

Public Health Care Practitioner's Reflections on Tuberculosis Patient's Perspectives on Factors Influencing their Adherence to the Directly Observed Treatment Short-Course

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Abstract: The high prevalence of tuberculosis (TB) in South Africa is well established. TB, Human Immunodeficiency Virus (HIV), and Auto Immune Deficiency Syndrome (AIDS) co-exist, which contributes to the high incidence, prevalence, and recurrent infection rate of TB. Despite the implementation of the Directly Observed Treatment Short Course (DOTS) strategy, a World Health Organisation (WHO) initiative to stop the spread of the disease by 2015, TB continues to threaten the health of many, especially those in under-resourced, communities. TB patients' adherence to the treatment programme (DOTS) is vital to the reduction of the re-infection rate and the prevention of new cases. Health care practitioner's commitment and professional engagement within a patient-centred health care model is essential to the success of the DOTS initiative.

INTRODUCTION

In 2005, the WHO ranked South Africa (SA) as having the 7th highest TB rate in the world, with a low treatment success rate [1]. It is reported that South Africa's cure rate for TB is 57% despite the implementation of the DOTS strategy [2]. Consequently, the effectiveness of this strategy has been called into question. Further, the fact that 70% of the budget of the TB Control Programme in SA is going into multi-drug resistant (MDR) and extensively-drug resistant (XDR), TB has been highlighted [2].

TB and HIV co-infection are added to the disease burden. TB speeds up the progress of HIV and AIDS and vice versa. The percentage of smear positive cases for TB and HIV co-infection in SA was 24.9% in 2005. Given the epidemiological context of TB and TB/HIV/AIDS co-infection, adherence to anti-TB treatment methods, such as the DOTS strategy, is critical. Treatment success is of course also influenced by external factors of the infected individual, such as the overall quality of the health care provided.

The aim of this study was to explore, through the use of a focus group, TB health care practitioner's responses to TB patient's understanding of the factors that promote and the factors that serve as barriers to their adherence to the DOTS programme. It was expected that ascertaining health care practitioner's perspectives will assist in improving health care by modifying existing programmes and introducing new and innovative ones. Understanding health care practitioner's perspectives is critical in promoting the anti-TB drive worldwide, primarily because it is well established that the quality of the communication between the patients and the health service practitioner may pose a barrier to adherence (or may indeed improve it) [3]. Moreover, there is an evi-

dence that the nature and the quality of the health care setting, which the health care practitioner's are a part of directly and/or indirectly, also affects adherence [3, 4].

METHOD

In keeping with the United Nations Millennium Development Goals, which include reducing TB prevalence and death rates by half by 2015, it is vital to examine the factors that may help alleviate the burden of TB as a disease. This means that those patients who are already infected and present themselves for treatment must be willing to adhere to their treatment regimen to improve their health status, and in doing so will prevent others from being infected. In a condition such as TB, a relatively strict adherence to the anti-TB treatment programme is essential for the patient to be cured. Adherence implicitly implies that an individual has to be personally invested and motivated in cooperating with health care practitioners to follow and complete a treatment and/or prevention programme.

The primary aim of the larger study, within which this study is located, was to explore individual factors-and those factors external to the patient with TB-that contribute to his or her adherence to the DOT short course, with the purpose of empowering patients, improving health services, and ultimately, increasing cure rates.

Study Design

The aim of the larger study was achieved through the use of a qualitative research design framed within phenomenology, which is considered to be an ethnographic approach [5]. In the first phase of the study, an interview guide was prepared to ascertain, during in-depth individual interviews, the factors that promote and hinder adherence to anti-TB treatment in an under-privileged group of TB patients attending a public health centre in a township in the Western Cape Province of South Africa.

