The Experiences of TB Patients in Mosvold Health District who have successfully completed treatment

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Abstract

Objective: To understand some of the reasons why TB patients were successfully able to complete six months of supervised ambulatory treatment.

Design: Descriptive qualitative.

Setting: Mosvold Health District, KwaZulu Natal, South Africa.

Methodology: Focus Group interviews were undertaken with 'successful patients', their families, Community Health Workers (CHW) who had supervised 'successful patients' and members of staff from the hospital TB ward. The major themes to emerge from each interview were identified and integrated into a schema.

Results: The major theme to emerge was the patient's need to choose between traditional and western treatments when becoming ill. The outcome of this choice is largely determined by the patient's and the family's beliefs about disease and ill health. The vast majority of ill people initially choose traditional forms of treatment and only entered the western system when these traditional methods failed. Factors shown to improve compliance with TB medication included: failure of the traditional treatment; sufficient food at home to prevent the occurrence of side effects when taking medication; previous experience of successful western TB treatment; support and encouragement from the family and community health worker and seeing one's own X-rays.

Recommendations and Conclusions: the need to accept people in a non-judgemental person-centered manner; to focus on successful information-sharing strategies (which include cured TB patients); to demonstrate 'sores' on chest X-rays and to provide patients with support and encouragement. A non-judgemental approach to traditional healing and working in co-operation with traditional healers is suggested.

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Introduction

Effective care of TB patients is critical in SA, particularly in the light of the HIV epidemic. Innovative strategies and adequate resources are needed to help improve the lives of those suffering from this imminently curable disease.

The Mosvold Health District is situated in the western portion of the Ingwavuma magisterial district in northern KwaZulu Natal and is part of the Jozini Health Region. The area is deeply rural, 250km from Empangeni and 420km from Durban. The economy of the area is largely subsistence-based and unemployment rates are high. A home-based, supervised, intermittent ambulatory TB programme (SIAT) was introduced at Mosvold hospital in 1989. This involved 143 trained Community Health Workers (CHW) or *onompilo* in isiZulu. The SIAT programme aimed to deal with the chronic bed shortage

at the hospital; reduce in-patient costs; interfere less with the patient's life style while still ensuring direct patient supervision; accessibility to medication; and consistency of care. Despite this extensive community health worker programme a significant percentage of patients still failed to take adequate medication to ensure cure of their disease.

Numerous studies have shown that even advanced TB can be cured with short course combinations of multiple drug regimes.[1,2] However many TB treatment programmes fail because: the correct dose of medication for the correct period of time is not taken; record keeping is poor; and patient follow up is inadequate.[3] Factors which reduce compliance in patients are: being unemployed; living in a rural area; certain age-groups (e.g. teenagers and children less than 5 years old); and those who are too weak or too sick to travel to treatment points.[1,4] Many of these factors pertain to the Mosvold District.

Patient compliance is one of the most important factors in determining outcome[5,6,7] and ideally every patient should have their TB treatment fully supervised. A participatory relationship between carer and patient is crucial for successful management of TB.[8] Knowing more about the experience of the patient will enhance participation. Liefooghie et al did a qualitative study in Kenya using focus group interviews to understand the community's perception of TB. They found that many vernacular names for TB exist, and that traditional treatment of TB was believed to be a valid alternative to modern treatment and was as effective yet much shorter. Social stigma attached to later stages of TB interfered with early diagnosis and effective treatment.[9] Thomson et al reported on the difficulties that patients have in obtaining drugs from centralised points and the negative impact of poor socio-economic conditions.[10]

AR works in the Mosvold Health District. As so many negative issues about TB abound, it was decided to rather focus on successes and if possible, to improve management of patients using that information. A qualitative study was undertaken to understand why certain TB patients were able to successfully complete six months of TB medication. These patients are referred to as 'successful patients' in this article.

Method

A descriptive qualitative study using Focus Group interviews was used. A focus group interview is a technique where a group of people discuss a topic in an open-ended way with a facilitator. The facilitator initially asks a question and facilitates the discussion around issues brought up by the participants. We chose focus group interviews as our method of data collection because rural people are more familiar with discussing matters in groups as opposed to filling in questionnaires, or taking part as individuals in interviews. This method has been successfully used in similar research before[9].

A purposeful sample[12] was chosen from all patients admitted to the TB ward between 01/01/1993 and 31/07/1993 at Mosvold Hospital, and who had subsequently successfully completed their TB treatment. Other people involved in the patients' care were also included in the sample.[11,12] Our assumptions were that: (a) successful patients could teach us from their experiences and help improve the TB programme, and (b) people involved with successful patients were more likely to participate openly. The research team consisted of AR and JH (researchers); our research assistants were three nurses involved with CHW's and community services.

