A qualitative study of the reasons why PTB patients at clinics in the Wellington area stop their treatment

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Abstract

Background

Tuberculosis (TB) remains the leading infectious cause of adult mortality, despite 60 years of effective chemotherapy. One reason for this is the problem caused by the interruption and failure of treatment, which usually are related to non-adherence. The reasons for non-adherence to TB treatment are multifaceted, ranging from the personalities of the patients to the social and economic environment. In South Africa, the most common problems have been shown to be the erratic way in which the treatment is taken, and not patients absconding from the treatment program. There is a strong suspicion that the disability grants issued to TB patients are acting as a disincentive to finish anti-tuberculosis medication. TB is a stigmatised disease and the lack of support from health workers, family and friends, as well as the length of the treatment period, all contribute to the temptation to discontinue TB therapy. This research was undertaken in Van Wyksvlei, a sub-economic area of Wellington. Wellington is part of the Drakenstein Municipality in the Western Cape, South Africa and is mainly an agricultural area. The aim of the study was to explore and describe the reasons why patients in the Wellington area do not complete their TB treatment, and then to make recommendations to improve adherence.

Methods

The method used in this study was a descriptive qualitative one. Free attitude interviews were conducted with six non-adherent patients from Van Wyksvlei, a sub-economic area. The exploratory question was: "Which circumstances resulted in your interruption of your treatment?" The patients' responses were recorded and transcribed, and analysed to identify common themes.

Results

The major themes that were identified were priorities, motivation and support. Priorities imply definite choices the TB patient has to make from the day the diagnosis is made. The patients are poorly equipped with decision-making and coping skills. A lack of motivation resulted from an improvement in the symptoms while on medication, group pressure, poor self-esteem, distance from clinic and lack of continuity of care. The support theme centred on lack of support from both the family and the community.

Conclusion

Patients should not carry primary responsibility for their adherence, but be part of a team. If TB treatment is to be optimised, patient cooperation and information need to be addressed, as these are essential for success. Existing services need to be made more accessible and acceptable. Additional effort needs to be made to educate the community.

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Background

Tuberculosis (TB) remains the leading infectious cause of adult mortality, despite sixty years of effective chemotherapy. Among the reasons for this are the problems of treatment interruption and treatment failure, usually related to non-adherence. Two specific patients raised concerns at the outset of this study: a GP in Wellington with pulmonary tuberculosis (PTB) and a paediatric patient with frontal lobe TB, both of whom had contact with non-adherent PTB patients.

The reasons for non-adherence to TB treatment are multifaceted, ranging from the personalities of patients to their social and economic environment.[1] In Bangalore, India, default rates are high because of the length of the treatment period, travelling to and from clinics, old age and lower socioeconomic circumsntaces.[2] In Ghana, long distances from the health centres, poor finances and poor motivation of health workers were some of the common reasons for defaulting.[3] Other causes for defaulting are a lack of motivation, a sense of wellbeing after the initiation of treatment, side effects attributed to the drugs, cultural perceptions of the disease, long waits in crowded facilities, a lack of symptoms in cases treated prophylactically, competing demands on time, and difficulties in communication between patients and health workers. Drug abuse and mental illness were also mentioned in an American study done in Georgia.[1]

In South Africa, the most common problems were recorded to be the erratic way of taking the treatment, and not patients absconding from the treatment programme.[4] A strong suspicion exists that the disability grants issued to TB patients act as a disincentive to finish anti-tuberculosis medication.[4] TB is a stigmatised disease and the lack of support from health workers, family and friends, as well as the length of the treatment period, all contribute to the temptation to discontinue TB therapy.[5]

The context of this research was Van Wyksvlei, a sub-economic area of Wellington. Wellington is part of the Drakenstein Municipality and is mainly an agricultural area. Many of the farm labourers live in the sub-economic areas around town. According to the 2000 health report of the Wellington Municipality, 366 families live in "squatter shacks".[6] The principal author visits TB clinics in the area each week.

The aim of the study was to explore and describe the reasons why patients in the Wellington area do not complete their TB treatment in order to make recommendations to improve adherence.

Methods

A descriptive qualitative study was conducted using individual free attitude interviews for data collection.

Six patients from Van Wyksvlei were interviewed. These subjects were selected from a larger group of patients who met the following criteria: Afrikaans- or English-speaking patients who interrupted their anti-tuberculosis treatment; registered TB patients of the Drakenstein Municipality District for the period 1 January 2000 to 31 December 2000; over the age of 16 years. Patients who were admitted to the hospital or were too sick to be interviewed were excluded.

