

# The Impact of Stigma on the Healthcare of Tuberculosis Patients in Kitwe

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**Abstract:** Tuberculosis (TB) is on the increase in Kitwe and TB related stigma makes it difficult to control the disease. The main objective of this study was to assess the impact of stigma on the healthcare of patients suffering from tuberculosis. The study was a descriptive cross-sectional study among TB patients registered at Buchi Small and Ipusukilo clinics. Simple random sampling method was used to select participants. A total of 115 questionnaires were distributed and all 115 were properly filled and returned. The study revealed that only 44.3% of the respondents had a high level of knowledge of TB. Stigmatization attitude was high among participants with 16.5% and 39.1% of the patients experiencing high and moderate stigma, respectively. 14.8% of the respondents reported having lost friend (s) and/or family and/or co-worker(s) because of their illness and 52.2% had had their illness used against them through verbal insults or being fired from their jobs. Furthermore, 44.3% of the patients felt like stopping taking their medication (even if the course of treatment had not been completed) once they felt better in order to free themselves from stigmatization and 40% felt disliked by the healthcare workers. Level of education correlated significantly with level of knowledge (P value = 0.002). Age showed strong relationships with level of stigma experienced by participants (P value = 0.004) and having feelings of stopping TB Treatment due to stigma (P value = 0.034). However, level of stigma experienced by patients did not show any significant relationship with level of education (P value = 0.764) or Religion (P value = 0.374). The study had noted the high level of stigma towards TB patients and its consequences on healthcare, especially on TB control. It is therefore recommended that health education programmes that aim at enriching the knowledge of TB and consequences of stigma be introduced and should cater for both the patients and the entire community.

**Keywords:** Tuberculosis, Stigma, Healthcare, Buchi Small Clinic, Ipusukilo Clinic, Kitwe

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## 1. Introduction

### 1.1. Background Information

Tuberculosis (TB) is a bacterial disease caused by infection with *Mycobacterium tuberculosis*. These microorganisms are also known as acid-fast bacilli (AFB) and enter the body by inhalation through the lungs [1]. Tuberculosis in human beings is mostly associated with infection by members of the *Mycobacterium tuberculosis* complex (MTC) which includes *Mycobacterium tuberculosis*, *Mycobacterium bovis*, *Mycobacterium africanum*, *Mycobacterium caprae*, *Mycobacterium microti*,

*Mycobacterium pinnipedii* and *Mycobacterium canettii* [2] of which *Mycobacterium tuberculosis* is the most common causative agent.

*Mycobacterium tuberculosis* mainly affects the lungs. The transmission of these tubercle bacilli occurs by airborne spread of infectious droplets and an individual with TB of the lungs coughing (sneezing, talking etc.) infectious droplets into the air is the most important source of infection [1]. TB may also progress to other parts of the body such as the meninges, kidneys, bones and lymph [1]. According to Ministry of Health [1] there are basically two types of tuberculosis, Pulmonary tuberculosis (PTB) which affects the lungs (lung parenchyma) and Extra-pulmonary tuberculosis

(EPTB) the disease that affects organs other than the lungs, such as pleura, lymph nodes, pericardium, spine, joints, abdomen or genito-urinary tract. The former is the more common type of tuberculosis.

The burden of Tuberculosis is high in Zambia. The disease still remains a major public health challenge ranked among the top 5 causes of morbidity and mortality especially among the young and economically productive adults aged 15 – 49 years in the country [1]. In 2010, TB notification rates were reported at 365 per 100,000 populations for all ages [1]. The disease varies among provinces, with the highest notifications being reported from Lusaka followed by Copperbelt and Southern Provinces [2]. In Kitwe, a district with a population of about 714, 407 people, TB continues to be among the major public health problems. In 2017 alone, 1865 cases of TB were notified for all ages in the district.

Tuberculosis is a widely stigmatized disease in Kitwe, and this is a serious barrier to effective tuberculosis control. Stigma causes individuals at risk to delay in seeking health care and hinders compliance with treatment. According to the World Health Organization (WHO), stigma is a major obstacle to TB control because stigmatization of patients renders them to deny the disease and discourage health-seeking services that lead to serious symptoms, noncompliance with treatment and increases spread of the disease [3]. Likewise, stigma leads to isolation from family and friends, loss of employment and exclusion from the community activities [3]. Several studies conducted in different African settings have revealed negative attitudes towards TB patients and/or described the subsequent consequences. Most of the time attitudes can be explained by local beliefs and knowledge of TB transmission, such sharing of eating utensils, hereditary factors, sexual intercourse, bewitchment, smoking, heavy labour, human immunodeficiency virus (HIV) – infection, and poverty. These perceptions lead to shame, fear of physical contact among community members, affected marriage prospects, social isolation, and discrimination [4]. Furthermore, the extensive systemic review of Chang et al. [4] highlighted that the consequences of stigma hinder, or even adversely influence, efforts to stimulate treatment compliance and reduce delays in diagnosis and treatment worldwide. Stigma also impedes the application of preventive measures such as coughing – hygiene and good ventilation at home which results in increased transmission risk, severe morbidity and mortality and increased development of multi – drug resistance tuberculosis (MDR – TB), thus undermining successful TB control.