The initial exploratory question used in all interviews was: "Why do you think that some patients are able to take their TB medication successfully for six months?" A research assistant facilitated focus group discussions which AR recorded on video. A review discussion took place with members of the research team at the end of each Focus Group. Each interview was transcribed verbatim in Zulu and later translated into English.

Data Analysis

The research team worked with the Zulu transcripts so that language-based and culturally specific ideas would not be lost. They analysed each interview separately. They identified common themes, established relationships between themes and constructed a schema to visually depict the information. Themes and schemas from all interviews as well as field notes were integrated into the final analysis.

Members of the research team authenticated the accuracy of the transcripts and the translations. The analysis of each interview was presented to two members from each of the Focus Group interviews for discussion and validation. This was done in the same venue used for the original Focus Group discussion.

Results

Five focus groups were conducted (Table I). The results are presented as themes which are described in Table II and related in the form of a schema in Figure 1. Verbatim quotes are indicated by italics.

Belief

The central theme to emerge was that belief about disease and its causes plays a crucial role when people enter the "western" health system; and as to whether or not they continue to take their medication. In all but one of the interviews a traditional syndrome called idliso was highlighted. (Idliso is a complex condition related, amongst other things, to the intake of food.) Patients believed that idliso needed to be dealt with by traditional healers before they could accept the possibility of having TB. Once convinced that idliso had been dealt with, or that they did not have idliso, patients were happy to take their TB medication. (They usually then 'converted' to a new belief that their illness was in fact TB.)

The role of the Traditional Healer:

Traditional healers play an extremely important role in issues of health and healing in our population. When a patient coughs up blood, the belief is often that he or she was 'bewitched' and needs to consult a traditional healer. Failure of the traditional healer to cure the problem helped in promoting good compliance with TB medication.

The role of the family

The family and its beliefs play a crucial role in determining where a sick individual goes to seek help. The family actively encourages people to seek help when they are sick and this usually means encouraging them to seek help from the traditional healer (if something like TB is suspected) because:

***Table I:* Focus Groups Conducted:**

Description of Participants	Number of Participants	Venue of Focus Group	Language of Discussion
Successful women patients chosen by Community Health Workers.	7	Nurses Home Lounge	Zulu
Patients and family members	12	Patient's Home	Zulu
Patient and his family	7	Patient's Home	Zulu
Successful Community Health Workers	9	Nurses Home Lounge	Zulu
Staff members from the TB ward	6	Nurses Home Lounge	English

***Table II:* Patient's experiences of completing TB treatment: Major themes**

Patients make CHOICES

Beliefs about disease and causes crucial in:
- Visit hospital or traditional healer
- Continuing with medication

Family plays role in:
- Decisions about when and where to seek help
- Motivation to improve health
- Support in treatment
- Pressure and conflict

Community Health Worker plays role in:
- Education
- Encouragement
- Support
- Provide food
- Problem solving

Involvement of traditional healer

No food

Side effects of medication

Compliance is seen as "Obedience"

Alcohol is a major issue.

"...you are suffering from idliso".

Maintaining family responsibilities was given as one of the reasons for wanting to get better, and this also promoted compliance with TB medication.

A patient:

"I cried to the nurses for permission to go home...because there is nobody there...I have small children and I want to be alive for a long time with them"

Some families provide support to patients who have TB and encourage them to continue to take their medication. Family pressure can however also lead to conflict within the family.

A family member:

" He refuse he become stiff headed... they don't want to hear from you... they want to fight with you... to hit you with knobkerries".

The role of the Community Health Worker (*onompilo*)

The Community Health Worker plays a very important role in education and encouragement and follow up of patients, as well as in provision of food where necessary, and in creative problem-solving.

Community health worker:

"If you see the patient has not come for 2 days, you must go and find the problem. You must talk together, what is actually better – to be attacked by disease or to get better?"

and

"Sometimes the onompilo is too far... she decides to give the pills to the neighbour so that it is easy for the patient to go there..."

Another role identified by the community health worker was to involve the traditional healer

Table III: Factors promoting completion of TB treatment

Improvement on medication
Failure of traditional healer's treatment
Belief in TB as being the illness ('TB-illness')
Personal motivation
Family responsibilities
Seeing others improve on medication
Fear of death
Seriously ill seeing TB on X-rays
Support of community health worker

"...then onompilo should visit the inyanga to talk to him about his patient, asking him not to treat him by vomiting because he is taking pills."

