Care seeking and attitudes to treatment compliance by tuberculosis patients prior to enrollment in the district treatment programme in rural western Kenya: a qualitative study

JG Ayisi, AH van’t Hoog, JA Agaya, W Mchembere, P Nyamthimba, O Muhenje, B Marston

Affiliations
1Centre for Global Health Research, Kenya Medical Research Institute, Kisumu, Kenya
2Directorate of Research Management & Development, Ministry of Higher Education, Science and Technology, Nairobi, Kenya
3Kenya Medical Research Institute, KEMRI/CDC program, Kisumu, Kenya
4Academic Medical Centre, University of Amsterdam, The Netherlands
5US Centers for Disease Control and Prevention, Global AIDS Program, Nairobi, Kenya
6US Centers for Disease Control and Prevention, Global AIDS Program, Atlanta, GA, USA

ABSTRACT:

Background: The two issues mostly affecting the success of tuberculosis control programs are delay in presentation for treatment and non-completion of treatment. There is need to further understand the factors that contribute to these issues, particularly in resource limited settings where rates of tuberculosis are high.

Objective: To assess health-seeking behaviours and health care experiences among persons with pulmonary tuberculosis, and explore potential for treatment non-adherence.

Design: Qualitative one-on-one in-depth interviews with pulmonary tuberculosis patients.

Setting: Nine health facilities providing diagnostic and treatment services (3 public hospitals, 5 public and one mission health centers) in Asembo and Gem areas of Nyanza, rural western Kenya.

Participants: Thirty one (31) patients [18 women aged between 20 and 45, mean 28.3 (SD 7.1) years and 13 men aged between 22 and 52, mean 37.3 (SD 9.9) years], residing in an area of western Kenya with a Health and Demographic Surveillance System (HDSS) and attending treatment for ≤4 weeks on scheduled TB clinic days in Asembo (Rarieda district) and Gem (Siaya district), Nyanza Province, in September and October 2005.
Results: Most patients initially self-treated with herbal remedies or drugs purchased from kiosks/pharmacies before seeking professional care. Median number of treatment seeking attempts was 2, (IQR: 1, 3). Reported time from initial symptoms to TB diagnosis ranged from 2 months to 9 years (median 11 months). Misinterpretation of early symptoms and financial constraints were the main reasons reported for delay. Potential reasons for defaulting treatment included not being aware of the duration of TB treatment, stopping treatment once symptoms resolved, and lack of family support.

Conclusions: This qualitative study highlights important challenges for TB control in rural western Kenya, and provides useful information that was further validated in a quantitative study.

Key Words: health-seeking; tuberculosis; diagnosis; delay; qualitative

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*Corresponding author: john.ayisi@yahoo.com
Introduction

Despite Kenya having a well-organized National Tuberculosis Control Program, the notification rate of TB in Kenya remains among the highest in the world, and the country is ranked 13th among the 22 TB high burden countries that constitute 80% of the global incidence of TB cases [1]. In 2006, there were 115,234 new TB cases identified in Kenya, a case notification rate 286/100,000 [2]. As in many African countries, these figures, although high, are still likely to reflect considerable under-reporting of TB cases [3], thus diagnosis and treatment of TB remains an important public health priority. Unless tuberculosis cases are identified and treated earlier and in greater numbers, tuberculosis-related morbidity, mortality, and drug resistance may be expected to increase [4]. A challenge to tuberculosis control programme is how to ensure that tuberculosis patients find their timely way to diagnosis and adhere to treatment.

In any cultural context, a precondition of health seeking behaviour is recognition and interpretation of symptoms, both by the individuals affected and by those around them [5,6]. Who is consulted once symptoms are recognized will depend on pre-existing beliefs about the likely meaning of the symptoms, and availability and accessibility of the various potential sources of help (traditional, spiritual, western medicine) [5]. This availability of multiple sources of care, combined with uncertainty about TB symptoms, stigma and problems of access and affordability may further lead to considerable delays in diagnosis and treatment of TB. Gaining ‘therapeutic narratives’ i.e., participant’s commentaries on illness progression, health seeking options and related events, is important for gaining insight into the complex relationship of ‘traditional’ and ‘modern’ medical systems, useful for designing tuberculosis case-finding and health promotion activities aimed at removing or reducing barriers to timely presentation to appropriate health facilities in order to improve community health [7].