Cremers et al. [4] explains stigma as discrediting attribute that often lead to an impairment of one's social status and position, rejection and/or exclusion. They further add that, stigma as a key factor in the production and reproduction of power structures, causes devaluation of certain social groups or individuals, and thus aid social inequality. Cremers et al. [4] differentiates stigma into three main sub – categories: experienced stigma (the experience of exclusion and/or discrimination), anticipated stigma (the perception,

expectation and/or fear of stigma), and internalized stigma (a loss of self-esteem, dignity and/or shame).

In 2012, Zambia ranked 29<sup>th</sup> among the world's top TB countries identified by WHO having 427/100 000 incident TB cases [4]. And despite the various papers written on the subject, stigma is still a low – priority issue in international TB control efforts [4]. It is vital to address TB related stigma among TB patients and other members of the community because of two good reasons. First, TB can be cured and proper treatment renders the TB stricken individuals non-infectious [3]. Second, TB is one of the major causes of death worldwide [4].

In Zambia, little research has been done on TB related stigma and an assessment of the scope, nature, and social consequences of specifically TB – related stigma has not been published [4]. No previous studies looked at stigma experienced by TB patients in Kitwe District. Therefore, the aim of this study was to assess the impact of stigma on the healthcare of patients suffering from TB in Kitwe.

## 1.2. Measurements and Operational Definitions

### 1.2.1. Measurements

Table 1. Scales of measurements for variables.

Number	Variable	Scale
1	Age	Nominal
2	Gender	Nominal
3	Marital status	Nominal
4	Occupation	Nominal
5	Level of education	Categorical
6	Religion	Nominal
7	Residential area	Nominal
8	Category of TB	Categorical
9	Level of TB knowledge	Categorical
10	Level of TB stigma	Categorical

Source: field data

### 1.2.2. Operational Definitions

- (1) Stigma: “refers to an attribute that is deeply discrediting” Goffman [5].
- (2) Stigmatizing attitude: the intension to avoid TB patients from social interaction, work place, and other related areas, support for coercive TB related policies, blaming a person with TB for acquiring the disease [6].
- (3) Attitude: a feeling that is directed towards a person, idea, object or situation [6].
- (4) Feeling: the extent to which participants (TB patients) felt angry at, afraid of and disgusted by other people because of their illness.
- (5) Avoidance behavioural intention: the intention to get TB patients away or avoid them from social interaction, work place and related area [6].
- (6) Healthcare: the maintenance or improvement of health via prevention, diagnosis and treatment of disease, illness, injury, and other physical and mental impairments in human beings [7].
- (7) TB Patient: An adult with a confirmed diagnosis of tuberculosis. In this study, TB patients were

interchangeably referred to as ‘patients’, ‘participants’, ‘respondents’ and ‘subjects’.

- (8) Re-treatment cases - Patients being treated for TB for a second or more times because of defaulting, relapse of TB or failure of the previous treatment.
- (9) Knowledge of TB - A measure of how much TB patients knew on the cause, infectiousness, mode of transmission, symptoms and treatment of TB.

### 1.3. Theoretical Framework

A theoretical framework is defined by Burns and Grove as a group of concepts that are broadly defined and arranged to provide a rationale or structure for interpretation of information [8]. Put another way, it gives a guide or acts like a map in research as it determines what things need to be measured and what statistical relationships are to be looked at. It gives an understanding to an empirical enquiry [8].

In this study, Goffman’s theory, Goodenough’s model, and Link & Phelan’s work [9] was applied to help better understand stigma. According to Goffman stigma is an attribute possessed by a person (mark) that is deeply discrediting causing her to be viewed as less than fully human because of it. Goffman strongly emphasises in stigma as a relationship between the mark and the group-related stereotype ascribed to that mark but he fails to explain the process of how stigma develops or how it is maintained [9].

It is challenging to relate tuberculosis to stigma because the definition proposed by Goffman assumes a visible “mark”, or physical difference that TB as a disease does not have. TB could be linked to visible attributes like the cough and disease consumption, as well as other attributes rooted in socioeconomic differences perceived as a proxy for the disease [9]. What makes stigma interesting and complicated, according to Link and Phelan, is that stigma is not only the attribute (label) but the consequent set of characteristics linked to that attribute (stereotype) and the following responses to the stereotype (status loss and discrimination) [9].

“Conceptualizing Stigma” Link & Phelan provides a good concept of stigma to work with in relationship to TB. The authors state that: “stigma exists when all its components converge”. Link & Phelan recognize five components of stigma: (a) the first one is the action of people distinguishing and labelling differences; (b) the second corresponds to the action of linking labels to negative stereotype, (c) the third refers to the action of placing distinct categories to make a line between “us” and “them,” (d) the fourth is related to the resulting status loss and discrimination, and (e) the fifth refers to the indispensable presence of power for stigma to exist. Based upon Link and Phelan’s work, stigma may be present even if a visible label is not present [9]. Hamsho – Diaz [9] uses this definition of stigma to discuss the label “Tuberculosis people” using all five components.