From this group, 12 key informants[7] were identified, i.e. patients whom both the nursing sisters and researchers felt would be rich in information and who were available for interviewing within the study period. Using convenience sampling,[7] six of these informants who were still living near the clinics and who were willing to be interviewed were chosen.

Data was collected by conducting free attitude interviews with the six sampled patients. The exploratory question posed was, "Which circumstances resulted in your interruption of your treatment?" This was followed by an informal conversational interview, the purpose being the maintenance of maximum flexibility and the pursuit of information in whatever direction appeared to be appropriate.[7]

The patients' responses were either video- or audio-taped and then transcribed. Data analysis took place immediately after the tapes had been transcribed to ensure that there were no gaps in understanding the meaning of the patient's verbalisation of his or her perceptions regarding the topic. The analysis was done through the development of specific themes. These themes emerged as slowly developing patterns throughout the interviews. Patterns regarding the topic were highlighted and coded so that later reference to the direct quotations would be easier. Verification then took place by constant comparison.[7] The emerging categories were then compared to each other, refined and reduced in numbers by grouping them together. The main themes of concern for the patients that emerged from the transcripts were summarised and illustrated with direct quotes from the interviews. These themes were then critically analysed and compared with other studies. Once all data that matched the first theme had been located, the process was repeated until saturation of the themes was obtained.

Results

Background of interviewees

The patients are from a sub-economic area where families live in wooden shacks.[6] The inhabitants of the shacks pay rent to the home owners. One jobless patient had to support his two children and his wife. Another had to leave his shack because he could no longer afford the rent. He had to move to a farm far away from the clinic. One patient who complained about victimisation by his sister lived with his mother, his wife and his child in the main house. In the backyard, his sister and her family of four, as well as his brother and his family of five, lived in two shacks. Only the mother had a stable income. All the other people lived from the income of casual jobs. The sister's husband was an alcoholic. During the informal conversation, it became obvious that they did not have food every day and only ate when there was food in the house. This patient occasionally had to take the TB treatment on an empty stomach.

Thematic analysis

The integrated themes that were identified are set out in Table I.

Table I: Integrated themes identified during the study

THEMES
Priorities:
Poor working conditions
Side effects of medication
Religious objections
Submitting to group pressure
Motivation:
Lack of motivation: patient feels better
Because of group pressure
Because of poor self esteem
Because of unavailable continuous care
Support:
Marital problems
Unreliable friends

Theme 1: Priorities

Making the "right" choice refers to decision making regarding taking treatment as compared to going to work, suffering side effects and dealing with conflicting religious beliefs. Most patients admitted to having trouble setting priorities. *"I worked out of town, as I have told doc, for a few days, now then I couldn't get the pills here." "Now I am ill again because I didn't take my medicine and things that week."*

Five of the patients said they had major trouble combining their working conditions and going to a clinic each day to collect pills. *"Then I had to take 'piece-jobs', I have to work two to three days per week for my child – to get a few cents … I get R60 per day, then we again have food for a week."* Another patient described having to weigh up adherence to his treatment to going to work in a different town with his employer. *"When I have to work in Hermanus, it is too far, and then I send my girlfriend or somebody else to fetch my pills, but sometimes they don't go."* He often ended up without treatment as a result.

In some cases, working conditions were too tough for an ill person. *"I said many times: give me a job downstairs …. but my legs can't take it – they are finished."* Other patients lost easy access to treatment when they lost their jobs. *"With my first treatment, then I worked at WI and got my treatment at the factory. December, Paarl Paper Mills closed … Then they paid us out."*

Some patients reported problems with side effects of the medication. To continue treatment despite the discomfort of feeling nauseous and dizzy takes some determination and many patients just could not adhere. *"See doctor, I can't really eat so early in the morning – just a small bowl of porridge. It was perhaps too little. That is what has caused my nausea." "I could not get anything in. Then it comes out again. Then I decided to stop the treatment."*

A Rastafarian respondent justified his non-adherence on the grounds of his religion. *"The other reason is that I belong to the Rasta's and we believe that a person should not take chemicals like pills."*

Patients also had trouble with group pressure. "*When I have finished eating, I walk down to the clinic, then I turn in at my friend, then I do not get here, then I turn around."*

Two participants had problems with substance abuse. *"I take the children to school early and then we drink beer … at the 'shebeen'."*

Theme 2: Motivation

Lack of motivation came about for a variety of reasons. As soon as some patients started feeling better, they lost motivation to adhere to their treatment schedule. *"Look, I was at the big days (Christmas), and then I thought, I feel better now – then I stopped my pills."*

Group pressure was also a cause. *"The time when we come back, we go to the birdcage where they sell beer. This is every morning's thing, there everything starts, that I don't come here."*

Poor self-esteem and depression go hand in hand with a lack of motivation. *"I am only the driver and only mix the cement, the other guy is actually the big shot."*

