

Original Research

p-ISSN 2672 - 5142; e-ISSN 2734 - 3324

Copy Right: @ Author(s)

# GENDER DIFFERENCES IN DISCLOSURE AMONG TUBERCULOSIS (TB) AND HUMAN IMMUNE-DEFICIENCY VIRUS (HIV) PATIENTS REPORTING IN SOME HEALTH FACILITIES IN THE GREATER ACCRA REGION OF GHANA

# <sup>1</sup>HANNAH Benedicta Taylor-Abdulai, <sup>2</sup>PATRICIA Akweongo, and <sup>3</sup>PHILIP Baba Adongo

<sup>1</sup>School of Medical Sciences, Department of Community Medicine, University of Cape Coast, Ghana <sup>2</sup>School of Public Health, University of Ghana

Email: <sup>1</sup>hannah.taylor-abdulai@ucc.edu.gh, <sup>2</sup>PAkweongo@ug.edu.gh <sup>3</sup>adongophilip@yahoo.com

#### **ABSTRACT**

The study explored the gender differences that exist in patterns and effects of disclosure among TB only and TB co-infected with HIV patients receiving TB treatment in some selected health facilities in the Greater Accra region and how these disclosure patterns for men and women affect the support they receive from family and friends as they circumvent the treatment processes. The study design was cross-sectional and qualitative using deductive reasoning design and conducted in six health facilities in the Greater Accra region of Ghana. A total of 30 participants were involved in the study. They were made up of 12 TB only participants, 12 co-infected TB/HIV patients, and 6 TB coordinators. Face-to-face interviews were used to elicit responses from participants and results recorded, using a digital recorder, after which verbatim transcription was done, and contents analysis used in analyzing the data. The study found that revealing one's TB and/or HIV status was problematic for married women. The men were more comfortable disclosing their status to their partners, whilst the women felt more comfortable disclosing their status to other family members other than their partners. In terms of support, some men indicated that their partners abandoned them when they lost their source of income because of their health conditions, making it difficult to manage their conditions. The women, however, received support from their external family members.

The study has implications for public health since non-disclosure could lead to further spread among close family and friends because both HIV and TB are contagious diseases.

**Keywords:** Gender, Disclosure, Support, Experiences, Co-Infection, Tuberculosis (TB), Human Immune-Deficiency Virus (HIV)

#### INTRODUCTION

The world is still battling with controlling tuberculosis (TB) and Human Immunodeficiency virus (HIV). The Global Tuberculosis Report 2023 estimates that about 10.6 million people contracted TB in 2022 indicating a rise in the global burden of TB (Global Tuberculosis Report 2023). While the 2023 TB report does not provide gender disaggregated data, the 2020 TB report provides comprehensive data of the global burden of TB. It reports of 10 million people

contracting TB globally, out of which, 5.6 million were men, 3.3 million were women and 1.1 million were children. World Health Organization (WHO), notes that TB continues to be a pandemic affecting all countries and all age groups. (World Health Organization, 2020). On the other hand, HIV continues to ravage the world with its lethal venom. It was estimated that about 38.4 million People were Living with Human Immunodeficiency virus (PLHIV) by the close of 2021 with 1.5 million new infections with HIV in 2023 worldwide (World Health Organisation, 2023). With the emergence of multidrug-resistant TB, increased prevalence of HIV, and the recent COVID-19 pandemic, the End TB Strategy adopted by the World Health Assembly in 2014 to end TB as a worldwide public health threat by 2035, is likely not achievable with these new developments (Jeremiah, Petersen, Nantanda, Mungai, Migliori, Amanullah, Zumla, (2022). It is, therefore, expedient to address these situations with effective social science and public health approaches. It is increasingly clear that some patients who had defaulted in treatment are candidates for multiple drug-resistant TB. A study conducted among drug resistance previously treated patients in a tertiary hospital in Accra, Ghana, found high prevalence of streptomycin resistance and Multidrug-resistant tuberculosis (MDR-TB) among previously treated TB patients, and a high prevalence of pre Extensively drug-resistant tuberculosis (pre-XDR-TB) among the MDR-TB patients (Forson, Kwara, Kudzawu, Omari, Otu, Gehre, Antonio (2018). Among these categories of patients, 28% of them had MDR-TB, 36% of the MDR-TB patients had resistance to either a quinolone or second-line aminoglycoside (pre-XDR TB), and would have a suboptimal response to the standardized MDR-TB regimen given to all patients with MDR (Forson et al., 2018). Significantly, a systematic study had found that HIV infection increases the risk of MDR-TB (Sultana, Hoque, Beyene, Akhlak-Ul-Islam, Khan, Ahmed, Hossain, (2021). Researchers have described this phenomena as the double trouble/burden due to the severity of both diseases (Day, 1999) and their attendant stigma (Wouters, Sommerland, Masquillier, Rau, Engelbrecht, Van Rensburg, Damme, (2020) The current situation is dire in majority of African and Southeast Asian countries which reported high prevalence of TB and HIV (World Health Organization, 2023). One of the commonest opportunistic infections of HIV is TB (Torpey, Agyei-Nkansah, Ogyiri, Forson, Lartey, Ampofo, Akamah, & Puplampu, (2020). Studies have shown that people living with HIV are more probable to contract TB and women are more probable to contract HIV because of their predisposition than men (Sia, Onadja, Hajizadeh, Heymann, Brewer, & Nandi, (2016); Nabunya, Byansi, Sensoy Bahar, McKay, Ssewamala, & Damulira, (2020); Lawn, Harries, Williams, Chaisson, Losina, De Cock, & Wood, (2011), therefore, it is no wonder coinfection is a common phenomenon at the TB clinics in Ghana. The treatment regimen for both conditions is quite long. Whilst people living with HIV are supposed to be on medication for as long as they continue to live, TB patients are required to be on a six-month directly observed therapy/treatment strategy (DOTs). Treatment regimen for MDR-TB is quite long: In view of the long treatment regimen, TB and/or HIV patients are required to have treatment supporters, to help them go through the long haul of the treatment. (This is where a patient is supposed to disclose their health condition to either close family members or any trusted person for support, refills, and supervising medication intake at the right time and the right dose). Supervision remain an essential component of the Stop TB Strategy in Ghana, as well as patient support remain the foundation of DOTS and help programs to achieve the treatment success (World Health Organisation, 2013). The treatment supporters ensure regular refill of medication

monthly and ensure that the patient takes the medication on time, and to ensure that the patient eats healthy diet.