The first component of stigma is the action of people learning and labelling differences and it is what Goffman refers to as the attribute or mark. This action may also apply to differences learned and labelled, but not directly visible,

and they will only be meaningful in the context of time and culture modelled by Ward Goodenough [9]. For this component to be applicable to tuberculosis, first, one should expect that people will perceive tuberculosis as a difference in a specific period of time and in a cultural context, and that this difference would rise above all other attributes, including those that are visible or those that are not visible. As a result, tuberculosis has had different meanings attached to it. We can find tuberculosis hidden all over scientific and fiction literature with its various names now known as conditions probably caused by tuberculin bacilli [9]. In addition, there are enough novels, dramas, plays and stories in fiction literature that suggest that there was a time when TB was seen as a melancholic tragedy that affects all. During the 19<sup>th</sup> Century, protagonists of famous theatrical plays suffered from tuberculosis and famous people died because of it. Because many famous people suffered and died from tuberculosis it was also thought to be a symbol of intelligence [9]. After the introduction of better sanitation systems and public health infrastructure, tuberculosis incidence started to decline. The differences between who was affected and who was not became clear. Tuberculosis started to take different meanings, and probably because of the decrease in incidence of the disease, the romanticism surrounding it disappeared. The “germ theory” of disease produced further changes in attitude toward tuberculosis, both in popular view and in the literature. Now, after having been both a symbol of the hero and of beauty, TB as an infectious disease became contagious and unclean, making affected people seem undesirable and untouchable [9].

Thus, as Dubos [9] notes, differences are meaningful only in the context of a specific time and culture; difference will only be understood and classified in the context of what is important and socially accepted. There is a social norm that will dictate what differences should be important and what should be ignored. It is not well known how culturally created categories arise and how they are maintained, but they will only matter in the cultures in which they are embedded.

The second component of stigma corresponds to the action of linking the differences, reflecting different cultures, to a category of labels that become negative attributes or stereotypes. These linkages between labels and stereotypes also will be defined by specific periods of time and in relationship to a given culture. The host society defines what labels correspond to which attributes. Attributes become so deeply imprinted in the minds of people that they become unaware of them; similar to how individuals acquire linguistic competence [9].

Numerous studies conducted in different cultural contexts suggest that culture is an important component of stigma related to TB, and that it will define its characteristics and implications. These various studies indicate that the label “tuberculosis people” will have different meanings and linkages to different stereotypes according to the culture in question. The most common stereotype mentioned in the literature regarding tuberculosis is the belief that people with

TB are poor and dirty with bad habits [9].

The third component of stigma relates directly to the process of stigma in which a line is drawn between “them” and “us”, the “tuberculosis people” and “us.” This level of culture is better described by Goodenough who states that culture may be understood as a taxonomic hierarchy of what he calls public cultures or subcultures [9]. These subcultures are based upon the classification of groups according to degrees of similarity and differences in their respective public cultures. A group’s public culture is defined as an individual’s perception of values and beliefs that a group’s members expect one another to use as their operating culture in dealing with others. This level of culture allows us to describe how stigma emerges in the interactions of public cultures [9].

The fourth component of stigma is related to the resulting status loss and discrimination. However, the hierarchy implied in the discrimination and loss of status requires description. In Goodenough’s model, the notion of hierarchy or a distinction between “them” and “us,” arises in the interactions of individuals and requires some understanding of previous experiences of individuals representing different groups [9].

The fifth component of stigma is related to the imperative necessity of a relation of power in hierarchies of public culture. In saying this, it is necessary that the people who are stigmatizing others have a higher social or cultural status of power over those who are being stigmatized, and are able to enforce the stigma over those suffering from it. Tuberculosis is a disease of minorities, poverty, and the foreign-born. This situation of unequal power places the host “public culture” in a powered position against those affected [9].

In summary, stigma exists according to the beliefs and values learned in a given cultural context. It develops in the minds of people as a process triggered by the linkages to stereotypes and the consequent behavioural response to persons likely to carry TB. The relationships between those who stigmatize and those who are stigmatized are reinforced by unequal power relations embedded in a hierarchy of public cultures. The label “tuberculosis people” links negative characteristics such as poverty, poor hygiene, and other bad habits to people from a different country, usually a poor country with a different culture. This perception triggers behavioural responses that reject others and place social distance between “them” and “us,” and those who suffer the disease risk being rejected by friends and family, isolated from society and to have unequal opportunities in a powerless situation [9].

## 2. Materials and Methods

This study was a descriptive cross – sectional study and involved the use of a structured questionnaire to collect data from randomly selected TB patients of Buchi Small and Ipusukilo clinics, consecutively until the sample size was obtained. All the patients gave informed consent and ethical standards were adhered to in this study. The research

proposal for this study was approved by the Tropical Disease Research Centre’s Ethics Review committee of Ndola Teaching Hospital. A total number of 115 patients (62 from Buchi small clinic and 53 from Ipusukilo clinic) responded to the structured questionnaire. After data collection, all uncoded questions were coded. Data was then manually entered into the Statistical Package for Social Sciences (SPSS) version 16.0 for analysis. Statistical analysis was performed and included descriptive statistics to determine frequencies of key parameters. Pearson correlation test of association and cross – tabulation were also computed to determine the relationships between variables of interest.

