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THE EXPERIENCE OF RECEIVING A TUBERCULOSIS DIAGNOSIS AND STIGMATIZATION: A QUALITATIVE STUDY

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The Experience of Receiving a Tuberculosis Diagnosis and Stigmatization: A Qualitative Study

Tüberküloz Teşhisi Alma Deneyimi ve Damgalanma: Kalitatif Bir Çalışma

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Anahtar Kelimeler (Türkçe)	Anahtar Kelimeler (İngilizce)
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to Mümü,

“The biggest disease
today is not leprosy or
tuberculosis,
but rather
the feeling of being
unwanted.”

Mother Teresa

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Abstract

This study aimed to explore the experiences of the patients with tuberculosis diagnosis along with the concept of stigma. The main focus was to understand the link between stigmatizing experiences and the diagnosis, along with its effects and consequences. In line with this objective, twenty-four in-depth interviews were realized with adult pulmonary tuberculosis patients, who were having or have been completed the treatment. Eight face-to-face interviews were done with the head-doctors working in the dispensaries, and a focus group work was made to collect diverse information from various groups. The data was analyzed using General Inductive Analysis and 17 main themes emerges: Physical, Social and Psychological Experiences of the Patients, Perception of Tuberculosis in Society, Self-Stigma, Self-Disclosure, Problems About DOT, Coping Mechanisms, Time Since Diagnosis, Family History of Tuberculosis, Support System and Demographic Background. Findings are discussed in light of existing literature and recommendations for future research was made along with possible clinical implications.

Keywords: tuberculosis, stigma, social stigma, health-related stigma, self-stigma, general inductive analysis

Özet

Bu araştırmanın amacı tüberküloz teşhisi almış bireylerin deneyimlerini damgalanma kavramı bağlamında incelemektir. Çalışmadaki temel odak, hastaların damgalayıcı deneyimlerini ve teşhis alma durumunu, etki ettiği alan ve sonuçlarıyla beraber anlamaktır. Bu amaç doğrultusunda akciğer tüberkülozu teşhisini almış, yetişkin, tedavi görmüş ya da görmekte olan yirmi dört bireyle derinlemesine mülakatlar yapılmıştır. Farklı gruplardan tamamlayıcı bilgiler toplamak ve çeşitlendirmek üzere, sekiz dispanser doktoruyla yüz yüze görüşmeler gerçekleştirilmiş, odak grup çalışması yapılmıştır. Data, Genel Tümevarımcı Analiz ile analiz edilmiş, 17 ana temaya ulaşılmıştır. Fiziksel, Sosyal ve Psikolojik Deneyimler, Toplumdaki Tüberküloz Algısı, İçselleştirilmiş Stigma, Kendini Açma, DGT Hakkında Problemler, Baş Etme Mekanizmaları, Hastalık Dönemi, Ailede Tüberküloz Öyküsü, Destek Sistemi ve Demografik Bilgiler. Sonuçlar literatür bağlamında açıklanmış, uygulama alanları ve ileri araştırmalar için öneriler sunulmuştur.

Anahtar kelimeler: tüberküloz, damgalanma, sosyal damgalanma, etiketlenme, içselleştirilmiş stigma, genel tümevarımcı analiz

INTRODUCTION

Tuberculosis (TB) is an important disease, as being one of the oldest diseases in the world. In general, it develops slowly and insidiously. The declaration of a tuberculosis diagnosis is obligatory, because of its contagious feature. There is a common belief that TB is no longer a problem in in the world including in Turkey. However, reports of World Health Organization show that more work is needed in order to decrease the morbidity rates of the disease (WHO, 2006). Although much research exists on the medical aspects diagnosis and treatment, there are not so much on its social and psychological effects. Considering the lack in the literature, the aim of the present study is to explore the experiences of the tuberculosis patients after getting the diagnosis. The study intends to shift attention from biological outcomes, to the psychologies of the patients, particularly in relation to social stigmatization.

Tuberculosis (TB) is one of the oldest diseases in the medical history of humanity. Even though there have been ups and downs in its incidence, the disease has kept its importance in terms of its contaminating feature. Especially with the rise of drug resistance during the 1980's, tuberculosis became one of the most significant disease in Turkey. The medical progress in the TB area in Turkey, especially the work of Tuberculosis Association cannot be denied, however, it is still a disease that is worthy of attention (Öztop, Şirin, Oğuz & Çakmak, 2000).

Besides its contagious feature, the fact that the disease requires a long-term treatment, the physical obstacles it creates, social stigmatization, possible loss of a job, the role changes in the family, isolation from the others, and the side effects of the medicines create psychological effects on the patients. These effects include depression, feelings of loneliness, increase in stress levels and feeling marginalized (Polat & Ergüney, 2012) Many studies show that TB is a personal, social and communal disease and even the diagnosis itself can make the diagnosed person take a step back from the others, and socially isolate himself or herself (Aslan, 2007). The patients may also get stigmatized by their social environment with friends, co-workers and even family members starting to step away from them (Velioğlu, Pektekin, & Şanlı, 1991).

According to the WHO Tuberculosis Report (2006), one of the major obstacles for the control of tuberculosis is social stigmatization. There are two major ways stigmatization affects the patients. First, because of the fear of being diagnosed with tuberculosis, people tend to ignore their long-term coughs, and tend to delay going to a doctor and seeking care. This delay makes the symptoms get worse and their treatment becomes harder. Second, once they are diagnosed with tuberculosis, the experience of discrimination and stigmatization become apparent, and patients experience more difficulties in continuing the treatment, a long-term and daily process (Mohamed, Abdalla, Abdelgadir, Elsayed, Khamis & Abdelbadea, 2011).

1.1. UNDERSTANDING TUBERCULOSIS

1. 1. 1. Definition of Tuberculosis

Tuberculosis (TB) is an infectious disease caused by the bacillus named "Mycobacterium Tuberculosis". Although most frequently, its effects are seen in the lungs (pulmonary TB), it can also be seen in other areas of the body (extrapulmonary TB) (WHO, 2017).

1. 1. 2. History of Tuberculosis

The history of tuberculosis can be investigated with the evolution of the medical information in five main periods. First, the bacteria of tuberculosis are thought to have existed even before the history of humanity. However, it was first recognized with the start of collective life, where people started to spend their times with others, in groups. With the rise of communal life and domestication of animals, tuberculosis started to develop and infect the others. Possibly the oldest evidence of a TB bacteria (ARB) comes from 5000 BC on the human bones. Similar evidence of TB has been found in the Egyptian mummies and skeletons collected in Jordan, from the 3500 BC. Likewise, the Code of Hammurabi that was created in 1750 BC mentions tuberculosis as a divine punishment (Barış, 2002).

The second part of TB history starts with the work of Hippocrates who lived between 460-375 BC. He used the Greek word “phthisis”, which means having a foot in the grave, to refer tuberculosis. He defined the disease as one of the major diseases of his time, and stated it as a fatal disease that affected individuals between the age of 18 and 35. His contemporaries such as Aristotle and Galen continued his work. Aristotle argued that it had a contagious feature, while others believed that it was hereditary. Galen proposed a definition for the phthisis as, “ulceration of the lungs, thorax or throat, accompanied by a cough, fever, and consumption of the body by pus”. He proposed three phases of pulmonary tuberculosis and explained the dangers of living in the same room with a TB patient, emphasizing its contagious feature (Pease, 1940).

Thirdly, with the authorization of medical practice during the 15th and 17th centuries, etiologies of the diseases started to be understood. Meanwhile, the work on tuberculosis accelerated. For example, Francastouris described the mechanism of contagious diseases, explaining the direct contact and the function of respiratory system, in his work named “De Morbis Contagiosis”, in 1546. Also, in the book written by Silvius in 1680 named “Opera Medica”, Phtisis was distinguished from other lung diseasees. The Industrial Revolution, which started in early 18th century, increased the urban population and led to malnutrition, poverty and unsanitary circumstances. With the rise of unfavorable conditions, tuberculosis started to spread in the population. During the 18th century, the 70% of the population could be diagnosed with TB. Meanwhile, the disease was described as a romantic disease by famous authors. It was used in the novels to describe the power of passion between two lovers and became one of the most common themes. However, thousands of people suffered and died from tuberculosis including many popular writers and musicians such as Moliere, Franz Kafka, Anton Chekhov, Frédéric Chopin, Frederich Schiller and Nicolo Paganini (Seber, 2010).

The fourth part of TB history started with the presentation of Jean Antoine Willemin in 1865. He explained the causes, symptoms and process of tuberculosis and clarified the etiology (Aksu, 2007). Another important incident of the time was the discovery of tuberculosis bacillus by Robert Koch in 1882. He gained Nobel Prize in 1905, for his great work on TB disease which proved its contagious feature. At the time, the bacteria were called Bacterium Tuberculosis. Then in 1886, Lehman and Neuman changed its name to M. Tuberculosis because of its fungus-like feature. With the discovery of microscope by Anthony Van Loeeuwenhock, and with the invention of x-ray by Wilhem Conrad Roentgen, the bacteriologic and radiologic definitions of tuberculosis were clarified. Types of TB bacteria are: M. Tuberculosis, Mycobacterium Bovis, Mycobacterium Africanum and Mycobacterium Microti. Today, the most frequently seen one is the M. Tuberculosis (Kıyan, 1999).

The fifth part of TB history can be reserved to the developments in Ottoman Empire and Turkey. It is known that Sultan Mahmut II and Abdülmecit I died because of tuberculosis. Sultan Abdülhamit II, the son of Abdülmecit I, was sensitive to and also afraid of the disease. With the influence of the declaration of Koch’s work in 1890, Sultan Abdülhamit II sent a committee to Berlin in order to examine the recent developments. In 1906, Besim Ömer Paşa was sent to the International Tuberculosis Congress in Paris and started to gather statistical data from the patients, which is the first data known in Turkey. The data showed that 92.942 people were died that year in İstanbul wherethe population was 200.000. İn İzmir, the mortality was 2.800 out of 200.000. These mortality rates, approximately %9-10, are very high (Vidinel, 2010). After that, preventive measures were taken and tuberculosis hospitals and sanatoriums started to open. In 1907, a part of Şişli Etfal Hospital was preserved for the treatment of children with tuberculosis including a 24 bed capacity. Meanwhile, a better environment for the patients was investigated with the help of German and Austrian doctors and Kütahya was chosen as a place to build the first sanatorium in the Ottoman Empire. Because of the political atmosphere of the time, the existence of the sanatorium did not last long. In 1918, “İstanbul’da Veremle Mücadele Osmanlı Cemiyeti” and in 1923, “İzmir Veremle Mücadele Hayriyesi” were founded.

With the establishment of Republic of Turkey, several tuberculosis associations (Veremle Savaş Dernekleri) were opened. In 1925, Heybeliada Sanatorium was opened with a 600 bed capacity, and it was closed in 2005 due to a change in treatment control. The first use of BCG vaccine through skin was made by Refik Güran in 1948. In 1960, head office for tuberculosis was formed and with the influence of the agreements made with WHO and UNICEF, the operational process of tuberculosis accelerated. Today, the work of Tuberculosis Association still goes on with the help of WHO, and still the major aim is to decrease the prevalence of TB in Turkey (Seber, 2010).

1.1.3. The Epidemiology

Tuberculosis is an infectious disease which is caused by bacillus *Mycobacterium tuberculosis (M. Tuberculosis)*. However, there are other types which are rarely seen in different parts of the world. For instance, M. africanum is only seen in some middle African countries. M. bovis is a different one, and contaminates with the unboiled milk and dairy products. Especially M. bovis is less likely to be reported as a problem in developing and developed countries (Kılıçaslan, 2010)

The epidemiology of tuberculosis investigates the development of the disease and provides the main information needed to control the infection. Tuberculosis pathogenesis emphasizes two main phases: the first one is contamination and infection, the second one is the shift to disease. Figure 1 shows the epidemiologic model of the disease regarding its pathogenesis. As seen in the model, the process begins with the contact of an infected person and may eventually end with death depending on different risk factors (Rieder, 1999).

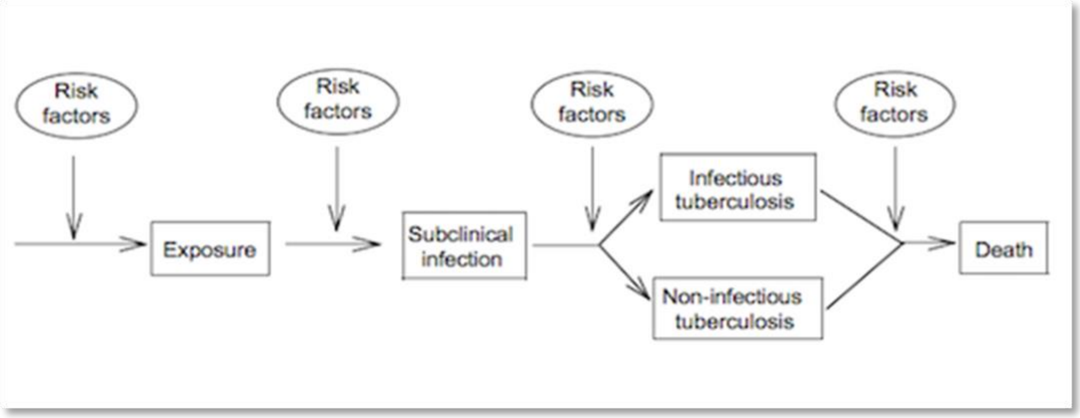


Figure 1: A model of tuberculosis epidemiology

The bacillus of TB typically effects the lungs in “Pulmonary Tuberculosis” (PTB). However, it can also be seen in the other areas of the body such as blood, central nervous system, digestive system, lymph nodes, ovaries, prostate and kidneys, generally classified as “Extrapulmonary Tuberculosis” (EPTB). Only pulmonary tuberculosis, including lung and larynx TB is infectious and there is no contagious feature of the extrapulmonary type. Pulmonary tuberculosis patients spread out bacteria through the respiratory system and infect other people. Patients produce droplets by speaking, coughing, singing and sneezing. The density of the bacteria depends on several factors. It is known that smear positive patients are more likely to contaminate others compared to smear negative patients (Kılıçaslan, 2010). The risk of being infected by the bacteria also depends on the number of contaminating patients, the level of contamination, the duration of contamination, and the duration and type of the contact with the patient. Studies detect 51,4% infection in the close contacts of the patients, especially living in the same house. This ratio may vary between 40% and 60% depending on the living conditions and other variables such as climate and population (Morrison, Pai & Hopewell, 2008).

It is important to note that, when one is infected with it, there is %5-15 possibility of developing TB during a life time. So, getting the M. Tuberculosis does not necessarily result in developing the disease. A person may be infected and live with the TB bacteria without being sick and without showing any symptoms. This is called “Latent TB Infection”. When the bacteria get active in the immune system, it is called “Tuberculosis Disease” and the person starts to show symptoms (WHO, 2016).

There are several factors that increase the risk of developing TB disease, and a most important one is being infected with HIV. Other risk factors are: past TB diagnosis, being under the age of 5, having active treatment of the immune system, being infected by M. Tuberculosis in the last 2 years, having chronic kidney disease or diabetes, being affected by silicosis, having a history of by-pass operation, low-body weight, being a smoker, long-term use of medication or alcohol and living in a population where the incidence of TB is high (Özkara, Türkkanı &

Musaonbaşıoğlu, 2011).

1.1.4. Major Symptoms and Diagnosis

TB diagnosis is a multi-step process and it requires serious attention from the health professionals. A good anamnesis, recording of physical indications, lung x-ray results and personal history are crucial in the first step. The symptoms of the disease such as a chronic cough lasting more than two weeks, pain in the chest and back, difficulties in respiration, hoarse voice, weakness, lack of appetite, weight loss, high body temperature and fatigue can be listed as the initial criteria for the diagnosis (WHO, 2016).

During the evaluation of disease, a physical examination is necessary in order to understand the distinctive features of TB types. The examination also helps to understand other medical problems which can influence the treatment process. Lung tuberculosis may not present many symptoms. Rarely, a specific sound during respiration or after coughing can be noticed and high body temperature may also be seen in some patients. In advanced TB cases, very low body weight and shortness of breath may be evident. Extrapulmonary TB types can be depicted with the difficulties with motion in visible areas (Özkara, Türkkanı & Musaonbaşıoğlu, 2011).

Radiology is another important procedure during the diagnosis of tuberculosis. The lesions seen on the x-ray of the lungs can lead the health professionals to the tuberculosis diagnosis; however, the lesions may be caused by other factors and other possible health problems. So the radiological results cannot be a definitive reason to make the diagnosis. The process of radiology should be seen as complementary to the bacteriological examination (Kılıçaslan, 2010). In order to be accurate in the diagnosis, the bacteriological analysis must be made by the professionals. This is done by the investigation of the pituitary of the patients with a microscopic investigation. The pituitary investigation must be done in three consecutive mornings in order to reach a healthy result. While this process is one of the most frequently used procedures in Turkey, there are other methods to strengthen the validity of the results. A method called "Polimerase Chain Reaction"

(PCR) is the most promising method for the diagnosis. Unfortunately, this method is not yet ready for use and does not have standardized means to apply. Tuberculosis professionals and researchers are still looking for more powerful ways to establish the diagnosis (Özkara, Türkkanı & Musaonbaşıoğlu, 2011).

1.1.5. Tuberculosis Prevalence and Incidence

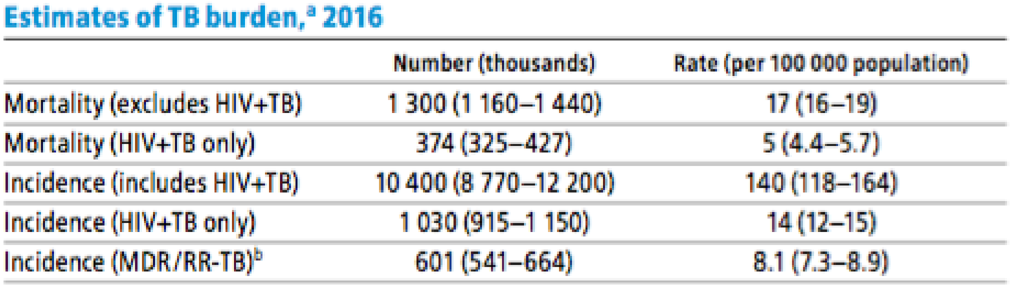
World Health Organization (WHO) reports Global Tuberculosis Report each year, and provides TB data among the different countries and regions of the world. TB records are collected and reported in most countries; however due to various reasons, many countries provide missing data. WHO reports estimated data, based on scientific material (Kılıçaslan, 2010).

WHO reports the burden of tuberculosis disease annually. TB burden is measured regarding the incidence, prevalence and mortality which can be explained as:

- Incidence: number of TB cases, new or relapse, in a specific time period (usually 1 year)
- Prevalence: total number of TB cases at a specific time point
- Mortality: number of deaths in a specific time period (usually 1 year)

According to the Global Tuberculosis Report (2017) of WHO, in 2016, 1.3 million HIV-negative and 0.37 million HIV-positive patients with TB died. Global mortality and incidence rates are presented in the Figure 2. Approximately 10.4 million people got the TB disease, with %65 men and %35 women. %56 of the new cases were from India, Indonesia, China, the Philippines and Pakistan. The incidence per population for each country is different and Figure 3 presents the world map with different colors indicating different incident rates.