Conceptual Framework

According to Kleinman [8], explanatory models serve as a representation of specific personal and social meaning to the experience of illness and are derived from a person’s knowledge, beliefs, and perception about health and illness and its cause, signs and symptoms, severity, transmission, options for treatment, and prognosis. The sources of a person’s health beliefs include ideas from the professional health sector, (where the person is exposed to the teaching of health care professionals); the popular sector, (where the source of beliefs is the social network in which lay beliefs and explanations about illness are shared by family, friends and other members of the social network and how they personally experience their symptoms, the ability to function and stigma); and the folk or traditional sector, (where beliefs originate from oral tradition or folk healers and nonprofessional specialists). Explanatory models are however not static, and a person may hold a plurality of beliefs from each of these sectors.
Gaining of ‘true’ picture of health seeking behaviours is particularly difficult and, if an accurate picture of health seeking behaviour is to be built up, careful attention needs to be given to the cultural sensitivity and appropriateness of data collection methods [9].

Despite their demonstrated negative effects on TB control globally, little is known about the extent and duration of delay in seeking care and its determinants and default from TB treatment among patients in rural Kenya. One previous study in Kenya used participant observation and informal interview of individual patients to assess social and cultural factors of TB treatment defaulting [10], while in another study, focus group discussions (FGDs) were used to assess community’s beliefs and knowledge about causation, transmission, symptomatology and treatment-seeking behavioural patterns in TB suspects and hospitalized TB patients; and attitudes towards the disease and afflicted persons [11]. In the latter study, even though FGDs allow participants to build on points or disagree with each other, therefore generating more points of view, they may not be the best method for gathering sensitive information, as participants may be reluctant to share such information in the presence of others [9].

To better understand the perception of TB illness in rural western Kenya and obtain an overview of the key factors of what people think and do which may influence their choices of action and provider when faced with TB symptoms [5], we explored culturally based explanations of illness and health among tuberculosis patients served in selected public health facilities in Asembo and Gem areas of Nyanza, prior to their enrollment in the district TB treatment programme. Information grounded in participants own perspectives was elicited through a “free-response format” [6]. The present study also explored the knowledge, beliefs, and perceptions about TB signs and symptoms, severity, causation, transmissibility, treatment and potential barriers to treatment adherence, including the role of stigma as reported by study subjects.

Methods

Study sites and subject selection

This study was carried out in Asembo (Rarieda district) and Yala and Wagai Divisions of Gem (Siaya District), Nyanza province, western Kenya. From 2002, The Kenya Medical Research Institute and Centers for Disease Control and Prevention (KEMRI/CDC) have been supporting a Health and Demographic Surveillance System (HDSS) in this area, which is referred to as the “DSS area”, and has previously been described in detail [12,13].

Nyanza province is very poor, with over two-thirds of individuals living below the poverty line [14], and has very high TB rates: in 2006 there were 23,273 new TB cases reported (case
notification rate >400/100,000 population); 85% were pulmonary TB [2]. Among TB cases aged 15-49 years, HIV prevalence was 73%, compared to 15% in the general adult population.

Study sites included 3 district hospitals of Bondo, Siaya and Yala (all provide basic in-patient and out-patient curative and preventive health care services), five public and one mission health centers (all provide mainly ambulatory preventive and curative services). The catchment areas for each of the facilities include parts the HDSS area and the facilities serve low to middle income clients. Generally, the diagnosis of TB is made on the basis of sputum smear examinations or chest X-ray. The facilities were selected on an even geographical distribution within the study area and on the basis of their ability to provide acceptable TB treatment (i.e., they had a qualified staff in-charge, and an adequate laboratory for diagnosis and follow-up). Each facility was visited daily Monday-Friday, between September 1 and October 31 2005.

**Sample and recruitment**

A convenience sample of newly diagnosed TB patients attending the study health facilities for no more than 4 weeks was interviewed rather than random sampling because it has the advantage of identifying persons who are willing to actively participate. Potential respondents were systematically invited during week-days during the entire study period to take part in an in-depth interview after their routine consultation. The purpose of the study was explained to potential participants and informed consent was obtained and documented. Interviews were conducted by trained staff; anonymity was assured, with no names being used throughout the study. Respondents were informed that participation would not affect their treatment. None of the invited tuberculosis patients declined participation. To avoid interference with and from health workers, interviews were conducted in a separate room.