## 3. Results

### 3.1. Socio – Demographic Characteristics of Participants

A total of 115 patients who had TB were enrolled in this study and among them 99 (86.1%) were new cases and 16 (13.9%) were retreatments. The age range of participants was from 18 to 75 years, with a mean age of 36.97 years (Standard Deviation: 12.059). Sex was not evenly distributed, there were more males (80/115) compared to females (35/115) (Table 2).

*Table 2. Frequency distribution of Age group and Gender.*

	Gender		Total	
	Female	Male		
Grouped Age	18 - 25	6	15	21
	26 - 35	12	28	40
	36 - 45	10	19	29
	46 and above	7	18	25
Total	35	80	115	

Source: Field data

Marital status: 52.2 % of the respondents were married, 21.7 % were single, 7.8% were divorced and 18.3% belonged to other statuses (e.g. widow, widower and separation) (Table 3).

*Table 3. Marital status distribution.*

	Frequency	Percent
Single	25	21.7
Married	60	52.2
Divorced	9	7.8
Other	21	18.3
Total	115	100.0

Source: Field data

Level of Education and Occupation: Majority of the respondents were not able to read and write. 62% of them had either completed primary school or dropped out, 31.3% had either completed secondary school, were still in school or dropped out, 3.5% had received tertiary education and 2.6% had no formal education. 3.5% (27/115) were in formal employment, 40.9% (47/115) were self – employed and 35.7% (41/115) were unemployed (Table 4).

Table 4. Frequency distribution Level of education and occupation.

		Occupation			Total
		Employed	Self Employed	Not Employed	
Level of Education	No Formal Education	1	1	1	3
	Primary and Below	10	35	27	72
	Secondary School	12	11	13	36
	College and Above	4	0	0	4
Total		27	47	41	115

Source: Field data

Residential area: Patients who went to TB treatment centers which were not in their residential area were grouped as Other, and made up 30.4% of the respondents. 26.1% of the participants were residents of Buchi Township and were registered at Buchi small clinic while 43.5% were residents of Ipusukilo Township and were registered at Ipusukilo clinic. However, 53.9% (62/115) of the respondents were registered at Buchi small clinic, of which 51.6% (32/62) belonged to Other (Figure 1).

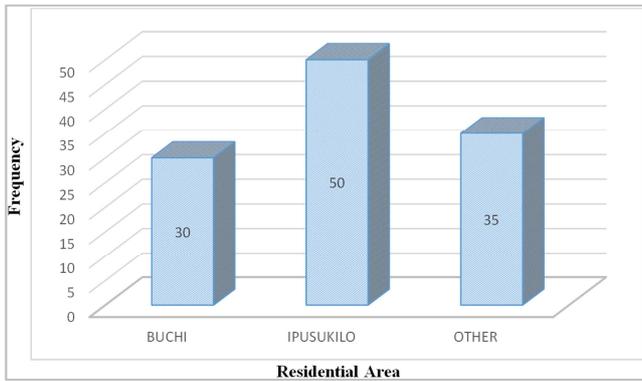


Figure 1. Frequency Distribution of Residential Area. Source: Field data.

Religion: Majority of respondents were Christians (90.4%). The rest belonged to other religions (e.g. Jehovah’s Witness) or were not religious. There were no Muslims or Hindus among the respondents (Figure 2).

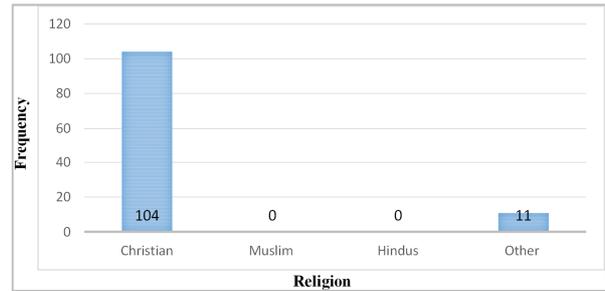


Figure 2. Distribution of Religion: Source: Field data.

3.2. Responses to Questions on Knowledge of TB

In this study, 87% of the respondents knew that the germ that causes TB is found in air. 66.1% and 27.8% of them answered that sharing a meal and toilet respectively, with someone who has TB causes TB. Furthermore, 91.3% of the patients strongly believed that smoking causes TB and 92.2% thought that one can get TB after being coughed at by person who has TB. 42.6% of the patients agreed that a woman who has TB can transmit it to the unborn child and 60% agreed that mothers who have TB can transmit it to their children through breast – feeding. In addition, 91.3% of the participants recognized coughing, fever and night sweats as signs and symptoms of TB. 24.3% of the participants thought that all TB patients had HIV while 54.8% thought that only some had HIV. Finally, 72.2% and 93% of the respondents agreed that TB is preventable and curable, respectively (Table 5).

Table 5. Responses to Questions on Knowledge of TB.