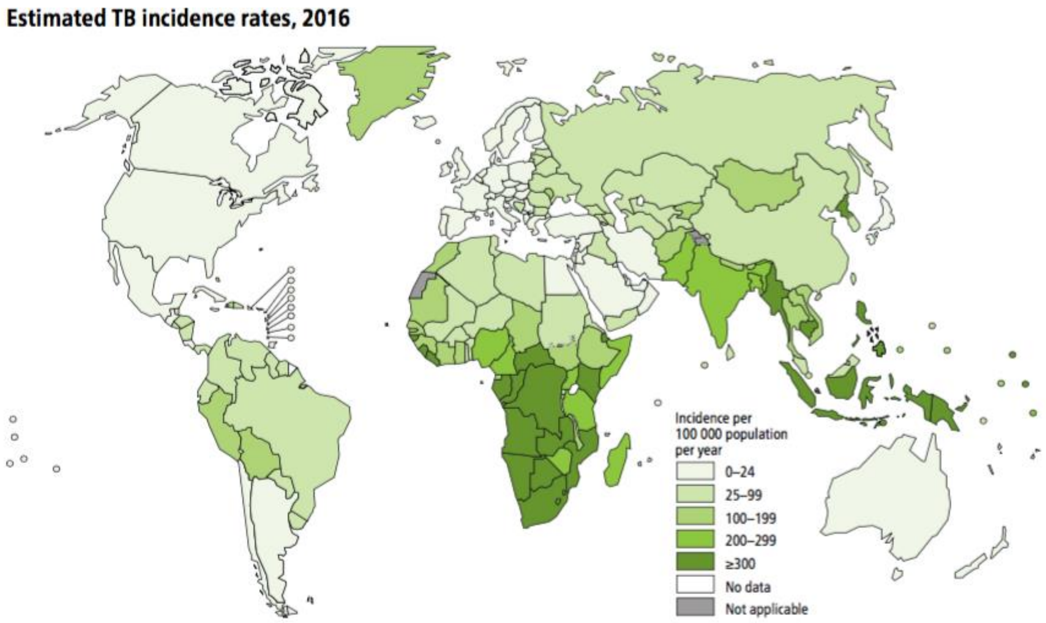
Figure 2: Global estimates of TB burden in 2016



Estimates of TB burden,[a] 2016

	Number (thousands)	Rate (per 100 000 population)
Mortality (excludes HIV+TB)	1 300 (1 160–1 440)	17 (16–19)
Mortality (HIV+TB only)	374 (325–427)	5 (4.4–5.7)
Incidence (includes HIV+TB)	10 400 (8 770–12 200)	140 (118–164)
Incidence (HIV+TB only)	1 030 (915–1 150)	14 (12–15)
Incidence (MDR/RR-TB)[b]	601 (541–664)	8.1 (7.3–8.9)

Figure 3: Estimated TB incidence rates of 2016



Estimated TB incidence rates, 2016

1.1.6. Treatment

The success of tuberculosis treatment is important for both the patient and the society. The health-care professional who is responsible for the treatment has to start the treatment, prescribe and provide the proper medications, maintain the ongoing treatment and try to sustain the treatment adherence of the patient. Main objectives of a TB treatment are to stop the contaminating feature of the early stage of the disease, prevent the patient from infecting others, identify the possible infected relatives or contacts, try to prevent occurrence of multi-drug resistant (MDR) patients and to prevent death (Özkan, 2010).

Regarding the infectious nature and social aspects of the disease, the WHO declared an emergency and proposed a strict and mandatory program named directly observed therapy short course (DOTS) globally. The main objective was to be able to control the use of medication of the patients, strengthen the adherence to treatment and prevent MDR patients (Chaudhry, 2012). DOTS is a treatment method wherein every single dose of medication is swallowed by the patient under the observation of a health-care professional staff. Since the treatment duration is relatively long, 6-8 months minimum, patients tend to quit receiving medication in the absence of DOTS. There are studies showing the successful consequences of the system when it is implemented properly and there are other studies finding the system disturbing and restricting (Arpaz, 2010).

In Turkey, DOTS first started to be implemented in three different dispensaries, in 2000. In 2006, Ministry of Health accepted the system as a health policy and made its declaration. In 2016, 96,6 % of recorded patients received their treatment under DOTS. This procedure is still being implemented in the dispensaries, but the patients can also be directed to get medications from the community clinics (Kuzuca, 2016).

1.2. UNDERSTANDING STIGMA

1.2.1. Definition of Stigma

Stigma is defined as “a mark of shame or discredit” and “an identifying mark or characteristic”; archaically as “a scar left by a hot iron”; specifically, as “a specific diagnostic sign of a disease” in Merriam-Webster’s online dictionary (“stigma”, n.d.).

1.2.2. Erving Goffman and Stigma

“Stigma” is a Greek word that historically referred to physical marks. Cut or burnt marks on the skin were used to expose immoral people such as criminals, slaves and traitors in order to identify them from the others. Today, it is generally used to refer to its original meaning, however not to a physical mark, but rather to an attribute resulting in social disapproval or rejection. There are several different definitions of stigma and their two common components are recognition of difference and devaluation. Another mutual factor is that stigma requires a social interaction. Stigma cannot be investigated with one person, but in a social context, thus it is important to note that a stigmatizing behavior may be pursued differently in another context (Bos, Pryor, Reeder & Stutterheim, 2013).

Today the work on stigma is substantial and there are many different disciplines that give attention to the concept. The roots of the concept and its definition can be found in the book of a well-known sociologist, Erving Goffman, named “Stigma: Notes on the Management of a Spoiled Identity” (1963), in which he defines stigma as “an attribute that is deeply discrediting” (p. 3) and as “an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one” (p. 11). Goffman introduces three major categories of stigmatization. The first one is aversions of the body, which is about the physical defects that can easily be seen by other people. The second one includes blots of people’s character, such as homosexuality, alcoholism and deviant political actions. The third category is called a tribal stigma, which can be explained as stigma-related associations of the individual that are inherited and can be transferred from generation to generation (Weiss et al, 2006). After presenting the stigma types, Goffman explains the individual results of the stigmatization. Accordingly, the individual eventually learns to accept the anticipated deviance as a result of the stigmatizing process, which then becomes the central aspect of one's life. The result, classified in four types, is called "moral career" (Goffman, 1963).

The moral career is a pathway of socialization of the stigmatized individual. Primarily, there are four different possibilities. The individual may have been born with a stigma and socialized in contexts which make the person aware of that personal stigmatizing feature. Secondly, a person can be protected by the neighbor or his family, and be socialized safeguarded against the stigmatized. A third way of socialization is about the individuals that acquire a stigma in the later years of life. The individual ultimately learns to accept the stigma and admits the personal difference. The last pattern of socialization is defined for the individuals who are raised in a secure environment, in which they are protected against the stigmatizing behavior. When the individual has to leave the familiar environment, he or she must adapt to the new rules of that different setting (Attell, 2013).

According to Goffman, another process that happens after a stigmatization occurs is the development of two possible groups in the society. The first group is called "the own" which is formed by individuals who are stigmatized. Understanding and empathy is very likely to be seen in this form of group and they show compassion to stigmatized others, having learned from their own experience. The individuals of this group can use their disadvantage to form small social groups or to develop powerful organizations. The second group form is called "the wise" in which understanding and sympathy is also present towards the stigmatized people, but in which the individuals are not stigmatized. He gives nurses and physicians as examples of this category, as well as straight people in places where homosexual people are more dominant. The wise can also be formed by the individuals who have a relationship with a stigmatized person, such as a mother of a disabled person, a wife of a psychiatric patient or a son of a swindler. (Flowerdew, 2008).

Goffman’s work on stigma explained the categories, forms and results of stigmatization in detail. He also proposed the process in the beginning of stigmatization, as the transfer of various social information. about an individual to a receiveing other, through signs and symbols that are called prestige and stigma symbols; and disidentifiers (Goffman, 1963). A disidentifier might be a scenario about a person walking with his black-dressed friend, who would eventually be stigmatized as a “goth”. Prestige symbols are signs that provide information about a person which might be desirable for the others and would not be stigmatized, such as a woman walking in the street with expensive clothes. Stigma symbols can be defined as the contrast of prestige symbols, which would result in a form of stigma. An example might be an arm cut that gives a clue about an early suicide attempt or a drug addiction. On the other hand, the negative social information which might result in stigma can be controlled by the individual with different methods. One might disassociate himself from the “biographical other”, the ‘old self’ which is the source of the stigmatization, and form a new social identity. A person can also control the transfer of his social information by “passing” which is a method in which an effort to hide a discrediting information is present. For instance, a male homosexual might present himself as a heterosexual in public places. Furthermore, one might hide a personal stigma-related feature about himself which is called “covering”. A wounded veteran might use a prosthetic device after a war, before going in the public in order to hide the physical signs of possible stigmatizing information (Attell, 2013).

According to Goffman, there are ways to control the negative information that may be the source of a possible stigma. Even if there are possibilities to exercise control overthem, it is likely that a person would have different identities (Goffman, 1963). One of them is a personal identity, which refers to the self that a person truly has. On the other hand, a social identity is an identity portrayed according to the needs of the society, or in order to control the social information accordingly. Having these two would create an ambivalence for the stigmatized individual and would be bothersome (Chriss, 2015).

1.2.3. Conceptualizing Stigma

After Goffman's great work on the term, mainly during the 1980's, the researchers began to focus on stigma from different perspectives and challenged the original views. Studies began to concentrate on the relationship between stigmatization and other factors such as self-esteem and academic performance. The incorporation of the individual and the self into the conceptualization of stigma led to an explosion in the field and numerous articles were published during the time. During the 1990's, review chapters started to be published, and stigma and related concepts, such as illnesses, socio-economic status and mental status, began to be seen as interrelated processes (Major & O'Brian, 2005). The enormous literature and various studies about stigma, gave rise to different conceptualizations of the term. Researchers and theoreticians proposed unique definitions by adding new components and by working inter-disciplinarily. The multidisciplinary nature of stigma research merged works of sociologists, psychologists, political scientists and anthropologists and resulted in various descriptions of the term (Link & Phelan, 2001).

The definitions of stigma went under changes over time and researchers began to reformulate the term (Weiss, 2006). In the work of Jones et al. the word "mark" is used in place of stigma, referring to the deviant labels and significant characteristics in the society (1984). Crocker et al (1998) stated the occurrence of stigmatization as a result of a presence of "some attribute or characteristic that conveys a social identity that is devalued in a particular social context" (p. 505). In the study of Link and Phelan (2001), stigma is defined as "the co-occurrence of its components: labeling, stereotyping, separation, status loss, and discrimination" (p. 363). This study also emphasized the difference between the individuals who comes up with a label and who are the subject of it, as well as the exercise of power between these two. Stigma is also defined as a merge of different mechanisms including attitudes, practices and experiences about the stigmatized group as well as the actual and self-perceived stigma experiences (Van Brakel, 2006). In another work, the definition of stigma is made emphasizing the attribute of negative marks such as powerlessness and inferiority to a group of people with a specific characteristic, by a part of or a group in society (Herek, Gillis & Cogan, 2009). Furthermore, Gonzalez and Jacobsen (2012) proposed the importance of the result of the stigmatization process and indicated the results of social roles given to the stigmatized group, such that. people who are labelled with certain properties would be influenced by those attributes, accept them and would eventually get damaged psychologically.

As different definitions suggest, stigmatization is a multi-layered process including societal, interpersonal and individual levels. Thus, conceptualization of stigma is a well-worked and rich area; however, it is also a source of concern for the researchers because of its compound mechanism. Because of the term's complex nature and multi-disciplinary research literature, it seems important to offer a clear understanding of stigma (Link & Phelan, 2001). It is therefore crucial to provide a recent work explaining the stigmatization process, which built on previous and core theories. A recent work of Pryor and Reeder (2011) proposed a model, which covered the broad literature and diversity of stigma. They built on previous research, utilized major features and proposed four interrelated stigma types: public stigma, self-stigma, stigma by association, and structural stigma.

First, public stigma is the major sub-type of this model, describing the behavior of people who stigmatize the others (perceivers), including their cognition, affect and behavior. The stigmatizing result is determined by cognitive representations of the individuals, which provoke an affective ambivalence towards the “deviant” people. The behavior then, is determined by these ambivalent emotions and results in implicit and explicit reactions. Pryor, Reeder, Yeadon and Hesson-McInnis (2004) showed that implicit reactions which are immediate reactions, are followed by explicit reactions that are controlled, in contrast. Second, self-stigma is about the personal impact of social stigma including both the worry of being stigmatized and the possibility of internalizing the negative attributes and feelings of the stigma perceivers. Self-stigma occurs as a result of being aware of the public stigma and its devaluating aspect (Pryor & Reeder, 2011). It is similar to public stigma in terms of its cognitive, affective and behavioral basics, which also has explicit and implicit features. The perceiver of stigma influences an individual through: a) his explicit negative behavior, b) stigma felt by the stigmatized person, and c) internalized stigma, which is a result of lowered self-worth and high distress as a result of public stigma (Herek, 2007). Third, stigma by association is about the individuals who are in relation with the stigmatized person such as relatives, friends or caregivers. The model of Pryor and Reeder is in line with the literature, proposing that the people around the stigmatized are also the subject of devaluation (Hebl & Mannix, 2003). The cognitive, affective and behavioral system and dual process of this sub-type are similar to public and self-stigma. Fourth, structural stigma is about the force and power of institutions which are the perpetuators of social stigma. In other words, social inequalities produced by the present public stigma is exacerbated by the ideologies and powerful organizations of the society.

1.2.4. Health-Related Stigma

The formulation of stigma went under changes over time. In parallel with the work of researchers from various disciplines, multiple definitions were produced. Researchers focused especially on practical implications of the term. The studies on practical implications brought attention not only to the symptoms and explicit signs of the disease, but also considered the social aspects (Weiss & Ramakrishna, 2006). Stigma researchers proposed that stigmatizing judgments can be applied to a disease, in addition to persons and a group (Scambler, 2009).

Health-related stigma was therefore recently defined as, “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem” (Weiss and Ramakrishna, 2006, p. 536) in the work of . The work of Weiss and Ramakrishna made a clear difference between stigmatizing behavior and precautions for the health problems, comparing appropriate protective measures to exaggerated perceptions. They also showed the similarities of stigma related to various health conditions, as well as their slight differences. As they stated in their definition, a health-stigma is a social or personal process, which may include real and perceived effects. Studies merged both aspects, including the community and the patient sides and summarized the process as stating the presence of the following: stigmatizing attitudes, practices and actions towards the patient from the community such as health-care workers; and perceived, experienced and internalized stigma of the patient (Van Brakel, 2006).

World Health Organization reported the importance of reduction of stigma in order to improve mental health care standards (WHO, 2001). The reason is the relationship between stigma and treatment of diseases. Weiss and Ramakrishna stated that, due to the wish to avoid presenting a sign that is discrediting among the society, stigma may be a powerful cause of both the patient's delay of treatment seeking and also the lack of wish to continue their treatment (2006). In parallel, the emotional impact of highly stigmatized diseases may be a greater reason for patient social and psychological suffering than the actual symptoms of the disease. For instance, especially during the early stages of leprosy, just getting and hearing the diagnosis may cause more distress than the current leprosy symptoms. The work of Link, Mirotznik and Cullen (1991) also shows the negative impact of stigma during the duration of recovery.

Researchers examined diseases associated with stigma such as HIV/AIDS, tuberculosis, epilepsy, leishmaniosis, buruli ulcer, obesity, cancer and mental illness such as schizophrenia, and proposed that they are slightly different from other types of stigma in terms of their characteristics. Researchers tend to associate stigma with chronic illness, rather than acute as far as health-related stigma is concerned. It is also important to note the possible differences of them between cultural environments, similar to general concept of stigma (Weiss & Ramakrishna, 2006). Among all diseases listed above, HIV/AIDS is the most studied one. This disease is preferred by the researchers because of its complex relationship between prejudice, stigma and discrimination. The literature of AIDS stigma is huge and includes different study methods, as well as published measurement scales (Deacon, 2006). Similarly, there is a considerable amount of study about the stigma of mental illness, epilepsy and disability (Scambler, 2009). However, the relationship between stigma and tuberculosis is not researched as much as in the other diseases.

1.2.5. Tuberculosis and Stigma

As noted earlier, the literature on stigma of tuberculosis is not very rich when compared to other illnesses. However, there are different reports coming from various countries on Asia, Europe, Africa and America. Qualitative studies are mainly conducted with tuberculosis patients, the relatives, focus groups and members of society. Quantitative research is even less, and in general focused on the components of stigma, and its assessment (Kipp, 2009).

Tuberculosis is mainly investigated as a social disease, and much research has reported its negative social impact. Most of the existing research investigated the relation between the disease and patient demographics, as well as the perspective of patients, caregivers and health-care staff, and focused on the well-being and life quality of the patients. Literature has studied quality of life in relation to physical symptoms, side effects of medication, emotional state, social and role functioning, financial and spiritual well-being and perceptions of one's health (Chang, Wu, Hansel & Diette, 2004). Researchers also found that the physical aspect of health-related quality of life of the patients improves during the TB treatment, whereas improvement in mental well-being takes longer. Qualitative research has focused on the stigmatizing experiences of the patients in addition to quality of life issues (Guo, Marra & Marra, 2009).

Considering the literature among stigma and tuberculosis, some negative consequences identified include separating the utensils of the patient at home, and making him or her eat and sleep apart from the household (Long et al, 2001). Long et al (2001) investigated social stigma among men and women, and showed the good knowledge about the disease in Vietnam. However, the impact of the stigma was different in practice. Women reported to having concerns around social consequences, and men reported to being distressed around work and economic results of the disease. Other studies also confirmed the fear of losing jobs among men (Demissie, Getahun & Lindtjorn, 2003). Isolation and avoidance as a result of the TB stigma was also found as a result of studies conducted in Vietnam

(Johansson, Diwan, Huong & Ahlberg, 1996). Regarding the relationships, the study of Liefooghe, Michiels, Habib, Moran & De Muynck (1995) researched the perception of TB and stated its social impact within the families. Participants, especially women stated the disease as a reason for divorce, broken engagements and risk for pregnancy. The study showed the negative perception of stigma as a reason for failure in tuberculosis control programs. Studies of Liefooghe et al (1995) and Long et al (2001) reported the duration of negative social impacts of tuberculosis beyond the infectious stage, and treatment period of the disease.

There are research findings explaining the reasons of stigmatizing behavior related with tuberculosis. Since the contaminating nature is known in the society, many people have fear about being infected from the patients. However, the transmission of TB bacteria is not well-known, and most of the non-patients have incorrect knowledge about contamination, such as guessing that it might be hereditary (Liefooghe et al, 1997; Long et al, 1999). Eastwood and Hill (2004) did a research on the access of tuberculosis treatment and listed the perceptions of patients and others. They showed that smoking is highly related as a cause of tuberculosis. In parallel, the work of Sengupta, Pungrassami, Balthip, Strauss, Kasetjaroen, Chongsuvivatwong & Van Rie (2006) showed the link between knowledge of tuberculosis and stigma, and mentioned the association of smoking with the disease. Research also shows the incorrect knowledge about treatment and curability, which worsens the reactions of patients when being diagnosed. This lack of knowledge also lengthens the duration of stigma and its effects (Liefooghe et al, 1997; Long et al, 2001; Baral, Karki & Newell, 2007). Baral et al (2007) also explained the self-discrimination of the patients including the anxiety of contaminating others and fear of gossip in their environment. Another reason of stigma is explained with the existence of negative associations with tuberculosis. TB is generally seen as a dirty disease, associated with poverty, as well as prostitution (Eastwood and Hill, 2004; Baral et al, 2007). It is also linked with negative life circumstances such as being imprisoned, using drugs and unemployment. There are studies showing the perception of link between tuberculosis and being a minority (Gibson, Cave, Doering, Oritz & Harms, 2005;

Dimitrova, Balabanova, Atun & Coker, 2006).

Stigma of tuberculosis has another component related with the presence of HIV/AIDS, since both diseases can be present at the same time. Studies show that HIV stigma is greater than tuberculosis stigma, which sometimes lead people to disclose their tuberculosis diagnosis rather than the HIV. This perception also causes delays in care seeking behavior and problems in treatment adherence (Ngamvithayapong, Winkvist, Diwan, 2000; Sengupta et al, 2006).

