for foreign and upper classes. According to the Temeke Municipal Council report (2006), life expectancy in Temeke district is 49 years for males and 51 years for females. Maternal mortality rate is 529 per 100,000 and under five mortality is 153 per 1000. According to the same resource, about 60 per cent of the population has access to clean water.

Temeke is also situated close to the harbour and many truck drivers from throughout eastern and southern Africa stay here for shorter or longer periods of time while reloading their goods.

Considering the fluidity of people who are involved in this economic activity – crossing countries and regions, the high turn-over of people and money are all factors that make it a high risk area for HIV-infections.

In the field: Preparing the random household sample in Azimio ward

FINDINGS:

Temeke district and Azimio ward

Beyond crude statistics about people's health situation there is scarce information available about people's livelihood in Temeke district. I had a meeting with the Dr. Machombo – the Research Coordinator at Temeke Municipal. Unfortunately, the unit had available the research proposals and applications only for studies carried out in the district, and lacked the final reports resulting from these studies.

To gain understanding of people's livelihood, we therefore carried out a small random sample study of two smaller areas in one of the sub-wards in Temeke. Due to time limitation, it must be noted, however, that the data collected are too limited for bold statements and generalisations.

The Azimio ward household study

The selection of the area and households aimed to reflect a typical population of Temeke District, with 30 per cent Christians and 70 per cent Muslims. Another community, Mbagala sub ward, was initially selected to represent a more rural population and their adaptation, however, time limitation did not allow for such a comparison. While Azimio sub ward was situated close to Temeke hospital and the MUKIKUTE office, Mbagala is situated at some distance.

The two areas, sub-wards of Azimio ward, were chosen to represent two different types of communities. One was dominated by "older" heads of households who have been employed by the government and lived in governmental buildings, but are now retired. The other community was dominated by "younger" heads of households. These households had either built their own houses or were renting one or two rooms from the house owner. The typical young head of household worked in the informal economic sector – usually with petty-trade (See enclosed maps, Appendix 2).

A typical "old household"

Most household heads were retired from previous government employment. Most of them were now grandparents and commonly lived with some of their children and grandchildren. The household sustained themselves economically partly through petty trade, such as preparing warm food, making mats (mkeka) for sale (the price for one small is TZS 5000.00 while a big one is sold for TZS 15000.00), some had one or more adult children who remitted some of their income on an irregular basis based on casual labour.

Most of the houses had one or more orphans in their care. In all households we found one or more unmarried, divorced, or separated daughter(s) and one or more of their children.

All families lived in the government house (a sitting room, and two small bedrooms), but a majority of those interviewed had built (illegally) a mud-house where their children and grandchildren slept.

A typical" young" household

Some of them had a small kiosk attached to their houses where they sold such goods as vegetables, salt, sugar, flour, bread, kerosene, cooking oil, to mention some of the most common goods.

Some of the families had built a house and with the exception of their own – two-rooms – they hired out the remaining rooms. Typically these houses had a common backyard used for cooking (charcoal), a bathroom and toilet shared by all the families (4 to 6) living in the house. The families who rented had an average of one room (used as a sitting room) with a small attached bedroom. The average family consisted of a young couple 20 to 30 years of age with 1 to 2 children.

In sum, everyday life is characterised by uncertainty, a struggle for survival, both economically and emotionally, and a strong trust in God.

While the latter community was densely populated, crowded and dirty, the former which was much more settled and ordered had a small garden (bustani) for everyday consumption of vegetables.

Characteristics

Most household heads interviewed were born outside Dar-es-Salaam and either came to Dar-es-Salaam as adolescents or as adults. All came to Dar to seek employment or, as they commonly put it "to try their 'luck' (bahati)". While some few came alone or newly married, most of them came accompanied by a younger sister or brother. Thus most of the interviewed were migrants to Dar-es-Salaam; and many maintained a close link to their rural homes. While some of them had married a partner from their home-area, others had married someone from other ethnic groups. Some stressed the importance of having a similar cultural background in their choice of marriage- or cohabiting partner as this would reduce misunderstandings based on cultural differences.

Network; health care network

Economic support networks seemed to be small in most households. Informants also stressed that care and economic support in case of illness is considered a 'family issue'. Unless it is a very serious disease, most informants underscored that one should not burden ones (extended) family for economic support, but rather manage on one's own. One of them explained that "If you often turn to your family [extended] for help, they will get tired of you". On the other hand, old grandparents had one or more of their children (both male and female) supporting them economically, whenever they could, but not on a regular basis. This was also the case for some households with single mothers who were assisted by one or more of their own brothers or one or more of their own children.

Due to urban-rural migration, poverty, but perhaps even more significant increasing socio-economic differentiation and increased acceptance among the wealthier not to share of their riches with their poorer kin, there is a need for more detailed study of the family and contemporary family life in the various forms of communities in Temeke district. The new forms of family units, including the single-headed households – often headed by females – is a particular phenomenon that needs further investigation in the context of TB and HIV/AIDS. A study will allow better understanding of poor people's health care seeking behaviour and support network (See also Tripp 1989).

It is fairly common for urban households to accommodate one or more kin / extended family member from their rural homes for shorter or longer periods of time while they are undergoing hospital treatment in town.

According to this limited study, it was not, however, common to draw upon economic support from one's neighbours in time of crisis (such as serious illness).

Asking people why this is the case, the informants commonly mentioned that all families are heavily burdened and that all are struggling to make ends meet. Although there is willingness to help and assist once in a while, hardly anyone have surplus resources permitting assistance to others over a longer period of time. Neighbours did, however, give social support and some patients told that their neighbours occasionally assisted them with cooking and washing clothes and cleaning the house.

Services to dispose of waste were irregular or rather non-existing in Azimio ward. According to the Municipal plan waste disposal was organized every third day. During my 3 weeks stay it was never removed. Disposal was, however, dumped by trucks several times daily at the ascribed open place immediately outside Azimio Ward office along the (Temeke) main road. The (open) garbage dung grew rapidly and people came to search for bottles and metal for recycling and sellable items (see picture).

Drinking water was supposed to be brought three times a week by the water company Dawasco. According to informants, however, the system did not function. It seems that the privatisation of water has caused problems in Temeke district as in much of Dar-es Salaam.

Environmental health is very poor and in need of much intervention in most parts of Temeke district. This is particularly the case with water safety, waste management, and thus with sanitation and hygiene.


Waste disposal at Azimio ward

Urban–Rural Links

Temeke district is mainly categorised as urban area, but the population has strong ties to their rural background.

Based on the data collected – albeit small – people maintain their relationship with their rural communities and in times of crisis this relationship seems to be further strengthened. Their rural ties to their family, their kin and their 'ancestors' seem to become important during time of illness and affliction.

'Local moral worlds' and Ancestors' spirits:

Some of the informants perceived that urban people's neglect of obligations to their kin in their rural homeland might cause various forms of suffering and afflictions. This includes the spread of disease and infections like TB and HIV/AIDS. This understanding of local moral words and illness explanation is illustrated in the case of Zenabu in the later chapter about patients' health-care seeking behaviour. The close causal link between illness and peoples' transgression of moral behaviour is also underscored in the local healers' explanation about AIDS (see the section on 'Local medical terms used for TB and HIV/AIDS').

Class and choice of health care facility:

Based on observations and interviews with a small number of patients, the health services at Temeke Hospital seem to be mainly utilised by the relatively poorer segment of the population. The wealthier patients were hardly observed at Temeke TB Clinic during our 3 weeks of data collection. According to some of the health personnel, the wealthier patients turn to private hospitals for care and treatment. It was commonly mentioned that they did so in order to hide the fact that they were suffering from TB and AIDS partly as a means to avoid stigmatisation.

It must be noted that this study did not look into why the wealthier were not seeking treatment at the Temeke TB Clinic. It could be due to several factors, such as for instance, a wish to hide their diagnosis, a stronger trust in private hospitals and their facilities compared to the governmental health system. It could also be due to a wish to keep their TB and/or HIV/AIDS diagnoses secret, perceiving their health situation to be a private matter, and finally it could be

due to a fear of being stigmatised. Temeke TB Clinic does not offer proper privacy. Patients are sitting 'exposed' in the open space outside the clinic while waiting for consultation and later for medicine. Health education is also given outside.

Addressing this issue to those (poorer) informants seeking treatment at Temeke TB Clinic, they commonly replied that they being poor could not 'afford to' keep their diagnosis secret [meaning both economically and socially]. Explaining that soon they will be bedridden and in need of help. Accordingly they claim that only the wealthy can afford to keep their diagnosis a secret.

Does class and gender make any difference?

Women – as mothers, daughters, and sisters – have traditionally been the main caretakers of the ill. With migration to town, the decrease in living standard coupled with the changes in marriage practises and, in most cases, a resulting marginalisation of women's position both socially and economically, women have increasingly also become the breadwinners. Thus their burden has increased. Many female informants, single mothers, divorces or separated, thus mainly had to cater for themselves economically – at times supported by old parents and the irregular income by one or two of their own brothers.

Recommendations:

Considering that the family and the 'family unit' is undergoing rapid change particularly in urban settings such as Temeke, it is highly recommended to make a more thorough study about issues like:

Who makes up the urban/modern extended family in contemporary Temeke?
Who are counted as reliable family members in times of need, that is, long-term illness, fatal illness, death and dying?
Are there other persons such as neighbours, colleagues and friends who are drawn upon for help in times of long-term illness and economic crises?
Are there any institutions which play a crucial role in the socio-economic and emotional care of the sick and dying (NGOs, church congregations, etc.)?

A more long-term and in-depth study of peoples' livelihood is strongly recommended.
It is also recommended to facilitate the Temeke Municipal (research coordinating unit) with the studies that have been conducted in the district (see for instance Strahl's study for relevant information).