**Interviews**

All materials for the study, including the informed consent form and the interview guide, were developed in English and written at or below a fourth-grade reading level. The documents were then translated into Dholuo (the local language for all the participants). The Dholuo version was then independently translated back into English. The results of the translated English version were compared with the original English version and decentered, i.e., both the source and the target language versions were modified to make them congruent [15,16]. Interviewers used open-ended discussion guides and covered areas such as symptom onset, perceived cause, treatment seeking trajectory, disclosure and
time to seeking care. Questions also explored experience of stigma, whether enacted (actual experiences of stigma) or felt (anticipated stigma) [17] relating HIV and TB and potential reasons for non-adherence to treatment. The questions were repeated, probing for detail by the interviewer until the story of how he/she got enrolled in tuberculosis treatment was completed. Interviews continued until all categories were well defined and saturated, i.e., no new or relevant data emerged, after interviewing thirty-one participants [18]. Interviews generally lasted between 60 and 90 minutes, and were audio-taped with the participant’s permission, transcribed, and translated into English.

Ethical clearance

The study protocol was approved by the Ethical Review Committee at the Kenya Medical Research Institute (KEMRI) and the Centers for Disease Control and Prevention (CDC), Atlanta, Georgia, USA.

Data analysis

Data analysis was performed using Glaser and Strauss’s (1967) grounded theory method, which involves continuous and simultaneous data collection, coding, and subsequently grouped into categories to produce “themes” [19]. Although the purpose of this study was not theory development, we felt that the grounded theory approach would be the most effective method of analysis. Information from some verbatim interviews is presented as quotes.

Results

Symptoms and perceived causes

Respondents’ stories started with a variety of non-specific symptoms, such as fever, headache, chest pain, fatigue and body pain. Persistent and prolonged cough was the symptom of tuberculosis most frequently mentioned by most participants. Participants’ awareness of TB, its symptoms, and the seriousness of the disease was poor. When asked about the cause of their TB, 14/31 responded “I don’t know.” Some participants thought that environmental factors, such as inhaling smoke and hot air from charcoal burning or sharing a house with domestic animals were the cause of their TB. Other patients thought that TB is acquired from alcohol, water or sharing utensils: “I got TB from cold drinks… drinking stagnant water… sharing food or utensils” (Interview summary 19, man, age 34).

Other perceived causes of TB predominantly related to physical factors, including injury on the chest or physical hard work: “TB got me because of the hard work that I do [riding ‘boda-boda’ (bicycle) taxi]” (Interview summary 30,
man, age 24). A number of participants also perceived TB to be inherited, “My mother told me that I got it since it is in our lineage (inherited)” (Interview summary 13, woman, age 24) or to be caused by spiritual or evil forces (7/31), often blaming neighbours for putting a curse on them as narrated: “….. some claimed that it (my sickness) is “chira” (i.e., curse/bad omen) type of cough or … somebody was trying to bewitch me … we requested a religious healer to pray for me”….. (Interview summary 11, woman, age 30).

Health care seeking delay

Although all participants reported symptoms typically associated with TB, treatment seeking was generally delayed. The period from symptom to diagnosis varied considerably both in length (3 weeks to 9 years) and in number of efforts to seek treatment [median 2, IQR (1, 3)]. 7/31 of the participants stated that they delayed care seeking because they were 'not concerned' about their symptoms:

“I thought that it was a normal cough” (Interview summary 2, woman, age 30)

Prolonged self-treatment prior to consulting a biomedical health facility was widespread among the participants (22/31), of which 12/20 did not know the cause their TB, while 8/12 had a misperception about the cause (Figure). Often patients chose self-treatment, for example using herbs or buying medication from a local shop or pharmacy, while those who attributed their TB to a curse/witchcraft contacted spiritual healers.

More than half of the patients (17/31) sought advice of a close relative, and most delayed seeking professional care because they were advised to seek help from herbal/spiritual healers (see Figure) as narrated: “…when my condition had worsened… my mother took me to some person…. who boiled some herbs for me to drink….“ (Interview summary 18, woman, age 22).