Both HIV and TB control programs in these regions have recorded some gains in terms of reduction in overall prevalence (World Health Organization, 2020, Amoh-Adjei & Awusabo-Asare, 2013; World Health Organisation, 2013). However, there are many other issues that pertain to prevention and treatment of TB especially at the community level. One such issue is the non- disclosure by patients of TB to significant people (spouses and close relatives) in their lives which, invariably, leads to lack of social support during the treatment process. Issues surrounding disclosure of one's chronic situation have moderately been researched (Rodkjaer, Sodemann, Ostergaard, & Lomborg, 2011; Visser, Neufeld, De Villiers, Makin, & Forsyth, 2008; Simbayi, Kalichman, Strebel, A., Cloete, & Henda, (2007). Two main issues, with debilitating effects of disclosure of one's health conditions, have to do with the level of stigma attributable to such health conditions and one's gender. TB and HIV are dual conditions which attract high level of stigmatization. Goffman (1974) posited three types of stigma: stigma that is linked with mental illness, physical deformation and a third one related race, ethnicity, religion, and ideology. He further noted that "Stigma is an illuminating excursion into the situation of persons who are unable to conform to standards that society calls normal." (Goffman, 1974). Goffman noted that stigmatization starts when individuals or groups have been identified with traits or characteristics that they (community members) identified (Goffman, 1974). Once, an individual internalizes such traits, they tend to exhibit behaviors inimical to such traits or characteristics (Dodor & Kelly, 2009; Goffman, 1974; Atsu, 2009). TB and HIV have etiology that are deep-seated in traditional beliefs because of the community's understanding. In Ghana, and other African countries, how TB and HIV are contracted and their mode of transmission make people, both health workers and community members, tend to stigmatize persons infected with these conditions (Atsu, 2009); (Dodor & Kelly, 2009). Ghanaians believe that TB is caused by a curse on an individual for indulging in wrongdoing (Tabong, Akweongo, & Adongo, 2021). Again, in Ghana, persons diagnosed with TB are prohibited from selling cooked food and handling children. In fact, one of the prerequisites of a person vending food and teaching at the pre-school level is to undergo TB screening before indulging in such an activity. Delving into one's TB and HIV status is not comforting, as this can lead to stigmatization of the individual or the entire family (Viss Visser. Neufeld, De Villiers, Makin, & Forsyth, (2008); Tabong, et. al., (2021). Amo-Adjei, 2016; Mbuthia, Nyamogoba, Chiang, & McGarvey, 2020; Mukerji & Turan, 2018; Chen, Du, Wu, Xu, Ji, Zhang, Zhou, (2021). Pieces of evidence abound that people with an HIV infection have a high rate of stressful life events (Rodkjaer, Sodemann, Ostergaard, & Lomborg, (2011), so is TB (Dodor & Kelly, 2009).

Several studies have noted that gender plays a pivotal part in determining healthy humans and health outcomes (The Global Fund, 2020; Stop TB Partnership, 2020; World Health Organization, 2000; Hudelson, 1996). It is worthy to note that sex, which connotes biological characteristic, and gender, which is a social construct, have some relationship to yielding differences with respect to risks and vulnerability to ill health and consequently, different health outcomes for women and men.

TB and HIV are dual diseases that are highly gendered. There is evidence to show that many more men are diagnosed with TB than women whilst more women than men are

diagnosed with HIV (World Health Organization, 2020; World Health Organisation, 2013; Daniel & Alausa, 2006). This is due to the nature of work men are involved in and the women's anatomical disposition and negotiating skills in having sex. As a result, when it comes to the socioeconomic effect of TB stigma, there are differences in men and women.

Dodor (2009)'s study found ten sources of TB stigma as; fears of infection, physical frailty, association with HIV/AIDS, perception about the etiology of TB, outmoded community beliefs and practices about TB, public health activities, health workers uncertainty about TB, TB patients self-stigmatization, judgmental attitude, humiliation of TB patients and previous experiences with TB (Dodor, (2009). He noted that "moderating elements enhance the fear of infection, and fear of infection enhances the moderating elements" (Dodor, 2009). Some of these causes of stigma were very prominent in this study.

Gender dimensions to these diseases (TB and HIV), as indicated early, exist to a very large extent. Women are more probable of contracting HIV and men are more probable of contracting TB and when it comes to stigma, the burden is more on women than men. As a result, disclosing one's status of these two health conditions becomes problematic (Nabunya et al., 2020; Rodkjaer et al., 2011; Visser et al., 2008; Mucheto et al., 2011). Simbayi et al., (2007) noted three strategies of disclosure when they interviewed HIV patients during their study. These strategies of disclosure they intimated are; disclosure to all (being open), limited disclosure (being partly open), complete non-disclosure (being closed) (Simbayi et al., (2007). This study delves into gender differences in patterns of disclosure among TB and TB coinfected with HIV patients and how disclosing one's health condition translates into treatment support for a particular gender and consequently positive treatment outcomes.

# **METHODS**

#### **Study Design**

The study was qualitative and adopted purposive sampling and deductive reasoning design. The researchers chose the purposive sampling technique because of the general notion that it is suitable for such a study. Some researchers acknowledged that purposive sampling technique is a sought-after technique in qualitative studies and is suitable to detect and consequently elicit data-rich occurrences for studies of this nature (Miles, Huberman, & Saldana, 2014; Creswell & Creswell, 2018). The study chose purposive sampling because the information needed could be elicited from only a certain group of people.

# **Selection of Study Participants**

The unit of analysis was TB patient only and TB/HIV co-infected patients receiving TB treatment in selected study sites and TB coordinators offering TB services. In all, thirty (30) participants were involved in the study made up 12 TB only patients, 12 TB and HIV co-infected patients receiving treatment in some selected hospitals and polyclinics in the Greater Accra region of Ghana and 6 TB coordinators. Table 1 shows how participants were selected for the study.