1.2.6. Tuberculosis, Stigma and Culture

The important work of Susan Sontag,"Illness as Metaphor" explains the use of illnesses in daily lives of people, in politics and in literature. (Sontag, 1978). She focuses on the use of cancer and tuberculosis in the literature after the 18th century, with the influence of romanticism movement, and explains the negative and rarely positive abstract meanings of these "mortal illnesses". Firstly, she focuses on the major illness of her time, cancer, rarely pronounced in society and rarely explained by the doctors due to its associations with death and hate. Sontag (1978) sees it as a current extension of the image of tuberculosis in society, culture and literature and finds its roots in the romantic literature. Ironically, romantics used tuberculosis as an aesthetic image in their lives and literary work with the associations of fineness, elegancy and kindship which went in line with internal beauty, mystery and novelty. However, the 20th century changes the connotations of tuberculosis; ugliness and malignancy start to become its determinants. Tuberculosis came to be identified with guilt, sin and punishment. For example, Nazis first defined the "Jewish Problem" first as a tuberculosis case", then as a "cancer tumor", referring to the link between tuberculosis and death, as well as a metaphor for an impossible problem to solve. These language and metaphors in the literature and politics influence the public and justify the discrimination and stigmatizing attitude towards them, which goes in line with the belief that they deserve a punishment (Güven, 2016).

There are many principal works in the Western cultures, including the Nicholas Nickleby (Dickens, 1839/1999), Crime and Punishment (Dostoevsky, trans. 2014), The Magic Mountain (Mann, trans. 2011) and the Black Swan (Mann, trans.1999) using tuberculosis and cancer as a metaphor for dying in life with dramatic and romantic components. It is also seen in the non-Western cultures, which is explained in detail in the work of Karatani (1993). He adds on the work of Sontag, and provides a perspective from the other side of the world, with the influence of the western currents, and points the use of tuberculosis in the Japanese art work which is majorly seen as the reason of death of the main characters of the novels. Furthermore, Turkish culture shows the influence of world literature and produces various work in which tuberculosis or other “mortal illnesses” are shown as important parts of the characters with tragic elements, not as an illness itself, but with discriminative factors such as falling in love, being in exile, or suffering with tremendous sorrow (Güven, 2016). The examples are Poor Kid (Kemal, 1873/2010), Illicit Love (Uşaklugil, 1900/2001), An Exile (Karaosmanoğlu, 1937/2007) and Night of Blackout (Ilgaz, 1974/2011). Also, in Turkey, tuberculosis becomes one of the major components of the films as a metaphor for melancholia, as an aesthetic feature to describe death and a portrait of the women with melodramatic ingredients (Çıraklı & Yemez, 2017).

1.3. PRESENT STUDY

Regarding the literature, the purpose of the current study is to understand the experiences of patients with tuberculosis diagnosis. Literature shows that the concept TB stigma has been found in research, incidentally, but not while focusing specifically on it. In general, researchers tend to examine the health-seeking behaviors and adherence to treatment with the aim to understand the problems in health-care services. Others focused on determining the existence of stigma, using quantitative measures. There are few studies focused on the experience of the disease, reasons of stigma and its consequences (Dodor, 2008).

In Turkey, Sert developed a stigma scale named Tuberculosis Patients Stigma Scale (THSO) in 2010. Using the scale, the study of Açıkel and Pakyüz (2015) showed that tuberculosis patients are moderately stigmatized, and that stigmatization is higher in low SES patients. The study of Öztürk (2013) found high stigmatization among patients with TB and compared stigma levels among demographic information of the participants through quantitative measures. There are other studies showing low levels of stigmatization, using the scale THSO, among tuberculosis patient (Bayraktar & Khorshtd, 2017). Furthermore, Şimşek et al (2016) found higher stigmatization among male and non-disclosing patients. Other studies in Turkey, researched other aspects of the disease such as self-evaluation (Aslan et al, 2004), compliance with treatment and social life (Özkurt, Oğuzhanoğlu, Özdel, Altın, Balkanlı, Konya & Akdağ, 2000), level of depression and loneliness (Polat & Ergüney, 2012) and life events (Ünalan et al, 2008).

Considering the gap in literature from other countries and contradictory findings especially in Turkey in terms of quantitative research, this study is designed to provide an understanding of tuberculosis patients lives, in relation with stigma; the mechanism behind it, its reasons, effects, consequences as well as the coping mechanisms of the patients. This study aims to explore the experiences of tuberculosis patients in İstanbul, Turkey.

METHOD

2.1. RESEARCH QUESTIONS

The main objective of the present study is to focus on the experiences of the tuberculosis patients after getting the diagnosis. The primary focus of the analysis is to understand the psychological influences of the diagnosis related with the stigmatizing experiences of people in daily life. Considering this major aim, the study is designed to explore the outcomes of being diagnosed with an infectious disease, to discover the subjective experiences of patients, understand its relations with social stigmatization, and their coping mechanisms. The following research questions are posed in the present study:

1) What are the major experiences of the patients after getting the tuberculosis diagnosis and being under the tuberculosis treatment?
2) How do the patients experience stigma-related tuberculosis?
3) What are the main coping strategies of the patients?
4) What are some factors that account for the possible variations in the experiences of persons diagnosed with TB?

2.2. THE RESEARCH SETTING

The participants were recruited from eight tuberculosis dispensaries located in different areas in İstanbul, including Üsküdar Verem Savaşı, Beykoz Verem Savaşı, Kartal Verem Savaşı, Ümraniye Verem Savaşı, Kadıköy Verem Savaşı, Pendik Verem Savaşı, Taksim Verem Savaşı and Şehremini Verem Savaşı Dispensary.

Dispensaries are one of the most representative establishments in İstanbul, where most of the population consult to obtain health reports for job applications and marriage documents. Dispensaries are also responsible for tuberculosis vaccination (BCG), tuberculosis diagnosis and treatment by providing routine medications, declaration of the diagnosed patients, scanning of the patient contacts, and providing socio-economical support to families (Özkara, Türkkanı & Musaonbaşıoğlu, 2011). Indeed, in Turkey, major information about tuberculosis patients comes from the records of dispensaries. In past decades, the data about tuberculosis patients was critical because of the lack of data recordings in dispensaries and hospitals. However, recently Verem Savaşı Daire Başkanlığı (VSDB) started to collect individual data from each patient, in order to report necessary statistics and evaluations (Özkara, 2010).

2.3. PARTICIPANTS

2.3.1. The Sample

Participants were recruited by convenience sampling. A collaboration with the head doctors of each dispensary was made, and they were asked to contact the patients who were registered in their dispensary, and who would be likely to participate in the study and share his or her experiences about the disease and the diagnosis. The people proposed by the doctors were screened according to the main criteria of the study, and the ones who are appropriate to the research were called and an individual interview with all of them in a single room was arranged.

First, based on the above convenience sampling method, 24 people (17 men, 7 women) who have a tuberculosis diagnosis participated in the individual in-depth interviews. The sample met the following criteria: (a) having the tuberculosis diagnosis, (b) the diagnosis type is at least lung TB, (c) between 18 and 65 years of age, (d) Being under treatment, and (d) being willing to volunteer for an interview.

Secondly, similar in-depth interviews were made with 8 doctors who worked as a head doctor in each dispensary. All of them was willing to participate to the study, and the inclusion criteria were: (a) being the head doctor of the related dispensary, (b) working at the same dispensary for at least a year, and (c) being willing to volunteer for an interview.

Thirdly, a focus group was made with 7 people from a private company. The participants were from different departments and their socio-demographic information were heterogeneous. The participants of the focus group met the following criteria: (a) not having a tuberculosis diagnosis, (b) between 18 and 65 years of age, (c) being willing to volunteer for the focus group work.

2.3.2. Participant Demographics

The interviews were made with 17 men and 7 women tuberculosis patients. The participants were between 21 and 64 of age (M=39,8). 11 participants were married, 13 of them were single. 15 participants had a job, 9 of them were not working. In terms of the sample’s revenue, 9 participants did not have any income, 11 of them had middle income (including minimum wage) and 4 had upper-middle income (see Table 1).

The demographical information of the focus group and interviewed doctors are presented in Table 2 and Table 3.

Table 1: Demographic characteristics of the sample (Patients with TB)

Variables	*N*	*%*	***Mean***	***SD***	***Range***
Age			39.8	12.28	21-64
Gender					
Male	17	70.8			
Female	7	29.2			
Marital Status					
Married	11	45.8			
Not Married	13	54.2			
Education Level					
No Education	2	8.3			
Primary School	13	54.2			
High School	5	20.8			
Undergraduate	3	12.5			
Graduate	1	4.2			
Employment Status					
Employed	9	37.5			
Unemployed	15	62.5			
Income Level					
Low (below-1500)	9	37.5			
Middle (1501-3500)	11	45.8			
Upper-Middle (3501- 6000)	4	16.7			
High (6000-above)					

Table 2: Demographic characteristics of the focus group

Variables	*N*	*%*	*Mean*	*SD*	*Range*
Age			35.7	10.219	25-52
Gender					
Male	4	57.2			
Female	3	42.8			
Marital Status					
Married	5	71.5			
Not Married	2	28.6			
Education Level					
No Education					
Primary School					
High School					
Undergraduate	5	72.5			
Graduate	2	28.6			
Employment Status					
Employed	7	100			
Unemployed					
Income Level					
Low (below-1500)					
Middle (1501-3500)	3	42.8			
Upper-Middle (3501- 6000)	4	57.2			
High (6000-above)					

Table 3: Demographic characteristics of the doctors

Variables	*N*	*%*	*Mean*	*SD*	*Range*
Age			51.4	8.7	38-62
Gender					
Male	3	37.5			
Female	5	62.5			
Marital Status					
Married	5	62.5			
Not Married	3	37.5			
Education Level					
No Education					
Primary School					
High School					
Undergraduate					
Graduate	8	100			
Employment Status					
Employed	8	100			
Unemployed					
Income Level					
Low (below-1500)					
Middle (1501-3500)					
Upper-Middle (3501- 6000)	8	100			
High (6000-above)					

2.4. PROCEDURE

Data collection process started after receiving the approval from Ethics Committee Board of İstanbul Bilgi University. Data gathering was done with the participants which were willing to attend an in-depth interview. Each of them was briefly informed about the study by the head doctor and asked to come to the dispensary. Interviews were conducted in a single room at each dispensary, privately. First the patient interviews were done. Then interviews with the doctors were completed. Regarding all three groups (patients, doctors and focus group) the purpose of the study was told at the beginning and all participants were reminded about their right to withdraw at any time, without any sanction. Then, they were asked to read the consent form on their own, written consents were obtained (see Appendix A). The interviews were audiotaped with the participants' permission, and transcribed verbatim. Considering confidentiality, the consent forms and written documents were kept in a locked drawer, and participant names were not included in the transcripts.

First, the semi-structured patient interviews were done, regarding five main questions. In the first question they were asked to tell about the diagnosis process. The aim was to collect background information about their individual stories and to understand the experiences and feelings they have gone through. In the second question, they were asked to describe the changes they experienced after the diagnosis in order to detect physical, social and psychological consequences of the incident. Thirdly, they were requested to explain their experiences about those changes. The aim was to identify if the experiments as distressing, exhausting or stigmatizing. In the fourth question, they were asked about their coping strategies and personal resources. The purpose of the question was to learn about personal differences on managing the disease. Lastly, they were asked to add any other comments about their experiences (see Appendix C).

Second, the semi-constructed doctor interviews were done, regarding 5 main questions. In the beginning, they were asked to give information about themselves as a doctor and give information about the patient characteristics in their dispensaries. The aim was to understand the overall percentages and the features of the patients they work with. Second, they were asked to describe the diagnosis routine in order to understand the process between the patient and doctor. In the third question, they were asked about their observations during the diagnosis and treatment. The purpose of the question was to comprehend the views of the doctors about different patients and their behavior. Fourth, they were requested to talk about different patients with the aim to understand different reactions to the disease and during the treatment phase. Last, they were asked to tell their opinion on perception of tuberculosis in the society regarding stigmatization (see Appendix D).

Third, the focus group study was done with 7 people from a private company named Biggplus Group. During this part of the study, the researcher was the moderator of the session and the intention was to conduct a group discussion. The discussion started with the moderator's general question to tell about their knowledge on tuberculosis. Several times, the moderator interrupted the discussion with other questions such as, a) what would happen if a person in the company had a tuberculosis diagnosis, b) what would happen if you have a tuberculosis diagnosis and, c) what comes to your mind when you see a person with mask.

The collection of demographic data was done at the beginning of each interview. All of the participants (patients, doctors and focus group) first were asked to fill the demographic form, including 6 short questions regarding their year of birth, gender, level of education, employment status, economic income and marital status (see Appendix B).

2.5. DATA ANALYSIS

Qualitative analysis includes several different assumptions and approaches including the following: grounded theory, phenomenology, narrative analysis and discourse analysis. While a group of researchers are preferring to use one of these traditions, there are others who do not select one of them, rather using "generic" and unlabeled qualitative methodology (Thomas, 2003). Thomas (2003) defines general inductive analysis as, "a systematic procedure for analyzing qualitative data where the analysis is guided by specific objectives" (p. 238).

In this study, a general inductive coding method was used and proposed process of David Thomas was followed. First, the raw files were prepared with a common format to prepare them for analysis. All recorded data were transcribed in MAXQDA, a software for qualitative and mixed methods research. Then, coding started with close and systematic reading of the text in order to gain an understanding of the details and possible themes in the documents. Thirdly, regarding the aim of the research and the literature, general categories of information were identified. Meaningful units were selected and labelled with relevant categories. Where necessary, memos were used with the aim to specify links or associations about the related segment. Smaller or lower level categories were then assigned, after making multiple readings of the raw material. Using the specific segments and wordings of the participants, "in vivo" codings were used also. As Thomas argues, there were segments that were coded with more than one codes, and there were some segments that was not even coded, since the parts were not relevant with the aim of the study (2003). Revisions, and continuous reading of the material went on, and lower level categories were started to be grouped regarding their meaning. Related subtopics were combined, and the number of codes were diminished. The grouping continued until the list was reduced to more generalized themes.

The analysis process was done by two separate coders in order to protect interrater reliability. First, the coding was done individually, and then two came together with the purpose to discuss their thoughts and findings. The core categories were set by consensus.

RESULTS

In this study, tuberculosis patients described their experiences related to the diagnosis and shared retrospective and current information about their life regarding social, physiological and psychological states. In order to gain another insight about the disease, doctors working at dispensaries shared their opinions and knowledges about patients, in relation with the diagnosis and treatment process. Furthermore, the focus group discussion provided additional information on the thoughts, attitudes and approaches of non-patients about tuberculosis disease and patients.

In this section the results from the analysis of 24 patients will be presented in addition with the results from the examination of 8 doctors and the focus group discussion. First, detailed information about each patient will be given regarding their demographics and personal history in order to provide more detailed information about their experiences. Second, the emerging categories from the interviews will be listed. Themes will be presented regarding the research questions described in the methodology chapter which include the changes after disease, the consequences of the changes and the coping mechanisms. Describing each category, narratives will be given using quotations from the interviews. Third, an overall picture of tuberculosis patients will be explained to have an overview.

3.1. INDIVIDUAL DESCRIPTIONS OF THE PATIENTS

In this section a brief information about each participant will be provided, including their demographic information and observations of the researcher regarding their state of being during the conversation. Numbers are used to name each patient, in order to maintain their confidentiality.

Table 4: Types of TB and time since diagnosis

Patient	**Diagnosis**	**Time**	**Patient**	**Diagnosis**	**Time**
P1	Atypical TB	2 months	**P13**	Multi Drug-resistant TB	2 years
P2	Pulmonary TB	1 week	**P14**	Pulmonary TB	2 months
P3	Pulmonary TB	2 months	**P15**	Pulmonary TB	1.5 years
P4	Pulmonary TB	4 months	**P16**	Pulmonary TB	6 months
P5	Pulmonary TB	3 weeks	**P17**	Multi Drug-resistant TB	2 years
P6	Pulmonary TB	3 months	**P18**	Pulmonary TB	6 months
P7	Pulmonary TB	9 months	**P19**	Pulmonary TB	3 months
P8	Pulmonary TB	2 weeks	**P20**	Pulmonary TB	2 months
P9	Pulmonary TB	5 months	**P21**	Pulmonary TB	1 year
P10	Pulmonary TB	2 months	**P22**	Pulmonary TB	1 week
P11	Pulmonary TB	2 weeks	**P23**	Pulmonary and Extrapulmonary TB	2 months
P12	Pulmonary TB	3 months	**P24**	Drug-resistant TB	7 months

3.1.1. Patient 1 (P1)

P1 is a 43-year-old man living in Üsküdar. He is diagnosed with atypical tuberculosis 2 months before the interview date. He got the diagnosis when he consulted to the dispensary for marriage report with his foreign national partner.

The dominant themes in his interview were the issues during the diagnosis process, disclosure about his disease, his search about the reasons of tuberculosis, economic and work related issues along with his disappointment by others. He described the period before the diagnosis in detail and the diagnosis itself as a "surprise". One of the major difficulties he faced was the irregular form of his disease, which is seen very rarely in the population. He could not have a clear description from his doctor, nor from any tuberculosis facility about his treatment. Even, his medication was not showing any assurance about his recovery. This was one of the reasons of the process' uncertainty. Besides, along with the disease his partner wanted to be separate from him, and went back to her country. He talked about her distant behavior along with his lack of support from the family and relatives. He has two children, but they live apart from him in the house of their mother, so the separate lives could not afford him a powerful support system. He wanted to talk about his family issues, and described his background and problems with his ex-wife. He defined his current life with uncertainty, and he explained problems at work. He was working as a private driver, and he had to tell his boss about his disease, regarding his close contact with him and the other workers of the company. He shared his concerns about infecting others with me, but at the same time he explained his concerns about making a disclosure with them. He was afraid of others' judgment and stereotypes about the disease. He told me that he disclosed everyone in at work, however he was distressed about the attitudes of the workers, such as cleaning his properties secretly, keeping away from him, and their questions about contamination. Furthermore, he was feeling that his boss wanted to send him to another place, far from himself which made P1 alone and rejected.

During the interview he seemed friendly and very willing to describe his experiences about the diagnosis process. Even before the meeting with me, his doctor told me about his enthusiasm about the interview. He answered the questions with many details, shared his past experiences and stories about his family. At several moments he seemed tired and sad, but in general his eagerness dominated the interview. When explaining confidentiality, he said that he has nothing to be afraid of, and that I can use his name if necessary. He mentioned his will to help other tuberculosis patients with his participation. In addition, during our dialogue his use of humor and laugh was worth of attention.

3.1.2. Patient 2 (P2)

P2 is a 30-year-old man living in Üsküdar. He is diagnosed with pulmonary tuberculosis 1 week before the interview date. He consulted the dispensary regarding his ongoing cough, by taking his brother’s past tuberculosis diagnosis into consideration.

The most frequent themes in his interview were his concerns around infection, making disclosure about his disease, and his concerns about doctors and tuberculosis facility. He mentioned his brother who had been through a tuberculosis treatment seven years ago, in the same dispensary that now he is under treatment. He could not describe any feeling about this experience, nor about his own. He frequently compared the diagnosis with his early life experiences such as his criminal background and his years in the prison. He told that it is impossible for him to be influenced by an disease. On the other hand, he had concerns about being stigmatized with the disease, just like his stigma as a criminal. He described the attitudes of other people, and society’s reaction to tuberculosis. He mentioned that he did not choose to share his diagnosis to people around him, but only with his close relatives. In general, his criminal story was at the center, along with his aggression throughout his life.

The interview was made outdoors regarding his early stage of disease and risk of contamination. He wore a mask during our conversation and at several times he mentioned the difficulty of using the mask. He asked questions about the study in the beginning, and wanted to know the benefits of participation. In general, he was indifferent but cooperative; he answered the questions briefly and did not provide very detailed information negative experiences, his affect was restricted. In addition, I advised him to take a psychiatric consultation at the end of the interview, he seemed very positive and wishful about this idea.

3.1.3. Patient 3 (P3)

P3 is a 48-year-old man living in Üsküdar. He is diagnosed with pulmonary tuberculosis 2 months before the interview date. He got the diagnosis after a long process of examination in different hospitals, which he consulted at the beginning with complaint of chronic cough.