Preference for a provider whom a patient knew and trusted and economic constraints also led to considerable time elapsing before obtaining a diagnosis and appropriate treatment, as narrated: “…I just decided much earlier on my own to go to “Russia” (in reference to Nyanza Provincial General hospital, a Provincial referral public health facility in the study region, built by Russian government as an aid to the Kenyan government) but not Yala that is nearby because I knew some of the doctors there (Nyanza Provincial General) … but I could not do it early due to lack of money” (Interview summary 26, man, age 47). Another patient who took 26 months to be diagnosed narrated: “---- I was told to go for an X-ray test at Yala …due to lack of money, I stayed for a while before going for the test … “(Interview summary 18, woman, age 22)
Other causes of delay included inconveniences with work or dislike of long queue at health facility:

“At my place of work I am alone…. I could not go to hospital, so I used to buy drugs to reduce the pain” (Interview summary 24, man, age 39).

“I was avoiding queuing at the hospital…….” (Interview summary 23, man, age 49)

**Decision to seek medical attention**

When symptoms persisted or returned after the initial treatment attempt or the respondents perceived the illness as being serious, the patient was motivated to visit a health facility in an attempt to receive proper diagnosis.

The figure shows the detailed efforts to seek help by study participants until the time of enrollment in the district tuberculosis treatment programme. Overall, 19 patients first visited a provider in the public health sector; where half (10/19) were diagnosed as having TB, while 12 visited providers in the private health sector of which only one (1/12) was diagnosed with TB. On the second attempt to seek treatment, 8 respondents were diagnosed as having TB, all in a public health facility. Of the remaining 12 patients, seven were diagnosed as having TB on their third attempt, and five on their fourth or subsequent attempt. In all but one, the diagnosis was made in a public health facility (Figure).

**Health provider delay of TB diagnosis**

Nine of 19 respondents who visited public sector providers and 11 of 12 who visited private sector providers reported that health care providers failed to consider TB early in the course of their illness (Figure). This results in patients making unnecessary trips to the health facilities, delays their care and inefficient use of scarce financial resources on a long and often difficult process of obtaining appropriate diagnosis for TB. A patient who took 20 months to be enrolled in the treatment programme reported: “I went to Yala sub-District hospital… I was told I had malaria… then Kenyatta National hospital…told had malaria…then to Malanga Health centre… was told had malaria …then to a private hospital… I was given eleven injections…to Yala again told to go for X-ray and VCT… then was found to have TB” (Interview summary 24, man, age 39).

**Social stigma associated with TB**
The family was perceived to be influential in helping one to seek for care, through economic support and in assisting to identify appropriate health facilities for medication. When asked: “Did you tell your people at home that you have TB?” 30/31 respondents stated that their relatives and friends knew that they had TB, and that they themselves had told them. When asked: “Do they (people at home) treat you different in any way since you have TB?” to explore enacted (actual experiences of) stigma, majority (24/30) stated that they experienced no significant change in the behaviour of people towards them, and maintained that no precautions were taken by other members of the family, and social interaction continued as normal and were supportive and assisted them in accessing their treatment as narrated: “… they make sure that I eat… and I take my drugs” (Interview summary 20, man, age 22).

However, the remaining 6/30 confirmed that their environment reacted negatively when they revealed they had TB, as family members tried to avoid close contact as narrated: “They have given me separate set of utensils and I don’t share meals…” (Interview summary 26, man, age 47). Another patient stated: “They treated me differently as if I had HIV because of my cough and mass wasting” (Interview summary 10, woman, age 32), revealing existence of some social stigma associated with TB in the study area.

HIV ‘cross-stigmatisation’ of TB

About half (15/31) of the participants felt that there is an association between TB and HIV/AIDS. When participants were asked: “If people with TB are asked to take an HIV test, how it would affect their going for a TB test?” One patient narrated:

“----- I have TB and hear from people that I will be tested for HIV, and that can make one not go to be tested for TB ---- if you hear they will test that (HIV), then you decide just to continue coughing instead” (Interview summary 12, woman, age 36).

“Q. Were you uncomfortable talking to certain people about your problem?” When asked this question to explore felt (anticipated) stigma, 11/31 participants had felt stigma, as summarized here by a participant: “… I was uncomfortable because I was thin…. people here associate it (wasting) with AIDS…” (Interview summary 20, man, age 22).

Potential for defaulting treatment

Completion of the treatment regimen among patients initiated on TB treatment is necessary to achieve cure and prevent transmission and development of drug-resistance. Participants described little communication with treatment providers and a lack of involvement in the treatment process. When asked
how long treatment will take, 14/31 patients lacked knowledge on the duration of treatment as narrated below:

“….I was just started on the medication… I haven’t been told (duration of treatment)” (Interview summary 8, woman, age 22)

“Q. Would you think of reasons that would make it difficult for you to complete the full TB treatment?” When asked this question, some patients felt that the duration of treatment was too long, particularly after symptoms had disappeared. Accounts indicate that potential for default from treatment would occur in the context of feeling better as a result of the early stages (intensive phase) of treatment and appear to be associated with a poor understanding of the need to continue treatment even after the symptoms of illness have subsided.