**Table 1. Hospitals and Sub Center Locations** 

		Number of Participants	
Name of Health facility	TB coordinator	TB only	TB & HIV
Ridge Hospital	1	2	2
Achimota	1	2	2
La General	1	2	2
Tema General	1	2	2
Kaneshie Polyclinic	1	2	2
Tema Polyclinic	1	2	2

# **Participants Involved in the Study**

Thirty participants were recruited from six TB clinics which provide TB patients with or without co-morbidities such as diabetes and HIV. Participants were patients aged 18 years and above, who had received TB treatment for a period of four (4) months and agreed to be part of the study. The sample consisted of 12 women and 12 men, out of which 6 women and 6 men had other co-morbidity such as HIV.

# **Data Collection Tool and Data Collection Strategy**

We used in-depth interview (IDI) guides and face-to-face interviews were conducted in four (4) hospitals and two (2) polyclinics. Two different sets of interview guides made up of structured questions with pre-determined themes were used. The interview guide for patient participants included themes on patients-related factors such as their demographic characteristics, initial diagnosis of TB, adherence to TB medication, gender and stigma, disclosure and social support, socio-cultural factors, and service factors. The second interview guide was tailored specifically for the TB coordinators, designated as key informants; there were seven sections in the guide for the key informants. They include human resource capacity, accessibility, facilities and training, patients' adherence to TB treatment and gender issues and barriers to adherence. All interviews took place in the selected hospitals and polyclinics, and each session lasted between 45 and 60 minutes.

Both interview guides and the actual questions were developed in English language and translated into the Akan language for those who did not speak English, using a back-to-back strategy (Poland, 1995). A pre-test of the interview guide was conducted at a health facility in Tema in the Greater Accra region. The outcome of study helped to fine-tune the interview questions for the actual study. The data collections were conducted in six health facilities from April 2013 to January 2014. The corresponding author conducted all the interviews. During the interview sessions, the researcher took detailed field-notes comprising interactions between interviewer and interviewee and associated moods, non-verbal cues, and some level of reflections from the interview content. According to Poland (1995), field-notes provides broad reflections and understandings of the shared experiences during field work.

The interviews were recorded using a digital voice device. Each session of the interview was played back for participants to listen and to confirm that the recording reflected what the interviewee said. This also gave the participants an opportunity to make changes and clarify issues raised which they felt were important to them. According to (Poland, 1995) participants

who listen to their voice played back after interviews is an essential step in qualitative data analysis.

### **Data Analysis**

The recorded interviews were transcribed into a written test with the aid of Microsoft word. Poland (1995) recommends editing during the transcription process of the interviews conducted in English, and this was done to correct grammatical errors. Data analysis was done alongside data collection with the goal of ending the interviews when data saturation is achieved, where almost the same responses were recorded. The study used content analysis in analyzing the data by following the recommendations of Hsieh & Shannon, (2005); Bengtsson, (2016) and Berg, (2017).

During the decontextualization processes, the researchers familiarized themselves with the data, by going through the text to make meaning out of the entire conversation, before they were broken down into smaller meaningful insights. Consequently, it leads to gathering pieces and sections covering portions linked to each other, that answers the objective/aim of the study. An open coding process was developed for each meaningful unit, which invariably has a relationship with the context (Berg, 2017). During the analysis process, codes enabled identifying key concepts that evolved out of the data, and these were put together to create ideas. The researchers used a coding list, which explained the codes to secure reliability of data (Berg, 2017; Elo, & Kyngäs, 2008). Coding list was developed before the start of the analysis process. However, the list was varied from time to time due to the elicitation of responses that did not fit in the codes. The second stage was to determine if all aspects of the content have been examined in relation to the objective of the study. The researchers reread the original text along the final list of the meaningful units. The units were highlighted to differentiate each unit in the original transcript. All unmarked text were excluded from being used in the final analysis. During the third stage we created categories and condensed all extended units without losing the content of the units. The categorization process enabled the researchers to identify and document themes and categories, sub-categories based on the transcripts and further sorted into broader categories. Further, the themes and categories identified provided progression development for the final stage which was the compilation initiating the writing process. Once the categories were established, the researchers analyzed and wrote the findings based on the objectives of the study.

# **Ethical approval**

The initial proposal for the study was submitted for review and subsequently approved by the Ghana Health Service Ethics Committee with ethical approval identification no. GHS-ERC:14/03/2013.

Participants were explained to the rationale for the research and assurance of confidentiality of their responses as well as privacy of the data collected were explicitly explained to the participants. Before the interview all participants were made to read or read to, for those who could not read, a consent document. Participants, after understanding the contents of these consent documents signed them before the interview commenced.

#### **RESULTS**

Results of the study are presented in sub-themes to depict how participants were able to circumvent the entire treatment process from disclosure to nondisclosure and the consequence thereof.

# **Socio-demographic Characteristics of Participants**

To situate the study in the right perspective, some socio-demographic characteristics were elicited from participants. A total of 24 patient participants between the ages of 30 and 50 years were recruited for the study. They were made up of Twelve women (6 TB patients and 6 co-infected TB and HIV patients) and twelve men (6 TB patients and 6 co-infected TB and HIV patients), 13 of whom were unemployed and 21 were educated. Table 2 provides data on the socio-demographic characteristics of participants.

Table 2: Socio-demographic characteristics of TB and HIV respondents

	TB participants $(N = 12)$		TB/HIV participants $(N = 12)$	
Female	Male	Female	Male	
1	2	1	1	
4	3	3	4	
1	1	2	1	
4	4	1	4	
2	2	5	2	
4	5	6	6	
2	1	-	-	
-	-	1	-	
4	2	2	2	
2	4	3	4	
2	1	1	-	
1	-	-	-	
1	2	1	1	
1	1	1	3	
-	-	3	2	
1	2	_	_	
_	_			
	1 4 1 4 2 4 2 2 1 1 1	1 2 3 1 1 1	1       2       1         4       3       3         1       1       2         4       4       1         2       5       6         2       1       -         4       2       2         2       4       2         2       4       3	

The TB coordinators had all been trained on TB and HIV management. They represented each of the health facility selected for the study. The health facilities were: Kaneshie and Tema Polyclinics, Tema General hospital, La General hospital, Ridge hospital, and Achimota hospital. All the TB coordinators in the study were senior nursing officers and had over five years' experience working with TB only and TB and HIV co-infected patients. They provided insights into issues of set-up of TB clinics and how initial diagnosis are made and patients' counselling and initiation of treatment, defaulting in treatment and the importance of shared assistance in navigating the treatment process.

