

Publisher

African Journal of Social Work

Afri. j. soc. work

© National Association of Social Workers-Zimbabwe/Author(s)

ISSN Print 1563-3934

ISSN Online 2409-5605

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Indexed & Accredited with: African Journals Online (AJOL) | University of Zimbabwe Accredited Journals (UZAJ) | SCOPUS (Elsevier's abstract and citation database) | Directory of Open Access Journals (DOAJ).

INSTITUTIONAL AND PERSONAL FACTORS INFLUENCING ADHERENCE TO TUBERCULOSIS TREATMENT AMONG PATIENTS IN HARARE, ZIMBABWE

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ABSTRACT

This study explores the influence of personal and institutional factors towards adherence to tuberculosis treatment among patients receiving treatment at Wilkins hospital and its catchment area. A qualitative research design was employed and information was elicited from respondents using focus group discussions, in-depth interviews and key informant interviews. Results from the study show that adherence to tuberculosis treatment is a function of institutional support and personal economic security. Fear of stigmatisation and the possibility of losing employment among employed patients negatively affects their adherence to treatment. In addition, availability of drugs, affordability of treatment, professional work commitment, acceptance and empathy promotes treatment adherence. The study concluded that medical institutions must address the software side of treatment developing professionals within the curing industry to professionally and confidentially handle those presenting themselves for treatment with diseases that attract stigmatisation. It is recommended that medical institutions should be fully equipped and retooled to enable them to attend to those patients presenting themselves for treatment with infectious disease of social significance. This paper also recommends that discrimination of poor tuberculosis patients be abated through the provision of inclusive welfare support services to all needy patients with a view to promote adherence to treatment.

KEY TERMS: Adherence, institutional, personal, treatment, tuberculosis, Zimbabwe

KEY DATES

Received: 06 March 2018

Revised: 08 August 2018

Accepted: 10 September 2018

Published: 02 December 2018

Funding: None

Conflict of Interest: None

Permission: Not applicable

Ethics approval: Not applicable

ARTICLE TYPE: Original

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INTRODUCTION AND BACKGROUND

Whatever else it might be, tuberculosis (TB) is a deadly disease. An estimated 9.6 million TB cases are reported annually, of which 1.2 million (12%) being co-infected with HIV and 1.5 million deaths occurring annually in the world (WHO, 2015). In 2014, South East Asia and Africa accounted for the highest number of TB cases with 29% and 26%, respectively, and both continents also shared 75% of global TB deaths (WHO, 2015; Woimo, et al, 2017). Countries such as India, China and South Africa have the highest burden of TB accounting for 1.98 million, 1.4 million and 0.5 million, respectively (Kanabus, 2016). According to the Citizens Watch (2015) the prevalence rate of the disease in Zimbabwe stands at 325 per 100,000 cases from the 547 recorded in 2011. In 2012, 15 of the 22 high burden countries reached or exceeded the MDG target set for a treatment success rate of 85% among all new cases. Zimbabwe is among the 6 countries that did not meet the Millennium Development Goal set target for a TB treatment success rate of 85% among new cases but reported lower treatment success rates of 81% (Citizens Watch, 2015). Non-adherence to TB treatment was cited as the major cause for Zimbabwe's failure to meet the set treatment global goals. Tuberculosis treatment is offered at selected hospitals and clinics in Zimbabwe. These hospitals are equipped with both human and material resources to fulfil the goal of providing treatment services to patients in need yet TB patients continue to die of a curable disease (WHO, 2015).

Despite the implementation of the Global Plan to Stop TB strategy, TB remains the second killer disease after HIV and AIDS in developing countries (WHO, 2015). One of the major challenges is the poor adherence to TB treatment that is blamed for the high death rate among TB patients. Adherence refers to the ability by patients to seek medical attention and take treatment, attend review appointments, exercise self-management and modify behaviour against taking alcohol, smoking cigarettes and having multiple sexual partners (WHO, 2015). Whilst there is a shared understanding of adherence to TB treatment, there is very little understanding about how this is associated with institutional factors. In this paper we examine personal and institutional drivers of adherence, using the case of Wilkins Infectious Diseases Hospital in Greater Harare. This study was conducted after 2008 when the Zimbabwe economy was in a fragile state. It is the period when jobs were hard to secure and business was non-viable leaving ordinary people vulnerable to poverty.