The dominant themes of his interview were his low hesitation to disclosure, his reactions to diagnosis process and the diagnosis itself, and appreciation to other's support. P3 described that he had consulted to many doctors and hospitals with his symptoms, however he could not get any clear information about what was going on. He visited several departments of the health facilities, blood tests and biopsies were done. At the end of six months, he was transferred to a dispensary and got tuberculosis diagnosis. He described his reaction to the diagnosis with a feeling "chilly". He mentioned the support of his wife during whole procedure, and he appreciated the support from his family. He had no hesitation to tell his disease to anybody. He thought that the society knew the disease, and did not have any negative attitude towards tuberculosis. He knew the progress about the disease, and he heard supportive comments from his environment. He did not define any specific changes after the diagnosis. When I asked the perspective of the society about tuberculosis, he mentioned positive changes during the history and believed that people gained knowledge about it. He did not explain any negative behavior or attitude, he made a comparison between tuberculosis and influenza.

At the beginning of the meeting, his wife wanted to participate to the interview. She told that they experienced the process together from the beginning. I told her that I had to talk with him in private, however her will to participate and talk about the disease was interesting. During the interview, P3 mentioned the support of his wife and he was thankful to her. Overall, he described positive feelings and he seemed hopeful about the disease, he was cooperative. Furthermore, his close relationship with the doctor and other employees of the dispensary was apparent before and after our interviews.

3.1.4. Patient 4 (P4)

P4 is a 26-year-old woman living in Beykoz. 4 months before the interview she was diagnosed with pulmonary tuberculosis. She got the diagnosis when she went to doctor to take a prescription for her regular medication of asthma.

The major topics of her interview were psychological consequences of the diagnosis, her appreciation of others support, the difficulties she faced during the diagnosis process and the problems she faced during that stage. She defined the diagnosis as a “miracle” and described how it was coincidental. Before learning that she was a tuberculosis patient, she suffered from asthma and regularly went to her doctor for control and medications. During one of her controls, her doctor wanted to see her lung roentgen and saw a spot. She then went to other hospitals for consultation, however it took 1.5 months to reach a conclusion. She defined the process as very exhausting and abrasive. In parallel, she frequently told about the misbehavior in government hospitals. She mentioned that she found the necessary support in the tuberculosis dispensary and showed her appreciation to its doctors. She also described her shock when she heard her diagnosis, she said that she could not associate the disease to herself. She related the diagnosis with a process of adjusting oneself to death, she compared tuberculosis with cancer and she depicted a hopeless picture. P4 also expressed the difficulties she encountered at her work. She worked in food industry, generally in the industrial kitchens. She had to quit her job regarding the contaminating feature of tuberculosis, and she could not find another one even after the infectious period of the disease was over. She mentioned the difficulty of finding a job in food industry as a tuberculosis patient. She did not define any negative attitude from her environment besides her work and distant relatives. She explained that she had a supportive family, friends and boyfriend, however she described her sadness about her job. She felt the isolating behavior of her co-workers, even if this was not verbalized.

During the interview P4 was very cooperative, willing to share her experiences and emotions. Her mood was anxious and her affect was variant. Our interview was disturbed by the staff, however she did not lose her attention and she could easily continue to share her experiences. In general, she was clearly showing her emotions during the conversation and was open to examine her experiences.

3.1.5. Patient 5 (P5)

P5 is a 45-year-old man living in Beykoz. He is diagnosed with pulmonary tuberculosis 3 weeks before the interview. He got the diagnosis after his own consult to the hospitals with the complaint of difficulty in breathing.

The major themes of his interview were the issues related to diagnosis and treatment, his concerns around infection and difficulties about disclosure. In the beginning of the conversation, he described the process until the diagnosis was clearly made. During the long and exhausting process, he went to several hospitals, and different tests were made in order to name his problem. When he learnt the disease, he had to quit his job and kept it as a secret from his family, especially to elderly. He explained it as making an emphasis on the perception of tuberculosis, and found it very difficult to explain to his mother. Another interesting detail was the form of his disease. Doctors told him that he was not infectious, so that there is no possibility of contaminating others. However, he was very anxious till the beginning of the disease, and during the interview when contamination was taken into consideration. He mentioned his fear of infecting others, also he was thinking about the reasons of tuberculosis. He explained the changes at home, such as separating his own fork and knife, as well as other kitchen materials. Furthermore, he was worried about the hygiene of the medications that he was taking from the dispensary. Generally, he said that he had a supportive family and that they were very much worried about him. At the end of the interview, he said that the government should inform the society about tuberculosis and educate people about its features, so that everyone can take care of themselves and make their health routines.

During the interview, P5 was talkative and was open to cooperation. His anxiety about certain topics such as contamination was apparent during the interview. His expressions and wording was demonstrating his preoccupation about hygiene, infection and possibility of infecting others. In general, he did not hesitate to answer the questions and show his emotions on the topic.

3.1.6. Patient 6 (P6)

P6 is a 47-year-old man living in Beykoz. 3 months ago he is diagnosed with pulmonary tuberculosis after his consult to health care facilities with a symptom of chronic cough.

During the interview of P6, the dominant themes were appreciating others support, managing the disease and his problems about work and economy. He described the early phases of the disease, with the symptoms of weight loss, transpiration and cough. As describing the disease, he always added to emphasize his wife’s support for him with his appreciation. Her support included psychological encouragement and backing him up with healthy food. When explaining the causes of the disease, he told that his father was a tuberculosis patient also. However, he did not think that he was contaminated from him, interestingly he hesitated to blame his father. He added that he was used to look after a patient, so that it made him familiar to the process. When asked about his feelings about the diagnosis, he did not define any specific emotion. Rather he explained indifference, emotionlessness and lack of fear. In addition, he described the changes in the house. His daughter’s interest on his disease, made her research about it, and she began to clean the house every day, continuously. They started to wash the clothes frequently, open the windows every time and make food lists for P6. He saw the changes as an advantage for him, and was happy about those precautions. During our conversation, he also told about his family background and the issues he faced with his brother. In that context, he explained his feelings towards his sister, which he saw as a mother, including guilt and shame about the disease. He did not want to make them sad and anxious about his health problems. Moreover, he believed that the society was informed about tuberculosis and there is not so much people who would be prejudiced against the disease. He emphasized the developments in the health system and his satisfaction with doctors.

Overall, he was talkative and cooperative during the interview. He was willing to tell details about whole process and express himself. He talked with excitement and his talk was fast. Also, his preoccupation with germs, cleaning and health was remarkable.

3.1.7. Patient 7 (P7)

P7 is a 55-year-old-man living in Kartal. He is diagnosed with pulmonary tuberculosis 9 months before the interview date. The diagnosis was made after his consult to the hospitals with weight loss.

The major themes of his interview were his distress about self-disclosure and his concerns around infection. In the beginning of the meeting he described his complaints before the diagnosis and said that he was treated in the hospital for a month, as an in-patient. When asked about his feelings during the diagnosis and treatment in the hospital, he did not define any negative feelings, rather he saw the disease as a fate. He got the diagnosis when he was alone, and he did not talk about any relatives during the interview. He was living by himself at home, and did not want to inform anybody about the process. Even, he did not share his disease with his ex-wife and children, living in another city. He described a lonely and isolated process after he got out from the hospital. He stopped talking to neighbors, quit his job and did not continue his routines in his quarter. He was afraid of infecting the others with his disease, and prevented the neighborhood when they wanted to contact him. The only people that knew he was sick was his friends from work, but they knew that he was suffering from leg pain. After the issues about disclosure, he explained his thoughts on society’s view of tuberculosis. He did not believe that there was a negative attitude towards the patients, and he compared the disease with influenza. He also compared today’s circumstances with past years, as telling about his aunt-in-law tuberculosis diagnosis, who died from that disease. At the end of the conversation, he recommended the patient to be indifferent and uncaring towards the disease in order to make the process manageable.

During the interview, he was quiet and did not answer the questions with many detail. He talked very briefly and he was looking tired. His simple description was in contrast with the intense feeling of sadness during our talk. His loneliness was salient.

3.1.8. Patient 8 (P8)

P8 is a 34-year-old man living in Kartal. He is diagnosed with pulmonary tuberculosis 2 weeks before the interview date. He got the diagnosis after his own consult to the hospitals with the complaint of phlegm and chest tightness.

The dominant themes of his interview were the changes he faced after the disease, the problems he experiences during diagnosis and treatment, and his concerns around infection. In the beginning, he wanted to explain the story from the beginning and described his job, the conditions of his workplace, his environment, nourishment order, and the loss of his father which was very new. He related his disease with all these factors, and most importantly with the environment after his loss such as funeral and crowded family visits. He frequently questioned the reasons of tuberculosis and possible variations of the contamination. Furthermore, he was unhappy about the number of medication that he used to take every day, as well as the DOT system. He saw himself as a conscious and well-mannered patient and declared that he could have his medications on his own. He had complaints about DOT workers and their behavior. On the other hand, he described the positive changes after the disease. He told about his daily routine, and the advantages of walking in the morning, eating regularly on specific hours. When I asked about his initial feelings about the diagnosis, he explained his shock and his attitude towards the disease relating it with dirt, low SES and bad conditions. He also shared his opinion about society’s attitude towards tuberculosis. He did specify a single event about one of his colleagues who did not want to come across to him after the disease with the fear of infection. In parallel he believed that people saw the disease as a witch or bugaboo.

During the interview he was very talkative, and he provided one of the most detailed explanations to me. He was anxious about certain topics such as infection and he was trying to find a meaning to the process. When we first met, he asked many questions about me, and the study. Similarly, at the end of the conversation he asked my opinion on him and his health, as well as his psychological well-being. When I explained my position as a researcher, he asked again and he was also curious about the other patients and their disease.

3.1.9. Patient 9 (P9)

P9 is a 21-year-old man living in Kartal. He is diagnosed with pulmonary tuberculosis 5 months before the interview date. He got the diagnosis after his own consult to the hospitals with the complaint of severe pain and shortness of breath.

The major theme of the interview of him was searching for reasons of tuberculosis and the changes after disease. He, as a sportsman, described the physical changes during the early phases of the disease. He lost thirty kilograms during the initial period, and lost his energy. When he went to a big hospital, he was diagnosed with pneumonia. He used his medications, however the symptoms were not healing. After the pneumonia treatment, other tests were done and when tuberculosis was understood he was transferred to dispensary. He mentioned that he knew anything about tuberculosis when he first heard about it. He was panicked and started to notice other physical changes such as whitening of his face. After the diagnosis he quit playing football, and started to take his medications which was very difficult for him. Another major change was the move to is mother's house. When I asked the reason, he described his father's busyness and inability to look after him. He explained that it would be better to live a mother during the disease when health and nutrition is concerned. He changed his daily routine and started to eat sensibly with the support from his mother. He was also satisfied with the support of his friends, and told that they were very much interested and concerned about him. He reminded the words of his doctor about the importance of stress during the healing process and described his obsessions about daily life. He questioned the effect of obsessive thinking on the development of disease and showed the importance of mental health.

During the interview he was very cooperative and compatible. He seemed honest and he was wishful to be helpful for the study. He was confident with himself and he believed the power of treatment. Overall, his physical and psychological strength was high, he was hopeful.

3.1.10. Patient 10 (P10)

P10 is a 63-year-old man living in Ümraniye. He is diagnosed with pulmonary tuberculosis 2 months before the interview date. His interview was made on the first day of his transfer to dispensary from hospital. He got the diagnosis after his own consult to the hospitals with perspiration and loss of weight.

Major themes of his interview were his concerns around infection and his disappointment about other's support. He described the process before final diagnosis as very complex and tiring. Initially he was told that there was a risk of cancer, and then he was diagnosed with chronic obstructive pulmonary disease (COPD) and tried to be treated as an in-patient. After 3 days, he was tested again and tuberculosis diagnosis became clear. The doctor asked him if he had tuberculosis during the childhood. When P10 asked his mother about it, he learnt that there were six children in their village who had the disease and were dead. He was surprised with that information and with the severity of his disease. When he first learnt about the disease, he felt anxious and questioned the reasons of it at the age of 63. He tried to reason it with his belief in faith. After the diagnosis, he stayed in the hospital for 2 months. When I asked what was it like to be an in-patient, he described the atmosphere as telling me about suffering people. Patient were vomiting and dying because of the disease. He saw many distressed people, and portrayed the storied of them. He was badly influenced from them, and his mind was occupied with the reasons of tuberculosis, he was asking the question "why". He explained his concerns about infecting others as well as feeling like an outsider. He experienced anxiety of the people in hospital when they saw him with the mask. He was not afraid of death, but contaminating his children. Furthermore, he said that he could understand the thoughts of the others, that they wanted to be separate from him. Even he felt that his wife would like to separate his plate, fork and knives and started to ask for separation. He recognized his wife while opening the windows so he felt the concern of her. His children wore mask when they came to visit him, but this won't help calming him down about infection. In addition, he frequently added the lack of support from his family including his own mother and father.

P10 was different from other patients in terms of his duration of treatment in the dispensary. It was his first day and we made the interview right after his entrance was made in the facility. During the conversation, he talked on the phone twice with his son. He explained the process in the dispensary and recommendations of the doctor. Overall he was cooperative.

3.1.11. Patient 11 (P11)

P11 is a 26-year-old man living in Ümraniye. He is diagnosed with pulmonary tuberculosis 2 weeks before the interview date. He got the diagnosis after his own consult to the hospitals with loss of weight and physical weakness.

The main themes of the interview were the concerns about disclosing and reacting to diagnosis. When I asked about the diagnosis process, he told that he had doubt about his own health, and regarding his physical symptoms he consulted to the hospital. He was asked for lung roentgen and next day his doctor told him to be treated as an inpatient. However, P11 did not want to stay at hospital, because of his negative experiences during the childhood. He wanted to be outside and had to take care of his diabetes during the process. When he first heard about the diagnosis he felt sad but, he did not attempt to rise against fate. He told that he thought about other people who have worse disease than tuberculosis. He also described his feelings about diabetes, and its effects on his daily life, which made him feel tired of being in hospitals. He also told me his experience about tuberculosis by witnessing his father, aunt and grandfather. The family history of tuberculosis made the patient more aware about the disease and its effects on the body. Relatedly, all these diseasees made him ask the question “why”, however he told that he did not remember his father and aunt when they were sick. Furthermore, he mentioned about the support he had from his family and friends. He told that he sometimes felt entrapped by his mother’s attention about his disease, especially about his nutrition routine. Besides the support, when I asked about the view of society about the disease, he talked about the society in two ways: one side with awareness, and the other side who do not want to be next to patients because of their fear of infection. He gave examples from his life, describing his coworker’s attitude, who were asking him about their risk of contamination and isolating themselves. He also felt responsible and guilty for them, and hesitated to make disclosure about his disease to everybody. He sometimes compared and contrasted diabetes with tuberculosis in terms of their importance.

During the interview he was short and clear when responding the questions. He did not seem very willing to talk long, which made our conversation very brief. Overall, he seemed happy with the treatment and satisfied with the process. He was also cooperative with me like the others.

3.1.12. Patient 12 (P12)

P12 is a 48-year-old man living in Ümraniye. He is diagnosed with pulmonary tuberculosis 3 months before the interview date. He got the diagnosis after his own consult to the hospitals with physical weakness, having difficult to walk and shortness of breath.

The main themes of our interview were perception of tuberculosis in society and his thought about doctors. In the beginning he described his consult to the family practitioner with his symptoms and his transfer to hospital. Then he talked about the process in hospital, including tests and examination. He first told that he might be cancer, so when he was first diagnosed with tuberculosis he felt sad, shocked but released. He was released that there was a treatment for that disease, and heard similar calming explanations from his environment. In parallel, he talked about the support of his family. However, he mentioned the bad reputation of tuberculosis in the society. He explained people’s behavior against the patients including himself. He told me about his relatives, who used to come to his house regularly and he described their isolated behavior after the diagnosis. He also talked about the difficulty of wearing a mask in public places.

During the conversation he was talkative and cooperative. He frequently mentioned his satisfaction with doctors and dispensary staff. He also added his opinion about the doctors at the hospital and made negative comments about them. He was open to describe his inner world, his psychology, feelings and thoughts.

3.1.13. Patient 13 (P13)

P13 is a 27-year-old man, living in Kadıköy. He is diagnosed pulmonary tuberculosis first in 2007 and got treatment. 2 years ago he got diagnosed with multi drug-resistant tuberculosis (MDR) and his control sessions were continuing during our interview date.

Main themes of the interview were changes after disease, appreciating other's support and experiencing discomfort in others. In the beginning he told about his disease in 2007. He was treated as an inpatient for 45 days, and then he was under treatment for 6 months. 2 years ago, he started to feel weak and with the suspicion of tuberculosis recurrence he went to the hospital in which he got MDR diagnosis. He was treated first for 2 months, and then he went into hospital for 60 days. When he was out from hospital, he had a break from work for ten months with a health report. When he was back to his work, he could not get enough support from the personnel. He felt the negative thoughts of other people even if they did not tell explicitly. He also heard questions from his coworkers about the risk of contamination. The personnel were concerned and very anxious about being infected. He was very upset and called the boss to consult him. He w supported his treatment and warned the personnel about their behavior. However, P13 was really influenced by their prejudgments. When he was back to work, he could not feel comfortable with the others, he became preoccupied with the thoughts of other people. He started feel himself isolated from others and heard his friends' silent judgements. He wanted to quit the job, but his boss wanted to help him, and make his transfer to another department. He became happier with the new people; however, he did not forget his experiences. Furthermore, he gave detailed information about the both diagnosis process as well as the treatment. He also wanted to share the results of his first diagnosis which was during his high school years. He described his isolation from school and his sufferings because of other people's behavior towards him.

During the interview, he was very talkative and cooperative. He was very willing to share his history with me. At some points, he started to cry. At the middle of our conversation we stopped the recording because of his emotional state. I remember myself feeling his sadness, hopelessness and disappointment at them same time with him. It was one of the most sensitive interviews. He was very thankful at the end and told that the interview made him feel better. I informed him about psychotherapy at the end.

3.1.14. Patient 14 (P14)

P14 is a 53-year-old man living in Kadıköy. He is diagnosed with pulmonary tuberculosis 2 months before the interview date. He got the diagnosis after his own consult to the hospitals with the complaint of continuous cough.

The major theme of his interview was the awareness of tuberculosis stigma. He first described the earlier phases of the disease and his transfer to the hospital from dispensary. He was treated as an inpatient for 39 days, and his treatment continued regularly when he come out of hospital. Then he explained that he was alone when he first heard about his disease and that he felt as an outsider. He had difficulties about disclosure, and he told the others that he had spot on his lungs. He chose to tell people with high education, who supposed to understand him but not the others, because he thought high educated people would comprehend him. He also isolated himself from the society, and did not want to meet anyone. In addition, he described the biased behavior of the nurses and doctors at the hospital,that made the patients feel terrible. He portrayed the bad conditions of the hospital, and told everything that he disliked about the place. Moreover, he described his living circumstances that he did not have a home. He wanted support from the government, considering his disease.

During the interview, he was cooperative with me. He showed several emotions throughout our conversation, including anger, sadness and hopelessness. He also shared his psychological problems and discussed its possible solutions.

3.1.15. Patient 15 (P15)

P15 is a 22-year-old woman, living in Kadıköy. She is first diagnosed with pulmonary tuberculosis when she was 15 years old. Her second diagnoses with pulmonary tuberculosis was 1.5 year before the interview date, in Kars. She got the diagnosis after her own consult to the hospital with the complaint of back pain. She was treated for 20 days as an inpatient. When she came back to İstanbul, her treatment continued. The interview was made after her treatment, while she was at the dispensary for routine control.

The dominant themes of her interview were family history of tuberculosis and predicting discomfort in others. The first thing she told was the tuberculosis diagnosis of her brothers. She described the atmosphere of the house when one of his brothers was diagnosed with tuberculosis. She remembered whole process, including his days at the hospital and the emotions of her family. She also talked about his other brother who was under treatment at that time. She said that she checked him in order to know whether or not he is using his medicines. When I asked about feelings about her own diagnosis, she could not define any emotion about the first diagnosis. She described the second diagnosis as worse, with more detailed sentences. She portrayed the physical effects of the disease and using medicines. She usually mentioned the importance of psychological well-being and positive thinking in the healing process, and added the effect of familial support system. She especially gave importance to the support of mother, and told that her mother had died a year ago. She shared her fear about having that disease again without her mother, and her support. When talking about the opinions of nonpatients, she depicted that she could understand the feeling of other people about her. She could understand their cold behavior, without any words. She shared her own experience, telling the isolating behavior of her boyfriend’s sister with the fear of being infected. At the same time, she could make empathy with them and understand their anxiety of contamination. Furthermore, she talked about her satisfaction with the dispensary personnel, and their warmth like a family. She told that she could get well with their support and stability.