#### **Experience with TB and HIV**

This section primarily sought to explain participants' experiences with either being a TB patient and/or TB and HIV co-infected. Participants were asked about the experiences they went/go through dealing with either TB alone or both. They showed some level of knowledge in TB and HIV. Both men and women participants expressed worry about their condition especially, the co-infected participants. To those who were co-infected they had to battle with ill-health

for about a year before they were diagnosed with either of them. One of them had this to say about their condition.

'I was very ill for about a year, all treatment failed until my sister took me to the hospital and I was diagnosed with HIV and TB. I don't know when the disease actually started, but I think I have lived with it for about a year because I used herbal treatment for some time now.' [39year old female co-infected participant stated] ....it took me about a year before testing positive for HIV and with the TB it took almost six months before I was diagnosed because apart from the cough both symptoms are similar if not the same. I was diagnosed with HIV about two years ago, so I have been on ART for the past two years. At the beginning of this year, I started coughing and I also experience chills at night accompanied by bodily pains, I told my ART nurse, and she referred me to the chest clinic where I was diagnosed with TB. [48year old male co-infected participant]

Similarly, experiences were share by TB only participants. However, they expressed experiences as those who are co-infected.

I started coughing, treated for some time but the cough persisted....and bought cough syrup from the pharmacy shop.... I was scared because I heard TB kills. [46year old female TB participant]

I initially treated for coughing, but it goes and comes again and again. Went to the clinic but was treated for malaria...after a long time, I was diagnosed with TB .... I was devastated, but I was counselled about the condition. [31 year old male participant]

# Gender differences in vulnerability

The study exposed the vulnerability of patients receiving treatment primarily for TB and with HIV as well. Gender as a constrained variable played out significantly. The study revealed the different vulnerability experienced by TB only participants as well as co-infected participants. Both genders were vulnerable depending on the financial standing and the extent of their condition when it comes to the needed support during the treatment phase. The male hegemony is broken at the household level because they no longer wield financial power. The following attest to the extent to which co-infected participants felt vulnerable navigating their treatment process. From the perspectives of male participants.

I felt like committing suicide, because at that time there was no free medication for HIV. We had to buy out of our pocket. Stigma was heavy – people looked down on HIV patients and so it was like a death sentence. [A 48year old male co-infected participant]

I was so afraid; I felt my world had crumbled. Initially, I did not tell anybody, but later they got to know, I felt weak each day and so I lost my job. At that time, my wife abandoned me. She left with our son. Am now living with my aged mother. [A 40year old male coinfected participant]

The female participants expressed their vulnerability in a different dimension.

When I was diagnosed with the disease my husband asked me to move to my mother's house and so I have been with my mother for about a year now. My sister, it has not been easy for me at all. Sometimes I prefer dying to living because of the situation I find myself in. [A 46year old female co-infected participant]

I was so terrified; I felt my world had crumbled. Initially, I didn't tell anybody, but later they got to know, because I could not do my trading...... At that time my husband abandoned me to my fate even though we are not divorced. I never expected to have this type of disease. It should rather have been a diabetic or hypertensive, but this is too much.... I could lock myself indoors and cry the whole day. But what has happened cannot be changed; we pray that one day there will be a cure just like TB. [A 38year old female coinfected participant]

With respect to TB participants in the study, the extent of vulnerability they expressed was quite like that of the co-infected participants. Just like what was experienced by co-infected men, the male TB participants shared similar experiences with regards to their feeling of vulnerability as follows:

I was not very worried because; this was not the first time I was getting TB. [A 56year old male TB participant]

I was devastated... but the nurse counseled me so I felt better. If you don't have money to care for yourself then you are in trouble, because nobody will help you. [A 31year old male TB participant]

Again, female TB participants equally shared similar sentiments about their vulnerability.

At first, I was afraid because I know TB kills. Well.... nobody in my
family knows about my condition. My parents and siblings treat
me well just like I was before I became ill with TB. [A 46year
old female TB participant]

I was scared, because my daughter had to drop out of the university after she was diagnosed with TB, it was a terrible experience for the female TB participant]

whole family because we all did not suspect it was TB until after all treatments failed and she had to be tested for TB. [A 52year old

Vol. 7 No. 1; 2024

The nurses also indicated their level of vulnerability when it comes to TB and HIV.

The patients are stigmatized by their families and they themselves have self-pity because of their conditions. We as TB nurses are stigmatized by our own colleagues – they call us names. .....Male clients are very difficult. Others will not accept that they have the disease, they go and never come back until the disease becomes serious and that is what kills them. [TB nurse, La General hospital]

#### **Gender Differences in Disclosure**

The issue of disclosure pivots on the fact that, TB and HIV are dual diseases that attract stigma and discrimination even among close family members. However, when it comes to disclosing one's health condition, those co-infected with HIV and TB were reluctant to divulge their HIV status. The study further explored participants' concerns about the difficult task of disclosure and more importantly identifying the right person to disclose their condition to and the repercussion on their integrity and self-esteem. Participants with partners were asked if they had told their partners the nature of their ill-health, some women, said their partners lack of interest in their welfare and general unenthusiastic attitude towards them, was the main reason for non-disclosure. Others also indicated that their partners might leave them for other women should they disclose their health condition to them. Ironically, some male participants, who disclosed their condition to their partners, were abandoned when they were seriously ill and had no jobs. The following were conversation ensued during the IDIs with male participants:

"My family abandoned me when I disclosed to them that I have TB. I take care of myself on my own with the support of the nurse." [A 37year old male TB/HIV participant].