Questions	Responses		
	Yes	No	I don’t Know
1 TB is caused by germs found in air	100 (87%)	7 (6%)	8 (7%)
2 Sharing a meal with someone who has TB causes TB	76 (66.1%)	37(32.2%)	2 (1.7%)
3 Sharing a toilet with someone who has TB causes TB	32 (27.8%)	72 (62.6%)	11 (9.6%)
4 Smoking causes TB	105 (91.3%)	7 (6.1%)	3 (2.6%)
5 Can one get TB after being coughed at by a person who has TB?	106 (92.2%)	5 (4.3%)	4 (3.5%)
6 A pregnant woman who has TB can transmit it to the unborn child	49 (42.6%)	24(20.9%)	42 (36.5%)
7 Mothers who have TB can transmit it to their children through breast-feeding	69 (60%)	18(15.7%)	28 (24.3%)
8 One has TB if he/she is coughing, has a fever and sweats at night	105 (91.3%)	6 (5.2%)	4 (3.5%)
9 People who have TB also have HIV	28 (24.3%)	14(12.2%)	10 (8.7%)
10 TB is preventable	83 (72.2%)	20(17.4%)	12(10.4%)
11 TB is curable	107 (93%)	7 (6.1%)	1 (0.9%)

Note: question 9 had 4 options (Yes, No, Some, and I don’t know). Response for Some was 63 (54.8%). Source: Field Data

### 3.3. Knowledge Score

Level of knowledge of TB was measured using 11 questions (see table 5). 1 mark was given for every right answer and no mark was given for a wrong answer. Subjects who scored 0 – 5 points were considered to have low (poor) knowledge, those who had 6 – 7 points were considered to have average knowledge and those who had 8 - 11 marks were considered to have high (good) knowledge. The study found that 44.3% of the respondents had good knowledge, 36.5% had average knowledge and 19.1 % had low knowledge (Table 6).

**Table 6. Knowledge Classification.**

	Frequency	Percent
Low	22	19.1
Average	42	36.5
High	51	44.3
Total	115	100.0

Source: Field data

### 3.4. Responses to Questions on TB Stigma

In this study, 53.0% of the patients found it difficult telling their families or friends that they had TB and 40.0% felt that most people did not like them because of their illness. Also, 24.3% of the patients felt isolated from their families and friends after they had told them their diagnosis of TB and 49.6% reported been given separate plates, cups, spoons, room etc. because they had TB. Over and above, 13.9% of the patients felt that doctors and nurses did not like them because of their illness while 24.3% felt that only some doctors and nurses did not like them. Furthermore, only 14.8% of the respondents had their relationships with their friends or family members or co-workers broken because of their illness. Worse still, 44.3% of the patients felt like stopping taking their TB medication once they felt better to prevent more people from knowing that they had TB. Finally, 52.2% of the subjects had their illness used against them (i.e. being abused verbally or losing their jobs) (Table 7).

**Table 7. Responses to questions on TB Stigma.**

Questions	Responses Frequency and Percentage (n =115)		
	Yes	No	I don't Know
1 Was it easy telling others (e.g. family and friends) that you have TB?	54(47%)	61(53%)	NA
2 Do you feel like most people don't like you because of your illness?	46 (40%)	69(60%)	NA
3 Did you feel isolated from your family and friends when they found out that you had TB?	28 (24.3%)	87(75.7%)	NA
4 Were you given separate plates, cups, spoons, room etc.?	57(49.6%)	56(48.7%)	2 (1.7%)
5 Do you feel like doctors and nurses don't like you because of your illness?	16 (13.9%)	69 (60%)	2 (1.7%)
6 Did you lose any friends, family members or co-workers because of your illness?	17 (14.8%)	98(85.2%)	NA
7 Do you feel like stopping your medication once you feel better to prevent more people from knowing that you have TB?	51 (44.3%)	64(55.7%)	NA
8 Has anyone used your illness against you (e.g. verbal abuse or being fired from your job)?	60 (52.2%)	53(46.1%)	2 (1.7%)

Note: question 5 had 4 options (Yes, No, Some, and I don't know). Response for Some was 28 (24.3%). Source: Field data  
NA = Not Applicable

### 3.5. Stigma Score

**Table 8. Stigma Classification.**

	Frequency	Percent
Normal	51	44.3
Moderate Stigma	45	39.1
High Stigma	19	16.5
Total	115	100.0

Source: Field data

Level of stigma experienced by patients was measured using 8 questions (Table 7). 1 mark was given for every answer that showed stigmatizing behaviour and no mark was given for an answer that did not show stigmatizing behaviour. Respondents who scored 0 – 2 points were considered to be normal. That is they had not experienced significant levels of stigma. Participants who had 3 – 5 points were considered to have experienced moderate stigma and those who had 6 - 8 points were considered to have experienced high stigma. Khalid et al [3] had used a similar approach to assess stigma in their study. In the current study, 16.5% of the respondents experienced high stigma, 39.1% experienced moderate

stigma and 44.3% were normal. (Table 8).