PLURAL MEDICAL SYSTEMS AND PEOPLE'S HEALTH-CARE SEEKING PRACTICES

The main objective is:

To assess to what extent peoples' health-care seeking behaviour and their disease aetiology (i.e. causal explanation) influence a decline in case finding / a possible increase in diagnostic delay and low ART uptake.

Health Education – TB and HIV/AIDS at the Temeke TB clinic

FINDINGS:

Based on the data collected and the interviews with traditional and religious healers, patients and their illness narratives (see the section on methods above), the following sections first seek to map the plurality of medical systems in Temeke. Secondly, it describes some main patterns in the patients' health care seeking behaviour. The 'patient flow' at the TB clinic will be described and discussed in the latter part.

In Temeke district there is a plurality of complex and co-existing medical systems and cultures, namely, 1) Traditional African/ Islam medical practices, 2) Religious faith healing which is practiced by the various charismatic church congregations, and 3) government / modern biomedicine – including the private institutions and practitioners.

It is important to note that these systems are more or less overlapping. The patient who shuttles between the various systems and their healing options bring the systems together. The traditional healer and health personnel also tend to borrow practices and ideas from each other.

1) 'Traditional' medicine

In Temeke, as in much of the Swahili areas along the Tanzanian coast, the traditional healers (such as the 'mganga', and the 'shehe'), combine the Islamic/Swahili healing tradition with their local ethnic healing tradition. In Temeke the *waganga wa tiba asili* or simply referred to as *mganga* (pl. *waganga*), are by far the most popular and typical healers. They commonly combine herbs, divination, and eradication of witchcraft – including spirit possession, which locally is referred to as '*jinn*' (pl. *majini*). As most of the 'traditional' healers in this area are Muslims, they also use the Koran and the 'medicine of the book' in their healing practice.

2) Religious healing

In Tanzania as in much of Africa, Charismatic Churches, including Pentecostal Churches, are growing rapidly. This is also the case in Dar-es-Salaam. In Temeke district, such faith healing congregations seems to be few. This could be due to the fact that Temeke district is populated mainly by Muslims (70 per cent), and only 30 per cent Christians. According to observations and interviews, both Christians and Muslims turn to spiritual healing ('spirit possession') in times of illness and afflictions. This is further elaborated in the chapter on the potential for collaboration between the various health systems, below.

3) Modern/ government health services:

According to the Municipal report, the council has 3 hospitals, 5 health centres and 108 dispensaries, 9 autonomous laboratories, 23 Pharmacies and roughly 220 drug shops. About 70 per cent to 90 per cent of the population lives within five kilometres from a government/ modern health facility.

The liberalisation and ***privatization*** *of health services* seem to be booming in Temeke as elsewhere.

Commercialization of medicine 'traditional medicine':

In addition to the multiple medical cultures and practices briefly discussed above, there is a rapidly growing commercialisation of medicine and new forms of treatment alternatives drawn upon by Temeke patient – also as a means to treat HIV/AIDS.

In Temeke district, as in much of Africa and beyond, there is an extensive and seemingly increasing commercialisation (commoditization) of 'traditional' or non-biomedical medicine, mainly herbs in dried and liquid forms. Such commodities are sold by individual healers in his or her office, at the local market, at the herbal shop. The herbal shop is annexed to the mosque which is commonly found in the Muslim communities in Temeke.

A strong indication that 'traditional medicine' is becoming increasingly commercialised was observed (during this study) at the *Saba Saba International Trade Fair*. The Trade Fair is arranged annually in Dar-es-Salaam to enhance trade and business activities inside Tanzania and across Africa. At the Trade Fair, prepared 'traditional' medicines were displayed and sold. When I visited the Trade Fair, I observed traders and various types of healers from South Africa, Uganda, Zambia, and Malawi who were selling medicine and handed out printed brochures and leaflets. These brochures listed the many diseases and afflictions the healers could treat – including TB and AIDS. While some offered medicine for AIDS, others offered treatment for some 'opportunistic infections' associated with the syndromes of AIDS.

These, as it is stated, are

"Dealers in safe and high quality herbal products in their natural form made traditionally and hygienically from the best Tanzanian medicinal plants for the prevention and cure of multiple diseases"

One of the brochures listed a menu of 53 named afflictions and services offered, which ranged from 'dental problems', 'diabetes', and 'women's diseases' to 'nguvu za kiume' (which literally means 'strength of a man') and is translated into English as 'manpower'.

With this brief background, we now turn to the patient's health-care seeking behaviour as it is played out in such a plurality of medical systems and cultures.

Patients' health care seeking practices

Based on the interviewed patients and their illness narratives (see the section on methods above), the following section seek to describe some main patterns in their health care seeking behaviour.

FINDINGS:

The most common health-cares-seeking-behaviour pattern among the TB and TB/ AIDS infected informants is as follow;

1. Self-treatment:

2. Governmental hospital/clinic

3. Private health facility

4. Local healers (including religious healers).

5. Returning to the Governmental hospital/clinic

Once falling ill, most TB and TB/HIV patients turn to self-treatment through buying medicine at the shop or at the dispensary. Secondly, the patient turns to the governmental hospital/clinic. The common pattern is that the patient is told that he or she is suffering from malaria, typhoid, or pneumonia – often in this sequential order. The diagnosis is, however, not necessarily based on a medical foundation nor on a proper medical examination. Informants reported that they commonly go through this treatment, but they do not recover and thus they return to – often the same – government health facility. This is illustrated in some cases below.

It is not uncommon that patients report that they have been given treatment (without a proper diagnosis?) two to four times before they are properly diagnosed and finally tested for TB. Some of the interviewed TB patients report that they at this stage are so frustrated by the many tests and the retesting that they ultimately insist on getting a thorough medical examination resulting in that they are finally tested. This, in turn, causes lack of trust in the governmental medical system. During this process of delays, some patients – often due to a loss of trust in the governmental health facilities – turn to **private health facilities.**

A few of the interviewees reported that they, at this stage, turned to a local healer. In Temeke, the healers referred to as 'waganga wa tiba azili' are by far the most popular and the most frequently / commonly consulted by the patient. In this case, the patient goes through a ritual cleansing treatment. This is a complex type of treatment and is explained in the case about Zenabu below.

Very few reported to have utilised the Charismatic 'spirit possession' forms of healing. Those who did, were perceived to be ill due to evil spirits which have penetrated and possessed their bodies and accordingly only may be healed through prayers and faith in God. According to one religious healer – the reverend in the Pentecostal church – spirits can also cause diseases such as AIDS. The same reverend claimed that faith in God heals – even AIDS.

The TB testing procedure is often long and costly, as patients are often asked by the health personnel to take an x-ray at a private hospital or to re-check the results. The cost of x-ray ranges from TZS 3000.00 (the cost at Governmental health facility) to TSZ 5000.00 (private health facility). (The equivalent in US Dollars 2.47 and 4.13 respectively).

During this period the patient is further strained both physically and mentally and often he or she is totally exhausted before he or she finally receives the correct diagnosis and medical treatment. At this stage, some are so week that they can't walk or take the bus, but must hire a taxi to be able to reach the hospital. The taxi fare costs between TZS 6000.00 to 10000.00 (roughly between US Dollars 5 to 9) which is a significant amount of money for any household economy and particularly for a marginalised household economy which is the case of most households in Temeke district.

The pathway to correct diagnosis and treatment is long and costly:
While TB services and treatment is free in Tanzania, the long journey in search for correct diagnosis and treatment is both time consuming and costly. Most patients shared this experience. It is not uncommon that the delay in correct treatment can take up to 2-3 months from the time of falling ill. (The data collected for this assessment/study confirms previous research findings in TB patients in Tanzania such as in Wyss, K. et al., 2005.)

In sum, the cost of multiple consultations, examinations, laboratory tests, and repetitive wrong medication, is high, and puts significant economic strain on the household's economy.

Delay of correct diagnosis
a) By formal health sector

- Due to lack of equipment
- Due to poor communications skills (patients express that they are ignored by health personnel. They are spoken to in a derogatory manner or told that they have come too late to the hospital – indicating that they have been 'ignorant' of their own health or that they have wasted their time and money with the 'witchdoctor'.) These factors generate mistrust in health personnel and the public health facilities by the patient.

Temeke Hospital is equipped with laboratory equipment and x-ray apparatus and is supposed to have the capacity to cover the hospital's need. At times laboratory equipment does not function. Patients often had to turn to a private and more expensive option.

b) By private / commercial sector.

Most informants turned to the formal governmental sector as their first option. It was not uncommon, however, to turn to the private sector once the governmental health services failed. Many of them considered the private sector to offer a better and more thorough service, although more expensive, compared to those offered by the government health facilities.

According to the narratives, many patients also turned to the private sector as a direct result of the health personnel's strong recommendation to take a second blood test or another x-ray. (The time limitation of this study did not allow for thorough investigation and it must thus be underscored that the patients may have misunderstood the message by the health personnel.)

c) Traditional sector and the patient's disease aetiology:

There are certain disease aetiologies – causal explanations – which appear more rampant than others and thus may be a delaying factor in obtaining the correct diagnosis and treatment.

The patients who turned to an Islamic / traditional healer did so usually when the hospital administered medicine failed repeatedly. They continued suffering ill-health and therefore searched for relief and treatment options elsewhere. While some turned to traditional healers on their own initiative, others were advised to do so by their closest kin, friends, and neighbours.

It is important to note that a high proportion of the urban Temeke population have strong ties to their rural homes – including their kin and their ancestors. As mentioned before, the urban population often migrates between rural and urban homes. Most of the informants were not born in Dar-es-Salaam, but came to Dar-es-Salaam as adolescents and some came to settle as newly married.

Case Story - Debora

A few of the interviewed patients turned to a traditional healer as their first or second option before they coming to the hospital/clinic – usually after self-treatment (purchased at the shop or the 'duka la dawa' – the chemist shop). Such is the case of Debora, who at the age of 45 fell ill of TB.