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In the second phase of the study, the results of which are highlighted in this paper, a focus group was conducted with the TB health care practitioners, to ascertain the level of receptivity and understanding of the various themes that emerged from the data analysis of the in-depth individual interviews of the TB patients, which explored factors that promoted or hindered their adherence to the DOTS programme. Using a focus group is one way of generating qualitative data. The purpose of a focus group was to facilitate interaction between the participants in order to obtain different view points for discussion [5]. The choice of using a focus group as a data collection technique, instead of individual interviews, in this study, rested on the fact that this particular health-care setting is based on a team approach to health management. It made practical sense, therefore, to allow the nurse practitioners to have a collective voice about the themes that emerged from the in-depth interviews of the 15 participants. Individual interviews with the health care practitioners would not have facilitated collective agreement regarding the possible recommendations that can be made to the Senior Management of the relevant Health Department with respect to the existing TB treatment programme, namely DOT.

Study Setting

The study was conducted in a historically under-privileged township in a sub-district in the Cape Town Metro Region of the Western Cape Province in South Africa. This township was established in 1983 during the apartheid era, and is a "large peri-urban" area situated 32km from central Cape Town [6]. Despite democratic governance in South Africa since 1994, the area is still marked by poverty, high rates of unemployment and poor infra-structure.

The study was confined to only one public health clinic, one of several clinics in the township. The relevant health management team requested to conduct the study in the particular sub-district because of the low cure rate for TB in this area at the time (2005/6), as compared to the other seven sub-districts making up the Metro Region. In the 2nd quarter of 2005, there was a 51% cure and success rate for new smear positive cases for TB in the township and a cure rate of 62% to 80% in the other seven sub-districts for the same period.

Participants

In phase one of the study (conducted from June to December 2005), medically confirmed adult male and female registered TB patients who tested smear positive and who were already in the treatment programme at the clinic, were eligible to participate. Purposive sampling techniques [7] were used to recruit respondents and saturation of data occurred with a sample size of 15. Only those patients who were exclusively on the DOTS programme were included in the larger study.

In phase two of the study, on which this report is based (conducted in December 2005), health care practitioners involved in the management of TB at the clinic were invited to participate in the focus group. All the participants were women health practitioners and comprised of the nurse

manager, the sister-in charge, a professional nurse, and a TB health worker assistant.

Procedure

A single focus group was conducted, in English, with the participants. The Principal Investigator (PI) acted in the capacity of the focus group facilitator and the research assistant as the co-facilitator. The focus group discussion was tape recorded and later transcribed for analysis. These tapes were also locked in a cabinet to ensure the focus group member's identities are protected and their responses are kept confidential. Only the PI has had access to the tapes since the transcriptions were done.

Ethical approval to conduct this study was obtained, separately, from University of Cape Town, University of the Western Cape and the relevant Health Departments ethics committees'.

DATA ANALYSIS

The facilitator (F) and the co-facilitator (CF) discussed the dominant themes that emerged from the focus group with the health care practitioners [8]. A consensus was arrived at regarding the final themes once the separate coding of the data was conducted by the F and the CF and reconciled.

FINDINGS AND DISCUSSION

The findings from the first phase of the study were presented as a departure point for an interactive discussion in the focus group with the health care providers, the participants of this study. The themes that emerged from the focus group are broadly clustered around the member's perceptions of adherence and non-adherence by the participants, in phase one, to the TB treatment programme.

The following themes emerged from the data collected during the focus group: (1) Perceptions of the pattern of TB patients' adherence to the anti-TB programme, (2) Recommendations to improve health service provision, and (3) Additional observations about TB patients and the quality of the health care provided by the relevant health department. The findings and the discussion are integrated in this paper.

THEME ONE: PERCEPTIONS OF THE PATTERN OF TB PATIENTS' ADHERENCE TO THE ANTI-TB PROGRAMME

The focus group members offered an extensive understanding of the reasons why TB patients often do not comply with the treatment programmes offered at the clinic.

The reasons for non-adherence can essentially be categorised into five components: (a) Socio-economic status of the patients, (b) Individual characteristics of the patients, (c) Nature of the DOTS strategy, (d) HIV and TB co-infection, and (e) Stigma.