During the interview she was very cooperative. She described her experience as providing many details, including her feelings. At the same time, it was not difficult to see her emotions on her expressions. Besides her story, the most striking thing was her gratitude towards the dispensary doctor and nurses.

3.1.16. Patient 16 (P16)

P16 is a 32-year-old man, living in Pendik. He is diagnosed with pulmonary tuberculosis 6 months before the interview date. He got the diagnosis when he consulted to the dispensary to obtain health report for insurance company.

The major themes of the interview were getting diagnosed and the reactions to diagnosis. At the beginning of the conversation he talked about the early phases of his disease, and the diagnosis which was a shock for him. He told that he was not expecting any disease, and that he could not accept it in the first place. When the diagnosis was clear, the doctors told him to have medication immediately, however he did not want to be treated. He explained this rejection with the unacceptance of the disease. After several months of rejecting the cure, he was called by the health practitioner and was forced for treatment. He talked about his fear of being under treatment in the hospital as an inpatient. When I asked the reason of it, he told me that he did not want to be on his own and think continuously about his problems. He also mentioned his addiction to work. However, he did not give much information of her environment, his support system or reactions of the others.

During the interview, he was not talkative and did not seem very willing to share his experiences. He seemed nervous and shy, and started to bite his nails when I asked the questions. I tried to be more active and motivate him for talking, however his timidity was permanent. Our conversation lasted very short.

3.1.17. Patient 17 (P17)

P17 is a 41-year-old woman, living in Pendik. She is diagnosed with multi drug resistant pulmonary tuberculosis (MDR) 2 years before the interview date. She got the diagnosis when she consulted to hospital with the complaints of night perspirations, cough with phlegm and physical weakness.

The dominant themes of her interview were concerns around infection, changes after disease, reacting to diagnosis and concerns about disclosure. In the beginning she described the process before tuberculosis diagnosis. She went to the hospital with her complaints, tests were done in order to understand it. However, she was diagnosed with asthma and used medications. When she could not get feel better, she visited other health care facilities, and after several months she ended up in a dispensary. She was transferred to the hospital, and had treatment as an inpatient for 2 months. Her treatment continued after the hospitalization. When I asked about her reaction to diagnosis, she told me about her shock and confusion. She thought about the possibility of death and well-being of her children. She talked about the difficulties of being drug resistant and how it affected the duration of treatment. She also talked about her psychology and that she used psychiatric medication during the last year of tuberculosis treatment. She felt useless and insufficient, she could not express her emotions to no one. She had to wear mask and thought that she should isolate herself from the others. Her mind was preoccupied with others and her perception of self was damaged. Meanwhile, her psychological treatment was effective, she mentioned the positive effect of psychological support. Another difficulty she faced was her concerns about disclosure. She informed her parents and close relatives, however she hesitated to tell the others. She was afraid of their thoughts, prejudices and she did not disclose in order to protect herself. However, she could also make empathy with them, understand their anxiety about contamination and did not want to scare them. Furthermore, she changed her mind about his work area. Considering the dirty and dusty atmosphere at textile factories, she wanted to find another job after her treatment. Another change was the difference in her house. When she was in the hospital, she could not take care of household and she was concerned about its cleaning. Also, her children were influenced by the absence of their mother, and started to react differently. Lastly, her wish about sexuality was decreased after the disease.

During the conversation she was talkative and seemed willing to answer my questions. There were times that she felt weak and she cried. Her preoccupations about her health and the treatment process was obvious. Overall, she was cooperative.

3.1.18. Patient 18 (P18)

P18 is a 33-year-old woman, living in Taksim. She is diagnosed with pulmonary tuberculosis 6 months before the interview date. She got the diagnosis when she consulted to hospital with the complaints of ongoing cough.

Major themes of her interview were about getting diagnosed, psychological consequences of the disease and searching for reasons of tuberculosis. She was first diagnosed with bronchitis and used medication. Her second doctor was suspicious about pneumonia and asked for tomography. After a while, her doctor told her about the tuberculosis diagnosis, explained the difficult proves that would begin for her treatment, and transferred to a dispensary. She did not know anything about the disease, and was very surprised. When she was out from doctor's office she could not find her way, she was lost and called her husband on the phone to ask for help. Her husband described the route and calmed her down about the diagnosis. During our talk, she described her feelings, and the impact of wearing a mask. She felt disappointed with the possibility of infecting others. The diagnosis and treatment made changes in the house also. She separated her bed form her husband, she stopped cooking, and started to observe other people's behavior. She mentioned the positive behavioral changes of her husband and asked to herself "why". She got support from her family and neighbors. She thought about her children, and get well in a short time. In addition, she mentioned the family history of tuberculosis that was seen in her uncle.

During the interview she was talkative. She looked tired and sad, she cried occasionally. Her concerns were visible, and she was expressive in her emotions. She shared her family problems with me, and her anxiety about her husband. In general, she was open to talk and communication.

3.1.19. Patient 19 (P19)

P19 is a 39-year-old woman, living in Taksim. She is diagnosed with pulmonary tuberculosis 3 months before the interview date. She got the diagnosis when she consulted to hospital with the complaints of perspiration, chill and ongoing influenza.

The dominant themes of the conversation were experiencing discomfort in others, concerns about disclosure and recommendation for others. She described the difficulties about diagnosis process. When she consulted to hospital with her symptoms, she was diagnosed with influenza and had medications accordingly. However, it did not get better and she went back again. The doctor told her that she was exaggerating and that it was psychological. She then consulted another doctor, and she was sent to cardiology, and after to check-up. After the check-up, the doctors could not reach a definite conclusion and transferred her to dispensary. She was very angry about the process and mad at the doctors. She felt underestimated and her voice was not heard. When she first heard tuberculosis, she felt weightless and empty. She also talked about the behavior of friends and family. She complained about the distant behavior of friends when they heard about the disease. She asked for help to me, that if something can be done about the disease. When I asked the kind of help, she proposed a change of the name of the disease. She talked about people's bias against tuberculosis and thought that using another name would help the patients while disclosing. She gave personal examples about difficulties she faced after disclosure. Her 4-year-old nephew started to stand away from her and called her germy. She could not get mad at him; however, she could guess that someone sad negative things behind her back. She also talked about the psychology of her son, that he started crying when he first learnt about the disease. He changed his behavior at home, and tried to be near his mother every time. They have consulted to psychological treatment for their son. The treatment made a progress, but her son continued biting her fingers.

During the interview she was cooperative and talkative. At the middle of our conversation I recognized that her child was waiting just outside the door, and I felt anxious that he might hear our talk. I asked her that we could take him to another place, but she told me that her son was aware of everything and that he was used to hear all the problems they were experiencing. Throughout the conversation she seemed very sensitive.

3.1.20. Patient 20 (P20)

P20 is a 45-year-old woman, living in Taksim. She is diagnosed with pulmonary tuberculosis 2 months before the interview date. She got the diagnosis when she consulted to hospital after she fainted at her house.

Major theme of her interview was experiencing discomfort in others. First of all, she talked about her diagnosis which was very hard for her to believe. She could not associate the disease with herself, looked at her face in the mirror and could not see any sign of disease. When doctors warned her about the severity of disease, she accepted the treatment. Her health report was sent to dispensary form the hospital that the diagnosis was made. She was called from the dispensary and started to take her medication. When I first asked about her feelings about the diagnosis, she said that she could remember the day. Then, I listed some feelings that she might have felt. She told me that she was sad about the disease, and called her mother. Also, she mentioned the difficulties of taking lots of drug, and explained its effects on her. She talked about the support she had from her family, however she did not provide much detail. She did not define any negative behavior, or stigmatizing attitude from her environment. She explained her thoughts about wearing a mask, and clarified its importance of protection for her. She did not have concerns about infecting the others.

Before our interview, the doctor called me and informed me that the patient could be nervous about a study. He said that she might not accept to make an interview with me. Conversely, when we met I informed her about the research and she accepted easily. During the conversation she did not talk very much, and sometimes she could not remember her experience easily. Overall, she seemed happy to share information about herself.

3.1.21. Patient 21 (P21)

P21 is a 34-year-old woman, living in Taksim. She is diagnosed with pulmonary tuberculosis 1 year before the interview date. She got the diagnosis when she consulted to hospital with the complaint of blood spitting.

The major themes of her interview were psychological consequences of the disease and physical effects of treatment. A year ago she was diagnosed with tuberculosis, however a doctor told her that she could not be tuberculosis but another disease about her intestinal system. She used medications according to that problem, but her symptoms continued. After 7 months, she consulted a hospital based on chest diseases and she was transferred to dispensary for tuberculosis treatment. She described her feeling of confusion during the diagnosis process and the difficulties she faced. She also mentioned family history of the disease, that it was seen in her brother and sister. The reactions in the family were normal, with her words, they were used to cope with the disease. Furthermore, she did not want to disclose to everyone near her, because of different advices that they would give. The support from her father, mother and husband was necessary for her, with their help regarding her nutrition and physical weakness. They also supported her, when she was preoccupied with the thoughts of death. They motivate her to be well, and explained the process of the disease regarding the possibility of healing. Considering the early phase of the disease, she defined her mood as depression. She was suffering from physical pain, and she thought of dying in order to get rid of her problems. She could not eat, and did not want to communicate to anyone. She wanted to be alone and isolated, as she was not answering any phone calls. When I asked the opinion of the society about tuberculosis, she told that she did not see any problem. However, she described that the mother of her husband was warning him, to keep his wife separate from the children. Lastly, she did not define any specific change in the house, but she mentioned the separation of forks and knives during her childhood, during the disease of her brother.

During the interview, P20 was talkative and was open to cooperation. Her intense emotions about certain topics such as isolation was apparent during the interview. In general, she did not hesitate to answer the questions and show her emotions on the topic.

3.1.22. Patient 22 (P22)

P22 is a 51-year-old man, living in Şehremini. He is diagnosed with pulmonary tuberculosis 1 week before the interview date. He got the diagnosis when he was taken to hospital after his faint, with the influence of excessive alcohol consumption.

The dominant themes of his interview were changes after disease and concerns around disclosure. First, he described his transfer to dispensary from the hospital, after the diagnosis was made. He explained the procedure, but did not provide any emotion or detail. When I asked about his feeling about the diagnosis, he told that he was indifferent and that this is a part of his character. He defined himself normal, and said that his psychology is fine. When I listed several emotions to him, he explained to me that he was not use to react to anything in his life. Then he compared tuberculosis to his epilepsy, and told that it was normal for him to be a patient. Furthermore, he gave information about his divorce, and that was why he did not want to inform his family about his disease. When I asked more about his disclosure, he explained that he had no need to share it with the others, and also no one was asking. When he became quiet, I asked about his support system, and similarly he told me that he did not need anything from anybody.

During the conversation, he was silent and quiet. He did not show any emotion; her mood was indifferent. He answered the questions very briefly. It was difficult to feel and understand his emotions during the interview.

3.1.23. Patient 23 (P23)

P23 is a 64-year-old man, living in Şehremini. He is diagnosed with pulmonary and extrapulmonary tuberculosis 2 months before the interview date. After a spleen surgery, he consulted to a hospital with the symptom of coughing in which he was transferred to dispensary for treatment.

The major theme of his interview was getting diagnosed. He faced many problems during the diagnosis process and early phases of his disease. He was first diagnosed with chronic obstructive pulmonary disease (COPD) and used medications accordingly. However, his coughing did not support and he came to dispensary in which he was diagnosed with tuberculosis. He could not provide accurate information about his first visit to dispensary, he had difficulty remembering the process. Besides the missing information about events, he talked about his emotions and thoughts. He had concerns about his dreams, and told them to me which was about his father, who passed away a year before. He also shared his anxiety considering the health of his mother and other relatives. An interesting thing was his disbelief about tuberculosis. He was using his medications but he did not believe that he was a tuberculosis patient. With that reason, he did not share his disease to anybody. He felt very healthy, so he could not understand the diagnosis.

During the interview, he was very talkative and cooperative. He wanted to share every information with me, and he seemed happy to be a part of the study. At several times he had difficulty remember the related information. For example, he did not know the name of his diagnosis. I had to learn it from the nurses. Also, he did not know the tuberculosis diagnosis of his wife. He asked questions about his medication and their usage, I explained my title and that he could ask those to his doctor.

3.1.24. Patient 24 (P24)

P24 is a 39-year-old man, living in Şehremini. He is diagnosed with drug-resistant tuberculosis 7 months before the interview date. He got the diagnosis when he consulted to hospital with the complaint of blood spitting.

The dominant themes of his interview were psychological consequences of the disease, managing the disease, and economic and work related issues. In the beginning he described his health problems long before the tuberculosis diagnosis, which started with his military service. Regarding his physical difficulties, he was sent to military hospital and diagnosed with measles. During his controls, the doctor saw a spot on his lungs, however he was not diagnosed with any disease and sent back to military. He finished his service with back pain, perspiration and respiratory difficulties. When he was back to İstanbul, he consulted to the hospital again and the doctor advised him a surgery immediately. His lung was cleaned from “bad blood", but he again was not diagnosed with tuberculosis he quit his job and rested for a year. When he went back to work, the physical symptoms started again, and one day he got worse and was taken to hospital. Doctors made a surgery again, and cut a part from his lung. Then they were suspicious about the possibility of tuberculosis and he consulted to dispensary. He also described his emotions when he learnt about the last diagnosis. He remembered his shock, and disbelief about it. He thought about his symptoms and asked questions to his doctor in order to give a meaning to the disease. He questioned the reasons of tuberculosis and tried to understand how he could be infected. Furthermore, he did not define any difficulty in disclosure. When I asked about the support system, he told that no one was supportive to him, and he was cold to his relatives for a long time. Because of the family issues, and his anger towards his father, his relationships with family was not very strong. Furthermore, he mentioned the lack of knowledge about the disease in society, and its importance in order to support tuberculosis patients. Interestingly, several times, he used "cancer" in the place of tuberculosis.

During the interview, he seemed very willing to share his experience about his disease process. He provided many detail and explained all in his mind. He seemed confused when talking about the diagnosis process, and he shared his psychological pain. The interview room was too small, and we were close. At several times, when he was coughing, I felt anxious but hesitated to manifest myself. At the middle of the conversation, nurses provided another room for us with open windows.

3.2. RESEARCH QUESTIONS

In this section the emerging themes from the interviews will be presented. These themes will be organized according to the research questions mentioned in the second chapter: 1) What are the major experiences of the patients after getting the tuberculosis diagnosis and being under the tuberculosis treatment? 2) How do the patients experience stigma-related tuberculosis? 3) What are the main coping strategies of the patients? 4) What are some factors that account for the possible variations in the experiences of persons diagnosed with TB? The data was analyzed using general inductive analysis concepts and methodology.

Table 5: Main Themes

Question Number	Themes
1	Physical Changes Social Changes Psychological Changes
2	Perception of TB in Society Self-Stigma Self-Disclosure Problems About DGT
3	Selective Disclosure Isolation Distraction Information Seeking Humour Religion
4	Time Since Diagnosis Family History of TB Support System Demographical Information

3.2.1. Research Question 1: "What are the major experiences of the patients after getting the tuberculosis diagnosis and being under the tuberculosis treatment?"

Three main headings emerged from the answers of the patients to the first question: physical, social and psychological experiences. Although all patients had unique experiences of tuberculosis, there were many common points in their stories concerning these three headings. They all had physical symptoms related with the illness and described these in detail. These included bodily changes after the illness, and the symptoms related with the use of drugs during first stages of the treatment. All of them explained social changes and several subthemes emerged including, social support, wearing mask, economic and work related issues, and predicting or experiencing discomfort in others. Patients also described the psychological changes they encountered as a reaction to diagnosis. Not only the diagnosis, but also other stages of the disease made psychological changes. However, for the sake of the second question, the first one will only cover the process of diagnosis.

3.2.1.1 Physical Changes

All patients gave information about the physical changes they combatted during the tuberculosis process. The physical experiences they described were mainly about two different stages of the illness: early stages of the disease before or during the diagnosis process, and throughout the treatment. Each one will be described below using quotations from the patient interviews.

Physical Changes Before Diagnosis:

When they were asked to describe how they were diagnosed with tuberculosis, almost all of the patients started to talk about bodily changes and physical difficulties they experienced. The changes during the process before diagnosis mainly included major symptoms of tuberculosis such as difficulty in breathing, weight loss, cough, cough with blood or phlegm, fatigue, loss of appetite and night perspiration. 10 patients mentioned cough as one of their major complaints. 7 patients talked about weight loss; phlegm, perspiration, pain in different areas of the body and problems about breathing were described by 4 patients when they were asked to talk about their experience. Fatigue was mentioned by 3 of them. P6 described his ongoing cough and a huge weight loss. He also shared his emotions accompanying the symptoms.

> I was coughing, but it was a dry cough. Like it was making fun of me. There was no phlegm or anything but only cough… I suddenly lost 10 kilos in 2 weeks…I was 52 kilos. In 10 days. I felt bad. With that sudden weight loss, my body got out of balance…My voice was gone. (P6, line 9-16)

P7 was a male patient who was treated in a hospital for a month. He also mentioned loss of weight, but added on by indicating his difficulty of breathing and physical incapability during the early phases of tuberculosis. P8 talked about his complaints about lung and spitting phlegm with blood.

> I felt that my lungs were full of something. It was full… I was spitting out blood with phlegm 3-4 times a day. I felt like they were coming out from a part of my lung. (P8, line 70-76)
>
> I was losing weight continuously, losing weight…I stayed in the hospital for a month, I also used medications after the hospitalization…We lost weight, I was feeling weak, having difficulty while breathing. Then I lost my ability to walk. (P7, line 12-16)

The symptoms could be so painful for the patients that they were influencing the daily routines.

> I could not stay at home, I could not lie down, I could not turn left or right in bed. Because of my back pain. I was whining, screaming, crying. (P15, line 50-52)

Most of the participants reported that they consulted a health care facility, considering their physical complaints with their own request. It is important to note the difference between the approaches of the patients to their symptoms, and the duration to decide consulting to health facilities. For example, P9 described his early symptoms and told that he first related them with excessive physical work, getting cold or problem with teeth. He waited for a while and tried to treat it on his own, then he consulted a doctor when the symptoms were persistent.

> It was happening during the nights. A strong pain was shooting through the back of my left leg… I used blasters, I thought it was a cold, but it continued…dry cough, fever in the mornings, and I was sweating unexpectedly. Then I lost weight. While I was 103 kilos, in 3-4 months, I turned out to weight 75. I thought it was from playing soccer…in the shower I tasted blood. I spit and saw blood. I thought it was coming from my teeth…then it continued after every workout. Then I decided to go to a hospital. (P9, line 19-29)

However, there were also patients who consulted the hospitals of dispensaries immediately. P11 described his complaints symptoms and he was right about his decision. A similar story was explained by P13, in which the patient’s suspects about his health revealed true and tuberculosis diagnosis was made.

> This month. I suspected myself… I wanted to come here and have an x-ray, and I was not mistaken. The next day, the treatment began. (P11, line 8-10)

> 2 years ago, it started like a cold, I suspected myself, since I was diagnosed before. (P13, line 10-14)

There were others, who were diagnosed without having any physical symptoms that they were aware of. They were diagnosed while being under treatment for other disease, or while they consulted a dispensary with the need to obtain a health report. P4 learnt her diagnosis with the help of her asthma doctor, who focused on a symptom in her lungs. P1 was preparing for marriage and had to complete the health procedure. The lung x-ray revealed that he had tuberculosis which was a shocking experience for him. P16, similarly, wanted to obtain health report for an insurance company and he also experienced it as a shocking moment.