Our argument is twofold; first, we argue that adherence to TB treatment is only possible where there is a permitting environment. In other words, this is where institutions provide adequate support both materially and psycho-socially to patients during their treatment. Where patients perceive the hospital to be poorly equipped and not capable of delivering medical support to them, they are likely to be open about their situation and also not to adhere to treatment. Similarly, where the hospitals lack professional and ethical conducts necessary to motivate patients toward adherence, patients are unlikely to participate in their treatment. Secondly, we argue that where patients feel that a disclosure might harm them economically they are likely to conceal their situation as well as seeking medical attention. In particular, where disclosure might cause employers to summarily dismiss the employee on account of poor health, and where disclosure might result in stigmatisation and discrimination at the workplace or in the community, TB patients are more likely not to disclose their status or adhere to treatment required of them. In arriving at this conclusion we use the case of Wilkins hospital which is described below.

METHODOLOGY

Study context

The study area is Wilkins Infectious Diseases Hospital, a local authority hospital that is located at the corner of Rekai Tangwena Street and Josiah Tongogara Avenue in Harare. The hospital specialises in the treatment of TB and other infectious conditions. The hospital was built in 1936 and was known as the New Isolation European Hospital (Dhedheya, 2015). As the architecture and standards show, the hospital was colonially established solely to cater for white settler health needs. Following the attainment of independence in Zimbabwe, the equity to health policy was introduced resulting in blacks seeking medical attention at Wilkins hospital. Even though the conditions have changed somewhat, Wilkins hospital is generally regarded a hospital of recovery and a bastion of excellence within its catchment. It boasts of equipment, including a modern laboratory, chest X-ray machine, and specialised health care practitioners. Today Wilkins hospital caters for walk-in patients from the northern region of Harare and those referred from government and non-statutory hospitals and clinics even as far as Domboshawa in Zimbabwe. On a normal day, the hospital deals with an average of 70 patients translating to around 840 patients per month, comprising of all frail patients who hope to be treated and cured of what many regard as a disease of death.

Data collection methods

The study utilised three key tools, namely, Focus Group Discussions (FGDs), Key Informant Interviews (KII) and In-Depth Interviews (IDIs). These are discussed below.

Focus group discussions (FGDs)

Five FGDs were conducted with patients of equal gender. Their ages ranged between 15-64 years. Because of ethical and practical concerns, patients require minimum time for the discussions to avoid stress. The time for interview rarely lasted beyond 40 minutes. For ease of management, each FGD had 6 patients as respondents. The selection of participants in FGDs was purposive sampling and based on voluntary and willingness to interactively participate in the study in ways that generated fresh perspectives on the meanings of institutions in the treatment process. One of the researchers facilitated the FGDs while at the same time recording responses. The key issues discussed during the FGDs related to how institutional forces either enhanced or restrained TB patients from seeking medical attention and taking medication from Wilkins hospital.

Key informant interviews (KII)

In order to provide for a broad range of perspectives and insights, the study employed a minimum of eight KII. In every case, interviews were conducted in the secluded office within the hospital premises. These KII were conducted with hospital health care practitioners who included the doctor responsible for the TB Clinic at the hospital, the Sister In-Charge of the TB clinic, and the hospital Social Worker. Caregivers of a patients on TB treatment, Social Work Interns and TB Nurse and Nurse-Aid and a patient who was residing in Domboshawa area were also interviewed as key informants. Key informants were selected on the basis of the broad knowledge they had about the hospital systems and also knowledge derived from the patients through their daily interaction with them. The experiences and perceptions of the key informants provided critical insights into the role of institutions in promoting adherence. Due to the level of data that they had, and the engaging and interactive nature of the study, the interviews roughly took an hour, the exact time depending on the informant being interviewed. The key questions addressed related to hospital strategies to retain patients, the existing policies designed to support patients during treatment, the level of training among the health practitioners and follow-up plans for patients. The key informants were given unlimited time and encouraged to purposefully express their knowledge and experiences regarding the influence of institutions on adherence to TB treatment.