> I realised that I had some problems because I had evening fevers and was coughing continuously. I bought some tablets at the chemist shop (*duka la dawa*) and took them for seven days, but they did not give any relief. My husband therefore took me to a traditional healer who told me that I had been bewitched (*nimelogwa*). According to the healer, we lived too well and had too good food at home [indicating that someone was jealous of their luxurious way of life. According to the local moral economy, they are supposed to share of their riches]. Therefore they sent 'demons' [which are also referred to as '*majini*' or spirits]. I was treated with three types of medicine, some which I inhaled, some I drank and some I put into my bathing water. I was supposed to stay at the healer's home for two weeks, but instead of getting healed my legs and mouth began to swell. Fortunately, my husband's sister came to visit me, and when she saw me she got shocked. She therefore asked my husband to bring me to Temeke hospital for treatment. There I took the sputum test and I was also asked to take an x-ray so that they could diagnose me and put me on the correct medication as quick as possible.
>
> Soon after my husband also fell ill and it did not take long before he died. Now I am alone. My three children and I are renting one room. Fortunately, my eldest son gets some small income by selling water and my daughter is selling warm food ['mama lishe']. She has recently given birth to a baby boy. My last born is still in primary school. We all share the one-room, except my eldest son who sleeps at a friend's place nearby.

Debora is supported by a guardian among the Mukikute's FTBs. When I listened to Debora's story – who has finished her TB treatment – I asked the guardian about Debora's health. Although the guardian had no responsibility towards Debora once she finalised the TB treatment, Debora lives in the guardian's neighbourhood and she sees Debora occasionally. She confirms that Debora is not well. Listening to the illness narrative I suspected that her

husband's death was due to AIDS and that it is not unlikely that Debora suffers from the same illness. The guardian had heard that the husband had died of AIDS, but she does not know Debora's diagnosis.

According to the Mukikute guardian who has been visiting Debora and her family regularly for some months, they can only afford to eat one meal a day (see below).

Sacrifice –'tambiko' – to restore health

Some of the interviewees had arranged a ritual as part of their treatment and given gifts to please their ancestors' spirits. This form of therapy/treatment is also referred to as 'tambiko'; sacrifice.

Tambiko is a form of an offering to ancestor spirits and is part of a treatment that goes far beyond a pure (bio) medical understanding of health and ill-health. This form of treatment is closely linked to people's illness causal explanation and is, of course, not superstition but deeply embedded in people's local moral worlds.

The illness narrative told by one of the Mukikute members, Zenabu, a former TB patient who suffers from AIDS illustrates this phenomenon.

Case Story - Zenabu

The case of Zenabu (fictive name)

Zenabu was born in a village in the coastal region in 1971. They were 8 siblings. When she was roughly 20 years of age she came to Dar-es-Salaam and began cohabiting with a man who became the father of her two children. They later divorced and she is now living with her two children in a one-room which she hires for TZS10.000 a month. She narrates,

> In January 2006 I began falling ill; having a severe headache, fever and backbone ache. I went to a dispensary and I was told that I had malaria. I took the malaria dose, but the fever continued. After two weeks the fever and headache was so severe, so I decided to go to Temeke Hospital. Once more I was examined and also an x-ray was taken. The doctor informed me that I had pneumonia and was given more medicine. However, there was no improvement and I once more returned to the doctor at Temeke and another x-ray was taken. This time a sputum test was also taken and I was then informed that I suffered from 'kichoni' [chest pain]. I was given yet another dose. However, there was still no improvement.
>
> By this time I returned back to my natal home at Midimuni. My father's younger brother who is a healer treated me with herbs and explained to me that my illness was partly caused by "*matatizo ya kiswahili*". He explained that I had to perform a ritual – a *tambiko*. Through this ritual we ask our forefather for forgiveness by giving them some gift. Since I have been living in town, I have not lived according to our customary way of life and by neglecting my duties towards the forefathers; the illness is their punishment and their way of reminding me of my duties towards them. [This treatment is a ritual cleansing which will clean Zenabu]. According to Zenabu, through the cleansing of her body the x-ray will now give a clear picture and the hospital doctors will be able to see clearly what I am suffering from.

> If you do not give such gifts and sacrifice to your ancestors they may cause illness and much harm in life. Normally, our fathers are supposed to perform such sacrifices annually by giving gifts to our forefathers to clean their families of whatever bad they have done. However, in more recent years such traditional rituals are not always performed, partly due to poor economy, but also because life is changing and the 'ngoma'-dances and rituals are not performed as our tradition prescribes.
>
> So helped by my fathers [her fathers brothers] in my natal village, we performed a sacrifice. I bough a two meter red bed sheet which I gave to my father's younger brother which he, in turn, gave to our forefathers by building a small hut / shrine under a big tree. We hung the gifts under the roofing. We – my mother, sisters and my father's younger brother – prayed together and pleaded our forefathers to release 'their child' [me]. When we returned home I got some herbal medicine which I drunk before I returned to Dar-es-Salaam.

The ritual, including the building of the shrine, the small gifts dedicated to the ancestors must, according to Zenabu and her local moral world, be performed for herself to recover from her illness. The total cost of this ritual treatment and sacrifice mounted to TZS 12.000.00 The amount of money covered the cost to build the 'shrine'; a shelter (2.500.00), a return ticket from Dar-es-Salaam to Zenabu's village (5.000.00) and another 5.000.00 which was given to the healer/ Zenabu's father's brother. And she further explains:

> After another two weeks the symptoms once more returned and now I went to a private hospital. I was examined and had yet another x-ray taken and this time the picture was clear and showed that my right lung was swollen and according to the doctor I had TB. The doctor told me to go to Temeke hospital for TB treatment. In mid March I was then enrolled at Temeke hospital and began TB treatment. I completed the dose six months later. When I finished my TB treatment, one of the nurses at Temeke asked me to join Mukikute.

Zenabu is currently being treated with ARVs, but she is also 'enrolled' in a treatment by a local healer who utilizes herbal products by a South African company. It is said that this medicine treats AIDS patients efficiently. Zenabu referred to an AIDS patient who had been re-tested with ELISA at the Muhimbili Medical Centre (University Hospitals of Dar-es-Salaam) and found negative. (This story – including the ELISA test – was told to us by one of the nurses at the Temeke TB clinic who also informed us that this form of combined treatment is not uncommon among the patients. Such kind of treatment, according to the nurse, is kept a secret.)

As illustrated in Zenabu's case, there is a close link between the well-being of the living in this world, on the one hand, and the dead, on the other hand. The living has obligations towards their forefathers who, in turn, will bless the living with good health, fertility and prosperity in life. When such obligations are neglected or not fulfilled properly by the living, the ancestors may hit back and punish the living with illness and, if they are not sufficiently pleased, ultimately, with death.

The cause that blurs the x-ray and hides the diagnosis.

It is important to note that according to Zenabu's disease narrative and explanation – there is something – *matatizo ya kiswahili* – which causes problems in her healing process. The 'swahili problem' – which in this particular case deals with the patient's immoral life in town, obstructs and blurs the x-ray, and the 'real' disease is therefore not seen [diagnosed]. Zenabu

questions why she did not get well in spite of her several visits to the formal health sector. “Why don’t I get well; why does the medicine not work; what is wrong with me”?

According to this disease aetiology (as illustrated in the case about Zenabu) there are certain rituals which must be performed to ‘clean’ the body. This form of ‘cleaning’ is a ritual cleansing and mainly aims to ‘clean’ immoral behaviour. Accordingly, when Zenabu asks her forefather(s) for forgiveness for her bad behaviour – through a sacrifice – she may get well.

When she once more turns to the hospital for another x-ray taken, it is no longer blurred but now clearly shows that she has TB.

Obviously, this cultural logic make sense to Zenabu, she is now correctly diagnosed because the x-ray is no longer blurred.

Case Story - Ashura

Ashura, another FTB at Mukikute is currently 37 years of age. She was born in Kisiju village where her relatives are still living as small farmers.

Her father had seven children with his three wives and Ashura is her mother’s first born and her father’s fourth born child. She got married and they had one child, but they separated after one year. She got married again and they lived together for almost two years when he suddenly (kwa gaffla) died.

> I remained in my home village and survived as a small farmer. Soon afterwards – in May 2006 – my health began to change and occasionally I experienced ‘fever’ [had a temperature]. I went to a dispensary in the village and was given malaria tablets. However, my health did not improve and my relatives began to worry. They discussed what to they should do and decided to take me to a traditional healer to find out what was ‘eating me’ [implying that they feared some form of witchcraft or evil spirits as the cause of her suffering]. Meanwhile, my father’s younger brother came and when he suggested taking me to a doctor, all agreed. I followed my father’s younger brother to Dar and went for a check up. Once more I got some chest medicine.
>
> However, while I was still in Dar, I meet with the man who later became my TB guardian [from Mukikute] and listening to my disease history he took me to Temeke hospital where the doctors asked me to take a sputum test. They also tested my blood and it showed that I am HIV-positive. I could not believe my ears, but the doctor told me not to worry because there are medicines which enable me to control my health. My guardian explained in more details about my situation and gave me hope and I gave up my initial idea of killing myself. I remembered my child and considered all the problems she will face if I kill myself and I therefore decided to take the treatment. I and my child are living at our father’s brother together with his two wives and their 6 children in four rooms altogether. He is renting out the reaming 3 rooms in his house.
>
> I feared that my family would avoid me once they learnt about my problems, however, they are not. I am cared for by the wife of my father’s brother – cleaning and feeding – and also by my ‘mjumba’ (mother’s brother).

Comments and recommendations:

TB in HIV/AIDS patients is very difficult to diagnose. More efforts must be put into the current diagnostic practices in the formal/governmental health sector in order to reduce the delay of TB diagnosis. At present too many patients are wrongly diagnosed.