> It was like a miracle, I learned it as a coincidence. I am an asthma patient. I went to my doctor, which I normally do not… There, my doctor told me that we should leave asthma aside, and that he saw a blot… after, the process till the final diagnosis was so painful. (P4, line 11-16)

> The diagnosis was a surprise. I was preparing for marriage. A health report was necessary for the procedures…When I went to have my results from the dispensary, the doctor told me that I had a problem in my lungs. (P1, line 15-19)

> I needed a health report for insurance. They asked for a lung x-ray. When I came here, they told me that I had tuberculosis. I was shocked…It felt bizarre. (P16, line 11-13)

The descriptions of doctors were similar with the stories of patients on consulting the dispensaries. D4 grouped the patients in three.

> Three types of people come here. People who want to obtain a health report, people who think that they have a disease, and others who already have a tuberculosis diagnosis. (D4, line 202-204)

Physical Changes During Treatment:

Patients described other physical changes that they experienced throughout the treatment. 16 patients explained difficulties about medication. These were mainly related with using drugs and their amount. They described the large amount of medications that they had to use, and the negative physical side effects. The side effects they mentioned included nausea, dizziness, vomiting, ache and pain in different areas of the body.

> Drug treatment affects people badly. Sometimes I did not want to come here, because drugs had a very different taste, a bitter taste. (P15, line 52-56)
>
> But I had complaints about the drugs…Because they gave me 8 pills. Those 8 pills are too heavy for me… So hard. 8. And it makes dizziness, also nausea. I can't go out on the street. (P20, line 65-73)

Patients related difficulties of going out from the house with the side effects of the drugs. They described their boredom using them, and reported unwillingness about going to health facilities to have their drugs as well as the difficulty of taking them because of their taste and amount.

> These drugs are making nausea. Now I'm sick of medicine. After the treatment, I will tell everybody that I don't want to hear anything about drugs. After that, I will remove all of the medicine bottles from the house. (P2, line 220-223)
>
> Initially, drugs had a lot of impact. You take them in large amounts… Nausea, headache, fatigue was really bad. I could not even make a car trip because of nausea. I mean, I was hardly coming here. (P4, line 132-136)

As seen in the descriptions of the patients, considering the amount of pills, the drug use itself was a different experience for the patients. Tuberculosis treatment is distinct than many other disease, which was unusual and uneasy for the participants.

> Drugs are a problem for me. I have trouble with long-lasting things, and these are the medications I've ever used this long… I do not like being

> forced to do something. I do not like it…And it is not a few, we have to take 10 pills, at a time. At least it's good to have them at a once. (P5, line 70-80)
>
> A bone will heal if it breaks. Lung is different, very interesting, look. I'm taking a lot of medicine, think about that. At first, I was taking 9 or 12 pills at a time, now it's down to 6 pills. They are muddling me. It is not easy. (P24, line 101-104)

As can be seen, the period of disease is mentioned by some participants while describing their bodily changes. It should be noted that, the side effects are mostly seen in the early phases of the treatment, and some patients tend to get used to the large amounts which they find very hard at the beginning.

> I was taking 9 pills and at first, it was hard. Now I can swallow two at a time, it is easy. I am used to taking them. I mean, I've never even had an aspirin before that. At first, it was so hard for me, it made nausea. In time I got used to it. (P6, line 122-124)

Furthermore, doctors mentioned the importance of regular medication use and its explanation to the patients. D1 mentioned his effort to prepare the patients for the upcoming treatment and the amount of pills. D2 described the difficulties of the patients about taking 8-19 pills at a time.

> We describe that there is a treatment for the disease and we try to prepare the patient for the duration of the process as well as the huge amount of pills. Some can oppose the drug use…but we spend an hour for explanation. (D1, line 67-70)
>
> They use 10 pills a day, this is difficult. Drug are autopathic. They create distress, boredom and patients worry about the side effects. It is tough to take 10 pills every day, all at once. (D2, line 126-128)

3.2.1.2. Social Changes

Participants described changes they encountered in their social context, when they were asked to talk about their experiences about the disease. The changes they mentioned were mainly about the characteristics of the relationship between them and the others. They designated the others such as their family, friends, neighbors, as well as, institutions and work places. Patients mostly portrayed worn out relationships and some talked about the lack of contact with the people around them, which showed the weakening of their relations with the others.

Social Support:

Perceiving the existence of supportive attitudes and behaviors of others seems to have a great importance and impact on the inner worlds of the patients. Social support seemed to be a crucial factor throughout the tuberculosis experience, and varied in terms of kind and intensity.

> The people I did not know called me, I mean the people who I was not in contact with. They and my friends came to visit me, to tell their get-well soon wishes. They did not see me as sick, and did not try to stay apart from me. I would feel if they did, or maybe I couldn't detect it. (P9, line 131-134)
>
> During this period, my husband supported me, my mother supported me. My father, he was also supportive. My children, one of the youngest is 7 years old. My daughter too, little bit, so they were caring. (P12, line 60-61)

11 patients out of 24 talked about the emotional support from their family and friends; some appreciated their care and encouragement, and some were not very satisfied with the attention they got from their environment. Based on the he diversity of the support system reported by each patient, wo main subthemes emerged in this category: appreciation of the support and closeness; and feeling disappointed by the others.

Appreciating Others' Support and Closeness:

The interviews showed that the support from family members and friends, aspects of a patient's close environment, are effective in terms of creating emotional backing. Patients described their feelings towards their support system and a group of them reflected that they perceived enough support from the others including friends, parents and siblings. The support from family and others was sometimes experienced as a huge difference, as a way to experience love, which was unusual for them before the diagnosis.

> Then I realized the great support of my family. I felt that I was really valuable in their eyes. I didn't notice this before. They did not show it though… I mean, I did not know that I was so loved. (P18, line 82-86)
>
> Everyone was sad, everybody was very sad, but everybody was conscious that I can heal with medications that treat this disease. Nobody looked at me with evil eyes, no one saw me as bad. They were supportive, they were helpful. (P17, line 183-185)
>
> You can see true lovers, true friends. I had friends that came over me, even though I had a mask on my face. We even took a picture together (laugh). I also had another friend, I told him to wear mask when we were in the car, he said no, I don't care about being contaminated. (P1, line 186-190)

Closeness was another factor that was appreciated by the patients and was seen as a healing element. They seemed to be sensitive about the behavior of their relatives, and physical availability seemed to be as important as emotional availability.

> He did not walk away from me. That is the biggest thing in my opinion. He said, "It will infect me, if it will. If you are okay, then I am too. It's fine if I get contaminated. Then, we will both be treated, together". The most important thing was his words. (P4, line 174-176)
>
> She was not affected by the disease; she was touched by me, about my healing process. She was never apart from me. In contrast, she was snuggling close, she was always coming closer. We are deeply attached to each other. (P6, line 200-202)

Institutions also seemed to be a part of the support system, where patients were willing to get help. Schools, work places and health care institutions are mentioned wherein the people were caring and compassionate about the patients.

> There wasn't a problem at school. It was very good; they were all supportive. My friends, teachers. Even the school did something like this: Hot food was coming to teachers every day. The assistant manager and principal said, "You will eat with us every day in front of our eyes." I was eating with them every day at 12. (P13, line 199-203)

> Thank god my boss is not…, he is a sophisticated person. He asked me if there is anything that they can do for me. I also went to my workplace, after the diagnosis. He talked with me, asked how it was going. Also the doctor of the company frequently called me. I guess it was because of the attitudes of my boss. (P1, line 649-652)

> The best part of the disease is the support among inpatients at the hospital. I am still in contact with them, there are patients that I have been seeing since 2007. We meet, talk. (P13, line 163-165)

Dispensaries and people working in them, including doctors, nurses and other staff are frequently mentioned by the patients. It is important to note that, without exception, all 24 patients appreciated the emotional and informative support they felt during the treatment process.

> First comes the support of my mother. Then comes the support from the staff and doctor. Their care was more than enough, just like my mother’s. They treated me same like my family did…they never surrendered. We gave up, we were the ones who had the disease, but they never, never gave up. (P15, line 171-175)

> You know, the most cheerful place is right here! Very smooth, everyone is so positive, doctors and the others. Very favorable. I observe. (P8, line 509-511)

Doctors mentioned the importance of their personal support on patients’ adherence and success of the treatment. They described the treatment process as a composite of various factors such as the personality and effort of the patients, the attitude and behavior of health care personnel. D1 talked about the influence of support of the doctors and nurses in the dispensary on the effectiveness of the treatment process. He mentioned the link between adherence and support system in the health-care facilities as making a direct relation between them. D3 talked about the support system in terms of understanding patients’ emotional states and making cooperation. When the descriptions of the patients’ and doctors’ are examined together, the importance of support system in the health care facilities by doctors and other personnel become prominent.

> Trust is very important. You will be together for 6 months; you will get him to adhere to the treatment. I believe in the importance of experience, that it is important to know how to approach the patients to get them to complete the treatment. If you are able to get attached to the dispensary, they won't easily quit the treatment. (D1, line 167-171)
>
> Difficult patients are the ones who do not easily accept their disease. But it depends on us, in terms of approaching them. We have to cooperate. We have to be psychiatrists at some moments. If you treat according to the psychological state of the patient, then you can get better results. (D3, line 83-87)

Feeling Disappointed by the Others:

Besides the patients who had powerful support systems, there were others who were not the same. There was substantial amount of description of the participants portraying the lack of emotional backing from their environments, and 13 patients out of 24 mentioned it explicitly. These included the distant behavior and negative attitudes, as well as their undesirable thoughts about the disease. People's questions about the disease and the possibility of infection aroused negative feelings for the patients. Participants perceived the questions as disappointing.

> What did they say? They say that it is contagious. "We have to stand away." For example, my nephew told me that he would not hug or kiss me anymore. When I asked why, he told me that I had an infectious disease…Was I upset with the kid, no, absolutely not. (P19, line 103-106)
>
> They were not positive about my return to work. They talked me with a distance. One of them came to me and asked whether I was totally fine at the moment. He told me that he had a child…his words were always in my head; I felt frozen off. (P13, line 30-34)

Some participants were frustrated with the people's behavior towards other patients. They described their observations about tuberculosis patients and people around them. It seemed that it was difficult for them to expect support from the people with negative attitudes.

> In my previous workplace, a friend of mine was diagnosed with tuberculosis… Most of the workers were keeping their distance from him. They were using harsh and offending words… they excluded him. They told him to quit work, keep away from them and separate his dishes. Hurtful words. (P11, line 117-120)

There were patients with no family support. They did not identify any friends, or family members who were encouraging them. There the isolation of the self was also remarkable.

> I live on my own. 10 years ago, my family system was ruined…My family, my brother, and my sister, we are distant. I am alone. Now, with this current situation, a man wants somebody nearby, expects attention from someone. (P1, line 110-114)
>
> Strictly speaking I did not get any support, because I live on my own. Anyway, I do not see many people. (P24, line 200-201)

However, it is difficult to identify a distinct group of patients in terms of their support system, since it is possible for a patient to get support from certain people, but not from others. A patient described the lack of support from his family; however he also mentioned the help of friends. Another patient mentioned the lack of attention from close relatives, however he named others.

> No one supported me in the family. My family did not support me, because of their lack of awareness. My friends were there, my neighbors supported me…When I was in Tunceli, I got very tired and then I fell on the ground. One of my neighbors called the ambulance and took me to the hospital. (P10, line 144-149)
>
> No. I did not feel any support from my family. Sometimes from my cousins, my aunt’s sons. Only them. (P16, line 100)

Wearing a Mask:

During the early stages of tuberculosis, it is common for the patients to use a mask. 12 patients mentioned their experience about the mask with different stories. However, the commonality of their descriptions was the difficulty in social areas. A patient shared his emotions about wearing a mask for the first time, in a hospital. The attitude of the health-care professional seemed as important as putting on a mask.

> We went to the doctor's room. He immediately made me walk out the door. I wasn't expecting that. He took the mask from his table. Two masks. "wear those two, and wait outside" he said harshly…I sat outside and cried. (P13, line 138-142)

Two other patients described their first contact with the mask in the hospitals. A patient expressed different emotions including being upset and shock, while she was trying to seem brave next to her husband. The other patient mentioned anger, when first being told to wear a mask.

> I never forget this. The nurse went out the room, gave me the mask, and told me to wear it. I was so bad…. walking around with this, around people. At that time, I was upset, I was shocked, shaken. I took it, whatever, and I put it on. I was trying to put a brave face next to my husband. I was crying, but not showing it. Because I was badly affected. (P18, line 37-41)

> The woman gave me a mask. I said "I won't put it on. I could hardly breath, I cannot inhale with that mask". I was a little angry. Then after, I read the information sheet that they gave to me. I realized that I had to wear it. Because I could infect other people. After that, I always wear a mask. I'm used to it. It is like a part of me now. It comes with me all the time. (P2, line 209-216)

P2 expressed getting used to wearing a mask, while internalizing the reason for doing it, regarding the infectious nature of the disease. Another patient mentioned the behaviors of other people when seeing a mask. He also made a comment on other's feeling about him, as a person with a mask.

> While wearing a mask, some people were pitying, some were moving away from me. For example, I was in a bus, I was on my way to hospital. They were all running away. Like I had something. (P12, line 82-84)

Another patient described the experience of wearing a mask, in the context of early stages of the disease. Her words were describing the infectious period, her isolation from the others in the house, and mask was like a symbol of her infectiousness.

> I was wearing a mask in the early times of the disease. I have a separate room in the house. I was never sitting in the living room. I wasn't sitting next to anybody indoors. The mask itself, is so demoralizing. (P4, line 93-95)

Furthermore, 2 participants had a positive opinion about mask wearing. It should be noted that they were during later stages of the disease. They were using the mask in order to protect themselves from the germs which could infect them in public areas, especially in hospitals.

> I was only nervous at the hospital. Very crowded, people are very close. The possibility to be infected (laughs). Because no one wears a mask in those hospitals. My doctor was giving me a mask, thanks to him. I always put that on…mask is a good method. (P5, line 218-223)

> Yes, I used a mask. But now, I wear it when I am in the hospitals. When I visit a friend in a hospital, I put that on…because of contamination. I become afraid, so afraid. (P20, line 107-108)

Doctors also talked about mask wearing during the diagnosis process in the dispensaries, and mentioned its necessity for the patients and the others around them.

> People come here with masks, it should not seem very normal for the others. Maybe because of stigma for the other non-patients who come here for regular controls. We make patients use mask, in order to protect the personnel and environment. (D5, line 95-99)

> If the patient is contagious, I make him wear a mask. (D2, line 187)

Doctors were asked to describe their methods to protect themselves and mask was one of them. There was a consensus about its necessity; however, in practice most of them did not prefer to use it in front of the patients. 2 doctors stated that they used a mask when doing a consultation with the patients. They mentioned the atmosphere and physical characteristics of the dispensary building which were not favorable for a healthy stream of air. 6 of them explained that they used a mask when they were with a new patient, however they did not prefer to use it with all new patients. D1 was one of them, who did not prefer using a mask in front of the patients; rather he was opening the windows and making use of ultraviolet lights. He mentioned the stigmatizing and distancing effect of the mask, when used by the doctors. Similarly, D7 explained the importance of communication of patients and doctors and that a mask could be a negative factor in that relationship.

> Wearing a mask is difficult, it creates a distance between patients and us…we know the contagiousness of the disease for each patient…I can protect myself, by creating a natural distance. (D1, line 182-184)
>
> We have masks, that we have to use. But I do not prefer it since I use glasses. I think that it negatively influences the communication between me and the patient. A patient would not be convinced without seeing my facial expressions. (D7, line 188-191)

During the focus group conversations, participants talked about people wearing the mask. Their thoughts were similar to patients' expectations or guesses about other possible feelings. One of them talked about his thoughts on that topic and infectious disease was one of his associations. Another participant mentioned fear and sadness when she faced a person with a mask. Similarly, F1 added another feeling of uneasiness. After their comments, others continued by saying that they would not think about the possibility of tuberculosis, but other diseases such as cancer.

> People who wear mask. I mean, when I see a mask on a person I understand that he is contagious… or maybe one of his family member has an infectious disease…2 things might be the cause. A disease about lung or leukemia. (F7, line 224-225)
>
> I am afraid. When I see them, I become sad. I feel that I would not see that person again. They might have a simple disease, I don't know, but this is the first thing that comes to my mind. (F3, line 361-363)
>
> Of course I feel uneasy. Maybe it is psychological, but you want to keep away from them.

Economic and Work Related Issues:

The diagnosis of tuberculosis confronted the patients with economic problems. After the diagnosis and during the early stages of the disease, patients had to quit their jobs, because of their symptoms. However, they were not all welcome about turning back to their jobs. One of them was anxious about the thoughts of his boss, and his mind was occupied about being transferred to another job, which was far away from other workers. He was also nervous about the possibility of being discharged, and the difficulties that he would face while searching for another one. Another patient described the importance of industry that she was working for, and its relation with her disease. Infectiousness kept her apart from her job, and also effected future possibilities of finding a place in other firms.

> My problems are also caused by my economic fears. I could lose my job. I live in İstanbul, I have nowhere else to go…I put the disease aside, I only think of these, what will I do if I become unemployed…If they discharge me, how can I find a new job? They will ask for reports about my health… I don’t know. Maybe they can send me to their summer house at the earliest opportunity. (P1, line 550-555)

> The worst thing for me was the business. I mean, I could not work. And it was impossible because I always worked in the food industry… For example, there is no contagious state at present... But anyway, you can’t work. You have a disease; you are still taking medication. Everyone is cautious. (P4, line 112-116)

A few patients mentioned being supported by their boss, which helped them to overcome financial problems. Their workplace was tolerant, and provided their salaries during the early months of their disease.

> I got 2 salaries in every 3 months. So, I my financial problem was small. My boss sent me money. He supported me during those days. I did not have so much economic burden on me. (P7, line 119-121)

> My workplace knows my disease. I told them, because I could not stand working anymore. Now, they handle the situation. My health was really bad, they covered up for me… (P24, line 160-163)

2 patients out of all participants, expressed the advantage of having their own job and company. They were not linked with a boss, so they did not feel the burden of being unwanted within a work place. They could also not work in the early phases of their treatment; however, they did not indicate any economic problems. One of them also mentioned being supported by the dispensary, in the form of food supplies victuals, which may also support his family's financial state.

> We have two places. We own both of them, me, my father or my uncle take care of the stores. Now, I do not work there. But since the owners are my relatives, I do not have any financial problem. (P9, line 138-141)
>
> No, we did not have any economic problems. They gave us food supplies here. I was surprise, I did not want to take it in the first place…I have my own business. I decorate. I did not work at the beginning of my treatment, now I started again. (P6, line 177-181)

During the interviews with the doctors, it was seen that they were also aware of the work-related issues of the patients, their economic concerns related with the tuberculosis diagnosis. They were conscious about the attitudes of the work-places about hiring or continuing to work with patients with TB. D1 mentioned his effort to support his patients not to lose their jobs and to protect their rights.

> Work issues are complicated; people fear being fired… No one hires a TB patient. Those who work search a way to continue working. When we stand behind them, inform them about their rights and provide courage, it changes. But if a person is a subcontractor, if he does not have an insurance or if the work place is not proper, they immediately get fired. (D1, line 96-100)

The focus group discussion a theme came up about being a tuberculosis patient in a work place. One of the participants was working in the department of human resources, and said that she would not hire a person with a tuberculosis diagnosis.

> I'm not sure. I'm thinking. For example, if a patient comes here to apply for a job, I would take a step back and think about it. It is not that easy for me…or would he be accepted here? Would people exclude him? (F3, line 547-548)
>
> Another participant responded to her question by saying that they would

immediately exclude him and be careful near him. There were others agreeing with that response and proposing that he would not be accepted at work and would not be hired to begin with.

> We would exclude him directly. We would be careful around him. (F4, line 559)

They also talked about the scenario of being diagnosed with the disease and the possible attitudes they would encounter in the work place. All of them agreed that the attitudes of the people would be different towards them. They guessed that they would not continue working and would be uncomfortable being with their colleagues. 3 of them mentioned the possibility that the negative thoughts and attitudes would remain even after the cure. F7 used the word “mark” and guessed that the mark will stick on the worker.

