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The Perceptions of Tuberculosis and Its Stigma Among TB Patients in Damascus, Syria Arab Republic

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Abstract

Tuberculosis (TB) is a major cause of illness and death worldwide and its' stigma is an important social determinant of health. The study aimed to investigate how TB patients experienced stigma associated with their disease. A qualitative study using semi-structure interviews was carried out in 18 primary health care centers in Damascus, the capital city in Syrian Arab Republic. Proposal sampling was used for recruiting 40 TB patients 23 women and 17 men. Majority of study participants have had misperceptions to TB and it consequences. Understanding of transmission model was more common among women than man, especially adult. All participants reported that they are sham and embarrass from TB disease. Hide disease as family's advice was common. Thirty one out of 40 (77.5%) of participants had been experienced with discrimination, and individually isolation from their family, friends, co-workers, other clients and health care providers. Physical and emotion problems were common among participants, especially among women and adult participants. The study findings have been provided the evidence for high stigma related to TB in Damascus, and for lack of TB patient's information about their disease including the consequences of TB. Further studies are necessary to address different of causes of discrimination and stigma with different community groups. Important recommendation is developing health education campaigns to improve of community's knowledge about TB transmission methods and reduce discrimination.

Keywords

Tuberculosis, Perception, Stigma, Discrimination and Isolation

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1. Introduction

Tuberculosis (TB) is an infectious disease and continuous to be a major public health problem in all over the word. Nearly, one-third (two billion people) of the global population have TB bacilli in their bodies [1]. Tuberculosis (TB) is a treatable and curable disease, but it remains a major global health problem. In 2007, there were 9.4 million new TB cases (139 per 100 000 populations) and 1.5 million TB deaths, including 0.4 million deaths among HIV-positive people. However, only one out of ten developed active pulmonary TB. If individual with TB are not treated well, each one will be infected on an average ten to fifteen people every year [2]. TB and HIV are both associated with stigma and discrimination. The result is reluctance on the part of infected individuals to seek health care services which are increased by the spread of the disease among people. The result is reluctance on the part of infected individuals to seek health

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care services which are increased by the spread of the disease among people [3]. Lack of awareness and incorrect perceptions of TB among communities increases the burden of disease and leads to many additional problems in individual's lives including reduction of socioeconomic status (SES) and reduction in contact with the local National Tuberculosis Pregramme (NTP) [4]. WHO has described of early diagnosis and treatment of TB as crucial elements in TB control and many of factors delays in the detection of new cases such as stigma, perception of disease, lack of awareness and incorrect perceptions about TB, and socioeconomic level. It is very important to address these factors to support the National Tuberculosis Program (NTP) in each country [5]. So, new international strategy for TB control was published by Stopping TB partnership, the aim was to implement an intervention, which focused on patient-centered approaches to improve the awareness of TB and to reduce the level of stigma among communities [5, 4].

In the Eastern Mediterranean Region (EMR), incidence cases were estimated 50 or more per 100 000 populations in Morocco, Somalia, Sudan, Yemen, Djibouti, and Iraq. While was estimated at 25-49 per 100 000 population in The Islamic Republic of Iran, Bahrain, Saudi Arabia, Egypt, Kuwait, and Syrian Arab Republic. Incidence cases was 0-24 per 100 000 population in Libyan Arab Jamahiriya, Jordan, Lebanon, Palestine, Oman, Tunisia, and United Arab Emirates [5]. TB death cases were common among young and adults in the world, especially in the developing countries, and increased in Asia [2]. TB death cases were common among young and adults in the world, especially in the developing countries, and increased in Asia [5]. The national tuberculosis control program in Syria has been using the DOTS strategy since 1995. By April 2000, the DOTS regime was covered 100% of the districts in Syria [7]. In 2004, the Syrian Ministry of Health's annual report showed that new cases were estimated at 1545 (44%) who had active pulmonary TB. The successful therapy was estimated at 1353 (88%) cases among new cases and was estimated at 19.6% of cases among patients who had previous TB (MDR-TB) [5].

1.1. Significant of the Study

Treatment delay has been associated with the stigmatization of TB [6]. The mean delay between the onset symptoms of TB and the treatment to be from one month and a half to four months in the different Eastern Mediterranean Region countries (MDR). In Syria the delay was 80.4 days and in Yemen the delay was 59.2 days [5]. In 2007, MDR-TB was estimated at 500,000 new cases globally [2].