"My wife left me when she realized that I have TB. At that time, I was not working so she left." [A 46year old male TB participant]

The women expressed similar sentiments, however, the reasons given were different from their male counterparts. These are some of the viewpoints expressed by some female participants.

"My nuclear family has been very supportive. I used to be a teacher, but because of the sickness, I have stopped, my parents and siblings have been encouraging me to take my medication and support me financially." [A 27year old female TB participant].

"Nobody knows of my TB status in my family, not even my husband. Apart from the nurses here, I have not told anybody." [A 41year old female co-infected participant].

"My daughter is aware; she sometimes comes for my drugs when I am busy selling. My husband does not know what exactly is wrong with me, even though he knows I visit the hospital frequently. He does not give me money and does not care what I do, so I have not told him anything." [A 62year old female TB participant].

The nurses at the TB clinics expressed diverse views about disclosure of their clients. This is what some of them had to say:

When we ask clients to bring their relatives, some don't want their relatives to know about their conditions. Women who are married when they are diagnosed with both HIV and TB, will not tell their partners for fear of losing them. Male clients are very difficult, some will give wrong address so locating their homes becomes difficult. [TB coordinator, Achimota hospital]

When disclosure becomes an issue, the nurses are compelled to disclose to their relations:

Some, because of their condition for fear of stigma, do no tell anybody about their condition. For the men, it makes their situation worse off because they don't get help from anybody. We are still doing the continuous education. We invite their partners and when they come, we ask the clients to tell them about their conditions themselves, we are not the ones to tell them. Sometimes we are compelled to threatened them. [TB nurse, Ridge hospital]

# **Social Support and Adherence to Treatment Regimen**

Adherence to treatment regimen pivots the important role social support plays. Social support plays a significant role in navigating treatment processes when it comes to chronic diseases and critical when it comes to adherence by those who receive care. It is therefore imperative that the study sought to delve into the sources of support for participants since it is particularly important in treating TB and HIV. There were differences in the level of support received from family members. The nature of support depended on whom one disclosed to. The sources of support ranged from parents, spouses, children, siblings, aunt to pastor. Some male participants in their responses expressed very low levels of support and these they expressed in the following:

...ever since my family got to know about my condition, I have become a second-class citizen in my household. I have lost my job and depend on my family for support, but the support is nothing to write home about.... Can you image, my things are separated from the rest of the family. ...they treat me like an animal. The stigma is too much for me to bear. [A 42year old male co-infected participant].

I live alone now. I take care of myself. My destiny is in God. He is my provider.... when it comes to my medication, I sometimes forget to take it. Hmmm I try my best, it is not easy at all. [A 42year old male TB participant]

Contrary to the sentiments expressed by some male participants, the women were found to receive enough support from their family than their partners, hence were found to be more adherent. This is what one had to say:

My sister is the one who takes care of me. I disclosed my condition to her and she did not judge me. She ensures I take my medication every morning before I eat breakfast. [A 31year old female TB participant].

The nurses corroborated the findings from the female perspective when asked about which gender is more adherent. This is what one of the TB coordinators had to say:

The female clients are better; a lot of them are mothers so they want to get cured so they can see to their families...... The female clients are more serious with their medication than men and do not need treatment supporters. [TB nurse, Kaneshie Polyclinic]

On the other hand, one of the TB coordinators indicated she has witnessed an instance where a female co-infected with TB and HIV had died as a result of lack of support from her family.

Female patients are disciplined, they care about their families as mothers and so they want to be cured quick so they can be strong enough to take care of their responsibilities as mothers and homemakers. However, I have also had instances where female coinfected clients have died because they did not get support from their families. [TB coordinator, Tema General hospital]

Poverty plays a significant role when it comes to TB treatment completion rate and positive outcomes in the treatment regimen.

Poverty on the part of patients, drug abuse and alcoholism and inability of patients to get reliable treatment supporter. [TB nurse, Ridge hospital]

### **DISCUSSIONS**

One of the biggest obstacles to ending TB is default and non-adherence in the treatment process and how to track contacts of TB patients. If patients are not able to get the needed support, the likely result would be high default and incomplete treatment. Gender issues in health reflect the broader perspectives on overall gender spectrum in terms of equality (Allotey & Gyapong, 2008; Sia et al., 2016; Atre, Kudale, Morankar, Rangan, & Weiss, 2004; van Hagen, Muntinga, Appelman, & Verdonk, 2021). TB and HIV are no exception as the two diseases are fueled by poverty (Sia et al., 2016; Allotey & Gyapong, 2008). The study shows that female participants are less probable to open up their health condition to their partners; this finding corroborates Visser et al., (2008) and Rodkjaer et al., (2011) studies which found that

