

ORIGINAL RESEARCH

Experiences of self-disclosure among tuberculosis patients in rural Southern Malawi

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ABSTRACT

Introduction: Tuberculosis (Tb) is a significant public health problem in Southern Africa, largely as a consequence of the HIV/AIDS pandemic. Self-disclosure of diagnosis to others within the patients' social environment may be problematic because the diagnosis of Tb may attract stigma, largely derived from the association of this disease with HIV infection. In Malawi, there are limited reports of the diagnosis disclosure experiences of Tb patients.

Methods: A qualitative study using in-depth interviews was conducted in Thyolo, a rural southern Malawi district to: (1) explore the relationship of persons to whom Tb patients disclose their diagnoses; and (2) identify the motivations for such disclosures.

Results: Thirty-two adult Tb patients participated in the study. Their ages ranged from 22 to 49 years (median 31 years), and 19 were male. The majority of patients reported having disclosed their disease status to close family members, such as spouses, siblings and parents; only a few had disclosed their status to their children. The most common way of disclosure was through personal discussion between the patient and their significant others. Study participants perceived that disclosure brought returns in terms of encouragement and empowerment. Some patients felt stigmatized or feared stigmatization following disclosure of their disease status, and some patients on antiretroviral therapy for HIV felt stigmatized by fellow patients. Patient-to-patient interaction was perceived as a valuable resource in trying to cope with a Tb diagnosis.



Conclusion: The findings of this study suggest that Tb patients in southern Malawi were interested in disclosing their Tb diagnosis if they felt they would not be stigmatized or stood to gain as a result of self-disclosure. Disclosure of diagnosis was facilitated by trust, a feeling of safety, and a sense of obligation to others. The perceived stigmatization of patients by other patients is cause for concern. This study calls for the health education of patients, with the intention of facilitating positive behaviors towards other patients.

Key words: Malawi, disease status disclosure, stigma, tuberculosis.

Introduction

Like many countries in Eastern and Southern Africa, Malawi has experienced a resurgence in the diagnosis of tuberculosis (Tb) in the past two decades^{1,2}. This has largely been due to HIV infection, which is estimated to affect 12% of the adult population³⁻⁶. In Malawi's adult medical wards, HIV-related infections are among the leading causes of admission, comprising at least 60% of all admissions⁷. Tuberculosis is also a leading reason for HIV-infected persons to seek care.

The Malawi Ministry of Health and other stakeholders have conducted basic, clinical and operational research programs into a number of critical areas regarding HIV diagnosis, care and support^{8,9}. There are, however, limited data on the social aspects of Tb, including its consequences among Malawians. For instance, while almost all official documents on HIV recognize stigma and discrimination as critical elements to consider at diagnosis and management of HIV-infected persons, there are limited data on how stigma or discrimination are manifested. In many cases, stigmatization and discrimination have been confused as being the same.

Although patients with a variety of clinical diagnoses may suffer from stigmatization and discrimination, AIDS and Tb patients may be more at risk^{10,11}. Patients who fear stigmatization and discrimination may fail to disclose their diagnoses to their significant others. In some cases, the consequences of non-disclosure may be relatively benign; however, non-disclosure potentially facilitates disease

transmission and prevents informed decision-making regarding patient management and support.

According to Goffman¹², stigmatization occurs when persons are discredited in the eyes of others because they possess an attribute collectively devalued in a particular society. They are negatively affected due to a particular condition or characteristic that they may possess or are perceived to possess¹³. The ensuing devaluation is associated with the stereotyping of and prejudice against the group to which the victim of the stigma is perceived to belong¹⁴. The subjective experience of stigmatization and the individual's response, may vary from individual to individual, and even within the same individual at differing times, places and situations. The factors that modulate how stigma is experienced may include the concealability of the attribute, (clinical) course of the disease, aesthetic qualities and cause of the attribute¹⁵.

Discrimination is probably the major, but certainly not the only, consequence of stigmatization. Discrimination occurs when an individual is treated unfairly or unjustly because of stigma. Discrimination may be overt, subtle (as in structural discrimination) or insidious¹⁶. Discrimination may result in strained social interactions, a restricted network or support system and reduced self-esteem, and may lead to depressive symptoms¹⁷.