1.2. Aim and Objectives

Aim*:* The aim of this study was to investigate how TB patients experienced stigma that associated with their disease.

1.3. Objectives of the Study Were

1. Identify the disclosure of diagnosis of TB and its' motivation
2. Assess the participants' knowledge of TB

1.4. Research Question

1. In your opinion, how did you catch TB?
2. Did you tell your family that you have TB?
3. Did you tell your friends/co-workers that you have TB?

2. Subject & Methods

2.1. Research Design

Qualitative design with semi-structured in-depth interviews used in this study.

2.2. Study Setting

The current study conducted in Damascus city, the capital of Syrian Arabic Republic.

2.3. Study Population

The study population includes TB patients who visited one of the 18 primary health care centers which administered DOTS regimen Anti-TB treatment facilities in Damascus.

2.4. Study Sample

The proposal sample was used for recruiting TB patients. Study participants were recruited from all health districts, which equal five health districts in Damascus city. It included eighteen primary health centers and main centre of TB disease. The total number of the sample was 40 patients divided to 23 female and 17 male who are agreeing to participate in the current study.

2.5. Inclusion Criteria

1. A participant age was ranging from 18 to 86 years old.
2. They should be receiving Anti-TB therapy from public health centers more than two months.
3. Included both TB patients of the new TB cases and patients who had returned after default treatment (MDR TB and X MDR TB) and,
4. Patients who have sputum smear-positive TB (active pulmonary TB) and sputum smear-negative TB (extra-pulmonary TB).

2.6. Study Tools

Semi-structure interviews used to collect data for the present

study, and included three parts:

Part 1: Demographic and socioeconomic characteristics of the participants.

Part 2: Perception of the TB patients about Tuberculosis, included causes, symptoms and model of transmission.

Part 3: Stigma and its consequences.

2.7. Validity of Tools

Ensuring of questions validity; they were developed and prepared by primary investigator after reviewing literary views and others study related to the present study. Also, questions were reviewed by three experts from Liverpool School of Tropical Medicine staff at UK, and Centre Strategic for Health Studies and Research Committee in Syria Arabic Republic.

3. Methodology

3.1. Administrative Phase

An official letter of approval which was obtained from Centre Strategic for Health Studies was sent to director of ministry of health in Damascus, who re-sent approval to health centers to carry out the study in select place. The letter included explanation of the purpose and the nature of the study and permission to carry out this research.

3.2. Pilot Study

A pilot test was carried out before starting the data collection phase with 14 TB patients who were excluded from current study. In the pilot test, ten questions were included and asked for participants at three health centers to test clarity of tools and estimate the time needed to fulfill the study tools. After the pilot test five questions were deleted and the others were modified.

3.3. Data Collection Phase

3.3.1. Ethical Considerations

Ethical review of the study proposal was conducted by the Ministry of Health Research Committee in Syrian Arabic Republic. Other ethical issues were considered by researcher in this study as confidentiality and the time taken to conduct the interviews. All participants were provided orally with information about the objectives of the study for their confidentiality that should be respected if they participated in the study. The participants were given opportunity to refuse participation and they were informed that they could withdraw at management questions without given any reason. Participants confirm was consents for participating as orally on audiotapes.

3.3.2. Field Work

Data was collected in the period from 15 Dec 2009 to 15 April 2010. It was collected three days/week. The researcher interviewed each patient individually according to attend the health center to obtain information after introducing researcher himself and explaining the purpose of the study. Every day one interviews were conducted and average each interview was taken from 50 to 60 minutes. Sometimes there was no patient attended to interview.

3.4. Analysis Data

Three main phases are used in analysis data: Preparing, Organizing and Interpreting

3.4.1. First - Preparing Phase

The interviews were translating from Arabic audio tapes into the English language with Microsoft office words by researcher then it was printing on papers. Researcher had been listening to audiotapes more than once to ensure the correction of translation.

3.4.2. Second – Organizing Data Phase

After preparing data, researcher had been considering about organizing open coding (notes and headings), and repeat reading the content of data to select open coding. Many notes were written into margins (coding sheets) during repeating and reading the data. The necessary notes (is related to all aspects of the data) were collected from margins and organized into groups, to ensure the validity of the findings researcher, and the repeated analysis of the codes, and also the sub-categories and themes which were more than once to link the themes with the codes by researcher. To create sub-categories and categories were developed under codes groups, many formulas sub-categories were generated to describe the topic. The similar sub-categories were collected and arranged together in groups according to events and incidents (codes) to select creating categories. Researcher was collected the similar codes in groups according to the response of the participants and select one code as a representative for each code group. The dissimilar code that was as one code also was analyzed into a comprehensive description of this phenomenon.