Patient-doctor consultation/dialogue must be improved; methods to improve it must be found.

Correct and efficient medicine must be given at an earlier stage.

Can diagnostic equipment be improved?

It is recommended that the common and often incorrect assumption held by much health personnel that a delay in correct diagnosis is due to a patient's "ignorance", "superstition", as well as "traditional healers' ill-treatment" and witchcraft practices, must be modified and nuanced.

According to the interviewed patients such statements are at times used by health personnel in an insulting way. The researcher also observed such the usage of such statements among health personnel. It is recommended that health personnel are made aware of the ill-effect of such rather arrogant ways of communication on the patient, and the resulting lack of confidence in the health personnel. The patients feel offended by such behaviour.

Socio-cultural factors are as relevant to obtain a correct diagnosis as the physiological data.

According to my observations, the health personnel express arrogance and superiority towards their patients. Health personnel are not necessarily aware of it themselves. Rather it seems to be embedded in (old-fashioned / colonial) health practices in which practitioners of modern medicine tend to have a superior attitude of representing the only correct medicine and also the only curable medicine. This is not a problem particular for Temeke, but is rather a common phenomenon (See Faxelid et al. 1997, Freudenthjal et al. 1997; Haram 1989, Haram 1991).

The social worker's position and capacity as a caretaker of the poorest patients should be looked into and strengthened. It is necessary to understand the current system and what the criteria are for receiving economic support. It is recommended to look into the budget and the money spent by this institution. If it is efficiently used for the benefit of the (poor) patients, this institution should be economically strengthened.

Poor diagnostic- and consultation practices in the formal health sector

Close to all the informants in this study turned to the formal health sector as their first, second and third treatment options. This finding stands in contrast to what health personnel often claim, namely that a patient first turns to the traditional healers before he/ she seeks treatment at the hospital/ clinic. Accordingly, it is said that this is the most significant factor in delaying a correct diagnosis in TB patients.

Obviously, improved procedures will reduce the TB patients' and their closest social environment much suffering, extensive cost of travelling, expensive consultations, (wrong) medicine, and loss of time.

Considering that most people in Temeke are involved in the informal economic sector and thus have no public services to rely on in times of crisis (such as a long-term illness), their income is severely reduced during this time span. Many of the patients interviewed – especially those with co-infection – were exhausted after the lengthy struggle for correct

diagnosis and treatment. *Unable to walk, some of the interviewed were carried to the hospital.* Others had to take a taxi to the hospital which easily amounted to TZS 10-12.000,00.

Religious healing and disease aetiology:

As briefly mentioned above, Charismatic Christianity and 'spirit possession' cults – including Pentecostal Churches – have become increasingly popular across contemporary Africa during the last decades. In Temeke district, there are as yet not many such congregations. This could perhaps be explained as did the interviewed reverend of the Tanzania Assembly of God (TAG), namely that there is a strong representation of Muslims (70 per cent) compared to only 30 per cent Christians in Temeke district.

According to the charismatic church congregations such as TAG, illness is caused by bad and sinful behaviour. Such bad behaviour is moreover linked to modern- and urban ways of life and what is seen as a neglect of God's commandments. The Devil ('Satani'), in turn, takes demand of people's life. Such a neglect of God's will, causes illness in people and is manifested by the Devil or evil spirits who torments the sick and afflicted person. The only means to regain health is to drive these evil forces out of the body. Ultimately, through prayers and faith the person may resume health.

Two minor case studies:

A man aged 24 years of age had recently been diagnosed with TB at the TB clinic. He came accompanied to the clinic because he also seemed to suffer mentally and had for some time dropped out from his TB treatment. During the consultation, the doctors at the clinic asked his mother to explain about her son's situation. According to the mother, the son had been well and was completing his diploma at the Bagamoyo Cultural College when he suddenly fell ill. While in class his vision vanished and the only signs he could see on the blackboard resembled Arabic signs. He then collapsed. He was brought to a religious healer and, fortunately, the mother explain, he has been recovering since.

The doctor asked why her son had been willing to test for TB, but still had refused to take his medication, whereby the mother explained that he wanted to know his diagnosis and instead of taking the medicine he wanted to return to the church and give his testimony. Then his congregation will pray for him and in the name of Jesus Christ, the TB can be cured [by prayers and faith in Jesus Christ].

One of the FTB who fell ill (in early January 2001) with heavy cough, went to a traditional healer who told him that he suffered due to 'jini' [the devil]. Accordingly the person who had sent the jini wished to kill him. The healer explained to him that his chest- pain – coughing blood – was due to the jini's need for blood [to survive]: "The healer treated me for seven days, but at last I got so ill that I could hardly stand and I then asked my son to go to the nearby dispensary to call upon the doctor whom I know. The doctor gave me four bottles of drip-water and afterwards I was taken to the hospital at Kizuiani where I was given cough syrup and some tablets. However, there was no improvement and when I returned the doctor referred me to the Temeke district hospital – and when the x-ray showed TB I was enrolled and began treatment. This was 27 June. Seven months had passed since I first went to the traditional healer.

According to the Charismatic churches and the Pentecostal churches in particular, it is the very faith in God that heals – including TB and HIV/AIDS. Thus to utilise any medication – beyond prayers and faith in God's healing power – is seen as a lack of faith by many

charismatic/ Pentecostal church leaders. Consequently, they urge their congregation not to utilise 'modern' medicine, but to rely on God's healing power.

"Patient Flow" (at the TB Clinic)

One of the main goals of this study/assessment was to look closer at the "patient flow" and to point to some possible factors which might explain why so many TB/AIDS patients become defaulters and do not utilise the opportunity to get free ART.

'Patient flow' is used to mean a patient's movement at the clinic, from entering the waiting area /consultation room, how they move through the system, the tests taken, filling in of forms, as well as the pre- and post-counselling routines and finally receiving the medicine at the clinic dispensary before leaving the TB clinic.

FINDINGS:

"Patient flow" or "patient queue"?

The staff at the TB clinic is under a heavy workload. In addition to their duties at the TB clinic itself, they also have duties to serve and supervise the many clinics and CTCs in their area / district. On the days when some of the staff work outside the clinic, the personnel remaining at the TB clinic is not sufficient to handle efficiently the consultations and obtain a (good) flow of patients through the system. At times, the situation is chaotic and leaves little space for a good and open dialogue with the patients. The so-called 'patient flow' often turns into a 'patient queue'. In spite of the heavy workload on the side of the staff, and the long time spent queuing by the patients, there was usually a good atmosphere at the clinic. However, some of the staff is overburdened by the heavy workload.

Management and planning
There is a lack of health personnel.

Due to the long working hours and continuous heavy workload, the staff is affected by a resulting lack of motivation and, ultimately, illness and sick-leave. Ideally there should be more positions for needed health personnel.

Perhaps more circulation of the staff should be encouraged.

Is the staff sufficiently trained?

Some of the health personnel need further training to be able:

- to analyse and to utilise their collected data.
- to generate change in procedures and practices

Are there too many forms?

The filling in of forms takes much time and tires the patients. Considering the patients' poor health, the many forms which are filled in during the examination is not only wasting the patients' time but may be exhausting considering their poor health situation.

Forms must be reduced to a minimum or the donors / agents must fund more staff to handle the paper work.

Communication skills by health staff:
There is a lack of (sufficient) knowledge among health personnel about the patients' socio-economic livelihood and their knowledge and practices concerning health and ill-health. At best, this generates simplistic causal explanations by the staff about their patients' health-care seeking practices and their knowledge about health issues such as TB and HIV/AIDS.

Patients are, at times, referred to by the staff as 'ignorant', 'superstitious' and 'mswahili', to mention some of the more commonly used terms.

The term 'Swahili' and 'mswahili', in this negative manner, needs explanation: Mswahili – a Swahili person – is used derogatorily by health personnel to refer to a patient's lack of knowledge, ignorance and dishonest nature, or if he cannot keep his appointment, this is some of the negative connotation of a 'mswahili'. Such more or less consciously held attitudes among the health personnel may disrupt efficient communication between staff and patient.

At worst, lack of knowledge among the health personnel about the livelihood of their patients results in offensive – even stigmatising – statements about the patients who do not adhere to the health personnel's perception of 'correct' health care procedures.

Registration at the TB Clinic

Why do not all HIV-positive patients identified by DCT take ART?

At Temeke there are many TB patients who have been tested HIV positive and through the DCT procedures, they know their results. However, not all come for ART.

One of the achievements of the project has been to provide ART to TB patients in Temeke TB clinic (80 TB patients since July 2006), CTC Temeke, CTC Rangi Tatu and PASADA (see Table 1b). Temeke is supposedly the only district in Tanzania where TB patients are treated with ART.

Table 1: TB Patients Referred, Enrolled and under ART and CPT

Period	Total	Referred CTC	Enrolled CTC		On ART		On CPT	
	HIV-pos		F	M	F	M	F	M
3rd.q.2005	276	275	47	55	9	17	27	30
4th.q.2005	277	277	51	23	35	31	24	11
1st.q.2006	224	223	47	32	42	21	26	18
2nd.q.2006	181	181	10	14	6	3	7	2
3rd.q.2006	255	251	70	69	17	13	58	57

Only a minority of those patients referred from the districts with positive HIV-test (DCT) were confirmed to have arrived at the CTC, and then put on ART. Monthly meetings are held between the coordinators of the two facilities to validate the data. Temeke TB clinic refers HIV positive persons on ART to CTC after finishing TB treatment. ART is followed up through home based care. We also know that in Temeke, 60 per cent of women with TB – compared to only 40 per cent men with TB – are co-infected with HIV/AIDS. Yet there are less women coming for ART compared to men.