Choices

Failure was seen as a choice that patients made. Patients choose to 'spoil their own lives'. They choose by being too lazy to go to the community health worker, and by running away from the hospital.

Family member states:

"He is old enough to look after his own life. I say it is he who is sick not me... but him... now he is going to die."

No food and the side effects of medication

The issues of food (or no food) came up in all but one of the interviews. Patients appreciate the information about the need to eat nutritious food before taking the pills:

"these tablets need food".

A community health worker stated:

"Sometimes she (the patient) says 'I didn't eat anything because at home there was insufficient food', then I (onompilo) will give her some tea and bread so that the pills will not make her vomit".

Side effects occurring at home and not in the hospital (usually because the patient is taking the medication without food, or after alcohol) confirm to the family that the patient had a traditional illness and not TB.

The community health worker may say:

"At home the pills make them vomit because there is nothing in his stomach."

The family may say:

"these pills make you ill. At the hospital you take these pills without any problem. The problem is here at home because our neighbour is bewitching you."

Completion of medication (compliance) was sometimes described in terms of 'obedience'. See Table III for other factors identified as helping a person complete their treatment.

Alcohol

The problem of alcohol abuse came up in all but one interview. Alcohol was recognised as dangerous and that:

"the germ goes quickly because of alcohol".

One women even suggested that:

"without alcohol it (TB) would not have come to me".

Now when her friends encourage her to drink with them she refuses because:

"I nearly died of this beer".

She has exchanged her beer for *amahewu* (a drink made from cooked porridge mixed with sugar and left to ferment). They also expressed the belief that those who:

"drink alcohol with tablets do something that is wrong".

Alcohol was seen as a major hindrance to successful compliance and people use alcohol as means of opting out from the challenge of living. As reported by a family member:

"My sister said 'I don't want to stop drinking beer. If I leave the beer...I will feel more pains'...she drinks the beer... feels drunk...goes to sleep... that way she feels better...when the beer is finished... she says I am feeling sick because I didn't drink beer."

Construction of the schema.