In-depth interviews (IDIs)

With a view to capture the living experiences of TB patients, six in-depth interviews were conducted with three male and three female patients aged between 15 and 64 years. These interviews were restricted to those patients who were willing to voluntarily share their lived experiences as TB patients and also could make time for the same. The interviews could take roughly an hour, depending on the ability of the respondent to narrate their story. The interviews were conducted in an isolated office at the hospital where the respondent could freely express themselves with the engagement of the interviewer. The in-depth interviews focused on how the patient came to know about the hospital, where the patient stays, the distance they travel to visit the hospital, how the patient was received at the hospital, their perception on the staff who attended to them, time spent at the hospital, whether they got the services they needed, the costs they incurred and the support they received from the hospital. These interviews were intended to reflect the influence of the hospital structure on adherence to treatment among TB patients.

In short, the study utilised FGDs, KII, and IDIs. These were largely participatory, but are obviously not immune to the criticisms that have been raised by social scientists, namely that they often deal with what people say, rather than what they do. Qualitative research is heavily criticised for being unable to determine whether the respondents would be telling the truth and also if the truth told is reliable and stable in all situations and perspectives. Since this study embraces biomedical components, the qualitative approach utilised may be criticised for lacking scientific rigour which is supposed to provide the highest form of knowledge as expected of any medical research. Thus, qualitative research is criticised for being a mere collection of anecdote and personal impressions which heavily suffer from researcher bias and lack of generalisability. Qualitative methods are further condemned for generating large amounts of detailed information about a small number of settings. The above shortcomings were addressed through carefully thought out planning on sampling, data collection and analysis to ensure that the results were accurate.

Ethical issues

Mindful of the need to protect respondents from possible psychological harm, the researchers sought the consent of those participants of sound mind for inclusion into the study. After making respondents aware of the study purpose, respondents were then asked whether they were willing to take part or comfortable in proceeding with the study. It was only after they understood the purpose of the study that they provided informed consent through putting their signatures on the written consent form. As regards confidentiality of participants which the patients also insisted upon, the research undertook to use of pseudo names and codes instead of their names on questionnaires. Thus, anonymity was upheld throughout the interview processes and even beyond the interview. The only circumstance where names and identity of sick patients were divulged was when the patients volunteered to share their lived experiences for the benefit of future patients. Approval to conduct the study was obtained from the Director Harare City Health Services through the Health Institutional Research Board.

FINDINGS

Findings from this study will be presented hereunder starting with the institutional factors which enhance treatment seeking behaviour and taking medication among TB patients. Thereafter, institutional factors that restrain TB patients from seeking medical treatment and taking medication will be presented. This will be followed by presenting findings on the institutional factors which promote keeping review appointments among TB patients, and then institutional forces that restrain TB patients from keeping review appointments will also be presented. Names of study participants in this section are all fictitious to protect them from possible harm.

Institutional factors that enhance patients seeking treatment and taking medication

Seeking medication, as has been intimated above, is never an automatic process. There are a number of factors and processes that trigger health seeking behaviour among those sick with chronic and controversial diseases like TB. In the paragraph that follows, we present three institutional factors that are likely to trigger treatment from among the patients.

A matter of acceptance and empathy

TB patients in the economically active age group seek medical attention and take medication if the health care service providers show acceptance and empathy to them. Generally, hospitals frown upon TB patients. And even if the situation is changing somewhat, some institutions condemn and judge TB patients, accusing them of bringing the disease on themselves. Where patients perceive a slight and positive change and a likelihood of them being accepted with empathy, they are likely to respond, and to come out of their shell and seek treatment. Evidence for this comes from Mr Gororo who remarked that:

`.... You can only divulge everything about your illness where you feel accepted. If the hospital health care workers show that they feel for you, it would be the beginning of your healing process because you will be sharing your burden with concerned experts`.

Another piece of evidence comes from Mr Shoko who suffered from TB and would not seek treatment because of what he perceived as non-acceptance by the relevant institution. When he was asked about why he would rather die than approach the place of treatment, the patient remarked:

`....How can I go to a place where I am treated like a leper? ...The hospital despised me a great deal; perhaps other people were lucky. Not so with me. I was a victim. The staff did not even bother talking to me. I was there in the queue, badly coughing as they avoided me while picking patients who had arrived after me. I sat there on the bench hopeless and uncertain whether I was ever going to be attended`.