### 3.6. Relationships Between Some Variables and Socio – Demographic Factors

The relationships of some variables and socio – demographic factors were determined using bivariate analysis and P-values were considered at 0.05 significant level. All P - values less than or equal to 0.05 showed a statistical significance. The main independent variables considered here were questions pertaining to knowledge of TB and TB related stigma. Level of knowledge of TB and level of stigma experienced by participants were the dependent variables. It was amazing to note some of the relationships. For example, level of education correlated significantly with level of knowledge (P value = 0.002). Occupation also showed significant relationships with one believing that people who had TB also had HIV (P value = 0.049) and with losing friends, family members or co – workers because of TB (P value = 0.040). Furthermore, age showed a strong relationship with level of stigma experienced by participants (P value = 0.004) and with

having feelings of stopping TB Treatment due to stigma (P value = 0.034). There was also a significant correlation between residential area and patients experiencing verbal abuse (P value = 0.027). Level of stigma experienced by patients did not show any significant relationship with level of education (P value = 0.764) or Religion (P value = 0.374). Likewise, category of TB (New Case or Retreatment) did not reveal any significant relationship with participant's level of knowledge (P value = 0.074) or level of stigma (P value = 0.205). Lastly, there was no relationship between level of knowledge and level of stigma (P value = 0.876).

## 4. Discussion

The aim of this study was to assess the impact of stigma on the healthcare of tuberculosis patients in Kitwe. Some of the stigma – related TB perceptions found in this study have also been mentioned in studies in other parts of the world. The mean age of the patients was 36.97 years (Standard Deviation: 12.059). This reflects the worst affected, the reproductive age group ranging from 25 to 45 years. This finding is quite similar to what was found in some studies [10, 11]. The middle age group being the major sufferers from TB has serious consequences on the economy [11] because this age group is the human resource base of the productive sector [10]. In countries such as Zambia where the prevalence of TB is very high, this will cause serious socio – economic repercussions [10].

In addition, this study revealed that 62.6% of the participants had education only up to primary school level of which some either completed or dropped out (Table 4). This figure is slightly bigger when compared to a study conducted in Lusaka, Zambia where 49.3% of the participants had a low education level (0 – 7 school years) [4]. The difference could be due to differences in socio – demographic characteristics. In the current study, such a finding could explain why 35.7% of the respondents were not in any form of employment and 40.9% were self-employed (Table 4). This finding reflects a high unemployment level in Kitwe District especially among those between the ages 25 and 45. The high unemployment levels in this age group pose a serious cause of concern in a country like Zambia, where the population is predominantly young. This age group constitutes the country's economic backbone, without which the country's economy will crumble [11]. On a slightly different note, the high prevalence of TB among the less educated and poor could explain why the disease is seen as a disease of poverty and therefore highly stigmatized.

Sex in this study was not evenly distributed among patients. The study found male predominance (69.6%) supported by similar studies carried out in Pakistan (72%) [11] and Zambia (63%) [17]. The Zambian male-to-female ratio of TB prevalence is 1.7:1 [4].

Finally, the study found that 30.4% of the patients were neither residents of Buchi nor Ipusukilo Township. They had come from other areas and most of them were registered at Buchi Small clinic. This finding could be attributed to the

high level of TB related stigma in Kitwe. A similar study revealed that some TB patients went to TB treatment centers which were farther from their home so that nobody knew that they were taking TB drugs [12]. A study conducted by Atre SR et al. also showed that most of the male and female vignettes (75%) wanted to hide disease from others [12]. Another study conducted in Southern India showed that 6.7% of patients gave wrong names and addresses to avoid being exposed as TB patients to their acquaintances [12].

### 4.1. Patients Knowledge of TB

Previous studies and reports have shown that there is sparing knowledge on TB in Zambia [10]. In a similar fashion, a general assessment on the level of knowledge of TB in this study revealed that only 44.3% of the patients had a high level of knowledge of the disease (Table 6). This number, however is twice as big when compared to what was found in a study conducted in Lusaka, Zambia (20%) [10]. The remaining 55.7% of the participants in the current study had a knowledge score of either low or average. Such a finding is alarming in this day and age when TB cases are in epidemic proportions. At this stage people ought to be well informed of the disease, in order for them to know how to protect themselves [10].

The high prevalence of TB puts everybody at risk, however, others, such as individuals who are HIV sero – positive are more at risk than people who are HIV sero – negative. There is growing evidence to show that a person with overt TB can infect 10 – 15 people per year and also that a person who is HIV – Positive is 5 – 10 times per year more at risk of developing TB compared to 10 – 15 times risk in a life time that one carries when they are HIV negative [10]. Thus, this figure of 55.7% with average or low knowledge on TB is a serious source of concern.

The study also found that some respondents did not know the cause of TB and they pointed to smoking and sharing a meal or toilet with a TB patient as the causes. Worse still, some believed that TB was not preventable (27.8%) or curable (6.1%) and that all people who have TB have HIV as well (24.3%) (Table 5). These findings are in line with what is in the literature. For example, some studies revealed that their participants held misconceptions about TB or lacked key knowledge of the disease [3, 4, 13]. These findings are worrying because such levels of ignorance put the public at risk of contracting TB because patients do not know preventive measures such as coughing – hygiene and good ventilation at home. Patients are also at risk of developing serious complications when they stop taking their medication. To give an example, a TB patient who believes their disease is incurable may find it difficult to adhere to treatment.