3.4.3. Third - Interpreting the Data

Key themes were put into list, to make the data easier by interpreting and less time consuming, the codes, categories and themes were divided into groups related to questions and participants responses. To ensure the validity, the themes were compared with all data through the repeated reading of the content data; every theme was matching with codes groups. Briefed and summarized the code groups was describing, illustrating and interpret king data. The

interpretation of data was conducted by one researcher. Different kinds of interpretations and descriptions were developed to explain context topic into three broad themes. Literary reviews related to the themes were studied and summarized to link it with the result.

4. Result

Forty TB patients were recruited in the study, 23 female and 17 male. An attempt was made to balance the number of men and women aged ranging from 18 to 86 years old. Most of participant's ages were under 50 years old. Half of participants were married, and two females were divorced. Most of the females were homemakers and ten males were workers. All participants were literate. Sixteen out of forty participants had infectious TB (active pulmonary TB); the remainders were non-infectious TB (non active TB entre others organs) see table 1.

Table 1. The site of TB enters participants body and (the active pulmonary TB (entre lungs) and non-active TB entre other organs.

The site of TB enters participants body and (the active pulmonary TB (entre lungs) and non-active TB entre other organs.				
Site of TB		**Female**	**Male**	**Total**
Lungs (active pulmonary TB)		11	5	16
	Lymph nodes	10	4	14
Non-active TB entre other organs	Bone	-	5	5
	Abdominal and water out lungs and renal	2	3	5
Total		23	17	40

4.1. Cause of TB

Despite all of study participants had received Anti-TB drugs more than two months; the majority of them still had misperceptions and lack of information about how they had caught TB and how it could be transmitted see figure 1. Lack of information was more common among men than women. Their answers included that it was appeared suddenly; they had no idea about how they had got TB. Some ideas regarding the cause of TB included cigarette, pollution, anxiety, stress, poor nutrition, unhealthy food, contaminated medical tools, heredity, coffee, polluted water, daily work and other diseases, such as Asthma. For examples 30 years-old, female, homemaker, mid level education said that: *"I do not know, I have no idea, how I caught this disease, I was treated to allergic in my chest more than two years before I knew I have TB. I think it was due to* cigarette *or daily work.*

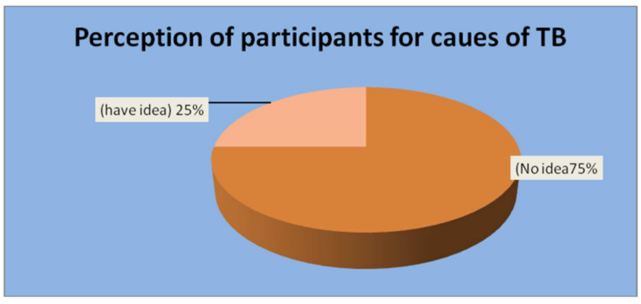

Figure 1. Perception of participants for cause of TB.

4.1.1. Symptoms of TB

The majority of study participants had described TB symptoms as weight loss, loss of appetite, acute cough, and sputum with blood, tiredness, dizziness, weakness, vomiting, high temperature, headache, anaemia, yellow face, discomfort, expectoration, hypotension, breathless, and pain at site of TB see. For example, 57 years-old male, active pulmonary TB) said that…*Cough for more two weeks, hot in chest, sputum with blood, weight loss, appetite loss, Weakness, fever, and headache*.

4.1.2. Stigma by Patients and Family

Disclosure: All study participants reported that after their diagnosis by TB. They were shamed and embarrassed with their disease and they were afraid of people reactions. *For example,* 22 years-old, and students) said that: *It was surprised when I was told at health centre of TB. I felt ashamed in front of other family members and did not know how I can explain it.*

Majority of the participants explained that the diagnosed person of TB was surprised for them and their family. They described their family's reaction as a fear of the disease. The family had gone to the main TB health centre to have TB tests to find out if they had infected with TB or not. This reaction demonstrates the link between discrimination and TB. Twenty-six out of forty participants had reported that the first reaction by their family members were at health centers. The family advised them to conceal their diagnosis and did not tell other family members in order to avoid embarrassment, and isolation. The family said this because they could not control the behavior of the rest of the family. The following quote demonstrates the link between stigma and disclosure. (18 years-old female, high education) said that: "*my parents said that: we should not tell my brother and sister because TB is known as bad disease in our area. So, we were afraid of telling other people outside our family".*