Stigmatization of and discrimination against persons infected with HIV have been identified as important barriers to HIV prevention and control^{18,19}. Stigmatized individuals may not disclose their infection to sexual or other partners, or may not access prevention services. A fear of stigma and



discrimination may also prevent an HIV-infected person from seeking care and support, both from the formal and informal sectors. In a study of HIV-infected adult men and women in Harare, Zimbabwe, 38.3% and 56% felt stigmatized by community and family, respectively²⁰. A study of South African Muslim university students reported that high religiosity was significantly correlated with a positive attitude towards HIV-infected persons²¹. Neville Miller and Rubin²² have reported that HIV-infected persons in Kenya used church ministers as targets for HIV status disclosure. This may be due to the expected acceptance of HIV-infected persons by church ministers. Otolok-Tanga et al²³ reported in a qualitative study that religious leaders in Uganda both promoted and diminished stigma and discrimination towards HIV-infected persons.

The present study was conducted in the Thyolo district, southern Malawi and aimed to understand to whom Tb patients disclose their diagnoses, and also to explore the motivation for such disclosure. Such information may enhance our understanding of the social experiences of Tb patients following their diagnosis, and may also inform treatment programs.

Methods

Study design and setting

This cross-sectional study utilized in-depth interviews to collect data. The study was conducted at the Tb ward at Thyolo District Hospital in 2007. The basic catchment area of the district hospital is the Thyolo district, but some patients come from surrounding districts in southern Malawi.

Participants

The study population included all Tb patients who were in the hospital's Tb ward during the data collection period (July–August 2007) and who had stayed in the ward for at least 2 weeks. These patients were in the initial phase of Tb treatment. A total of 44 patients were invited and 32 were

interviewed. Nine patients were not eligible to participate because they had been in the ward for less than 2 weeks. Three patients were too ill to speak to the interviewer. No patient refused to participate for personal reasons. The subjects' ages ranged from 22 to 49 years (median 31 years) and 19 were male. Of the 32 patients who were interviewed, 27 had been diagnosed with sputum-positive Tb, two had Tb meningitis and one patient each had Tb adenitis, Tb pericarditis and milliary Tb.

Data collection

Ethical review was conducted by the College of Medicine Ethics and Research Committee (COMREC) and informed consent was obtained from the study participants before the commencement of the interview. An information brochure was read to the participants in either the Chichewa or English language. They were then asked to sign the document or confirm verbally that they consented to participate in the study. The participants were assured of confidentiality because only the researchers could access the data. Furthermore, the participants were assured that their hospital and post-discharge care would not be affected by whether or not they participated. Interviews took place in a private room attached to the hospital.

Data were collected by in-depth interviews using a set of guiding questions (Appendix I contains the questions pertaining to disclosure experiences). Pre-testing the interview schedule was conducted to assess whether the phrasing of the questions enabled capture of the study objectives, that is to explore the diagnosis disclosure experiences of Tb patients. At this stage, the aim was to identify whether the questions were valid, as understood by the patients. Some changes were made following pre-testing. Limited demographic data were also collected on age, education and residence. The data were collected by the interviewer by physically writing the responses that participants provided. The information gathered spanned the time of the patients' first symptoms, to diagnosis and their period of stay in the ward.



Results

Three of the authors (KM, BP, DZ) analyzed the data by systematically coding the text using the semi-structured interview questions as a guide, consistent with a standard approach to thematic analysis²⁴. Common themes were captured and some phrases were further explored through peer discussion and debriefing. This resulted in two broad themes: (i) to whom and how patients disclose their disease status; and (ii) patients' perceptions of the consequences of this disclosure. The themes are reported below with selected illustrating quotes from the interviewees.

Theme 1: To whom and how patients disclose their disease status

All study participants reported that they had disclosed their Tb diagnosis to at least one significant other. They had done this in one of several ways. Patients reported instances of personally informing others that they had Tb; this was the usual method of disclosure. Other study participants informed people through second persons. A 22 year-old man said:

...but the other relatives and friends knew through my parents whom I personally informed.