Additionally, it is a well-known fact that TB is caused by bacteria and is usually spread by air. However, 98% of today's TB is HIV related. People should understand the “present day TB”, also known as “non – conventional TB.” The close association of TB and HIV warrants the two to be taken as one entity when formulating strategies for

prevention and control of the two epidemics. Therefore, there is need to re – visit health education packages and to re – focus the strategies on the present – day” TB, other than the traditional disease. This shows that health workers still have a big task of educating people on today’s TB [10].

Lastly, the results of this study revealed some relationships between variables on knowledge of TB and socio – demographic factors at a significant level of 0.05. For example, it was observed that education played a significant role on the level of knowledge of TB participants had ( $P$  – values = 0.002). This is in line with what was found in a similar study [10]. Religion did not seem to have any significant relationship with level of knowledge ( $P$  – value = 0.461). This was surprising because some churches are very supportive of their members who are burdened amongst other things with disease. The church not only offers spiritual and material support, but also skill and education and in this case, health education. Category of TB did not reveal any significant relationship with participant’s level of knowledge ( $P$  value = 0.074) as well.

#### 4.2. TB Related Stigma

On the level of stigma, the study approved that 16.5% of the patients experienced high stigma while 39.1% experienced moderate stigma. That is 55.6% of the patients experienced stigma. These figures however are lower than those found in a similar study conducted in Sudan in which 63% and 29.3% of the participants were moderately and highly stigmatized respectively [3]. In the current study, stigma was more prevalent among participants in the age group 18 to 45 years and affected more males (59%) (47/80) than females (49%) (17/35). Some studies have shown that in some regions TB stigma is more prevalent among males than females [11] while others have shown that it is more prevalent among females [4, 12, 14]. The findings of this study are supported by the studies that found TB – stigma to be more prevalent among males.

The study also revealed that some patients (53%) felt uneasy telling others that they had TB and only revealed it to a few family members or friends. This could be attributed to the fact that some patients felt disliked (40%) and isolated (24.3%) because of their illness. Furthermore, 49.6% of the respondents were given separate pots, plates, cups and/or room. Similar findings were observed in Ethiopia where patients were expected to employ separate tableware and serving dishes when eating which further fueled patient isolation from society [15]. This finding is somehow surprising because sharing of household activities, such as cooking and eating from a common bowl is the norm in most African societies. In that study, the researcher argued that the unjustified prohibition of such cultural norms and practices because of the disease can result in further isolation of the patients in society.

With regard to disclosing the patient’s TB status, one study found that 71% of their participants had no fear to disclose disease to their families [11] which is different from what the current study found (47%). However, there are some studies in which it was evident that 51.3% of the participants had

fear of disclosing disease to their families, 47.3% felt hurt of others reactions to their disease and 41.7% were fearful of being a burden on their families which was attributed to their low socioeconomic status and productive age group [11]. All these results are a matter of serious concern because without the support of the people around, such as family members or employers, it becomes difficult for TB patients to successfully complete their treatment. And in the effort to control TB, completion of treatment is crucial and should be emphasised. Also, family, friends, co – workers and employers are in a strategic position, who if supportive, can contribute to a great extent in the control of tuberculosis.

Furthermore, this study revealed that only 14.8% of the participant had lost friend(s) and/or family and/or co-worker(s) because they had TB. However, this number is very small when compared to one study where 52.2% of the patients had lost their friends [11]. The current study also showed that 52.2% of the patients had their illness used against them through verbal insults or being fired from their jobs (2 reported being fired) and 40% felt disliked by the healthcare workers. It was therefore not surprising that 44.3% of the patients felt like stopping taking their medication (even if the course of treatment was not completed) once they felt better in order to free themselves from stigmatization. This finding should be taken seriously because of its consequences on the TB control program which include poor treatment adherence, poor prognosis and delay in seeking healthcare. These consequences lead to poor treatment outcomes and treatment failure, fuels on-going transmission, facilitates the emergence of TB drug resistance, and development of severe complication and/or death [1, 4].

This study like other studies [4, 16, 15] have identified poor treatment outcomes, poor prognosis and delay in seeking medical care as the major impacts of TB stigma on TB control. It is true that the attitudes of others, particularly health professionals, towards individuals with TB may affect adherence to TB treatment [16]. In one study it was evident that health professionals often showed discriminatory attitudes and behaviours towards TB patients. This put the patients in a difficult position since the support expected from the health professionals was not available. Such negative attitudes affected the motivation of the patients to adhere to treatment [16]. In the same study, some of the patients indicated that they could not withstand the stigmatising attitudes and behaviours of some of the health professionals and had to move to another health institution to be able to continue with the treatment. Another study found that many patients were not accepted or treated well by health workers, friends, and their family members. Patients then suffered in silence and did not ask for appropriate support. As a consequence, they often defaulted from treatment and continued to spread the disease in the community [16]. Another study done in Ethiopia found that TB patient used non-adherence to treatment as a strategy to relieve themselves from the pain of stigmatization [15].