women are unwilling to disclose their HIV status during pregnancy and (Simbayi, et al., 2007) study on HIV positive male and women divulging their HIV status to their partners. This finding poses a threat to public health efforts at mitigating TB and HIV, there might be a likelihood of the spread of infections to negative partners. Earlier study by Simbayi, et al., (2007) had indicated constraints such as lack of care by male partners in showing empathy and providing the necessary assistance during illhealth. This study revealed that women experienced a different form of constraint contrary to (Simbayi, et al., 2007) assertion. Some female participants indicated that their partners did not provide any form of support during their treatment period, emphasizing that their partners did not show any form of concern and never inquire about their regular visits to the health facility. In this study, the fear of being ill with TB was also a factor, this made them uneasy divulging their TB and/or HIV status to partners for fear of a break-up of their marriage. On the contrary, the men did not feel uneasy about stigma thereby openly revealing their status, this finding supports a study by Nabunya et al., (2020) and Visser et al., (2008). This study revealed that women who were found to be coinfected were more at ease deliberating about TB condition and not HIV, the men on the other hand, openly revealed their condition without being asked. On disclosure to significant others, a few participants were not bothered informing their family and close contacts about their status. Others were skeptical and reiterated their resolve to maintain secrecy about their health status. This finding demonstrates how TB and HIV are highly stigmatized, invariably leading concealment of one's health condition. This finding corroborates studies by Mukerji & Turan, (2018) in India and Nabunya et al., (2020), in Uganda. Again, in a recent study in Ghana, women were found to be more probable to hide information when a member of their family was affected by TB (Boah, Kpordoxah, & Adokiya, 2021). This invariably may lead to the spread of the infection to healthy family members and friends and even re-infection of previously treated people. Participants gave varied reasons for concealing their health conditions to close family members; stigma and discrimination came up strongly as very important reasons. In Ghana, there is a high degree of stigma attached to HIV hence, persons living with HIV tend to hide their status compared with TB. To many, TB is curable, whilst HIV is a long-term condition that is not curable but manageable. Again, in Ghana there is a perception that HIV is associated with promiscuity and so female HIV/TB co-infected patients are not comfortable disclosing their status even to researchers and some health workers. Three out of the six female co-infected participants earlier denied having HIV. They also intimated that; their partners are not aware of their health condition. The male participants indicated that they were abandoned by their wives to their fate after they had informed them about their health status. They indicated that side effects of their medication and inability to eat healthy meals were exacerbated due to loss of income. This finding corroborates a similar study conducted by Nyangoma, Bajunirwe, & Atwine, (2020). Stigma associated with TB and HIV led to coinfected participants travelling long distances to seek treatment to avoid being recognized and labelled as such. This was found to be common among the female participants and some male participants. This finding corroborates a Daniel & Alausa, (2006) study which was conducted in Nigeria.

The study found significant evidence of gender differences of the level of support that participants received from their partners and family based on disclosure. Male participants who disclosed their condition to close family members had some form of support. This level of

support was not adequate as revealed by a couple of them. Again, disclosure by some male coinfected participants led to their partners abandoning them.

Chen et al., (2021) and Dodor & Afenyadu, (2005) studies posited that stigma is a possible obstacle to treatment since it makes patients unwilling to go for treatment in health facilities sited in their communities. This study corroborates (Chen et al., 2021; Dodor & Afenyadu, 2005) studies, since some of the participants had to travel from far away towns to access healthcare. Mukerji & Turan, (2018) study found that disclosure can play a positive role since it improves the patient ability to marshal social support thus aiding adherence which is an essential element for public health reasons such as avoidance of further infection transmission (Mukerji & Turan, 2018). Again, Mukerji & Turan, (2018) intimated that women described the consequences of stigma to include non-disclosure. They resort to keeping their conditions secret and divulging them with only trusted people. Others resorted to what Mukerji & Turan, (2018) termed "negative coping activities", such as "self-imposed social isolation". Albeit this study has found that stigma was a protective means which engineered female participants in the study to go the long haul at adhering to the treatment regimen to be completely cured of TB and look healthy even with HIV co-infection.

Studies have highlighted the negative impacts of HIV-related stigma and hence disclosure on TB treatment in co-infected patients (Dodor & Afenyadu, 2005). However, female participants who were HIV/TB co-infected were found more comfortable talking about their TB status and not HIV. This is because of the high level of stigma attached to HIV in Ghana and therefore, concealed their HIV status as a result of the fact that TB is curable, and HIV is not. Again, in Ghana there is a perception that HIV is associated with promiscuity and so female HIV/TB co-infected patients feel shy disclosing their status. Three out of the six coinfected HIV and TB had earlier in the interview denied having HIV. These three female participants concealed their health condition from their husbands because of the repercussions of being separated. Nevertheless, male participants who disclosed their condition to their wives were abandoned to their fate. The situation was exasperated when the men had to stop working due to the adverse effect of TB and HIV high doses of drugs. This finding corroborates a similar study conducted by (Nyangoma, Bajunirwe, & Atwine, 2020). The debilitating effect of stigma compelled co-infected patients to seek care far away from where they reside. More female participants were probable of seeking care far from their place of residence as compared to a few male participants. The main reason was to hide from neighbors who might see them and point accusing fingers at them. This finding corroborates with a study from Nigeria where patients defaulted because their treatment centers were relocated to neighborhoods closer to their homes (Daniel & Alausa, 2006).

The study has been able to provide trajectories to ascertain the nuances of various factors involved in adherences to the treatment regimen on one hand, and non-adherence to treatment regimen among patients on concomitant treatment for TB and HIV. That notwithstanding, there was no significant difference in terms of adherence between participants who had TB and that of TB & HIV co-infected. Nevertheless, between TB and HIV co-infected significant women compared with men were found to be less probable to be non-adherent. The reasons attributed to non-adherence among co-infected participants were side effects and high pill burden for both genders.

#### **CONCLUSION**

Disclosing one's health condition such as TB and HIV is guided by the nature and level of gender underlying forces of women and men. The dynamic powers might be variable depending on one's circumstances, either socio-cultural or socio-economic. It is imperative to acknowledge the challenges that disclosure as a constraint has on gender and as public health professionals develop culturally sensitive strategies to ameliorate them. A culturally sensitive strategy will not only avert the challenge with non-adherence to TB and HIV treatment, but also reduce the incidence of multi-drug resistance TB, which has become a major threat to control TB in Ghana.

#### RECOMMENDATIONS

The study recommends that the various TB and HIV centers collaborate with the Ministry of Gender and Social Protection and other Non-governmental Organizations (NGOs), Civil Society Organizations (CSOs) to put in place some form of stipends to support women and men who have lost their livelihoods due to TB and/or HIV to support during treatment.

The TB control program with the support of other health agencies working in TB and HIV should develop health promotion interventions/strategies from a gender lens to reduce the burden of TB in communities by incorporating gender nuances into the world view of community members into co-creating health promotion/education messages. Finally, a lot more health education on TB and HIV should be conducted at the community level to debunk the stigma attached to this duet.

#### **Limitation of the Study**

Despite the useful insights into the gender differences in disclosure patterns, the study had some limitations. A weakness inherent in qualitative studies is the lack of generalization to the findings. That notwithstanding it has been able to provide enough evidence on the gender differences in disclosure patterns of persons with TB and/or HIV receiving treatment in some selected TB centers in the Greater Accra region of Ghana.