Some significant others knew the disease status of the patient because they were with the patient at the health facility when the patient was given their diagnosis. In such cases, it was not necessarily that the patient wanted to disclose their status. A 24 year-old man said:

My wife and I knew together at the time of diagnosis because we were together but I personally told my parents.

For some people, relatives had suspected a Tb diagnosis before it was confirmed at the health facility. This is not surprising in an environment where the public media

provides health education on pulmonary Tb and suggests that a chronic cough is a key symptom. A young man said:

Before the diagnosis, my wife and my parents told me that the way I was coughing it was likely to be Tb. So when the diagnosis was made I just confirmed to them that the results are consistent with what they were saying.

A minority of patients reported that when relatives came to visit them in hospital, their diagnosis was disclosed by the fact that they were admitted to the Tb ward.

Most of the study participants had personally disclosed their disease status to more than one person. A majority of the participants had disclosed to their spouse and/or siblings. The explanation for disclosure to these groups were that they were the ones who loved them, understood them, gave them support and took care of them.

All the people who are close to me I did tell them, my brother, parents, best friend and neighbours. I told these people because they are the ones who can support me and take care of me well. (34 year-old)

Some study participants also reported disclosing their diagnosis to their parents. A minority of participants, however, had disclosed to their children, relatives and friends as well as neighbours due to the proximity of these people to where they lived. Some participants felt their children should not be told because they were young and should not be burdened by knowledge of their parent's illness. Other study participants, however, thought that it was not fair to withhold information from their children. A 38 year-old man said:

My children are all young that's why I didn't tell them. They cannot understand.

However a 30 year-old man said:



I told all my relatives; my children, my mother, my brothers and my sisters. I told them because they have the right to know what is happening to me.

Theme 2: Perceived consequences of diagnosis disclosure

Following disclosure of their disease status, the majority of patients reported having experienced benefits. The gains from disclosure ranged from moral support, especially encouragement, to assistance received for basic necessities. A 24-year-old woman reported:

...they wanted to help me so much that I should get well. They provide my needs such as money and corn flour. They come to see me and I know they remember me.

Only two patients felt that they had been stigmatized or discriminated against following the disclosure of their disease status to relations. Some participants reported having disclosed to trusted significant others who were perceived as less likely to have negative feelings towards them following disclosure. A 28 year-old man said:

I do not feel any stigmatization maybe because I told a few people and only a few know.

Some patients reported that they were exposed to verbal stigma from other patients because of their known co-infection with HIV.

A 47 year-old man said:

The problem I have faced from fellow patients is the way they speak. Some Tb patients laugh at other patients who are on (Tb) treatment and ARVs [antiretrovirals] and this plays a role on their psychological status. The patients end up isolating themselves and some become worried, while others stop taking the drugs.

A 43 year-old man was straightforward about stigmatization from fellow patients within the hospital:

I would love if we could all live as patients without laughing at one another. We are all waiting for two outcomes in this hospital, either to be discharged or to die and I don't see any laughing matter.

Discussion

The present study aimed to identify disclosure histories and the consequences of disclosure among Tb patients in rural southern Malawi. All 32 Tb patients interviewed reported having disclosed their diagnosis to significant others. Although studies on patients' disclosure of diagnosis to significant others have been reported elsewhere, we are unaware of such reports from Malawi, a high HIV-prevalence setting where it has been presumed that patients would choose not to disclose their Tb diagnosis because of the link between HIV and Tb. Although patients feared potential stigmatization and discrimination, all had disclosed but had done so to people with whom they felt comfortable. In cases of disclosing to their children, though, some study participants perceived that disclosure could be more harmful than beneficial.

Of interests in the present study were reports that some study participants had been victimized by other Tb patients, especially when the victimized Tb patient was also receiving treatment for HIV. It was not possible to explore the motivation for such behaviors by fellow patients; however, it is reasonable to assume that the stigmatization suffered by dually infected patients (HIV and Tb) arose from the devaluation of HIV-infected persons. Although unjustified, Tb patients without HIV, or those who have not been tested for HIV, may perceive themselves as better off.

It was also found that in some cases the patient's significant others who suspected a Tb diagnosis had been crucial in motivating the patient to seek treatment. A man reported:



Before the diagnosis, my wife and my parents told me that the way I was coughing it was likely to be TB. So when the diagnosis was made I just confirmed to them that the results are consistent with what they were saying.