FINDINGS:

Co-infection and integration of TB and HIV/AIDS

Some possible explanations to this complex research question are illustrated and discussed above in the sections 'Patient's health care-seeking behaviour' and 'Patient flow'. The coming sections further explore the patient's own reasoning when falling ill and the process of seeking treatment. The sections further aim to point at some factors contributing to why a patient becomes a 'defaulter' (also referred to by the staff as a 'complicated case' or someone who 'refuses' treatment).

Recent statistics shows that approximately 50 per cent of the TB patients in Temeke district are co-infected with HIV. This brings new types of challenges to the co-infected patient but also to the health services, as well as to health campaigns and community sensitisation. The notion of co-infection (of TB and HIV) is increasingly becoming known to people. This is partly due to health campaigns but also because co-infection is increasingly becoming more common and thus part of peoples' lived experience.

Informants in this study express co-infection as '*wana oanana'* – the two diseases 'come together'. This perception is also held by members of Mukikute and is present in their approach to the community (see the chapter on Community sensitisation, below). The close link between the two diseases does create new challenges for all parties involved. Since TB is curable but AIDS is not, this seems to have generated a situation in which TB is perceived if not (more) stigmatised, it has become a more feared disease among people.

The patient's own reasoning about medicine and drugs and their effects on the bodies

"Kuchanganya dawa" means the danger of "mixing" different medical treatments. It is a widespread notion among the patients that it can be harmful – even fatal – to mix medicine/ treatments.

While some patients perceive that it is dangerous to mix bio-medicine and traditional / local medicine at the same time, others fear mixing TB-drugs and ART. It must, however, be noted that some of the interviewed TB/AIDS patients combined ART with (commercialised) herbal medicine.

"Kuzidisha dawa"; the danger of "overdosing the body"

To combine or mix the anti-TB treatment with ART is strongly feared by some informants. The logic is that the double dose will "overburden" their body. The body is simply "too weak" to tolerate or manage such a huge load of medicine. While some patients perceive that the body is simply not sufficiently strong and accordingly wish to portion out the doses, others argue that – without sufficient and nutritious food – the body will not manage. The medicine will overdose the weak body and instead of getting healthier and stronger the patient becomes weaker – and ultimately dies.

The prescribed amount of medicine

It is important to note that the informants' fear of getting "too weak" is not rooted in superstitious cultural beliefs, but is rather rooted in their material world. It is closely linked to people's livelihood and their ability to generate sufficient income to feed their family. Almost all informants were self-employed in the informal economic sector often with small scale petty-trading activities, or work as occasional labourers. In a situation of crisis, they have no welfare system to lean on. They do not receive any social services to maintain their own and their family's well-being. Lack of regular income and a marginal household economy, makes it impossible to provide for sufficiently nourishing food in line with recommendations for people on TB and TB/AIDS treatment.

A worried TB patient, a young man aged 25, had just been told that he is also HIV-positive. During the DCT session, he asked the nurse, "Can the ART enable me to work hard again?" This man had not been able to work for some months and already depended economically on his sister's husband's income and his sister's care. He used to earn TZS 75000.00 a month. His "official" monthly salary was TZS 35000.00, but to make ends meet he cheated on the measurement and thus managed to almost double his monthly income. This had made it possible for him to give some economic support to his sister. In fear of losing physical strength and consequently the ability to generate an income for the household, the logic reasoning seems to go as follows:

1) Go through the TB treatment and become cured.

2) If the body gets sufficiently strong and healthy, turn to the next step, ART.

However, while the patient is on TB treatment and experiences that he or she gains health, the motivation for ART declines accordingly. Some of them probably get less opportunistic infection while under TB-treatment. Consequently, whereas some intend to delay the initiation of ART, others simply drop out – probably returning for treatment when the symptoms once more become intolerable.

"Food is medicine":

The close perception of the connection between food and health and the idea that "food is medicine" is a very strong notion and strongly embedded in people's notion of a healthy / unhealthy body.

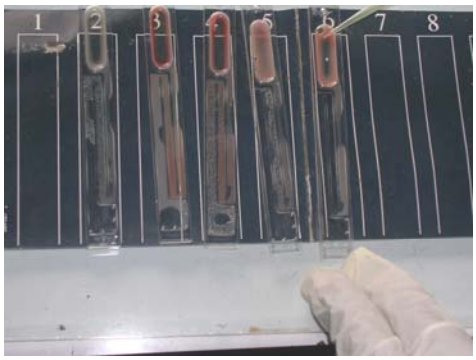
In Temeke district many are too poor to afford sufficiently nourishing food, and some can only afford the staple food, i.e. the maize-porridge *ugali*. Ugali is very low in nutrition and is not sufficiently nourishing for patient under treatment of ART.

Lack of proper and nourishing food – or even sufficient food – caused some patients not to take the medicine. It is likely to assume that some fail to take ART 'simply' because the hunger becomes unbearable and combined with the strong medicine the body is simply too weak to tolerate the treatment.

Measuring CD4.
According to the current DCT-procedures, once the TB-patient is diagnosed, he or she is – if agreed upon – counselled (DCT) and tested for HIV. However, unless the HIV-positive patient agrees to get enrolled and to initiate ART, the HIV/AIDS file is not opened (but remains with his TB file). Consequently, his or her CD4-level is not measured. (CD4 is a primary receptor used by HIV-1 to gain entry into host T cells. HIV infections leads to a progressive reduction in the number of T-cells possessing CD4 receptors and, therefore the CD4 Count is used as an indicator to help physicians decide when to begin treatment in HIV-infected patients.)

Recommendations:
Firstly, the time of measuring the CD4 code should not depend on, as now, the opening of the HIV/AIDS file. If the system allows, the measuring of the HIV positive patients' CD4 should be undertaken as soon as possible whether the patient has agreed to initiate ART or not. A TB/AIDS patient's knowledge about the CD4-level might motivate the patient to initiate ART and thus reduce the number of those who currently are defaulters or refuse ART.

Above we pointed to the common notion of a healthy / non-healthy body and the use of medicine. Many of the interviewees expressed a concern about how much medicine their fragile and sick body can tolerate. With reference to the CD4 code, information about how strong or weak a patient's body is could possibly motivate more TB/AIDS patients to begin with ART when this is medically appropriate and thus reduce those who currently become 'defaulters'.



Positive and negative HIV blood samples

An alienation of medical terms and languages.
The term 'CD4' is currently a relatively meaningless term for the patient. In line with multiple other anglicised, meaningless medical terms, they merely serve to alienate the patient to his or her medical treatment and care. Another local/ Swahili term should be used.

All English terms should be translated to local terms and notions of the body.

There is an increasing usage of English/ American medical terms by the health personnel also when they communicate with patients. The extensive use of English/American language is partly due to the many forms and cards which are in English only. The Anglicism is also increasingly alienating the Swahili speaking people to health and illness. Using terms such as 'TB' or 'CD4' creates an atmosphere of secrecy and misunderstanding and, at worse, increasing alienation among the patients.

All medical terms used in dialogue with patients should be translated into Swahili.

The issue of disclosing HIV/AIDS
It is often assumed that people are hesitant to disclose their HIV/AIDS diagnosis for fear of being stigmatised. This was also a common attitude among the health-personnel at Temeke TB Clinic. With reference to the collected data, I point at some other causes expressed by the interviewees. TB is curable, but AIDS causes severe illness and fatal death:

People have – as yet – not sufficient information about the ART. Some are sceptical, and refer to horror-stories about people who have swollen into the unrecognisable, or died suddenly. Some refer to first-hand observations; they have seen and cared for dying kin.

People need more and correct information about ART – including the many side-effects – and the importance of proper nutritional food. Some said that they planned to finish the TB treatment first and later, in stead of ART, they planned to begin with traditional/ herbal treatment.

"AIDS is the end of me";
The social meaning of this statement refers to a common attitude that AIDS, in spite of ART, is a killing disease. Peoples' experience about their TB/AIDS decaying body being too fragile to cope with ART is of course closely related to the fact that most people in Temeke – particularly the affected households – are too poor to ensure a sufficiently nutritious diet. Many patients feel worse, and are convinced that the body is not able to tolerate the ART unless they get proper and nourishing food. During the early reign of Nyerere, a health programme was referred to as "Chakula ni uhai" – food is life – a simple but very significant wisdom which perhaps is more important now as a means to reduce peoples' suffering due to TB and AIDS. 'Food is health' is a slogan, and a health strategy, which should be revitalised in the time of TB and AIDS.

People still have little knowledge about the ART. Many of those who have some knowledge have a negative attitude towards ART. Some refer to family members or friends who have died, according to them, due to the treatment.

Some HIV/AIDS patients reported that they experienced that their closest may express an ambivalent attitude in their duty or obligations to care for them and to support them economically. This can be taken as a refusal to assist their sick and dying relatives. It can even

be an expression of stigmatisation of the HIV/AIDS patient. But it can also "simply" reflect a vulnerable household economy and a resulting lack of means to give care and support.

After all, the logic goes, ART simply postpone death.

The importance of a proper funeral

Many studies show that it is a not an uncommon practice to spend more money on a funeral than on the treatment and care for the sick (World Bank 1997). In a study conducted in Kagera in north-western Tanzania in the late 1990s, the average amount households spent on death was USD 104.00, of which USD 40.00 was spent on medical costs and USD 64.00 on the funeral itself. This expenditure was unequally distributed; with some households reporting zero expenditure other households had spent more than USD 1000.00 (World Bank 1997: 211-213). In many parts of Tanzania, the cultural and moral prescriptions – the obligations towards the deceased to give a 'proper' funeral – are very strong (see also Haram 2008). Such practices reflect and underscore the importance of people's local moral worlds and the perceived close relationship between the living and the dead. Such a moral worldview may have a negative effect on the care for the living and their health care seeking behaviour. It is important to note that most families aim to care properly for the ill person while still alive, as well as to give the dead a proper funeral according to local practices. It seems however, that the cost of a proper funeral is comparatively more costly than the cost of a patient's care and treatment.