“…I don’t usually finish taking my drugs… If I start taking these drugs and feel well, I will leave but so long as I still cough, I will just continue” (Interview summary 3, woman, age 23)

In some cases (perceived), side effects resulting from chronic hunger (6/31) could lead to defaulting treatment:

“….these drugs make one feel fatigue, improved appetite…when there is no food, it is not easy…” (Interview summary 27, man, age 46)

Anticipated lack of adequate supplies of TB drugs at health facilities (8/31) also has the potential to contribute to poor compliance with treatment as narrated below:

“I will stop medication if at all I come to collect drugs from the dispensary and I find that there are no drugs…” (Interview summary 19, man, age 34).

The social support of family members is also important especially during the intensive phase of treatment. A male patient explained how lack of family support can affect adherence: “Stress from family members can discourage one from taking drugs” (Interview summary 24, man, age 39).

Discussion

In general, most participants had low knowledge of TB; a majority self-treated before seeking care from the formal health sector, and most sought care at public health facilities. A diagnosis of TB was confirmed at public facilities in all but two of the patients, however, only half of patients visiting these public facilities and one of the twelve patients who visited private facilities for first time were diagnosed with TB.

Understanding of TB aetiology:
Many TB patients started with relatively non-specific symptoms, partially explaining the observed delay in health seeking or difficulties in obtaining appropriate treatment among the study participants visiting health facilities. Many participants held multiple conceptions of TB, most of which were inconsistent with bacteria as the cause of TB. Client explanations of aetiology of TB in this study suggest the presence of popular and folk beliefs [20], with some patients mentioning sharing utensils, food and water as the cause of their TB; others attributed TB to hard physical work or exposure to cold or smoke, still others believed that TB is inherited. Similar findings have been reported in a previous study [11] and elsewhere [21]. This finding is of concern, as participants should have been clearly informed in this regard at the start of their treatment.

**Health seeking:**

Early detection and treatment of tuberculosis is critical to controlling the disease [22]. Although cough and fever were common symptoms at onset, these symptoms alone did not always prompt patients to seek medical treatment early. Symptoms in the early stages of TB are not very specific and may be attributed to self-limiting illnesses, such as viral infections, and only if symptoms become worse or persist will the person consult a health service. Symptom misinterpretation has been associated with 'patient' delay in other studies internationally, where symptoms are attributed to external causes such as overwork or exposure to cold [23,24]. This delay in health-seeking behavior is likely to have increased their risk of morbidity, mortality, and tuberculosis transmission to contacts.

Personal and community knowledge of TB and interpretation of health beliefs influences attitudes and health seeking behaviours significantly [25-27]. Self-treatment, involving a variety of home remedies, traditional and modern drugs, is the first step in the health-seeking behaviour process in the study area, consistent with previous studies, and is linked with the perception of the seriousness of the symptoms and the label the patient attaches to his/her condition [9,11,28]. Persons with untreated sputum smear positive tuberculosis can infect 10 to 14 others in a year [29], thus there is a need for interventions designed to encourage symptomatic individuals to seek appropriate medical help early.

**Missed diagnoses at health facilities:**

Lack of money for diagnostic tests and low suspicion of TB at health facilities also caused further delay in obtaining correct treatment, once a decision to seek
care at a health facility had been made. Only half of patients who visited public health facilities and only one among those who visited a private facility for the first time were diagnosed with TB. This confirms findings from a previous study in Kenya which showed that health units failed to investigate chronic coughs in a certain proportion of TB suspects [30], and raises several programme and policy issues [31]. There are many consequences of missing the diagnosis of tuberculosis. For the patient, misdiagnosis and faulty treatment leads to loss of scarce time and money in the search for treatment, and may increase the duration of illness and the possibility of death. For public health officials, misdiagnosis represents an underestimate in the incident cases of tuberculosis, and importantly, increases the duration of infectivity. Interventions that could improve the likelihood of TB diagnosis at health facilities may include implementation of standard screening procedures, additional training of health care workers, education of patients (so that they expect and request diagnostic testing for TB when appropriate), and improving the accessibility and reducing the costs for diagnostic tests.