#### ACKNOWLEDGMENTS

The authors are grateful to the research participants for making time to be part of the study. Appreciation goes to the Institute of Infectious Diseases of Poverty secretariat for their support in funding this research.

#### **Author contributions**

HBTA conceptualized the study, collected data and analysis thereof, and wrote the manuscript; PA and PBA provided scientific advice on the study design and data analysis.

# **Data availability**

All persons who meet the criterion for access to confidential data can contact corresponding author through the email address: hannah.taylor-abdulai@ucc.gh

# **Competing interest**

We declare that no conflict of interest exists

# **FUNDING**

This study was supported by the Institute of Infectious Diseases of Poverty Scholarship.

African Journal of Social Issues

#### **REFERENCES**

- Allotey, P., & Gyapong, M. (2008). Gender in tuberculosis research. *International Journal of Tuberculosis and Lung Disease*, *12*(7), 831–836.
- Amo-Adjei, J. (2016). Individual, household and community level factors associated with keeping tuberculosis status secret in Ghana. *BMC Public Health*, *16*(1), 1–9. https://doi.org/10.1186/s12889-016-3842-y
- Amo-Adjei, J., & Awusabo-Asare, K. (2013). Reflections on tuberculosis diagnosis and treatment outcomes in Ghana. *Archives of Public Health*, 71(1), 1–8. https://doi.org/10.1186/2049-3258-71-22
- Atre, S. R., Kudale, A. M., Morankar, S. N., Rangan, S. G., & Weiss, M. G. (2004). Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India. *Tropical Medicine and International Health*, Vol. 9, pp. 1228–1238. https://doi.org/10.1111/j.1365-3156.2004.01321.x
- Atsu, D. E. (2009). Dodor, Emmanuel Atsu (2009) An exploration of the causes, manifestations and consequences of tuberculosis stigma in an urban district in Ghana. PhD thesis, University of Nottingham. An exploration of the causes, manifestations and consequences of. 36–39.
- Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8–14. https://doi.org/10.1016/j.npls.2016.01.001
- Berg, B. L. & L. H. (2017). Qualitative research methods for the social sciences. *Pearson*, (9th Ed).
- Boah, M., Kpordoxah, M. R., & Adokiya, M. N. (2021). Self-reported gender differentials in the knowledge of tuberculosis transmission and curative possibility using national representative data in Ghana. *PLoS ONE*, *16*(7 June), 1–14. https://doi.org/10.1371/journal.pone.0254499
- Chen, X., Du, L., Wu, R., Xu, J., Ji, H., Zhang, Y., ... Zhou, L. (2021). Tuberculosis-related stigma and its determinants in Dalian, Northeast China: a cross-sectional study. *BMC Public Health*, 21(1), 1–10. https://doi.org/10.1186/s12889-020-10055-2
- Creswell, W. J., & Creswell, J. D. (2018). Research Design: Qualitative, Quantitative adn Mixed Methods Approaches. In *Journal of Chemical Information and Modeling* (Vol. 53). Retrieved from file:///C:/Users/Harrison/Downloads/John W. Creswell & J. David Creswell Research Design\_ Qualitative, Quantitative, and Mixed Methods Approaches (2018).pdf%0Afile:///C:/Users/Harrison/AppData/Local/Mendeley Ltd./Mendeley Desktop/Downloaded/Creswell, Cr
- Daniel, O. J., & Alausa, O. K. (2006). Treatment outcome of TB/HIV positive and TB/HIV negative patients on directly observed treatment, short course (DOTS) in Sagamu, Nigeria. *Nigerian Journal of Medicine : Journal of the National Association of Resident Doctors of Nigeria*, 15(3), 222–226. https://doi.org/10.4314/njm.v15i3.37217
- Day, M. (1999). Double trouble. New Scientist, 161(2170), 11.
- Dodor, E. A. (2009). An exploration of the causes, manifestations and consequences of tuberculosis stigma in an urban district in Ghana Emmanuel Atsu Dodor (BSc. MB ChB

- . MPH ). (May).
- Dodor, E. A., & Afenyadu, G. Y. (2005). Factors associated with tuberculosis treatment default and completion at the Effia-Nkwanta Regional Hospital in Ghana. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, Vol. 99, pp. 827–832. https://doi.org/10.1016/j.trstmh.2005.06.011
- Dodor, E. A., & Kelly, S. (2009). "We are afraid of them": Attitudes and behaviours of community members towards tuberculosis in Ghana and implications for TB control efforts. *Psychology, Health and Medicine*, Vol. 14, pp. 170–179. https://doi.org/10.1080/13548500802199753
- Elo, S & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115.
- Forson, A., Kwara, A., Kudzawu, S., Omari, M., Otu, J., Gehre, F., ... Antonio, M. (2018). A cross-sectional study of tuberculosis drug resistance among previously treated patients in a tertiary hospital in Accra, Ghana: Public health implications of standardized regimens. *BMC Infectious Diseases*, 18(1), 4–9. https://doi.org/10.1186/s12879-018-3053-5
- Global tuberculosis report 2023. Geneva: World Health Organization; 2023. Licence: CC BYNC-SA 3.0 IGO
- Goffman, E. (1974). Stigma; Notes on the management of spoiled identity. *Jason Aronson*, *New York*, *N.Y.* https://doi.org/10.2307/2575995
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. https://doi.org/10.1177/1049732305276687
- Hudelson, P. (1996). Gender differentials in tuberculosis: The role of socio-economic and cultural factors. *Tubercle and Lung Disease*, Vol. 77, pp. 391–400. https://doi.org/10.1016/S0962-8479(96)90110-0
- Jeremiah, C., Petersen, E., Nantanda, R., Mungai, B. N., Migliori, G. B., Amanullah, F., ... Zumla, A. (2022). The WHO Global Tuberculosis 2021 Report not so good news and turning the tide back to End TB. *International Journal of Infectious Diseases*, (xxxx), 5–8. https://doi.org/10.1016/j.ijid.2022.03.011
- Lawn, S. D., Harries, A. D., Williams, B. G., Chaisson, R. E., Losina, E., De Cock, K. M., & Wood, R. (2011). Antiretroviral therapy and the control of HIV-associated tuberculosis. Will ART do it? *International Journal of Tuberculosis and Lung Disease*, Vol. 15, pp. 571–581. https://doi.org/10.5588/ijtld.10.0483
- Mbuthia, G. W., Nyamogoba, H. D. N., Chiang, S. S., & McGarvey, S. T. (2020). Burden of stigma among tuberculosis patients in a pastoralist community in Kenya: A mixed methods study. *PLoS ONE*, Vol. 15. https://doi.org/10.1371/journal.pone.0240457
- Miles, M., Huberman, M & Saldana, J., C. (2014). *Qualitative Data Analysis: A methods Sourcebook*.
- Mucheto, P., Chadambuka, A., Shambira, G., Tshimanga, M., Notion, G., & Nyamayaro, W. (2011). Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe, 2009. *Pan African Medical Journal*, 8, 1–12. https://doi.org/10.4314/pamj.v8i1.71169
- Mukerji, R., & Turan, J. M. (2018). Exploring manifestations of tb-related stigma experienced by women in Kolkata, India. *Annals of Global Health*, Vol. 84, pp. 727–735.