The issue of stigma and stigmatisation

According to the Evaluation Report (Heldal et al. 2007:12), "In Tanzania as in other countries of sub-Saharan Africa, stigma against HIV/AIDS remains very strong and plays a major role in fuelling HIV infection". Stigma which is referred to locally as 'kunyanypaa' (recoil in disgust) was one of the topics that was addressed in the study. Most informants, patients and their caregivers were well-informed about 'stigma' and referred to both *kunyanyapaa* and *kutenga*, the latter meaning 'to isolate, separate'. The following are some examples given in the study:

A separated woman aged 35 who suffered from AIDS and lived with her 3 married sisters and their families, explained: "Yes I have heard about kunyanaypaa. For instance, if my younger sisters begin to abuse me, to avoid me or to 'separate' me (kutenga), we would refer to such behaviour as kunyanypaa. However, my sisters would not do that because they love me very much. The whole family [her sisters and their husbands] care for me and they give me what I need."

A young 25-year-old man who suffered from TB explained: "Concerning kunyanyapaa, I was open and told my family and friends about the treatment and that I would be cured. Many of them were generous to me and brought me fruits and food."

Another man aged 24 years of age, and a FTB, who fell ill in July 2005 and received correct treatment in late November the same year, lived at that time with his brother and his brother's TB-ill wife: Since they both suffered from TB he feared that friends and neighbours would avoid them, "but they came and they even helped us with cooking, calling the house and washing our clothes. We did not feel that we were kept 'separate' or 'stigmatised'.

When I asked TB patients and those co-infected with HIV/AIDS about the issue of stigma and whether they had experienced it themselves, some gave examples about how they had been told by their family members to eat on their own separate plate etc., according to the health messages. Such behaviour, however, is not necessarily a sign of stigmatisation. Such behaviour could 'simply' be signs of healthy precautions taken by family members to avoid further contamination and needs to be looked into more carefully to make the correct analysis. Thus, to differentiate between stigma and contamination precautions is not always easy.

Self-stigma, i.e. the perceived fear of being stigmatised by others, seems to be common. Many informants had heard stories about people who had been stigmatised. A few had observed that people in their community had been labelled or even stigmatised when a person with TB/AIDS passed by.

It is however, important to note that none of the patients interviewed in this study had themselves experienced to be stigmatised by their community or by those closest to them upon disclosing their diagnosis. This could of course be due to the small size of this study, a biased sample or to poor interview techniques. But it must also be noted that many interviewees gave examples that illustrated the opposite. Their stories were full of examples of care from their family as best they could with the limited time and money available.

"I cannot afford to keep my disease secret"

It was said that they could not "afford to keep my disease/ diagnosis secret [meaning both socially and economically]. Very soon I will be bedridden and will be in need of help. Only the wealthy can afford to hide. We [the poor] can't."

"Loss of value"

Another explanation to why some informants did not wish to disclose the diagnosis to their closest, was what they referred to as 'a loss of value' (*kupotese thamani)*. 'Loss of value' does not express an economic loss, it deals with a social loss and a fear that they will not manage socially and mentally if they are told that their closest is suffering from fatal disease.

Some of the patients who had not yet told about their AIDS diagnosis feared to tell them. This was explained by various reasons. One reason was the patient's strong concern for the well-being of their closest. Many of them expressed a much stronger concern for how their family and kin would cope economically and emotionally upon their own fatal illness, rather than expressing a fear for their own illness and death.

"AIDS is the end of me"

The fact that ART is available and can prolong life and delay death does not seem to make a difference among the complicated / defaulter-cases and their health care seeking behaviour. Some of the informants said that "AIDS is the end of me!"

This statement points to several things but firstly, it expresses the patient's perception that AIDS cannot be cured, but is a fatal disease. Secondly, it expresses little trust in the ART. And thirdly, it points to the perceived importance of the reproductive order and the importance to have offspring. One young man, aged 25, who had not settled with wife and children said that "I am left with my sister. Both our parents are dead. We are so few in our family. My sister will be left alone. I know that I myself have come to an end."

Is there any gendered tendency in the health care seeking behaviour?
Do women tend to 'choose' more short-termed options in their health-care seeking behaviour compared to men? Research shows that women are much more vulnerable to being blamed than men – also in the context of HIV/AIDS. (Haram 2004, Haram 2005; Maman et al. 2000, Maman et al. 2002). HIV-positive women experience more violence by their partner(s), more males leave their HIV-positive partners compared to women.

Men (as fathers are grandfathers) feel less economic responsibility compared to women (as mothers, grandmothers, aunts). Thus, once the female caretakers cannot feed the children, they are often left to struggle on their own. Consequently, based on a clearly gendered livelihood (blaming, gender based violence, men's more peripheral obligations to their children) women 'naturally' might not wish to share her diagnosis with her partner(s) and close kin. Such calculations are not necessarily due to a fear of stigmatisation, but could rather be guided by what she perceive as the best life situation – long or short termed – for her and her children.

Lack of social services hits the poorest segment of the population harder because they are more frequently involved in petty trading in the informal economic sector. Thus when they fall ill of a long term illnesses such as TB and TB/AIDS, they are unable to carry out their income generating activities and the household suffers economically, socially and emotionally. Generally speaking single-headed household, and particularly those headed by women, are the most vulnerable in times of crisis such as long-term illness. In some of the poorest households, children are forced to become the breadwinners and the main caretaker of the ill, and are likely to drop out from school.

Studies on TB and TB/AIDS – also in this study area – have found that stigma and stigmatisation is widespread (Heldal et al., 2007, Nguma et al., 2004). As illustrated, my observations and findings do not show such an obvious tendency. Rather, to a certain extent this assessment contradicts such results. There are several possible explanations to this, such as:

- The Government's national campaign to reduce stigmatisation of people living with TB and HIV/AIDS in 2007, has given results.
- The notion of stigma is used inadequately and indifferent by lumping different types of behaviour under this label.
- Fear of contagion is, in some cases mistaken as stigma and discrimination.
- Health messages given by the health personnel, such as to 'eat with a separate spoon', 'use a separate plate', and 'use a separate cup' to avoid contamination are good rules to live by in order to avoid contagion and infection. Such slogans must not, however, be seen as some do, as signs of avoidance and stigmatisation of the TB infected-patient.
- Blame or self stigma is mistaken as stigma and discrimination.
- Poor care of the HIV/AIDS-patient by his or her closest is too often taken as signs of stigma and stigmatisation, but may be caused by a poor household economy.
- Stigma and stigmatisation has become an 'accepted' or likely explanation – although wrong – for other phenomena and socio-economic dynamics.

COMMUNITY SENSITISATION – THE CASE OF MUKIKUTE

During the assessment/study, a "community sensitisation"-meeting was organised by the newly established Mukikute – a TB patient NGO – and supported by staff from Temeke Hospital including some staff from the TB Clinic. Mukikute members were also responsible for the health education given at the meeting. The meeting was held at the Mbagala ward (in Temeke district) together with the Mbagala CTC. The meeting attracted lots of people. More women than men attended the meeting. Some adolescent as well as children between the ages of 5 to 15 also attended (see pictures).

Community sensitisation – through health intervention activities, such as song, dance, theatre, and drama based on local people's own experience – has an enormous potential to enhance people's knowledge and possibly to change people's health care seeking behaviour about TB and HIV/AIDS. Some of the songs and dramas performed are, however, less informative and, to some extent, ridiculing – even stigmatising – of people's health care seeking behaviour, that is, when he or she seeks treatment outside formal health care services.

Community sensitisation

Case Study
The following case study, illustrates some of the challenges in 'community sensitisation':

The song-dance (ngoma) group is dancing while singing:

"Human beings have turned into animals and we are killing each other. When animals are killing each other they do so in order to get food. That is the law of the jungle. Human beings have turned into animals and we are killing each other", etc

The role play:
Two of the singers then begin to act in a role-play / drama. While one of them acts as a 'witchdoctor' – symbolised by his 'tanguri' (bones) – the other person – who acts as a patient who is seriously ill – is invited into the witchdoctor's hut. The patient asked by the witchdoctor to tell about her problems: "I have been suffering for three days, coughing and sweating heavily at nights". The healer quickly responds by informing her that she is suffering due to one of her neighbours who is bewitching her and wishes to destroy her plans of getting married. To eradicate the evil witchcraft, he asks her for TZS 50.0000.00 [roughly USD 40] and promises her that she will recover. If she takes the medicine as prescribed – salt from the ocean – she will recover and get married. [People are laughing]. The patient leaves the healer's hut, but some days later, when she is close to dying, she is brought to the hospital. Here she is quickly diagnosed and receives the correct medicine and recovers quickly.

The ngoma group continues to dance while singing; "Human beings have turned into animals and are killing each other". The Mukikute commentator then asked the meeting if the patient's symptoms resembled TB. He gets a positive reply by the meeting. He underscores the importance of not going to a healer. The witchdoctor will merely cheat you for much money. Rather he urges his meeting to come straight to the hospital for proper treatment.

The ngoma-group continues by singing; "A belief / faith can cure, but a belief / faith can also kill" (*Imani inaponya lakinin imani inaua*). The acting witchdoctor is then asked if he truly knows TB and has the necessary medicine to cure it. Under much amusement and laughter by the audience, the witchdoctor replies by telling them that he cures TB by salt water from the ocean.

Co-infection of TB and AIDS; they "come together"
Later the meeting turns from TB to the issues of co-infection HIV/AIDS and to the use of ART. These issues are introduced by informing the meeting that; "Ukimwi na kifua kikuu wameoana" *(they "come together*). The co-infection of TB and HIV/AIDS was referred to as the "TB's guest of honour".

When referring to how the two diseases resemble each other, words such as "-oana" [join / marry / resemble] were used. [When I later discussed the word/ term used in "Oana" with Mukikute members and with staff at Temeke Clinic, some said it was used to mean a resemblance between the two, while others argued that it referred to "married each other" meaning that TB and AIDS have married each other.]