4.2. Motivation of Disclosure Related to Family

Majority participants reported that they had got experience

with isolation by family and themselves in order to avoid gaps with others as discrimination see Figure 2. This was more common among men than women, and among participants with high education. All active pulmonary TB and parents who had had TB reported isolation. (57, years-old, man, active pulmonary TB) said: "*I had isolated myself for more than one month in a separated room upstairs to avoid infecting other family numbers".*

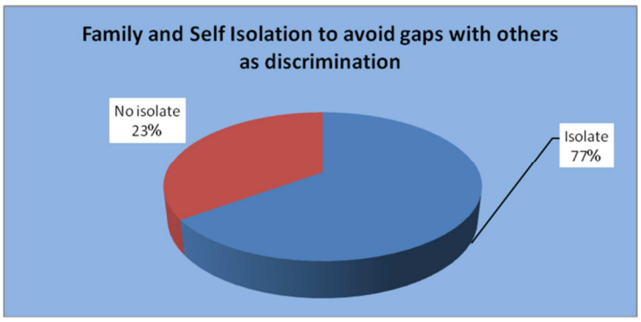

Figure 2. Family and self-isolation to avoid gaps with others as discrimination.

However, the majority of participants reported that they had experienced the disclosure of their disease to their family as benefit. They said that they had got moral support such as encouraging them to take anti-TB drugs; and paying the cost of the diagnosis and surgery, and also procuring a quiet environment and saying that TB had had drugs and cures, but less dangerous than other malicious diseases like cancer. For example, (26 years-old, and woman) said that:*"… Everything I need my family gives me, such as health food, money and support to continue TB treatment.* Other 40 years-old man, noninfectious said that:"*....my children told me that TB has got treatment and it is less dangerous than cancer".*

4.3. Stigma by Friends and Co-workers

Disclosure: The majority of participants reported that they had been afraid of disclosing their diagnosis to people other than family members. They said that the TB had been considered as a bad disease within society. They were afraid of the discrimination, prejudice and isolation. This feeling was common among women and all participants with infectious TB. (54-years-old, man, infected TB) said that:"*I am afraid that they will not accept my condition. So, I told two friends who have known of my infection TB*".

Majority of them described their experience of disclosing diagnosis to their friends and co-workers as an embarrassment, frightening and upsetting. Despite that, 23 participants out of the forty had disclosed their disease to their best friends, neighbours, co-workers and colleagues at school or university. This description was more common among patients with un-infected TB and men. For example, (65 years-old, man) said that: *"This disease comes from God, so why should I conceal. If anyone asks me about my disease, I will tell him it is TB".*

4.4. Motivations of Disclosure to Relatives, Friends and Co-workers

Most participants who had disclosed diagnosis to their friends and co-workers reported discrimination, such as stopping to work with them or paying them a visit see figure 3. They reported that their friends and co-workers had asked them many questions about their disease and its consequences. (57-years-old, man, worker) said that:".... *My boss at work has terminated my work due to TB ...*" experience.

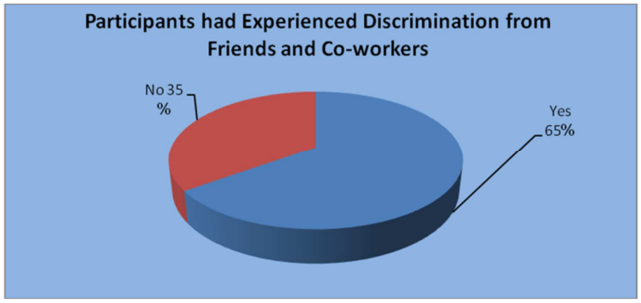

Figure 3. Participants had experienced discrimination from friends and co-workers.

Some participants had experienced discrimination from health workers and other patients when the participants were receiving anti-TB drugs at health centers. (38-years-old woman, homemaker) said that: *"One day I went to the primary health care to receive my anti-TB dose. I was covering my mouth; I sat with some health workers at their reception room. One worker at health care came and asked me to remove cover, but the other worker called out that I should cover my mouth".*

5. Discussion

Studies carried out at Syria in order to investigate the delay in diagnosis and treatment. It's revealed that stigma associated with TB influenced the delays [7, 5, 8]. Along with Syria, most countries in Eastern Mediterranean Region (EMR) have been applied to the DOTS regime. Syria used case-finding approaches for the detection and identified new TB cases. This means that all infected people with TB should have contact with Syrian health care service. As demonstrated by WHO research, the level of knowledge about the modes of transmission and stigma has played a critical role in delay of diagnosis and treatment of TB [5].