Component One: Socio-Economic Status of the Patients

There was an overwhelming agreement by the focus group members that one of the main barriers to adherence to

the TB treatment programme is the limited social and economic resources that TB patients endure. It was evident that the health care team felt helpless in the face of the patient's poverty and because it was a factor beyond their control, they could not address this barrier to adherence. According to the focus group members many patients often report that they are not able to meet their basic needs for food and adequate shelter. The patients also reported that there was a lack of an adequate transport infra-structure and that they found it difficult to get to the clinic because their places of abode and the clinic were not in close proximity to each other. Of course, the patients also found travelling long distances in poor weather conditions hindered their attendance at the clinic. The following statements reflect these perceptions of the health care team regarding the social and economic status of the patients at the clinic:

It is true but also it is because some of them say they do not have something to eat and that is why they do not take their treatment. Sometimes for some of the clients it is far for them to get to the clinic everyday and it is worse in winter when it is raining. Sometimes we can understand as most of them are poor and if they get wet and must return to a house with no heater then we cannot do anything. (Stated with a sense of helplessness).

The extent of poverty and its relationship to disease onset is well established. The findings of a South African burden of disease study conducted by the Medical Research Council confirmed the relationship between poverty and disease. The study indicated that mortality due to diarrhoeal disease, TB, and nutritional deficiencies are significantly greater in the poorer provinces and rural regions [9].

Component Two: Individual Characteristics of the Patients

The individual characteristics that posed a barrier to adherence were the negative attitude patients regarding the recommended treatment programme to combat TB. Faced with unemployment and low household income, patients were dependant on others for survival. This dependency made them vulnerable and decreased their capacity for self-control and self-efficacy.

However, in addition, the health care team perceived many patients to be "ignorant" as illustrated by the statement made by one of the focus group members, which served as a basis for discussion as one of the reasons for non-compliance to TB treatment: "*And sometimes it is also ignorance and not wanting to take care of themselves, where you just get someone who decides that they won't take their treatment*". They perceived patients not wanting to "take care of themselves" despite being given information about the nature of TB and the consequences of not adhering to the treatment programme. This implies that the health care practitioner's perceived that there was a dissonance between what the patients know about their diseased condition and the type of behavioural measures they adopt to enhance their well-being.

The focus group members were also of the opinion that patients' were often resistant to taking their medication and

made a conscious decision not to take their treatment. The following statement illustrates this: *you just get someone who decides that they won't take their treatment.*

The negative attitudes of the patients as perceived by the health care practitioners in the focus group could possibly be linked to the causal attributions that individuals assign to their illness condition. These attributions will ultimately affect the way a patient copes. If a treatment regimen recommended by a health practitioner is consistent with an individual's understanding of what caused his or her illness, then the individual is more likely to adhere. An individual, who ascribes external factors that are out of his/her control as causing the illness, is less likely to be self-motivated to improve his/her health status as compared to an individual who rates highly on self-efficacy. Those high in self-efficacy believe that they are able to carry out tasks and engage in behaviours that matter and provide direction in their lives. Increased levels of self-efficacy has also been associated with better disease management, such as adhering to prescribed medicines, managing stress, and following a recommended nutrition programme [10]. The reality is, however, that in socially and economically under-resourced communities, there may well be factors that individuals have very little control over. This presents as an immense challenge for many individuals in these communities who rate high on self-efficacy and have the personal will to improve their quality of life but are overwhelmed by their currently adverse life conditions and are unable to effect changes in the short-to-medium term.

A gender dimension to adherence was also reported by the health care practitioner's, with a higher frequency of non-adherence amongst males. They related this to risk-taking health behaviour, reflective of the perceived general risk-taking behaviour usually displayed by males. Studies conducted in South Africa provide evidence for this perception [11].

Finally, it was reported that there is a sub-group of patients that experienced side-effects from the medication and may, therefore, voluntarily stop taking the treatment as a result. There was a general agreement to the explanation offered by one of the focus group members in this regard: "*Another factor that would also affect adherence is the reactions some of the people get from the medication and by that I mean being allergic. Because if you react to a specific medication then you do not want to use it again.*"

Non-adherence to drug therapy is well documented [12, 13]. Ill-health felt as a result of the side-effects of drug therapy can also be conceived of as being caused by a health care practitioner, by virtue of the pharmacological drugs he/she prescribes and is called *iatrogenic illness* [12]. Non-adherence because the patient is unable to tolerate the drug therapy may, therefore, be beneficial to the patient at times. In America, it is estimated that 100, 000 deaths occur as a result of medical errors, which range from poorly performed surgery to unsuitable drug therapy [13].