Why patients should only initiate treatment where there is empathy is difficult to say. Some patients say non-empathetic doctors or nurses make them feel worse about their condition. Mr Tobias gave evidence through his lived experiences after interfacing with the nurses and he made the following remarks:

`If you raise a complaint regarding the treatment process they quickly accuse you of knowing too much. My sick friend was pained to the heart and deteriorated as result of being accused if wanting to take over the nursing roles`. This was after he had said ``tipewo mapiritsi edu tikasire kuenda kumabasa nokuti tikadzingwa basa zvirwere zvinozoti wandira`` can you quickly serve us our medication before we report late for work because we may suffer from more diseases if we lose employment.

Others say they do not want to be a subject of discussion on how they came to be sick through poor handling of patients' confidential information at the hospital. One patient was once embarrassed to be told publicly that he had a sexually transmitted disease that required treatment before seeking TB treatment.

Whatever the reason, it is very clear that TB patients remain people with needs and sensibilities, and that it is only when these are respected that they can initiate treatment. In other words, being sick alone is not sufficient to induce treatment, a point that doctors and nurses are far from comprehending.

Affordability of treatment

The study revealed that the affordability of hospital administrative fees also encourage patients to seek for TB treatment. Patients may afford to seek treatment where treatment costs are subsidised and TB treatment is provided free of charge. However, most patients are expected to meet the attendant costs of treatment for them to enable them to seek medical attention and take medication. Money becomes the medium of exchange where patients are

able to purchase good health in exchange for TB disease afflicting them. This finding was supported by Mrs Lazarus a patient during the FGD observed that:

“It would be foolish for someone with a lot of money to die from a curable disease. People should learn to buy back their lives by spending on their own health instead of leaving that money to be inherited by people who never contributed towards your savings. People should travel places even seeking treatment outside our borders because our health has greater value than any currency. Thus the issue of expense should be set aside by those who can afford to pay towards their treatment”.

Whatever the reason, it is very clear that TB patients remain people with economic needs, and that it is only when these needs are respected that they can initiate treatment. Where it remains expensive and unaffordable patients are unlikely to seek treatment. They are likely ‘*kufira momo*’, meaning that they would rather die as a result of being unable to afford the cost of treatment. This is a phrase that constantly popped up during fieldwork, describing undeclared suffering by the poor victims.

Professionalism and work commitment

Our study results revealed that the TB patients are likely to seek treatment from health centres where staff members show commitment to their work and display high levels of professionalism when attending to patients.

When asked why they would rather spend hours at Wilkins, than go to other centres, informants were quick to say that they were attracted by the professionalism displayed by staff at the hospital. One patient said that the staff especially the doctors ‘*vanoona*’, a term summarising diagnostic excellence characteristic of famous healers. But there was other sets of evidence as well: one patient travelled all the way from Zvishavane because he had heard that ‘the staff *vaimutsavakafa*’ raised people from the dead. None had of course died and been raised at the hospital; the patients used this term to describe excellence of treatment echoing the power of religious figures from the Christian bible.

But how do these patients get to know about the excellence of treatment? From some testimonies, patients learn from caring relatives. Other testimonies suggest that patients learn through the network of the sick. Mr Robertson remarked that TB people act as a reference facility giving information regarding the capacity of the hospital to treat and cure TB patients. This is why you have people travel all over Zimbabwe despite the distance. It is the power of testimonies.

Drug availability

Patients also seek treatment from health care service centres where they perceive to have constant availability of ‘*mushonga*’ medication. What they mean is hard to say, but there is no doubt that that a full measure of drugs that are provided at the centre rather than prescribed for or purchased elsewhere is part of it. Indeed one informant said he only came to the hospital because he was told he would get all the drugs they needed for curing their illness.

“I was told that the hospital had medicine. At first i thought this was not true, so i went to test for myself. After the consultation i was given a njumba yemapiro, a wide assortment of medication. Since then i have been coming for treatment, because ‘panechokufambira; i get all the drugs on my prescription”.

Another informant said he knew of many people who had died in the village because they would not waste time travelling long distances only to be given painkillers/vachifambira mapain killers’. He added,

“One cannot consciously seek treatment from a hospital where you know that they always run short of drugs. We always seek treatment here because we know from our network that the drugs akazara kuti pamupamu. i.e the drugs are always readily available”.

The testimonies given by the patients are difficult to ignore hence they suggest that availability of drugs structures health seeking behaviour. Again we arrive at the simple point that medical practitioners often miss, that people will not simply come to hospital because they are in pain. The data suggests that they only do so where minimum conditions of key drug availability are met.