5.1. Knowledge About TB

Despite the participants have been received drugs more than two months; present study revealed that majority of

participants has lack of information about causes TB. The participants regarded caused to pollution, smoking, contaminated medical tools, and heredity. This finding out are not similar to the biomedical model described in [9]. So, misunderstand causes of TB refers to continuous spreading disease among Syrian communities. The current result was supported from other study conducted in Syria [8]. Furthermore, being found in the regional and international studies ensure there is still a little knowledge about TB among community [11, 12, 13, 3].

For most participants, TB symptoms were described as weight loss, cough, with or without fever, headache, loss of appetite and sputum with blood. The description reflected the biomedical model [14]. The findings of the current study were clearest among active-infected TB patients and those with higher education. This current result agrees with other studies in Syria [8, 7]. Moreover, all non-active pulmonary TB in present study referred to the mass (lymph node) as symptoms that appeared suddenly in their body. This current result agreed with other study in Amhara region, Ethiopia [15].

The present study did not find an influence of socioeconomic state on knowledge or stigma among participants. This current result disagrees with other studies conducted in Syria [8, 7]. The difference between the present study and other studies might have been due to all present study participants having the same access to health facilities, being lived in the capital city in Syria, all of them were literate.

5.2. Stigma

5.2.1. Stigma Relative to Family Members

All participants had a negative reaction toward their disease at the point of diagnosis and were afraid of discrimination from their family members. But, they had disclosed their disease to one or more of their family members. The current result has similar findings from other study conducted in Thyolo [16]. The present study disagree with other study was conducted in Syria who showed that only 40% of TB patients in Syria had felt ashamed at diagnosis with TB [7]. The different between the present study and Maamari's study might have been due to all present study was literate. Hide disease and never tell other family members was first reaction family members who were accompanying the patient during diagnosis and know about caught TB disease, this current result reported from majority of participants in present study. This present finding was supported by another study carried out in Thyolo in rural southern Malawi [16].

One of the interest findings in present study was that the study participants were negatively encouraged to disclose their disease among most of their family members. The family members were scared unless a non-infectious diagnosis was known. The families' participants were scared and surprised when they found out TB disease. Present research findings on strong stigmatization regarding TB supported. These current results agree with other Syrian and international studies [7, 8, 10, 15, 17].

5.2.2. Stigma Related to Friends and Co-workers Members

Although, most of present study participants were embarrassed, scared and upset about their diagnosis, but most of them reported that; they had disclosed their disease to close relatives and best friends. The present finding was common among man and participants with non-infectious disease TB. This current result was agreed from other studies [7, 16]. Hiding disease and not telling anyone out family was reported from feared participants who have wrong beliefs of their friends and co-workers, if they did not accept their disease, they would be terrified from discrimination and stigma in the present study. They attributed that saying they have no friends or work and some said why they should tell others about their disease which is unnecessary to tell them anything could make them feel ashamed and embarrassed. These current study reports were linked to stigmatization. It is among all the active pulmonary TB patients. This current result agrees from other study in Nepal [18] and other in New Delhi, India, which showed that 60% of patients had hidden their disease from their neighbors and friends [11].

Some participants in present study who disclosed their disease reported that they were stopped from their ex-works and asking about their situation by cell-phone. This was reported by all participants with infectious TB and few with non-infectious TB. This current result was similar for other studies findings, were conducted in Nepal and India [11, 18]. In the present study the participants said that they had experience with many ways of discrimination from other friends, co-workers, and from health care providers such as cutting social relation or visiting. This present finding agrees with other study conducted in Nepal [18].

6. Conclusion

This study is achieved to explore TB patient's experiences with stigma and also the clear knowledge about transmission model among TB patients in Damascus, Syria. The study results provide evidences to high stigma, and many causes of discrimination and lack of knowledge about consequences relating to TB. Finally, the study addressed many recommendations as the following:

Developing health education campaigns to improve knowledge of TB and reduce the stigma regarding TB in

Syria, through mass media as TV and Radio and posters in public places.

Periodic training for health care providers DOTS regime to upgrade their knowledge about TB.

Enhancing health education at primary health care centers among TB patients about modes of transmission.

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