Individual testimony based on self-experienced narrative is a much used method in community sensitisation and it is very efficient. Former TB patients and TB/AIDS patients from Mukikute, gave their own testimonies about how they were suffering before they finally got proper treatment and recovered by the use of ART.

In the current version, narratives given by HIV/AIDS patients and accompanied by the dancing group, tend to give a too positive image of the life situation of a person with AIDS. Considering the enormous suffering experienced by the HIV/AIDS patient's, a more realistic testimony and dance should be developed. This should also illustrate some of the many problems an HIV/AIDS patient under ART faces physically, socially, and economically.

Community sensitisation - Some recommendations:

Mukikute organisation should be strengthened – but gradually.

FTB should be encouraged to continue their very important work in community intervention as well as their work as guardians.

For their important work to become more efficient, Mukikute members and / or 'actors' need more training in communication skills.

Members and those who create the content of the programme should continuously make sure that the message is grounded in people's actual life-situation.

Most importantly, members must learn how to utilise and build on their own experience both as FTB and as HIV/AIDS patients. They must be encouraged to integrate the experience they continuously get through their work in the community as caretakers of TB and HIV/AIDS patients.

Their strength is their closeness to their community.

Mukikute should try to integrate more HIV-positive people as their members and create a more acceptable atmosphere. Currently there are HIV-positive members who hesitate to tell their diagnosis openly.

Mukikute must also educate people about the many (negative) side-effects of ART. Hopefully, such increased knowledge will reduce the patient's and their closest environment's fear of the many side-effects of ART. It is believed that more realistic information will reduce the 'horror-stories' which are currently flourishing. The fact that people worry about the side effects, was also observed at the *Local Council Commemorate Day* at Mbagala (July 1). Many of the questions asked by people while the health personnel informed about ART, reflect, I believe, people's scepticism towards ART and their side-effects.

Mukikute members are uniquely situated and positioned to create a close communication between health personnel at Temeke TB/AIDS Clinic and the community.

Potential for Collaboration between the health cultures / systems

The Evaluation Report (Heldal et al., 2007) reads: "Temeke should find new innovative strategies to increase TB case detection including engaging traditional healers in TB control, using health communication strategies and involving former TB patients in follow-up of TB suspects in the community".

The second main goal of this study was to explore and assess the potential for collaboration between the traditional/religious practitioners and the clinic/ hospital sectors.

The data collected during this study is not sufficient for bold generalisations. Rather, based on these observations along with my longitudinal studies with such and closely related topics in Botswana (1985-1986) and northern Tanzania (1989-2008), I first account for some of the findings from Temeke and secondly I suggest some recommendations for collaboration between the multiple partners in Temeke (Haram 1988; Haram 1991; Haram 1999; Talle, Haram and Heguye 1995).

FINDINGS:

The typical career of a healer

In much of Africa and beyond, traditional healers often become healers upon a crisis in their life situation. All seem to experience a dramatic episode in their life when they are called upon by God, angels (mahudami), or their forefathers to take up the heavy burden of healing. At first they all deny, as they explain, they will rather enjoy life and are not prepared to forsake a materially better life than that which they are called upon to live as healers. This is a life characterised by hardship and sacrifices As a consequence of their denial – refusing the call from God, angels, spirits, or their forefathers, they will be punished and fall into serious illness and while they are close to dying they will finally accept their duty to heal people. They will now begin to learn how to heal. Some learn through a series of dreams. They will be informed about how to heal and which herbs to use.

Their illness episodes differ in duration and while some healers give in after one illness crisis others experience repetitive episodes before they give in. For some this process can go on for years. One of the healers I interviewed, the priest in the Tanzania Assembly of God (TAG), left his job as a Senior Auditor at the University of Dar-es-Salaam when he finally gave in and became a reverend of TAG in Dar-es-Salaam - and a spiritual healer.

Their spiritual background is usually combined with the knowledge they inherit either from their father or a close elderly kin who teach them about the art of herbs and healing. Again for some categories of healers, like the *waganga wa jadi* or the *waganga wa tiba azili*, their knowledge is also combined with the use of holy texts, the Koran and the use of 'tanguri' and 'bao'. The latter two are bones and a piece of black board respectively and both techniques are used as part of the divination/ diagnosis procedure.

Knowledge of TB and AIDS

The healers interviewed all claimed to have knowledge about both TB and HIV/AIDS (one of them had himself suffered from TB). While only one of the '*waganga wa jadi*'-healers

claimed to be able to heal TB – with herbal medicine – the Reverend-healer was the only one who claimed to be able to treat – and cure HIV/AIDS through prayers and trust in God.

One of the waganga wa jadi, however, referred to AIDS as '*kinyaranyara*' and '*Yabisi ya tumbo*'.

Local medical terms for TB and HIV/AIDS

There are multiple local terms which are used interchangeable to refer to TB and AIDS instead of the biomedical- or English terms (the following information was collected through interviews with FTB at Mukikute).

The local terms for TB such as 'kifua kikuu' (literally meaning the big cough), seem to be used interchangeable with TB and do not seem to refer to another type of disease or illness. Thus, 'kifua kikuu' is not 'mistaken for' TB as is the case for instance in Botswana. In Botswana the 'big cough' is an illness/disease which is perceived to be slightly different from TB, and therefore commonly require a local form of treatment in addition to the TB treatment prescribed by modern medicine. Thus in Botswana the TB patient commonly undergoes multiple treatments within the plural health care system. It is common to differentiate between them as a Tshwane on the one hand, and a European-disease, on the other.

The case about Zenabu previously in this report clearly resembles such a disease classification between 'Swahili', on the one hand, and the government/ hospital, on the other. That is, there seem to be a need for a traditional / religious form of treatment for the hospital treatment to be efficient. This case, however, was the only I came across during the study. The remaining cases did not seem to be in need of multiple forms of treatment, but in some cases the patients seem to prefer a combination of (multiple) treatments.

Local terms for AIDS

AIDS also seems to have several local terms. However, they do not seem to be mistaken for AIDS and thus require another treatment. Rather, the local terms for AIDS, seem to be used instead of AIDS to avoid the harsh and fatal meaning of AIDS and because it is synonymous with death and dying. I do not know how frequently these terms are used, but some of them seem to be 'popular' among the (male) youth. AIDS is (still) strongly associated with death and dying and the ART treatment option does not seem to have changed this logic. Thus by using the following terms people can talk about a fatal disease in a 'joking-manner and thus avoid the strong association to death:

'Umeme' (electricity) is used as a synonym to AIDS. AIDS is like electricity, once you are connected or struck by it, you die. It is also held that like the electricity (lightening), it strikes as suddenly and randomly as lightening.

'Ngoma' (dance and drums; but also initiation ceremonies) AIDS is like *ngoma*, it is something big and important.

'Minyeanze'; an insect with a very sharp sound which everybody can hear from far; meaning that a person with AIDS cannot hide.

'Upupu'; There is a certain tree which produces a powder which irritates the skin to an intolerable extent.

'Minyenyere': A very small ant which can eat something very big in a short time because they are so tiny that the person will not be able to notice them.

'Ngwengwe' is a local term which is known by most. It resembles TB but is not similar.

It is a very dry cough without sputum.

'Kinyaranyara' and 'yabis ya tumbo'
According to one of the traditional healers, "was there long time before the Tanzanian Government announced HIV/AIDS. In 1948-1949 and in the 1960's, HIV/AIDS was called '*Kinyaranyara*', and some named it '*Yabisi ya Tumbo'*. The most common symptom was the person's loss of body weight." And the healer continues his explanation, "By that time, it was very hard to meet people with Kinyaranyara (HIV/AIDS). In the Zaramo language 'Kinyaranyara' means dry / hard things and refers to the person who simply dry out. As you can see, to day HIV/AIDS is all over the world and it's a serious problem. 'Yabis ya Tumbo' results from something like a worm, who tightens the stomach. This ailment is cured by traditional herbs. You know that most people held that HIV/AIDS patients suffer due to their wrong doings. Also they claim that the disease is given to them through supernatural power."

I do not know how common this explanation about kinyaranyara is among other healers. Neither do I know how common it is among the people in Temeke. The term was however, not mentioned by the Mukikute members. As illustrated in the case about Zenabu, this healer likewise perceived of the spread of illness and disease (such as HIV/AIDS) as caused by immoral behaviour in people and their disease aetiology is as such closely associated with their local moral worlds.

Referring and exchange of patients
Only one of the interviewed healers claimed to be able to heal TB (with herbs), and one claimed to be able to cure HIV/AIDS (through spiritual prayers), it is important to note that because HIV/AIDS is a syndrome of diseases, and thus difficult to diagnose, the healers attend to the opportunistic infections. "While some of my patients have first been to the hospitals for medical treatment – but lose hope when the treatment fails – others come to me first. Whenever I see a seriously ill patient, I will refer him/ to the hospitals and ask to consult a hospital doctor".

Attitudes to collaboration with the formal health sector.
One of the healers had some previous experience of collaboration with the formal health sector and had been participating at a seminar arranged by the formal health sector in Temeke. The initiative taken by the formal health sector some few years ago had, however, according to him fizzled out and the healer had not heard anything since. At the mentioned seminar, the healers were taught about TB, how to recognise the symptoms, and advised to refer TB patients to the formal health sector.

The healers I interviewed were too few to make generalisations. However, they were generally positive to collaboration "for the benefit and well-being of the patient". Some did mention obstacles or limitations to such collaboration and expressed concern for a misuse of their herbal medical knowledge. One healer referred to their colleagues who had experienced that the Traditional Medicine Research Unit (at the University of Dar-es-Salaam) had tested their medical herbs for their pharmaceutical effectiveness, but not given them any information about the result. One expressed some scepticism towards such collaboration as he feared that his knowledge of herbal medicine could be misused, i.e., stolen by pharmaceutical companied and the practitioner of modern medicine. "It is not likely that the hospital doctors will acknowledge our medicine and forms of treatment."