Lack of motivation could also occur as a result of continuous care being unavailable. One patient got his treatment from a woman at his work, but he had a problem accessing it. *"I got tired of going up and down the steps to see if she was there. She was good, she was right, but sometimes she was too busy and often she wasn't there and then I would also not get my pills."*

Theme 3: Support

A happy home was noted as a critical factor when a particular patient needed to take treatment for a prolonged period of time. A lack of support caused many instances of non-adherence and subsequent relapse of the disease: *"I can't take it any more. My wife is working again, but she drinks. Weekends we are always quarrelling."*

The absence of a supportive infrastructure was a major factor: *"I don't have a mother or a father. I was only 14 when I had to leave school to go and work. Then my father died. I worked only now and then."*

In many instances, chronic patients need to send somebody they can trust to collect the pills on their behalf. If that support is not in place, the treatment is often incomplete and the response poor. A patient working in a town two hours' drive from home explained: *"Then I send the girl or somebody else who is not working, but now they do like this, see doc, they don't come, the people that I send, see doc. To fetch my pills now, then they just say the people were not here. Yes, then I send somebody else. But they don't take the trouble, they just turn in the road and say they were not here."*

Discussion

The main reasons for non-adherence to TB treatment amongst poor patients in Wellington are socio-economically linked. These include the understandable inability of patients to prioritise treatment over work, which takes them away from the clinic, a lack of motivation to complete the treatment and a lack of support at different levels. In Ghana, financial barriers were reported as common factors by almost all defaulters.[3]

Patients should not carry the primary responsibility for adherence, but rather should be part of a long chain of responsible agents, extending from the decision makers to the patient and his or her employers. Health workers must try to find solutions with their patients and the communities. If tuberculosis is to be controlled effectively, patient cooperation and information are essential. Strong social support, as provided by the DOTS programme, improved adherence in patients in India from 28% to 56%.[8] If existing services are to be utilised more effectively, they must be made more acceptable. This may require modifications in services and changes in the attitude of personnel.

Intervention in the TB programme in the Wellington area can be planned in the light of the knowledge gained. Simply having services available does not mean people will use them. Additional efforts are urgently needed to educate the community on the importance of completing treatment. Patients need to be counselled and accompanied on the long road to recovery. They need to learn skills to discriminate between what is important (for example, keeping their work) and what is urgent (continuous, uninterrupted treatment.) They also need employee assistance so that this does not continue to be an either-or choice.

Many patients grow up without a proper role model – some reported losing their parents at an early age. Practical ways to equip patients with skills to prioritise, to keep them motivated and support them as far as possible could include the following:

- *TB clubs or social incentives:* Health workers could monitor the patients more closely if they have to sign an attendance book daily. The patients have to enter into a social contract with the provider of health. There should be an oral and a written commitment by the patient. The resulting kinship amongst the patients might motivate them to complete their treatment.
- *Lectures:* Education on the outcome of their disease and on social behaviour therapy could be given to the patients and DOTS contacts at these meetings. Medical information about the symptoms and signs and possible side effects could prepare patients for what to expect. This may help patients to express possible fears and ask questions. This may relieve pressure on the DOTS volunteers to provide in the daily needs of the patients.
- *Incentives:* Financial and other incentives, in the form of disability grants, which are already issued to patients, taxi fares and food,[9] should be linked to attendance of the TB programme, as evidenced in the attendance registers.
- *Social support:* TB open days, with regular public awareness campaigns in the Wellington area, and an "adopt a TB patient" campaign, where members of the public can get involved in the fight against TB, may assist in supporting patients financially and morally. Churches and other religious groups should also become involved by helping to eradicate victimisation, launching support groups and supplying food. Referral to other social services, such as FAMSA, if necessary, could allow the patients and their families to share their beliefs, fears and ideas.[10]
- *Intervention at level of employer:* Stigma must be addressed and victimisation should eliminated at the workplace. A standardised letter of information on TB, the outcomes and treatment should be issued to every patient and employer. The contact telephone numbers of the clinics and the attending doctor should be made available to employers and they should be encouraged to be part of the support group of every patient.
- *Specifically dealing with substance abuse:* Patients with a substance abuse problem should be identified, counselled and referred to a rehabilitation centre if necessary.
- *Depression:* The DOTS workers and medical staff should be sensitised to pick up emotional disturbances in their patients and refer them to an attending doctor for help.

Conclusion

The results of this Wellington-based study correspond well to other findings. Patients should not carry primary responsibility for their adherence, but should rather be part of a long chain of responsible people. If TB treatment is to be optimised, patient cooperation and information need to be addressed, as these are essential to success.

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