Another man supported this observation:

The way I was coughing most of my relatives suspected that I had TB.

Certainly, public awareness of the clinical features of Tb is a resource for increasing the number of Tb sufferers who present for health care. The Ministry of Health in Malawi has, among other resources, adapted the *Manual of the National Tuberculosis Control Programme of Malawi*²⁵ to promote HIV awareness among the general population.

Some patients did not disclose their status personally to friends and relatives but allowed them to be present at the time of diagnosis. This may have been due to trust or because the patient was too sick to object to their presence. However, most of the significant others present during diagnosis were close relatives. That patients limited disclosure to only a few trusted family members and friends may explain why the perception of stigma was not strong for most patients.

Brou et al²⁶ studied HIV-status disclosure practices among women attending antenatal healthcare services in Abidjan, Cote d'Ivoire. They found that women who were HIV infected were less likely to inform their male partners about their HIV status compared with women who were not infected. Living in households with a co-spouse or living away from their spouse resulted in less likelihood of disclosure. The authors did not report reasons for these disclosure differences among people living in different social or marital arrangements. However, it is plausible that confidentiality concerns may have limited willingness to disclose. It is also possible that in situations where the husband had other wives or lived away from the HIV

infected woman, she may have perceived a higher likelihood of adverse spousal reactions if told of HIV infection.

Social capital is defined as an individual resource that includes social networks, and support and trust in local environments and in relations between individuals²⁷. The literature on social capital suggests it is associated with diverse health outcomes^{28,29}. Within an individual's social capital, the individual benefits directly from their own social network. Consequently, the participants in our study were more comfortable disclosing their diagnosis to trusted peers and those related by social network. Their social networks were a source of moral and material support following disclosure. We conclude that individuals without trusted relations and friends may have limited motivation to disclose.

Methodological limitations

This study was based on a rural district in southern Malawi where pertinent factors such as level of education and culture may be different from other settings; thus, disclosure experiences in other areas may be different. Thyolo district is one of the first settings to provide free antiretroviral therapy in Malawi^{30,31}. The center is, therefore, experienced in dealing with Tb and HIV-related situations. The availability of HIV testing and treatment may have facilitated Tb diagnosis disclosure.

Conclusions

Although fear of stigmatization and discrimination is a concern to many Tb patients in rural Malawi, it was found that all the study participants had disclosed their diagnosis to at least one significant other. Disclosure of diagnosis was facilitated by trust, a feeling of safety, and a sense of obligation to others. Our results suggest that patients obtained social and financial benefits from the disclosure of their disease status to significant others.



Suggestions for future research

Based on the results from this study, it is recommended the following future research be undertaken. Similar studies should be conducted in other settings where the quality of Tb and HIV care and treatment programs are not so well established. In addition, whether the clinical outcomes of patients who disclose are different from those who do not should be explored. Such a comparison study may not be possible in an environment where almost everyone discloses their disease status, as was the case in our study.

A review of the assumption that Tb patients in Malawi are unlikely to disclose their Tb status is also suggested. It appears that where patients are confident of confidentiality and compassion from others, they are more likely to disclose their status. The fact that fellow patients may stigmatize sufferers calls for health education targeting Tb patients in order to influence positive perceptions and behaviors among patients. Finally, it was not clear whether patients disclosed their disease status in order to gain benefit, or whether the social support they received was unexpected. Future studies may clarify this.

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Appendix I: Key questions asked during in-depth interviews to assess disclosure experiences

1. Once you were diagnosed with Tb, did you disclose your status? If yes, to whom and why?
 2. How did they respond?
 3. How did you feel about their response?
 4. What do you think of the treatment you have received from the hospital (TDH)?
 5. How do you look at the care that patients get from this ward (putting aside the medication)? Why?
 6. How do you relate to those who provide care in the ward? Why?
 7. How do you relate with fellow patients in this ward?
 8. Do you have a guardian(s)? How many? How do you interact with your guardian(s)? How many would you love to have? Who would you prefer to be your guardian if you were to choose? Why?
 9. How would you want to relate to the care providers?
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