**Stigma:**

Very few people felt that their TB had affected their relationships with friends and family, and if it did, it appeared more supportive, and this is consistent with other studies that have documented social stigma of TB to be more extra-familial than intra-familial [32]. This is important since social support provided by family often plays a pivotal role in promoting early TB diagnosis and adherence to treatment [11,33]. However, a small proportion of our participants expressed how they were treated as though they had HIV due to their cough and mass wasting. The association between HIV and TB could enhance existing TB stigma further as observed elsewhere [34,35]. Our study also suggests that stigma related to HIV infection may reduce TB test uptake among TB suspects. Stigma is linked to concealment of symptoms, treatment default, isolation from support networks, and decreased self-esteem, self-perception, and self-care [36]. Health education should therefore aim at reducing tuberculosis-related stigma, and the key here is that Provider Initiated Testing and Counseling which is now part of the integrated service delivery in Kenya is to raise awareness that TB is not always associated with HIV [37], and that it can be cured in both persons with and without HIV.

**Potential for treatment default:**

An essential part of tuberculosis treatment is advice regarding the long duration of treatment and the dangers of default. One of the objectives of our study was to assess the potential factors for treatment default. We found that a decision to interrupt TB treatment may be taken by our study participants
because of improvement in symptoms, lack of knowledge on the duration and the importance of completing full treatment course, drug stock outs at the health facility, side effects of TB medications and lack of social support, findings consistent with other studies [38,39]. Patient narratives seem to suggest lack of communication and involvement of the patient in the treatment process leaving them poorly equipped to take an active role in managing their own health, and poorly prepared to make necessary informed decisions about their treatment [40], factors that have been found to be associated with higher rates of treatment default [41]. An improvement in these aspects of TB treatment is crucial in encouraging patients to continue with treatment for the full duration of the regime.

**Limitations:**

This was a sociological study involving in-depth interviews. For this reason the sample size of our investigations was relatively small, with only 31 respondents selected by a nonrandom sampling method which could have introduced bias into the results. We tried to reduce recall bias by including only patients who were diagnosed ≤4 weeks before the interview. Undetected “cases” were not included, and have been addressed in our recent study that actively identified TB cases in a TB prevalence survey in the same study area [42]. Our outcome measure of delay in seeking care was self-reported and no attempt was made to verify the patient reports. We did not collect HIV status of the interviewed participants, hence a possibility of misclassification of non-TB symptoms as those of TB, with consequent unrealistic long periods of delay (several years). Our findings may only be applied to the factors studied, for this study did not intend to assess other important aspects of TB control such as perceptions and attitudes of health care providers, the community and suspects; and quality of the TB control programme.

**Conclusion:**

Overall, the high number of patients who shared their TB diagnosis with family members and the subsequent high numbers who did not experience enacted stigma in this study population are very encouraging for the district TB control programme. However, although we explored the experiences of only a small number of individuals, several recurring themes highlights important challenges for TB control in rural western Kenya. Lack of awareness of treatment duration, stock outs and lack of family support were reported as reasons for potential treatment default. The low knowledge of TB among the participants and low suspicion of TB among health facility staff in addition to few reported experiences of both enacted TB-related and felt HIV/TB-associated stigma should be of concern to TB control programme in the study area.
Competing interests:

The authors declare that they have no competing interests.

Authors’ contributions:

JGA, AHvH, BM conceived of the study, and participated in its coordination. All authors participated in the design. JGA, JAA and AHvH carried out the study. WM, PN and OM assisted in the analysis and data interpretation. JGA and AHvH drafted the manuscript. All authors read and approved the final manuscript.

E-mail addresses: JG Ayisi (john.ayisi@yahoo.com), AH van’t Hoog (Avanthoog@ke.cdc.gov), JA Agaya (JAgaya@ke.cdc.gov), W Mchembere (wmchembere@ke.cdc.gov), P Nyamthimba (POnyango@ke.cdc.gov), O Muhenje (OMuhenje@ke.cdc.gov), B Marston (bxm5@cdc.gov)

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References:


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Abbreviations:
Herbs= Herbalist, Disp= government dispensary, MS=medical shop/drug retailer, PDis=Private Dispensary,
Figure:

Attempts made by TB patients prior to enrollment in a tuberculosis treatment programme, Nyanza, western Kenya, 2005