Component Three: Nature of the DOTS Strategy

The members of the focus group expressed many opinions regarding the DOTS strategy. They were in general agreement that the length of the programme served as a

barrier to adherence. Many patients comply with the treatment in the first two months and default as soon as they experience some relief from the physical symptoms of the disease. Consequently, many patients become re-infected.

A senior member of the health care team stated that there is an alarming increase in the rate of multiple drug resistance (MDR) because patients do not adhere to treatment consistently. When the focus group was given the feedback that that the re-infection rate among the participants was high, they confirmed that this pattern was also reflective of the general TB patient population that attended the clinic. One of the more experienced members of the focus group stated: *“Now regarding the re-infection part that you mentioned it is true what you were saying because we have a lot of MDRs because our clients take their treatment and then they stop. Our scale of MDRs is very high now and before it was not. (Pause) In so much that we had one doctor at the time and he could manage all our cases and I am talking about XXX alone not other places.”*

The health care team also felt that daily visits to the clinic proved too demanding for patients. They compared DOT to other treatment programmes, such as the anti-retroviral (ARV) roll-out where patients were given a weekly dosage of medication. A member of the focus group stated: *Also when they get their ARVs, they receive a packet for the whole week and as time goes on they get a months supply as compared to having to come everyday for their TB treatment.* Another comparative advantage of the ARV programme they expressed is that *“the ones who get ARVs have a support system where there needs to be someone who reminds the patient to take medication, showing that they care.”* Clearly, members of the focus group that have experienced other areas of health service delivery outside of TB care recognise the importance of building in socially supportive elements in improving adherence rates. Support from significant family members, friends, neighbours, and health care workers who are specifically assigned to the task of monitoring and reminding the patient to take his/her medication was perceived to be critical to the success of anti-TB treatment programmes.

Finally, the health care team felt that the TB treatment programme did not consider in a substantial way contextual factors, especially with respect to the role of traditional healers. Our data supports the fact that many individuals straddle mainstream and alternate healing systems. Despite this, the treatment for TB is not tailored to these cultural practices of the affected communities. Focus group members did not, however, discourage patients who wished to see a traditional healer whilst they were on the TB treatment programme. Instead, they emphasised the importance of continuing to take TB medication, especially at the beginning of treatment, even in the event that they decided to seek alternate methods of health care. This is illustrated in the following statement related to medication usage: *“Ja and what we usually do is to discourage them from taking both medications. We often tell them that for the first few days they must only use clinic medication as to see whether it works for them.”*

Previous findings with respect to the nature and the (in) effectiveness of the DOTS strategy support the findings of this study [4, 17]. In a social study on TB patient's adherence to direct observation, it was recommended that the

approach to direct observation should be flexible and treatment support as opposed to tablet watching should be encouraged [4].

Component Four: HIV and TB Co-Infection

Patients who are co-infected tended to take their HIV status more seriously than they did their TB status. There was general consensus among the focus group members to the following statement offered by one of them: *“What you also find is that they take HIV more seriously than TB.”* Patients who were both on ARVs and DOT also took the treatment for their HIV positive status more seriously.

Non-adherence to TB treatment often occurred after participants discovered that they were co-infected with the HI virus. The emotional reaction to the news of their HIV positive status was probably one of the shocks, psychological numbness and disbelief [15]. This feeling of being over-whelmed with this news hampered the participants from psychologically integrating and accepting their TB infected and HIV positive status. Instead they needed time to process the fact that they were also afflicted with HIV, an incurable disease.