> I would feel uncomfortable even in the regular meetings, because of people’s look. Their look, the look in that meeting. (F3, line 628-629)
>
> First, it will be heard by everyone slowly. Then, an economic support will be given by the company…people would be sad for me, and talk about it. After several months you would not be working here. You would be excluded; people would not meet with you. (F4, line 635-638)
>
> It will stick with you. That won’t change…A question mark will remain. Is he healthy now, or not? Is he pretending as he is treated? This mark will remain. (F7, line 649-651)
>
> It won’t change, even if you get cured, treated. (F3, line 647)

Predicting or Experiencing Discomfort in Others:

Throughout the interviews, patients talked about their experiences when being with another person. They shared true examples in which they encountered discomfort in others, as well as their predictions about other’s negative feelings. 8 patients described their experience in details. P8 explained a moment, where his friend was being distant from him, with the anxiety of transporting the bacteria to his own family. P15 described the behavior of the sister of her boyfriend, when informed with the diagnosis. While facing the discomfort of the others, it is important to note patients' effort to find a meaning for those behaviors and to understand them.

> First, he did not kiss me. I told him that the viruses were killed already. He was shocked, he did not kiss me when he was leaving the house. "You cannot be a germ carrier, and transfer it to your wife" I said. His wife was pregnant, that was the reason of his worries. I was not going to their houses; I was being prudent. (P8, line 467-471)
>
> I had a boyfriend. He knew my disease…Then his sister heard it. Then I started to feel her distance, she did not want his brother to be near me. I could feel it. She is right maybe, I have to accept it, but I could feel it. (P15, line 114-118)

Another patient described that she noticed a discomfort in her friend, after sharing the diagnosis. The distant behavior of the people made her cry, and she asked for a solution for the aloofness of the people, which could be even more hurtful for the younger patients.

> Once, my friend asked me about my diagnosis… When I told her, she stood up and sit far away from me, did not call me during 2 months, I mean she thought that it was contagious. Can someone find a solution for this? Not for me, for the other patients. I am 40 years old, but there are young patients…I cried a lot because of people's behavior. Look she has tuberculosis! My disease did not make me cry, because there is a solution. I cried because of their look. (P19, line 52-60)

Patients also had an image in their minds, and predicted the possible behavior, thoughts and emotions of the non-patients around them. They felt that the others would fear of being infected when being near them, and some stated that they could feel the emotions of the people, such as their coldness and antipathy. P13 mentioned the prejudice against tuberculosis patients, and described the unwelcoming attitudes of the workers in his company.

> I learned that the type of my tuberculosis is not contagious, it is different. But again, I am nervous, also I guess there are people who are also worried about being infected. Even if they do not tell me directly, if they do not show it. Or maybe it is my opinion (163-167). I sometimes try to understand

> them…for example I wonder if a person gets nervous when we sit at the same table, or what happens if I cough. I wonder if the man will become uneasy. (P1, line 133-135)
>
> When I was not working, a staff change was made in my workplace. I heard that new people were prejudiced against me, without seeing me…I could also feel it. I felt their coldness, their antipathy. They were not positive about my return to work (P13, line 20-26)

P24 described a similar feeling about the possible opinions of the others, and added another point by indicating the difficulty of communicating with them. He emphasized the need to talk to somebody, but at the same time the hesitation about their possible behavior. Another patient, showed the link between self-disclosure and feeling of discomfort in others. She shared her belief that the others would talk about her disease in different environments, in the case of a disclosure. The difficulties of self-disclosure will also be discussed in later sections.

> Sometimes I want to talk to somebody, but I can't find anyone. Some become distanced, some turn their back. Few of them are nice, the others are, I don't know. (P24, line 316-319)
>
> When people ask, I do not disclose about my disease… I don't want, I don't because I know their nature. They are not close-lipped. They will talk around. They will tell everybody that I am ill. They are bad, I don't know, no I don't want to. (P20, line 140-147)

3.2.1.3. Psychological Changes

When patients were asked to describe their experiences about the tuberculosis diagnosis and the process following it, their psychological state came up as one of the important topics. The changes they shared were present at different stages of the disease. Especially, the process of diagnosis was confusing and disruptive for most of them. Emotional impact of the diagnosis and the process following it were also described by many of them, with unique stories. Experiences related with their psychological state will be presented in other chapters, as an answer to the second and third research questions.

Reacting to Diagnosis:

One of the most detailed part of the interviews was about the diagnosis process and all of them described it. Patients seemed enthusiastic to describe their experience about different hospitals, doctors and the dialogues between them. There were few patients, who directly consulted the dispensaries. Most of them accessed the hospitals with their complaints, and the diagnosis was not immediate and easy for them. Some were diagnosed with a different disease in the first place, and tuberculosis was established with the continuing symptoms. Patients shared their effort, worry and procedural problems which they faced before the final diagnosis. P5 described how he was diagnosed with another disease, and got a treatment accordingly in the first place.

> It was a year ago. I realized when I spit blood. Then after, I went to emergency at that night. There, they told me to see a pulmonary specialist. Everything started there. I went to Yedikule, they sent me here. Since then, I come here. (P21, line 8-10)
>
> I was having difficulty breathing. I went to the hospital 2-3 times…when it continued, I wanted to understand it. I went to another hospital. They said that my lungs were blistered. They started a treatment. When nothing was changed, they transferred me to Süreyya Paşa Hospital…there I was diagnosed with tuberculosis. (P5, line 8-17)

Patients frequently proposed solutions to major problems about the diagnosis process which was mostly experienced in the hospitals, and this was one of the most important topic for them. They found it difficult, and wanted a change in order to quicken the process. P4 expressed the difference between diagnosis and treatment, and portrayed diagnosis as a process of suffering in comparison to other stages of her diagnosis.

> Diagnosis. Absolutely. I suffered a lot for this. I did not have any problem about the treatment, but diagnosis was really hard. Because it doesn’t work properly anywhere. (P4, line 268-270)

The procedure before the diagnosis was problematic for most of them; however, after that long and difficult process, hearing the finding of tuberculosis was also tough. P16 explained the difficulty of acceptance and struggled to believe it. Similarly, P18 described a state of shock and difficulty understanding what she was being told.

> I could not accept it, you can't embrace it at the beginning. Like I don't have a disease. Like how can I be sick at that age, there must be a mistake (P16, line 23-24)
>
> First, I tried to understand. Tuberculosis? What was that? My mind was frozen. I even lost my way home…the doctor saw my shock too; he told me to calm down first. I was alone, my mind was frozen. Okay, tuberculosis, tuberculosis I said. (P18, line 146-151)

Feeling of shock and the stunning effect of the diagnosis was affected by the previous thoughts of the patients. P4 explained that before this, she never thought of being sick,as a reason for her astonishment. Also, first emotions gave place to other thoughts after a moment. P4 compared tuberculosis with cancer, and the curable nature of this disease was a source of relief for her. Another patient was concerned about future, and thought about separation and death.

> You think nothing could happen to you. So, I was so surprised…the doctors were suspicious about the possibility of cancer. So tuberculosis relieved us a little bit, because it could be curable. (P4, line 86-88)

Patients also questioned the causes of tuberculosis and tried to understand why they were sick. Some of them perceived the disease as given by God. P10 explained a feeling of worry after the diagnosis, and his following thoughts were related about his religious feelings.

> I mean, of course I was a bit worried, suffering. Why I asked, I am 60 years old, why did God gave me something like this. Because I see it in the hospital, there are many poor people, there are people who die when they vomit…5-6 people die each day. I was living there and saw them. My psychology was harmed. (P10, line 50-53)

P11 also mentioned his questioning about the causes of the disease, but he hesitated to rebel at God.

> I was not upset, there are patients worse than me. I never rebelled, only my eyes filled with tears. Why do bad things come to me? That was the first question in my mind. (P11, line 29-31)

As seen above, belief in God and destiny was dominant for some patients. For some of them, the belief had a soothing effect. P7 described lack of negative feelings towards the diagnosis and did not show any negative emotions.

> I did not put myself into pessimism at the time. Because this comes from God, you cannot do anything. I did not feel fear. I was calm and continued to take my medications. (P7, line 31-35)

Furthermore, anxiety, shock or fuzziness were not always present. Two patients described feeling nothing. P2 compared the diagnosis with previous life experiences and portrayed the illness as a smaller factor in his life. Similarly, P6 had a tuberculosis patient in his family and described himself as powerful.

> I sincerely did not feel anything. Really. Because my life is a chaos, it's shady. I see prisons, police stations. Compared to these, this disease cannot hurt me. (P2, line 49-52)

> I didn't feel much. I was not afraid. I have an iron will. Really it's powerful. I also trust my wife, and I experienced it with my father. (P6, line 42-45)

Doctors were also asked to describe their observations about the first reactions of the patients when they were first diagnosed with tuberculosis. The main theme about patients' first reaction was the difficulty of accepting the disease. All doctors explained their effort to draw a clear picture for them, while making them comfortable and explaining the scientific information about the disease. D1 stated that he made an hour long conversation in the first place, wherein he explained the reasons of the disease as well as the process of the treatment. The misinformation of the patients seemed to include relating tuberculosis with cancer, faulty beliefs about its contagious nature and treatment process. D4 and D5 explained patients' first emotions such as fear and panic and their distress about the reasons of the disease. Descriptions of the doctors showed the importance of informing the patients at the beginning, after their first reaction to diagnosis in order to prepare them to the next stages of the process.

> Especially in the first session we labour an hour long time. The time depends on the neeeds of the patient. I focus on the necessary topics such as stigma or problems about work. I explain general scientific evidence and treatment process. Because patients can see TB as the same as HIV or cancer, they can have difficulty in accepting or perceiving it. (D1, line 60-65)
>
> They feel very bad. They say that they used to wash their hands, and question the reasons of the disease. We have an information booklet; I explain to them with pictures... I explain to them that it is not their fault. (D4, line 56-60)
>
> Patients come here with fear and panic. First I try to make them calm. I always tell them that it can happen to everyone, just like cold or flu. I explain that it is curable, treatable. (D5, line 30-33)

3.2.2. Research Question 2: "How do the patients experience stigma-related tuberculosis?"

Patients described experiences that are directly related with social and self-stigma. Some were asked to describe the perceived stigma, and some were not directly asked. However, most of them talked about stigma-related issues and occurrences. First, the perception of tuberculosis in society was portrayed by the patients and revealed as an important theme. There was not a consensus among 24 patients, however it was possible to group them according to their different opinions. Second, reflections of self-stigma were evident in the patient descriptions even if they did not explain directly experiences such as emotional changes, isolation, concerns around infection and changes in daily routines. Third, self-disclosure was a major topic throughout the interviews. A group of patients preferred to share their disease, whereas the others were anxious about making a disclosure. Finally, problems about the DGT, which is a part of tuberculosis treatment, emerged as another theme.

3.2.2.1. Perception of Tuberculosis in Society:

Participants were asked to describe the perception of tuberculosis in the society. The analysis revealed two groups with different opinions. A group of 9 patients portrayed a negative picture, mentioning the exclusionary behavior of the non-patients and their faulty beliefs about the disease. P12, explained his opinion by sharing his real-life experiences and mentioned the negative attitudes of the others that she encountered within the family. P4 also described that he had problems sharing the disease with the others, which is a form of difficulty of self-disclosure that will be discussed in the further below.

> They see it bad, very bad, they find it odd. They think that it is bad, like it will infect them immediately…This is the society. Ignorant. (P12, line 73-78)
>
> Tuberculosis is so different. People find it strange. For example, my wife has a relative. She came to us… She saw me with a mask. After leaving the house, she called my wife and asked whether my children are infected by me. After the day, she did not come again… I mean, they are ignorant. It's a point of view, though. (P12, 89-93)
>
> When you say tuberculosis, people immediately assume that it is infectious. They would not want to hug you. You have many difficulties in public. You don't want to share it with anybody. (P4, line 88-91)

The negative attitudes they encountered and the beliefs that people might be anxious being near a tuberculosis patient showed that a stigma was apparent to the patients. According to the patients, the misbeliefs of the others were caused my lack of knowledge about the process of tuberculosis and the fear of being infected.

> Their prejudice is so powerful. They don't know even the name, and the place of the disease. They don't know the mechanism of infection. They think that it is a lifelong disease…half man, they say so. (P13, line 117-119)
>
> It's apparent. They treat us like we are bugaboos. Doctors, nurses they don't come near us. Freaky, repulsive. I saw when I was at the hospital. They treated like us animals. Who are they? (P14, line 35-38)

When talking about stigma, patients frequently mentioned cancer. They compared it with tuberculosis and showed their difference in terms of the perception in society. Cancer is seen as different because of its non-contagious feature.

> If you look at society, to my life style and my problems you can understand it. If I say that I'm cancer, or if I get cancer, they won't discharge me. (P1, line 374-376)

Comparison of tuberculosis to other diseases such as seen in the descriptions of the patients and in the observations of the doctors, especially with cancer, revealed as a theme in the focus group discussion. Cancer was seen as a more dangerous and also more familiar disease for one participant. Another participant made a comparison between tuberculosis and the flu, and identified tuberculosis as a more serious form of flus.. In F3's opinion, tuberculosis was the same as being cancer.

> For me the most dangerous disease is cancer. I recently talked about AIDS in another atmosphere…this is not over also…if you asked us to talk about cancer today, we would have more information. But I would not remember tuberculosis if I didn't see you. (F5, line 424-426)
>
> I see tuberculosis like a form of flu. It is like a higher level of pneumonia. Maybe I'm wrong, I don't know. (F7, line 463-464)
>
> I think tuberculosis is the same as cancer. I don't care if it is treatable or not…. (F3, line 523-525)

The other group of 5 patients portrayed a society, in which different opinions and beliefs are present. They mentioned the presence of negative perception of the disease, next to a better one by people with accurate information about tuberculosis. Patients linked true knowledge with a better understanding of the disease, and some compared the perception of the disease in the past with today's. P6 and P7 indicated that they believed in progress when compared to the past. P10 also talked about conscious people who are aware of the curability of the disease, which seemed to be a reason for non-stigmatization.

> I don’t know, but I’m sure that it is not bad. Absolutely. It was different in the past. Now, it is normal. (P6, line 157-159)

> Certain people find it bad. But conscious people know that it is treatable... But other ignorant part, disregard their symptoms and think that it will pass by itself. They come here, when they spit blood. Then, it is too late. (P10, line 202-205)

> I know many friends with tuberculosis. One of them explained it clearly. He told me that it is like a regular flu; it may be infectious but when you keep a distance from the others, it is okay. Today, no one despises it. In the past, during our childhood it was different. But now it’s changed. (P7, line 139-143)

There were 3 patients, describing society’s belief that tuberculosis is no longer present. Similar to others, they related it with lack of knowledge. The belief that tuberculosis is not seen in the country, might be another source of stigmatizing behaviors of the people, when they hear about a patient. A participant of the focus group shared a similar thought that he did not know that tuberculosis was present at the moment, or a current problem in Turkey.

> Nice question. People think that this disease is sleeping, like it is not seen in the society. However, it is a pandemic…and they don’t have enough information. I think they have to educated…now, cancer is popular, but this is a disease also. (P5, line 170-174)

> Honestly, I would not guess that tuberculosis is still a problem or a disease that should be taken into consideration these days in Turkey. I should say that clearly; I did not know. (F7, line 23-24)

Another participant of the focus group agreed with F7 and added on by presenting his associations with tuberculosis. Turkish movies was one of them, that made all participants laugh and agree. Other participants mentioned dying and spitting blood that they saw in the films, which was shocking and devastating for them while watching them.

> I thought that it is no longer present, like it is in the past or extinguished. If I think about it, I recall dispensary, lungs and Turkish movies (laugh)…being tuberculosis because of love. (F6, line 68-70)

Doctors were also asked about the perception of tuberculosis in society. Their descriptions were similar to the patients' beliefs about the perception of society. Two main opinions emerged. The first one was the belief that tuberculosis is still perceived as a very bad disease, that it relates with bad health and environmental conditions such as malnutrition, dirt and low socio-economic status. Doctors related this perception with early movies and presentation of the disease in relation with negative psychological states. D1 and D4 are the examples of that group of opinion.

> After the examination of phlegm and lung, after the diagnosis, psychological part of the disease starts. There is a problem of stigma in our country. There is an inclination to exaggerate the disease and another to keep the diagnosis as a secret. (D1, line 55-57)

> Society is still under the influence of Turkish movies and I believe under its negative effect. They believe that this disease is caused by internal mechanisms such as sadness and stress. Because they have always seen and heard like that…it is still seen as a bad disease, people look at it as bad. (D4, line 230-233)

The second group of doctors, which were approximately the half of the participants, believed that there is progress in the perception of the society, that there is a change in the attitudes of the majority of the people. However, they did not believe in the disappearance of stigma, rather they mentioned a slight change in people's attitudes with the help of providing information to them in magazines and health-care facilities.

> People are afraid about its infectious nature. They know the disease with their past information and they believe that it is fatal or difficult to recover from… very slowly, I believe that people are learning the disease. Associations are publishing pamphlets, there are public advertisements. (D2, line 105-107)

> I was seeing in the past; it is not that much at the moment. It was very much in the past. It is there at the moment too, but not as much as earlier years. (D3, line 39-41)

3.2.2.2. Self-Stigma:

As explained above, stigma towards a population might influence the members of that group in different ways and this was the case with tuberculosis patients. Internalization of the stigma or perceived stigma in the society might influence patients in emotional and behavioral ways. Participants' descriptions showed that, a variety of negative emotions were experienced throughout the disease which may be caused by different mechanisms. However, it seems that self-stigma was one of the major components of these reasons.

Emotional Changes:

There is a diversity of emotional states that accompanied the process after diagnosis, during treatment and following stages. Mostly, depressive feelings and anxiety were described by patients. They mentioned loneliness, tiredness, and difficulty in social interactions. In the story of P1, his experience was majorly dominated by depressive thoughts and feelings. He expressed it by referring to songs which told stories about patients who were diagnosed with important illnesses. He seemed to be labelling himself and acting upon that label. P17 mentioned the feeling of worthlessness, which is another form of self-stigma. The lowering of self-worth led her to be isolated from the others and consulted a psychiatrist to help her reemotional tension.

> You start to listen to patient songs (hasta türküleri). You maybe know those from the past, but after the illness it starts to catch your attention. You then try to relate the songs with yourself. You can better understand loneliness… I was denying myself to others. (P1, line 123-126)

> I felt myself worthless…I already had a disease…I saw a psychiatrist, and then a psychologist. They diagnosed me with… What was that? The fear of talking to people. (P17, line 211-214)

P24 was concerned about her health and had to consult doctors frequently. She also mentioned the feeling of loneliness.

> My hair started to brake. We see tuberculosis and cancer patients. I was afraid of becoming worse. I was nervous. When I feel a little tired, I was

> going straight to see a doctor…sometimes I can forget, but it cannot be the same. It's difficult when you're alone. (P24, line 224-227)

Another difficulty of connection was seen in the descriptions of P17. She had difficulty with her husband about their sexual relationship.

> I distanced myself from my husband…I was staying away from having sex with him. But my love was the same, it was nothing to do about it. I only couldn't feel like having sex. (P17, line 153-156)

Other than anxiety and depression, the existence of fear was seen in the patients. P2 described problems about tolerating others, which showed another form of problems in relationships.

> I said that I don't care about the disease at the beginning of our conversation. However, the disease made me so angry. I mean, I don't know whether it made me angry, or ruined my psychology. After the diagnosis, I started to be unable to tolerate anything. (P2, line 133-135)

In the presence of difficult and heavy emotions, patients were showing apprehensive feelings towards other patients. However, during the interviews, altruistic thoughts of the participants were also present. Patients gave advice to other patients and also proposed solutions for the problematic areas. P9 talked about the importance of bodily changes after the diagnosis and tried to be informative for people. P19 wanted a system change that would be beneficial for future patients.