When it comes to delaying in seeking medical care, it is evident that because of fear of being stigmatised, community

members with symptoms suggestive of TB fail to report to health facilities, especially those who knew other close contacts, friends, and community members who had had TB in the past, and might have been stigmatised. Consequently, when they develop symptoms suggestive of TB, this is disturbing enough to warrant concealment or denial [15, 16]. Stigma usually makes patients to refuse to acknowledge the signs and symptoms of the disease, and explain it as due to non-stigmatising conditions, such as, common cold or malaria, just to reduce the contempt of others [15, 16]. This makes patients spend extended periods in the community self-medicating. It is only when such searches do not yield any result that they report to the hospital [16]. A study done in Ethiopia revealed that most (5 of 10) patients reported to the hospital after they spent long periods at their homes, characteristically in a very awful state, due to the stigma attached to TB in the society. Consequently, this led to poor prognosis since the late beginning of treatment makes successful treatment outcome less probable [15]. Delays in reporting to the hospital and the subsequent late initiation of treatment may account for the high mortality documented among TB patients in Africa. The increased mortality from TB may also invariably heighten the fear of the disease, and result in stigmatisation of the patients in society [16].

Lastly, the results of this study revealed some significant relationships between variables of TB stigma and socio – demographic factors at a significant level of 0.05. For example, young age was strongly associated with experiencing stigma (P value = 0.004) and having feelings of stopping TB Treatment due to stigma (P value = 0.034). There was also a significant correlation between occupation and losing friends, family members or co –workers because of TB (P value = 0.040). Residential area had a significant relationship with patients experiencing verbal abuse (P value = 0.027). Level of stigma experienced by patients did not show any significant relationship with level of education (P value = 0.764) or Religion (P value = 0.374). There was also no relationship between level of knowledge and level of stigma (P value = 0.876). These findings are identical to what is in the literature.

## 5. Implications of Findings

It is evident that stigma has a tremendous impact on the healthcare of TB patients and reducing it, is an effective way to ensure that those with symptoms seek medical attention early, those on treatment adhere to it and prognosis of the disease is improved. But reduction of stigma is unlikely to be successful if the public and patients themselves have a poor understanding of TB and the consequences of stigma. To hammer the nail on its head, it is high time educational programs that aim to enrich the knowledge of TB and eradicate stigma associated with it are introduced.

## 6. Study Limitation

The limitation faced in this study was that most of the participants were illiterate and had little experience of

completing a questionnaire or being interviewed. Thus they may have been acquiescence bias. According to Dodor [16] acquiescence bias, also known as the “friendliness effect”, is created when respondents tend to agree with what an interviewer presents to them. This can happen if respondents feel the tendency to agree and to give the “right answer” as they wished not to offend the interviewer. Such kind of bias however was reduced by the interviewer by providing thorough information about the research activity. The interviewer stressed the importance that it would be much more helpful if they provided information that was accurate and true.

## 7. Conclusion

The study has established that the level of stigma towards tuberculosis patients is high in Kitwe district and this impact negatively on the health care of the patients. The main consequences identified were poor treatment adherence, poor prognosis and delay in seeking health care for those experiencing symptoms of TB. The findings of this study provide vital information for policy makers, especially those who design TB control program to include stigma reduction interventions. This will ensure that people affected by TB receive crucial preventive, diagnostic and treatment services that are free of stigma.

## 8. Recommendations

First and foremost, educational programs should be introduced that aim to educate TB patients and community members about TB and the consequences of TB related stigma. This will help eliminate common misconceptions about the disease and will eventually lead to eradication of stigma. Secondly, the government through the Ministry of Health should protect health workers by building proper infrastructures at TB treatment centres that limit transmission of the TB germ. These should be well stocked with equipment and other tools needed in the diagnosis and treatment of TB and should include proper masks (e.g. N95) for health workers to wear when handling extremely infectious patients (those with Multi Drug Resistant TB). Provision of adequate resources will decrease the exposure of health workers to tuberculosis and will help minimize their fear of infection. The resulting sense of security may help improve their attitudes and behaviours towards the patients [16]. Furthermore, churches should be used as a medium of educating members of the community about TB and the consequences of TB related stigma. The church ought to encourage its members to help TB patients cope with the illness. This strategy could be effective especially in areas (like Ipusukilo and Buchi) where illiteracy levels are high but people are committed to their churches and highly trust their spiritual leaders and their teachings, whether spiritual or scientific. If this is done, myths and misconceptions about TB could reduce to the lowest possible degree. Likewise, it is essential that when a person is diagnosed with TB, those

close to the patient (families, friends etc.) are counselled extensively as these offer support to the sufferer and thus may improve adherence to treatment. Last but not least, there is need to expand on this research, thus other researchers are encouraged to conduct this study on a large scale in other communities. Their study should include health workers, community members and TB patients who seek treatment from private health centres and traditionalists.

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## Conflict of Interest

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