Component Five: Stigma

There was general agreement that many TB patients experienced actual stigmatization or perceived stigmatization at home, in the community, and at the work place. Stigma was experienced as especially problematic in the work place and many patients have reported to health care providers of stigmatization by employers. There was consensus on the following statement made by a senior member: *“That's true as some of our patients have reported incidents even at work. But what happens TB care does go to the workplaces of our patients to conduct talks about TB and issues around stigma so that those who are infected are not victimised.”*

The actual experience of facing prejudice, discrimination, and disadvantage is termed “enacted stigma” by Kelly [15]. The fear of anticipated discrimination is referred to as “felt stigma” by Kelly [15]. In the larger study, “felt stigma” is likely to be complicated because of the 50% HIV co-infection rate of the sample, as HIV remains a highly stigmatized illness in many South African communities [14]. Participants who were co-infected with the HI virus perhaps experienced increased levels of anxiety and avoided disclosing their health status for fear of both enacted and felt stigmas. Disclosure of their TB infected status and HIV positive status could possibly lead to double stigma. When individuals try to preserve their identities they present themselves to others in a certain way, which may not be consistent with the “true self” [16].

The health care practitioners in this study concurred with the findings of the larger study with respect to the infected patient's perception of being stigmatized within their family, work, and community contexts.

THEME TWO: RECOMMENDATIONS TO IMPROVE HEALTH SERVICE TO TB PATIENTS

The main recommendation made by the providers was the establishment of a support group for the TB patients'

attending the clinic. They felt that as most of the education about the disease is provided on the day the patient is told that they have tested positive for TB, patients are often overwhelmed by this knowledge at the same time as being informed of their diagnosis. They are, therefore, unable to process and absorb all the information about the disease. An on-going educational support group may improve adherence rates to TB treatment. The following opinion offered by a senior member of the focus group received support from the other members and captures the essence of the critical need for an "on-going" support group for the TB patients: *"I think on their first day after given their diagnosis that in itself is overwhelming for them and it is asking a bit too much to expect them to be able to hold all that information on education. That's why I feel that there needs to be an ongoing support educational group."*

A treatment support approach to TB management as opposed to singular policing efforts through direct observation has previously been recommended [4, 18].

THEME THREE: ADDITIONAL OBSERVATIONS REGARDING TB PATIENTS AND THE HEALTH CARE PROVIDED BY THE RELEVANT HEALTH AUTHORITY

A few important observations made by various members of the focus group regarding TB patients adherence to DOT and the health care provided by the health authority concerned were discussed by the focus group participants.

One of the factors believed to contribute to poor TB cure rates is the fact that it is common for those individuals who are infected with the disease for the first time to adhere to their anti-TB drug treatment for two months initially and then stop the treatment once they were feeling well again. These are the patients who often get re-infected.

A critically important issue raised by the focus group participants related to the ineffectiveness of support staff. Paid community support staff was meant to monitor, especially those TB patients that do not attend the clinic for treatment as regularly as they should and motivate them to adhere to TB treatment. However, there was consensus that the support staff were ineffective and had a low work ethic as illustrated in the following statement: *"Just to add something regarding the DOT programme, the community supporters who are suppose to monitor the TB patients who cannot come to the clinic and take sputums are not doing their job. And they do get paid R30 (about 3 USD at the current rate) per patient."*

A factor felt to promote higher levels of adherence was the provision of food incentives to patients. The health care team reported that *"in winter when there are soup kitchens that are done by community members then you find that the level of adherence goes up because then the patients go for soup and bread"*. As part of the health service patients receive porridge and powdered milk if they request for a food parcel or if the health care worker thinks it is warranted.

CONCLUSION

The health care provider's perspectives indicate that adherence to TB treatment in a public health service must be understood within the context of poverty, the health belief system of the individual, cultural beliefs and practices, social support, stigma, the high rate of TB and HIV co-infection, the health practitioner-patient alliance, and the nature of the DOTS strategy. Non-adherence to TB treatment clearly poses a challenge to the already over-burdened public health system in South Africa.

This study clearly demonstrates the importance of obtaining health worker's perspectives on existing health care treatment and prevention programmes. Ultimately, patient's well-being is partially determined by the quality of care they receive. A good "therapeutic alliance" between the patient and the health care practitioner is a process in which the practitioner effectively communicates the patient's problem and formulates a management plan that is conducive to patient compliance [19].

It must be noted that the WHO has recently recommended a treatment support approach to the DOTS strategy.

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