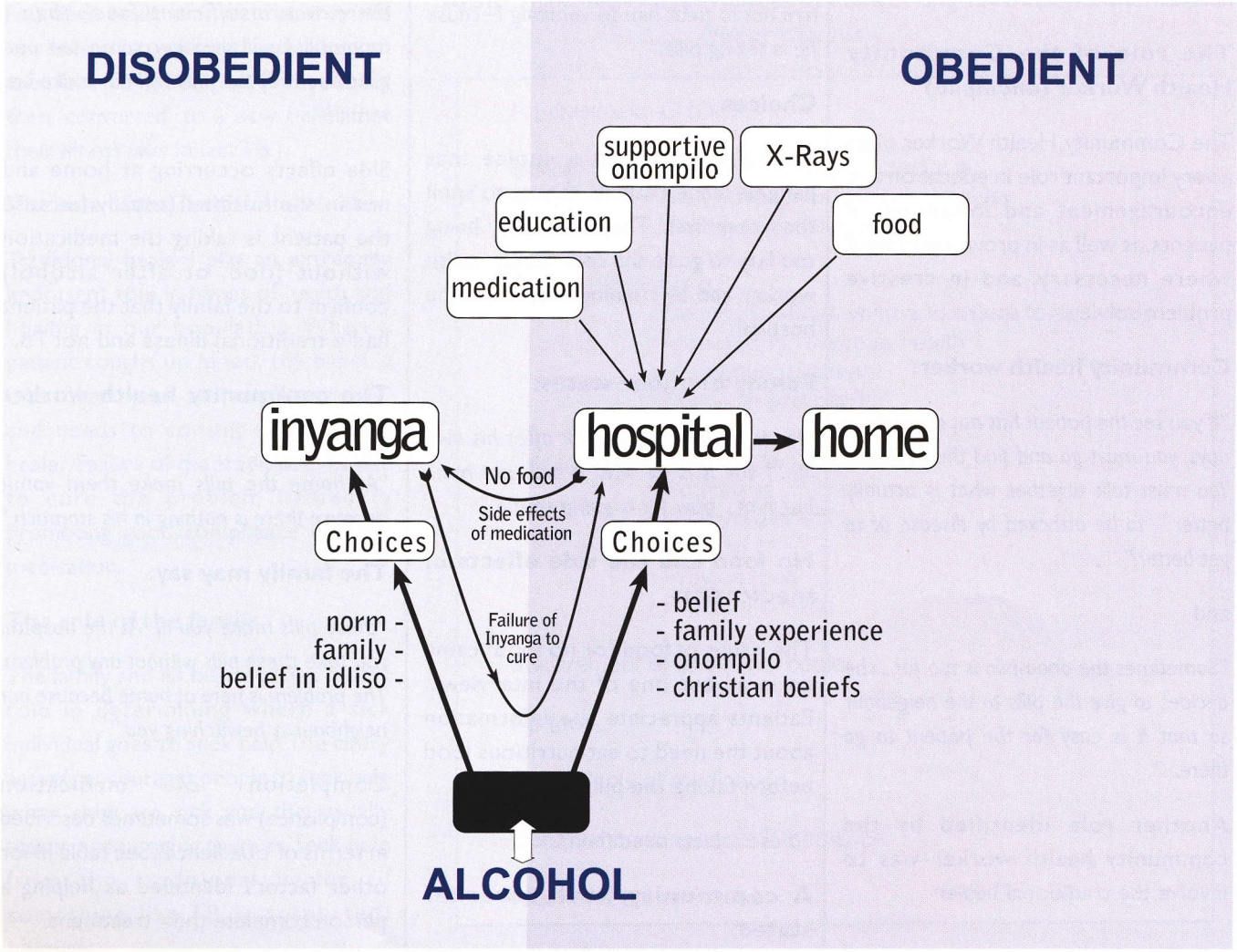
See Figure 1

Explanation of schema

'TB-Illness' is the entry point. People's beliefs determine the choices they make concerning their illness. Pain and suffering; fear of death; family pressures; and social responsibilities; all contribute to the need to make a choice. Most people with 'TB-Illness' initially believe that they have *idliso*, which needs to be cured by the *inyanga*.

Failure of treatment with the *inyanga* leads to people changing their belief about their illness, and trying the hospital methods. They may also be encouraged to go to hospital by seeing others who have improved on TB medication; by family members; and by the *onompilo*. Encouragement from the hospital, family and *onompilo;* — and seeing their own X-rays — helps patients take and complete their medication. Some patients however, choose to opt out by abusing alcohol. Others stop taking their medication because of side effects, and as a result some of them return to the *izinyanga*.

Figure 1: Patients' experience of completing TB treatment



Methods

Qualitative methods using focus group interviews enabled us to elicit information of which we were previously unaware in terms of the world view, culture and beliefs of our patients with TB — as well as practical aspects of treatment.

The use of vernacular in the interviews enabled rural, poorly schooled Zulu people to participate comfortably and freely. Transcribing and translating was time consuming and highlighted the need to be proficient in isiZulu.

Team-participation enabled the pooling of ideas in interpretation of the data and in the construction of an integrated schema. Using the hospital as a venue appears to inhibit the free flow of information and may have introduced bias. Conducting interviews in the community may have helped reduce this bias.

Implications

The following implications need to be considered in order to improve the TB programme in Mosvold District:

1. An acceptance by the medical and nursing staff that most patients have come from the *izinyanga*. (Failure of traditional healers' treatment, coupled with a desire to get better probably prompted the hospital visit.)
2. The change in belief about the illness to recognising and understanding that "this is TB" is an important step. This can be facilitated through using a non-judgmental, patient-centred approach, where information is shared in an open way and where patients and families can share their beliefs, fears and ideas.
3. A negotiated plan, in partnership with the patient, the family and the community health worker, (with an emphasis on supporting the patient), has the best chance of success.
4. Creative ways of working with traditional healers need to be explored. These could involve, *inter alia*, information sharing and/or referral between traditional healers and the hospital.
5. Constant reinforcement of those factors that promote success. Viz., i) information about: the long duration of treatment; possible side effects; and the need to take medication with food; ii) allowing patients to see their X-rays. iii) discussion of beliefs about 'TB-Illness'; iv) Involving other patients who are doing well.
6. Emphasising to community health workers the important role that they play in the success of the TB programme. Encouragement and support for these workers is essential.
7. The community health worker should determine every patient's ability to obtain food. Appropriate food supplementation should be provided to those patients unable to purchase adequate amounts of food.

Conclusion

This article highlights some of the factors that promote compliance in successfully completing TB treatment. To help people complete their medication caregivers need to develop a programme which is holistic, non-judgmental, person-centred and which includes the family. Consideration for the environment from which the patient has come should also be taken into account in any treatment decisions. The central role that beliefs about the causation of ill health play in determining where people seek healing is schematically demonstrated. Some of the reasons why people change from traditional healing practices to western healing practices (and vice versa) for the treatment of TB are explained.

The article does not attempt to generalise the findings to all TB programmes in SA. It describes the experiences of people involved with TB in Ingwavuma. It is hoped that those who can identify with the people and circumstances described, may be able to apply any insights gained to their own situations.

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