Personal factors influencing adherence to TB treatment

In the section above we identified the positive factors that might spur patients to get treatment. The above factors are institutional. In the sections that follow we present data on factors that relate to the person, and which factors

might constrain medical support. We proceed by discussing fear of stigmatisation and how it structures health seeking behaviour.

Fear of stigmatisation

The fear of stigmatisation leads many people not to reveal their status to the supervisor, let alone seek medical support. This is clear from testimonies gathered on the ground. One informant Mr Chako said that patients feared being a discussion point at lunch where people converged during lunch break. As he said, 'unoitwa lunch', meaning a discussion topic at lunch breaks. Another FGD participant agreed, adding that:

``The moment you disclose your TB positive status you become 'nhau dzepabasa' (breaking news) As a result of being a subject of discussion one becomes isolated and feels empty and worthless. In my case i started losing the value of life under such torturous conditions''. I regretted why i had divulged my condition to people who are unprofessional and unable to accept people as they are despite existing differences''.

One of the participants in the FGDs said that it was easier to become a subject of gossip if one declared his TB status to authorities at the work place. This stigmatisation has got real consequences beyond being a subject of discussion. In some instances the TB patient becomes marginalised or excluded from daily activities. Some of the activities may be basic, but others may be serious touching on livelihoods. In our interviews we came across people who were marginalised from key functions just because they were on TB treatment. More evidence came from the FGD where a participant expressed his lived experiences in the following manner:

``Given that all TB patients are screened for HIV and that in most cases those tested for HIV will be found positive exacerbates the negative attitudes towards TB patients. TB patients are often blamed for their condition and lambasted for being reckless and careless for their ill conditions. In one instance where my expertise was required, i overheard the boss insisting that ``siyai weTB akadaro mungatipinza busy nokukosoregwa'' leave out the one on TB treatment because he might infect us''. Often they removed me where critical decisions would be required saying ``angafungei chinemusoro iye achitadza kuti apore neTB'' i cannot think properly as a result of TB which am failing to find a cure''.

Other informants said that a revelation of status to superiors and co-workers instantly lead to derogatory language towards them. One informant remarked that he was referred to as 'chigurani' (sickly and useless person at work)

``My supervisors told me in my face that ``hatidyi TB yako pano'' (they do not benefit from my illness and that the company needed productive people not ``zvigurani'' the sick''.

Stigmatisation had other material consequences which no doubt contributed to secrecy among potential patients. The study came across patients who upon revelation of status were subsequently looked down upon and marginalised by fellow workers. In some instances, revelation was followed by demotion of sorts.

``Before I got sick i was a Ward councillor in my constituency. I was responsible for coordinating all economic development activities in my area. The moment people in my area came to know that i was on TB treatment, they secretly voted me out. They would not want to be led by a TB patient and rather to have their grain and food donated the Ward be administered by myself. I wondered what crime i had committed only to learn that they believed i was no longer of sound mind to handle development matters of the ward''.

Clearly, the fear of stigmatisation which has real consequences at the workplace and the community does structure the way people reveal their personal status to superiors at work. It also structures the way people seek medical attention.

Possibility of losing employment

The fear of retrenchment following disclosure of one's TB positive status influences patients to conceal their status to employers. Operating in fragile economy, such employers are often not interested in engaging sickly labour and TB patients are fully aware of this. All the TB patients reported thorough TB screening by their organisations before and during work engagement. All those testing positive to TB were no considered for work. For this reason TB patients avoid disclosure of their status at work or in the community where they reside.

Mr Murapata a key informant made the following remarks in support of the foregoing observation:

``...Giving your employer a letter from the hospital which reveals your TB condition can be an automatic ticket to kuchigumuro (self-precipitated dismissal from employment).

The experience of Mr Murapata is not unique as there are people that have been forested upon discloser. For example, one caterer was relieved of his duties even though he had benefitted from staff development.

“I got employed as a cleaner at my workplace and received on-job training as a cook. I was elevated to become the senior cook and this is the only work i know best and have been doing for the past 15 years. When i got diagnosed with TB and put on treatment, i was asked not to work in the kitchen until i was cured of TB. I was excused from doing heavy and energy sapping work by the doctor but my boss could not take any of it. He told me to go home and rest and come when i get cured. He then told me that “unodya zvawakohwa” meaning to say that i would only earn after providing work service”.