- https://doi.org/10.29024/aogh.2383
- Nabunya, P., Byansi, W., Sensoy Bahar, O., McKay, M., Ssewamala, F. M., & Damulira, C. (2020). Factors Associated With HIV Disclosure and HIV-Related Stigma Among Adolescents Living With HIV in Southwestern Uganda. *Frontiers in Psychiatry*, Vol. 11. https://doi.org/10.3389/fpsyt.2020.00772
- Nyangoma, M., Bajunirwe, F., & Atwine, D. (2020). Non-disclosure of tuberculosis diagnosis by patients to their household members in south western Uganda. *PLoS ONE*, Vol. 15. https://doi.org/10.1371/journal.pone.0216689
- Poland, B. D. (1995). Transcription Quality as an Aspect of Rigor in Qualitative Research No Title. *Qualitative Inquiry*, 1(3), 290–310.
- Rodkjaer, L., Sodemann, M., Ostergaard, L., & Lomborg, K. (2011). Disclosure decisions: HIV-positive persons coping with disease-related stressors. *Qualitative Health Research*, 21(9), 1249–1259. https://doi.org/10.1177/1049732311405803
- Sia, D., Onadja, Y., Hajizadeh, M., Heymann, S. J., Brewer, T. F., & Nandi, A. (2016). What explains gender inequalities in HIV/AIDS prevalence in sub-Saharan Africa? Evidence from the demographic and health surveys. *BMC Public Health*, *16*(1), 1–18. https://doi.org/10.1186/s12889-016-3783-5
- Simbayi, L. C., Kalichman, S. C., Strebel, A., Cloete, A., & Henda, N. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sex Transm Infect*, 83, 29–34. https://doi.org/10.1136/sti.2006.019893
- Simbayi, L. C., Kalichman, S. C., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Disclosure of HIV status to sex partners and sexual risk behaviours among HIV-positive men and women, Cape Town, South Africa. *Sexually Transmitted Infections*, Vol. 83, pp. 29–34. https://doi.org/10.1136/sti.2006.019893
- Stop TB Partnership. (2020). Gender and TB Investment Package.
- Sultana, Z. Z., Hoque, F. U., Beyene, J., Akhlak-Ul-Islam, M., Khan, M. H. R., Ahmed, S., ... Hossain, A. (2021). HIV infection and multidrug resistant tuberculosis: a systematic review and meta-analysis. *BMC Infectious Diseases*, 21(1), 1–13. https://doi.org/10.1186/s12879-020-05749-2
- Tabong, P. T.-N., Akweongo, P., & Adongo, P. B. (2021). Community beliefs about tuberculosis in Ghana: Implications for the end tuberculosis global agenda. *Cogent Medicine*, Vol. 8. https://doi.org/10.1080/2331205x.2020.1870069
- The Global Fund. (2020). Technical Brief Tuberculosis, Gender and Human Rights. *The Global Fund*, (February), 1–21. Retrieved from https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/RES/73/3
- Torpey, K., Agyei-Nkansah, A., Ogyiri, L., Forson, A., Lartey, M., Ampofo, W., Akamah, J., & Puplampu, P. (2020). Management of TB/HIV co-infection: the state of the evidence. *Ghana medical journal*, *54*(3), 186–196. https://doi.org/10.4314/gmj.v54i3.10
- van Hagen, L. J., Muntinga, M., Appelman, Y., & Verdonk, P. (2021). Sex- and gender-sensitive public health research: an analysis of research proposals in a research institute in the Netherlands. *Women and Health*, 61(1), 109–119. https://doi.org/10.1080/03630242.2020.1834056
- Visser, M. J., Neufeld, S., De Villiers, A., Makin, J. D., & Forsyth, B. W. C. (2008). To tell or

- not to tell: South African women's disclosure of HIV status during pregnancy. *AIDS Care Psychological and Socio-Medical Aspects of AIDS/HIV*, Vol. 20, pp. 1138–1145. https://doi.org/10.1080/09540120701842779
- World Health Organisation. (2013). End TB Strategy. World Health Origanisation, 53(9), 1689–1699.
- World Health Organization. (2000). Gender and TB. *Health Policy*, *52*(3), 267–292. Retrieved from http://www.springerlink.com/index/10.1007/978-3-531-90355-2%0Ahttp://www.who.int/gender/other\_health/Gender,HealthandWorklast.pdf%0Awww.who.int/gender/documents/gender\_health\_malaria.pdf?Cached%5CnSimilar%5CnShare%5CnView shared post%5Cnhttp://www.who.int
- World Health Organization. (2020). Tuberculosis Report. In Baltimore Health News.
- Wouters, E., Sommerland, N., Masquillier, C., Rau, A., Engelbrecht, M., Van Rensburg, A. J., ... Van Damme, W. (2020). Unpacking the dynamics of double stigma: how the HIV-TB co-epidemic alters TB stigma and its management among healthcare workers. *BMC Infectious Diseases*, 20(1), 1–12. https://doi.org/10.1186/s12879-020-4816-3