Some of them asked for help and assistance to commercialise their herbal medicine. Commercialisation and commoditisation of traditional medicine seems to be an increasing phenomenon in Dar-es-Salaam as in most of Africa (see Murray and Chavanduka 1986; Whyte 1997). The fact that traditional herbal medicine is being commercialised was observed at the Fare Trade in Dar-es-Salaam (as described above). Obviously, it has an enormous business potential. Some patients in this minor study drew on commercialised traditional medicine in stead of, or in combination with, ART.

Another expressed concern was that a dialogue between the sectors easily would become a one-way dialogue, whereby the health sector would be teaching about the symptoms of TB and advised the healers to refer patients with such symptoms to the modern health care facilities and there would be no strategy for an exchange of patients. Considering that patients – including some with TB and AIDS – use traditional and religious forms of treatment and that the traditional healers expressed an openness to such a collaboration, the health sector should utilise such an opportunity and initiate a collaboration.

Recommendations:

Any collaboration between modern and traditional medicine should take place between two independent partners, based on mutual respect, open-mindedness, and interest in learning and a sharing of knowledge.

A locally designed strategy should be developed addressing the means and goals in an efficient collaboration between the parties which will sustain an engagement by the healers.

Health community strategies must be adapted to the particular local realities of people's livelihood in Temeke (see above on the suggested strategies for Mukikute).

Is there a potential for collaboration between the health cultures/ systems?

Efforts to encourage collaboration between the traditional healers and biomedical practitioners began many decades back. This has also been the case of Tanzania ever since colonial time. More systematic collaboration, however, was initiated by WHO through the Alma-Ata declaration in 1976. Traditional healers and witchdoctors were approached as so-called Traditional Health Practitioners (THPs) and 'health workers' on equal terms and as collaborating partners. This collaborating approach has been further encouraged in the struggle against the spread of HIV/AIDS infection and disease.

Due to the wide difference in medical cultures, training and practices – including their very different disease aetiology (causal explanations), collaborating efforts have however, varied in success and often proven difficult (Haram 1988; 1991; See also a recent study conducted in Tanzania on this issues by Mbwambo et al. 2007, Kayombo et al. 2007).

To exercise collaboration on equal terms is difficult, but the danger is that a fictive collaboration quickly turns to confrontation or silence between the involved partners. Taking the potential role of traditional/ local healers in promoting primary health care, to educate communities, and to bring about behavioural change concerning prevailing health problems and to reduce stigma or ill-behaviour due to blame, is, however, significant if approached in the most appropriate way, namely a locally situated approach.

Strategies in approaching traditional and religious healers in Temeke:

Trusted community leaders should map the range of traditional/ religious healers and the health care alternatives available.

Health personnel should arrange workshops and invite traditional healers to discuss problems they experience and what they would like help in doing. In teamwork, find further strategies for a mutually fruitful collaboration.

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APPENDIX 1:

App. 1. Questions for FTB Patients and their Patients

MASWALI KWA FTB Patients & Patients

Ask and write the history of the patient.

1.Uliza na uandike historia ya mgonjwa

When the patient was born and where.

- Alizaliwa lini,alizaliwa wapi.

Was parents here or they came/moved here

- Wazazi wake walikuwa hapa au walihamia?

How many children did they get (male/female) age.

- walipata watoto wangapi (me / ke) umri wao

are they all alive, where are they? If dead what diseases.

- wapo hai wote na wapo wapi? Kama ni marehemu kwa magonjwa yapi?

Write anything else if there is about history

- Andika kama kuna kingine kuhusu historia.

Ask for patients household economy.

2. Ulizia juu ya uchumi wa kaya husika ya mgonjwa

household member depend on who to give them income

- wanakaya wana mtegemea nani awape kipato

The income depended on comes from where

- je ni kipato kinachotegemewa kinatokana na nini

How many people in this household?

- kwenye kaya hii kuna watu wangapi?

How many rooms does their house have?

Nyumba yao ina vyumba vingapi?

Patients history that has health problem

3. Historia ya mgonjwa

What happened whe he felt sick? Did the patient noticed or someone else, who?

Ilikuwaje hadi akahisi anaumwa? Je ni yeye aliyegundua? Au ni mtu mwingine? ni nani?

Treatment history

4.Historia ya matibabu

After feeling that you are sick where did you go for the 1st time to get treatment,

Baada ya kuhisi unaumwa ulienda wapi kwa mara ya kwanza kupata matibabu? (duka la shop, traditional healer, prayers, to medical doctor

dawa baridi, kwa mganga wa kienyeji kuombewa, kwa mganga wa hospitali)

Explain all steps taken in testing and treatment being in a hospital or

eleza hatua zote ulizofuata katika kupimwa na kupatiwa matibabu iwe ni hospitalini au ni kwa mganga wa kienyeji a traditional healer.

Were you contented with the first treatment? Or you changed treatment where did you go

Je hayo matibabu ya kwanza yalikuridhisha? Au ulibadilisha matibabu ukaenda pengine?

Stigma - where were you afraid of telling other people that you have TB/HIV

5. Stigma - je uliogopa kuwaambia watu kuwa unaumwa na TB/Ukimwi?

Did you notice that people were afraid of you?

- jekama ulipata kuona kuwa watu wanakuogopa?

Word / local names for TB and AIDS

6. Maneno / majina ya mitaani / yaliyopewa TB na AIDS.

Ask about overdosing medicine and mixing both medicine what do they say

7.Uliza juu ya kuzidisha dawa na kuchanganya dawa ,mgonjwa ana maoni gani?

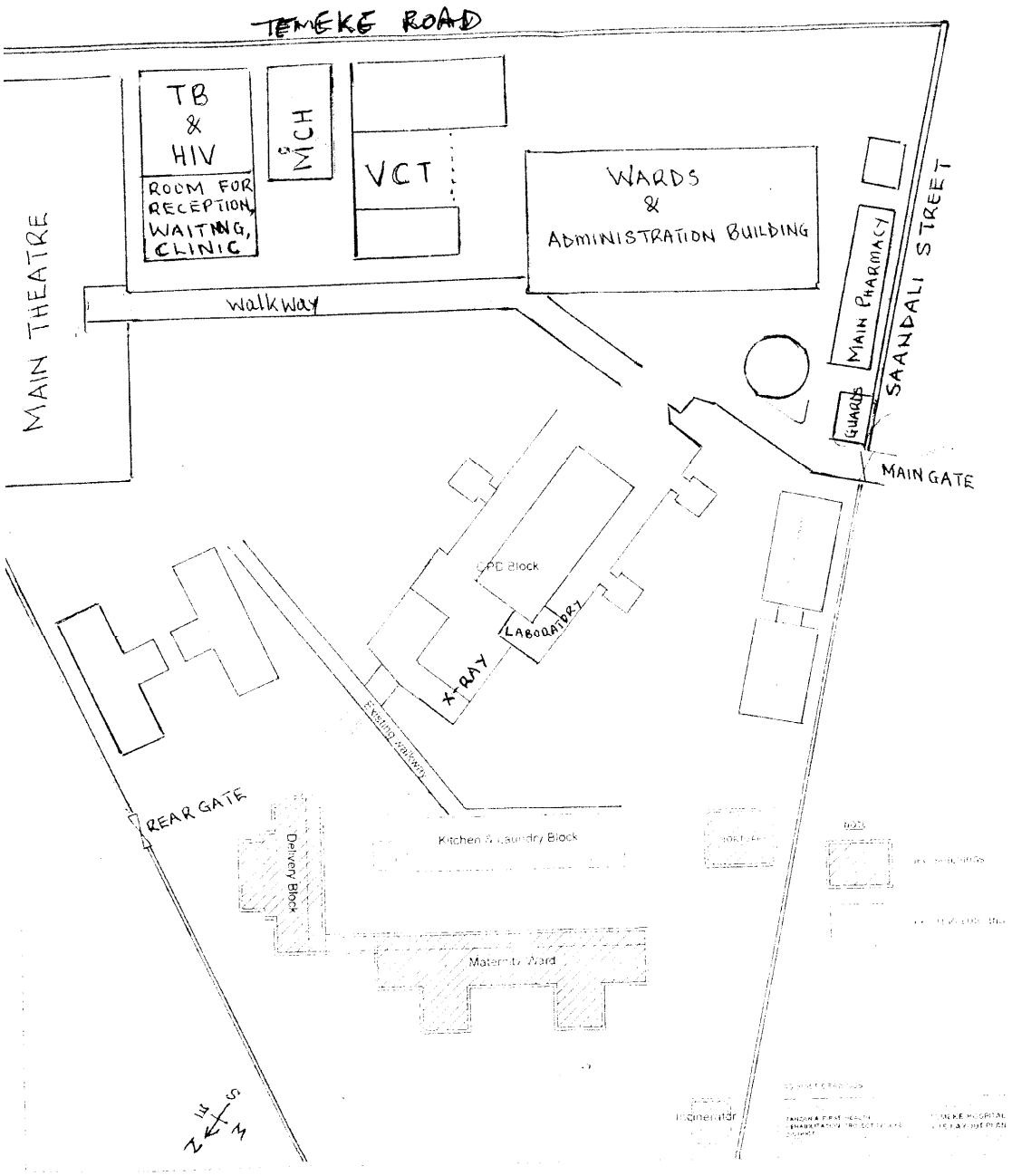
For TB and AIDS patient could sex intercourse boost their health is it the

8. Je, kwa mgonjwa wa TB na AIDS je kujamiiana kutaboresha afya zao je ni sawa kuwa mwanamke na mwanaume?

same for female and male?

APPENDIX 2:

App. 3



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