Yet another case showing the consequence of disclosure related to another patient Mr Tongai who noted that dismissal was always the option adopted by employers and that these did not tolerate welfare cases at work.

“I was told that patients are to be accommodated at the hospital and not at the workplace. I regretted telling him about my illness. I started to wonder what was going to happen to me and my family in the event that the employer decided to retrench me. I was the sole bread winner and “ndaingoti Mwari wangu ndibatsirei” prayed for God’s intervention towards protecting my job”.

Fortunately for this particular employee with long term service, the employer decided to retain his services, and some workers said this was miracle as the company often dismisses those who are not fit to work. Clearly the possibility of losing employment leads many patients to conceal their status to employers. This is even more so where such employing organisation are struggling to stay afloat and cannot afford sickly labour patients. In the section below the paper makes a discussion of findings.

DISCUSSION OF FINDINGS

In the study we observe that there is big problem with the hospital at least in respect of two issues. To being the hospital is poorly equipped, and there is only one chest x-ray machine. There is only 1 doctor, and erratic supply of drugs. In addition to this, there is the problem of limited capacities to deliver counselling and confidentiality. There are many other factors, but these are cited by the people as driving them away from hospitals and the instructions to complete particular treatment. Patients, especially the poor, cited these challenges saying that they were behind their limited adherence and those of their friends. These findings were confirmed by the Citizens Watch(2015) which found out that most TB hospitals in developing countries are poorly equipped both in terms of human and material resources. Situations where doctors and nurses have huge caseloads creates fatigue and burnout and poor treatment outcomes among patients.

This study shows that adherence is very much a function of two issues. Firstly, it is a function of institutional support, where the institution is able to provide back up support to the patients, this causes greater participation in the treatment regime by the patients. Secondly it is a function of personal economic security. Where the patient fears to lose employment and being stigmatised as a result of disclosure of their TB status, they are likely to conceal their situation. These findings are different from the expectations of WHO (2015) which takes for granted that TB patients receive the best of care and treatment without providing water-tight follow-up mechanisms in support of the patients. These two findings are very important, because they potentially explain what has remained enigmatic and mysterious to social workers and medical sociologists working on African material. What these experts observe is that there is a general lack of adherence in African hospitals, even where chronic diseases such as TB and HIV are concerned. They cannot understand why this is the case. Our data therefore, provided a clue to this conundrum, suggesting that institutions and personal considerations have much to do with adherence to treatment. In this general conclusion we have three suggestions of how institutions can restructure themselves to deal with the challenge of adherence.

Firstly, medical institutions must address the software side of treatment. This means developing professionals within the curing industry to professionally and confidentially handle those presenting themselves for treatment with diseases that attract stigmatisation.

Secondly, medical institutions involved in TB treatment must also retool and equip them materially. The situation where there is a single chest X -ray machine to cater for a large hospital does not and cannot encourage confidence on the part of the persons needing treatment. Equally the situation in which drugs are perennially in short supply can and where staff is inadequate cannot encourage potential patients to frequent the hospitals; rather it encourages the sick to explore parallel forms of treatment including in Africa the usage of traditions and religious therapy. It also contributes to the propagation of a mentality of hospitals as places of death (Leach and Waldman, 2009). Our finding is that non-adherence is endemic in hospitals. Because they fall short on the software and hardware side of things, hospitals hardly provide confidence among the patients to adhere to treatment.

Finally, there must be policy consideration of the livelihoods of those who are sick, and if possible, to organise some assistance where it is required. The practice now is for people to hide their status as they fear stigmatisation and discrimination at work. Providing assistance to the sick and assuring them of support in sickness will encourage people to be open about their situation and adhere to treatment.

The above are what we consider to be elements of proper reform. Of course governments in Africa are already reeling under severe cuts in public health finance which are so severe that we cannot expect any meaningful re-equipping, retooling and welfare support to the sick in the short term. But our argument is that anything less than a political economy approach will only serve to consolidate the image, among patients and society, of hospitals as places of danger and death. This in our view hardly encourages adherence.

CONCLUSION

This study has demonstrated that adherence to TB treatment is indeed a function of personal and institutional factors. Therefore, it is recommended that medical institutions should be fully equipped and retooled to enable them to attend to those patients presenting themselves for treatment with infectious disease of social significance. It is also recommended that welfare support whose basis people use to conceal their status be provided to those who cannot afford to meet TB related costs, as way of promoting adherence to treatment.

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