> They must pay attention to their weight. Because I was 103 kilograms, and lost 30 kilos in 4 months…I advise them to take control of their weight. To go to a doctor even when a small thing happens to them. (P9, line 176-179)

> I want to tuberculosis departments in hospitals…they keep dispensaries apart, and it becomes a burden for the patients. It should be in the hospitals. I want it. Not for myself, I want it for the others. (P19, line 266-268)

Isolation:

Patients were experiencing negative feelings and negative thoughts about their lives. Isolation was another important result of their emotional state and the experience of internalized stigma. They separated their rooms at home, spent their times by themselves and minimized their interactions within their community. The self-devaluation of the patients pushed them away from the others.

> I didn't have any problem with the others. Something happened to me after the disease. I started to keep away from everything…I was far away from society; I was going straight home after work…this way I felt more comfortable. (P7, line125-128)

P4 portrayed a family in which the members seemed worried about the patient. However, P4 tried to stay away from the others who are trying to comfort him about the disease, and chose to be alone.

> My parents have done everything for me. They were so sad for me, when I was sitting in the house with a mask. They were telling me to let it go, and take it off. But I can feel their sadness. Which is why, I was always in my room alone. (P4, line 182-185)

As described by the patients, isolation was a result of the changes in their inner world, which served as a way to comfort themselves. The isolation was not only physical, but also a step away from facing the reactions of people around them. Similarly, doctors also talked about the isolation of their patients. D5 thought that her patients had feelings of guilt, as a part of their emotional changes that were mentioned above, that eventually made them isolated from the others. Another factor that was creating isolation was the anxiety of infecting others. She proposed a relationship between feelings of guilt, anxiety of harming others and isolation. Concerns around infection, which were observed in relation asked self-stigma during the patient interviews, will be presented in the following section.

> There are patients who feel different than the others and also guilty. This creates an unnecessary isolation. Like "I can infect my granddaughter, I should not see my neighbors". Even if we explain the possibilities, because some of them are not infectious, they isolate themselves. They can create a self-exclusion on purpose. (D5, line 83-86)

Concerns around Infection:

The feeling and well-being of the others were very important for the patients.

18 patients out of all were preoccupied with infection and possibility of infecting someone. With the presence of that concern, they thought about people they contacted with, gave information about the disease and made them aware of the possibility of infection. Patients made their contacts reach the dispensaries in order to get their current state of health checked. These concerns showed that most of the patients were internalizing the thoughts and stereotypes of the society, and commonly experiencing it with anxiety.

> I told everyone, I told them to go and have their lungs checked. It's easy, it takes 5 minutes. All of them are informed, I would never disregard it…I called everyone who was in touch with me. (P8, line 279-282)

Isolation was a result and also a way to cope with concerns about infection. P7 explained his isolation related with his anxiety around harming others.

> I didn't want to be in public areas. I could infect others. I didn't want to be near them, and make them nervous. That's why I stayed at the hospital for 2 months. When people called me and asked me where was I, I didn't tell my place. (P7, line 54-57)
>
> We separated the room of my husband, I slept alone...he slept in a different room for 2 months. (P18, line 50-52)

The concerns about infecting others were in relation with certain feelings. The dominant emotion was guilt. Patients mentioned the feeling of guilt in case they infect others. They described the importance of people around them, and did not want them to be hurt because of their disease. P1 described his beliefs and that he gave more importance to others' health than his own. Similarly, P5 was focused on his girlfriend.

> I am a fatalist and a believer. Everything can happen to me, it doesn't matter. But I don't want to hurt anyone. The health of my boss is important for example; if something happens to me, then I feel guilty. (P1, line 63-68)
>
> The closest person to me is my girlfriend. So I brought her too. I made her get a lung film and made the test. Just in case. I never want anybody to get hurt because of me, on purpose or not. (P5, line 232-235)

Similar to the descriptions of the patients, infection was a theme mentioned during the interviews with the doctors. Two different profiles were portrayed by the doctors. D2 shared her observations about the patients who had questions about being with the others. She explained that she observed people who did not want to accept the possibility of infecting others, who wanted to be with the others in contact. In contrast, D7 observed patients worried about other's health, and were concerned about infecting their relatives.

> They ask whether they can see their relatives or if they can kiss other people. They cannot accept it at the beginning, but when we insist they accept grudgingly. We have to warn them about infecting others. (D2, line 52-55)
>
> I explain possible ways of infecting others. I tell them that they would not contaminate others by utensils, by kiss or clothes. Even that can make them comfortable. Because they worry about infecting others, more than their own health. (D7, line 146-148)

When one of the doctors was asked to describe her thoughts on self-stigma of the patients, she mentioned the anxiety of infecting others, especially people near them. She also described two different group of patients, a group who are concerned about infection which leads to a natural self-disclosure and the other who prefer not to share their diseases, even if they are concerned about contaminating others.

> Yes, of course. Because no one wants to infect others, the loved ones. In my opinion they worry about the possibility of making the others sick because of them. We also make controls of the families; by that way they understand its importance and tell their close relatives. But some of them want to keep it as a secret, no matter what. (D2, line 121-124)

Changing Daily Routines:

Besides the emotional changes throughout the process, patients made other changes in their daily lives and routines. However, it is not easy to separate emotional changes and changes in daily routines. The descriptions of the patients showed a link between emotions and changes they made in their lives. The changes included differences about their eating habits, physical activities and their way of spending time.

> I quit drinking coke and eating sugar. I thought that these were harmful…I also stopped eating snacks, especially I stopped ordering outside. (P9, line 102-106)
>
> I was always cautious. Even during my university years. I didn't start anything that could make me tired. I was cautious about cold weather, and especially paid attention to my nutrition. I learned to cook. (P13, line 232-235)

The change in their nutrition was also important for the other people around them. Patients who had support from their family or relatives, were also supported in terms of their eating routine.

> Food cooked for me was changed. Because I normally don't like to eat. They say that it is important to eat well during the illness. So, they started to make me eat a lot. (P4, line 185-187)

Another important change was about cleaning. Patients and the people around them gave major importance to dirt and tried to avoid dust that could be harmful to the disease. Cleaning the furniture, beds and airing the room was common in the patient stories. It should be noted that, the preoccupation with infection might be related with preoccupation with cleaning. This may show an inner attribution to tuberculosis that is related with dirt, also seen in the stigmatizing beliefs in the society.

> We were airing my room out every day, there was a continuous cleaning in the house. (P13, 426-427)
>
> I changed my room, I painted the walls with light colors. I made myself comfortable, I cleaned the air of the house frequently…I clean the house all the time. I bought new pictures, changed the colors of my furniture. (P24, line 268-272)

3.2.2.3. Self-Disclosure:

Most of the patients reported having difficulties of making self-disclosure about their diseases. Each patient had a different story about their disclosure, and people they chose to share their diagnosis were various. It was interesting to see that even the close family could be unaware of the disease, including mothers, children and wife/husband of the participants.

> No, no. my wife doesn't even know what tuberculosis is. (P10, line 93)

There were different reasons for each patient. However, the first difficulty can be described as mistrust in others, as P2 describes in his interview. He was careful about the possibility of a trump, which shows that the disease was a bad thing for her as well.

> I did not tell anybody. 2-3 people know in my neighborhood, and my family. No one else knows…because one day they can use it as a trump. (P2, 276-278)

A second reason is related with the awareness of stigma in the society, that creates a concern about the possible thoughts of the others. P1 described his life and assumed that people could make assumptions on his disease and may find misconnections about his health and lifestyle. He did not want to be seen as a dirty, disordered and poor person and chose to disclose to certain people. He also chose to be distant from the others which is a form of isolation.

> I can guess what they can assume about me, I heard. I was together with a foreign woman. So maybe they can think that I was with many women and was infected by them. Or they may think that I had problems with cleaning or nutrition…so I didn't tell everybody, but stayed away from them. (P1, line 150-154)

A third reason of selective self-disclosure had to do with the problems in the families. Patients did not want to badly influence their relatives and make them concerned.

> No, I didn’t to anybody, only my sister…because I didn’t want them to be sad. My mother ‘s psychology is not healthy, she lost his sister. If I tell her, it will be too much for her… but then I looked, I had to go home. (P5, line 21-24)

There were patients who chose to use other names for their disease, such as flu, osteolysis and cold. They reported being afraid of the reactions of the people, which created an uncertainty for them.

> No one knows, no one…my children don’t know either… the people in my workplace think that I have problems with my bones. (P7, line 48-50)

> I don’t want to tell my close friends or others. I tell them that it’s a flu, cold, infection. Not tuberculosis…I think they can disseminate the information to others. (P20, line 141-145)

> When people ask, I told them that the doctor told me to rest. Because we cannot know how people will react, if this was something tolerable, I could say it... That's why I don’t go near them. (P11, line 110-112)

Some patients were warned by their friends to be careful about people before making a disclosure. P19 described that her friend told her that sharing this information with the others could harm her. The patient was positive towards the warning and appreciated it.

> People were cultured and decent in my neighborhood…one of them told me that I should not tell everyone about my disease. “you tell with a good intention, but they can harm you”. She warned me, it was nice, I appreciated. (P19, line 289-292)

Fewer patients did not report any hesitation or problem about self-disclosure. P12 saw the disease as a giving from God and did not relate it with negative beliefs. P22 mentioned a disconnection with the others and the lack of a need of information sharing.

> My relatives know, they heard about it. The neighborhood learned. I don’t care, I don’t because I don’t do anything bad. It a disease coming from God. (P12, line 113-114)

> I don’t find it necessary to tell. No one asks, and I don’t say. (P22, line 122)

Doctors talked about their observations including self-disclosure. P1 described a female patient and her father, who were not aware of each other’s disease, although they were being treated in the same dispensary. P6 remembered another female patient who preferred to keep her disease as a secret from her fiancé.

> For example, I treated a man and his daughter separately, they did not tell each other. It was very striking to me. They were coming to their routine controls on different days. They told me to keep it as a secret. (P1, line 90-93)

> They do not show this concern explicitly, but for example I had a patient who was planning to get married. They consulted here to get a health report. She did not tell her fiancé; she came here and warned me not to tell to him. I proposed her to share, but she continued as the same. This is a sort of stigma. (P6, line 69-73)

3.2.2.4. Problems About DOT:

As described above, Directly Observed Therapy is obligatory for the treatment of tuberculosis. During the interviews, it was revealed that some patients were not satisfied with the ongoing system. 6 of them made clear explanations about their dissatisfaction. Few patients stated that they did not find difficulty going to dispensaries or health-care centers; however, must of them reported their concerns about the system. P8 explained the rationale behind the system, and said that he can take his medication routinely, without the assistance of anyone.

> I don’t let myself go. Why would I do that? What happens if they don’t observe me? Yes, it’s nice, it is for uneducated people, but it’s not applicable to me. I can take medications at home. (P8, line 214-216)

Other patients explained their reasons for their discontent with DGT, stating its stigmatizing characteristics. P1 mentioned the difficulty of working and going to dispensaries every day. He mentioned a way of dependence on the health centers and showed it as an obstacle for work life. P19, described his difficulty by sharing her negative feelings about the system. She was afraid of being heard or seen by the people in the neighborhood.

> It is an obstacle for working. Taking the medications with signature. I have to take a health report if I'm working...you are dependent… (P1, line 416-418)
>
> I go once a week. But I don't want people to hear about it. It's close to my home…I don't want others to see, know, hear, about it. Because I'm really tired. (P19, line 282-285)

Similarly, doctors explained the difficulties of the patients about the system and described their opinions. The advantages of the system were clear for the doctors and they were aware of its necessity. However, they were also aware of the stigmatizing factors of it. D4 shared her knowledge about the negative feelings of the patients, and thought that it was hard for them to be seen or heard in their environments. P1 on the other hand, focused on the application of it and compared the system in Turkey with other countries. Another doctor proposed a solution of revisiting the system for every single patient, and that it can be applied to patients using different strategies.

> Health care centers are near the houses; however, some patients don't want to go there. There are several reasons. First, it is difficult to go every day. Personal factors are important. People would think that he is sick, people will question his routine…I think they experience it as a punishment. (D4, line 128-131)
>
> Normally, the staff has to go to the houses of the patients, we do it inversely. This creates the problems. Work hours and waiting in the line with many people every day creates a stigma. especially young people, young girls who have marriage concerns don't want to go. (D1, line 120-124)
>
> DGT is necessary and studies show the positive impact of the system. However, I don't think that it is properly applied in Turkey. I think this must be shaped according to the patients. (D5, line 57-59)

3.2.3. Research Question 3: "What are the main coping strategies of the patients?"

Patients tended to use different coping strategies after being diagnosed with tuberculosis. The disease itself was a major of source of stress for themselves and their environment. The strategies included active and passive ways, such as taking action about the problem or managing the emotional states which is way to manage focusing on himself. Selective disclosure, isolation, and distraction.

3.2.3.1. Selective-Disclosure:

The stigma-related experiences of the patients were described above, and self-disclosure was one of them. Self-disclosure seemed as a problematic experience for the patients; however, selective disclosure can be also a way to manage stress, while keeping oneself away from potential danger. It seems like the patients were protecting themselves from the prejudiced behavior of the society by making attentive choices when sharing information. Patients tried to be careful about the possible negative reactions and found a way to selectively eliminate them. 18 patients out of 24, reported that they selected people to make a disclosure. So, this strategy was dominant for most of them. For example, P17 mentioned the possible labels that can be associated with her and used non-disclosure as a protection. She was aware of her choice to use it as a safeguard.

> Because they would label me and try to put a distance, for themselves and their children… I think it was to protect myself. I knew that it was curable. People would think different things for me. It might be for protection. A kind of defense. (P17, line 102-105)

Another patient described that she did not prefer to share her disease with everyone, because of her fear that they would tell everyone. That may show us that she was relating the disease with negative connotations, which could be used as a potential attack. She told that she was seeing the others as "bad", as people who could talk behind her about the disease.

> I don't want to I don't because I know their temperaments. They all have a

> loose tongue. They will spread it, . Aa, they will say, she has a tuberculosis! They are bad. I don't know, I don't want it. (P20, line 144-146)

Selective disclosure as a coping strategy seems to be in a circular relation with self-stigma of the patients, as seen in the descriptions of P20. Tuberculosis and its negative associations get internalized and result in self-stigma, which results as a selective disclosure in order to self-defense against possible stigmatizing behavior. So, it can be stated that selective self-disclosure is a mechanism that is created by and is continued to avoid social and internalized stigma.

3.2.3.2. Isolation:

A similar coping mechanism is isolation, which is used by some patients. Depending on the personal characteristics, social environment and personal sources, some chose to physically stay away from the others. Being isolated from others was not explicitly stated in most interviews; however, keeping a distance from other people was mentioned by most of them. 12 people out of 24 mentioned being isolated from the others at different phases of their disease. P19 described a form of disengagement in which she motivated herself by being on her own and speaking with God. She talked about a form of isolation, in which she did not prefer to communicate with people, but with God.

> How I motivate myself? When I see the reaction of people, I did not want to talk with them. I was staying in my room, on my bed, I was speaking with God. Or I was going to bathroom and speaking to water. (P19, line 254-257)

Isolation was especially evident in the early stages of the disease, in which infection could be a major source of anxiety for them. Patients tried to avoid contact with the others in order to eliminate the risk of contamination. However, it is known that infectious stage of the disease lasts less than 2 months. So, it can be understood that isolation is both a form of self-stigma, and also a way to cope with feelings of anxiety and distress.

> I prepared a private room for myself, in order to be far away from the others. I slept and woke up there for 2 months. Now, everything is normal…during these months I continued my life apart from my children and husband. (P19,

> line 199-202)

The similarity of isolation and selective disclosure comes from the fact that they are both caused by social and self-stigma, and perpetuate in self-stigma.

3.2.3.3. Distraction:

Distraction is a way to shift attention to something else, rather than focusing on the current problem. In the case of tuberculosis, some patients preferred to distract themselves emotionally and behaviorally on various subjects. 5 patients out of all described that they were not fully concentrated on tuberculosis. P11 talked about distracting himself from tuberculosis and focusing on another disease that was a more familiar one, which might be a way to keep a distance from his current problem. For him, diabetes was a disease that he was used to cope with, which was there from his childhood.

> I don't do anything for myself. I only don't get obsessed with the disease. I know that it will pass… and since I have diabetes, I focus my attention on it. I give importance to that, not to tuberculosis. (P11, 146-149)

Another patient talked about the importance of work, and focusing on it in order to step away from thinking and paying attention on the disease. He compared working with being under treatment in the hospital. Similarly, P3 mentioned being cheerful in his workplace, that made him feel far away from being sick or the diagnosis of tuberculosis.

> I prefer to spend time focusing on my work. I don't know, a person continuously thinks in the hospital. That's why. (P16, line 47-48)

> I don't feel myself as a patient. We are so happy in my workplace. I don't have an idea that there is a disease. We are cheerful just like before. (P3, line 132-134)

Furthermore, other active strategies were used by the patients which could be another way to shift attention from the problem itself. Physical activities and health-seeking behaviors were described as habits that appeared after the diagnosis.

> My first aim was to stand up. I did not come out of the house in the first two months. I was walking in the garden. I walked, walked and came back home. (P6, line 236-238)

> I walk every day. 10 kilometers. I just arrived from walking. I live healthy. (P8, line 102)

Different from most, a patient mentioned his positive view point towards his experiences. He underlined the contributions of the disease as making him more patient and more mature in certain circumstances. He did not prefer straight distraction from the disease, but he shifted attention to more positive outcomes of the negative experience.

> This disease contributed too much to me. So much. Understanding, patience. Patience is the most important…maturity, it taught me so much. (P15, line 250-253)

3.2.3.4. Humour:

There other patients who were inclined towards using strategies to regulate their emotions. Their aim was to cope with their negative feelings related with their stigma experience, such as feelings of depression, anxiety, guilt, loneliness and lack of self-worthiness. In order to manage the difficult and heavy emotions, 9 patients out of 24 preferred making jokes or funny statements about their current states. They laughed at emotional moments during the interviews, or described making jokes about their diseases. P3, who also used distraction as a strategy, described a moment with his friend, where they made a joke about dying from tuberculosis.

> I don't see myself as a patient…For example, my friend comes and says "when will you die?" and we make jokes. We don't do anything that could be a pressure. (P3, line 132-135)

P17 was another patient who was laughing or smiling during her interview. She was smiling while she was talking about a serious problem for herself. When she was asked to describe physical changes at her home, she laughed while she was describing her changed cleaning routine. She also talked about her current problem on the difficulty of remembering things. She made a joke about killing herself because of forgetfulness.

> Yes, in my home. My house could not be cleaned (laughed). I had changes like that. My children became rebellious. (P17, line 150-151)
>
> My husband says…what was that…he says…I can't remember again. I will jump from the window because of my memory problem, that's it (laugh). You see, I forget everything, amnesia.

P18, used laugh when she was talking about her family issues, about her anger towards her husband and his family. She was suffering from family problems for a long time and looked emotional before her little joke. While she was using a common expression used in Turkish about having tuberculosis, she smiled. This could be seen as a moment where sadness, anger or distress was replaced by humour.

> I told him that he finally done it to me. "Look you did it altogether; I became a tuberculosis patient" I sai5. They used to say, "you made me tuberculosis", I said like that. Because I'm sure that things grow inside, you suppress them. (P18, line 212-215)

3.2.3.5. Religion:

Religious beliefs and the faith appeared in the descriptions of the patients. 12 patients out of 24 mentioned their faith and explained that they believed that the disease was coming from God. Powerful religious belief served as a mechanism to regulate patients' concerns about the disease and thoughts about death. They mentioned the worst possibilities about the end of the disease, and showed an acceptance. P5 and P1 mentioned death, but did not show any anxiety about its probability for themselves.

> I did not ever say "oh I will die", I did not. If we have more time to live, then we will. We will do whatever we can, and then we will leave it to God. (P5, line 40-42)
>
> Even if death comes for me, I know that it will come from God. So I don't have any concerns. If God choose it for me, then I will live that. (P1, line 360-362)

Religious beliefs were a mechanism to manage issues around self-disclosure. Faith made it easier to externalize the disease for the patients and P12 was one of them. He believed that he was not doing a bad thing, or he was guilty.

> Everyone heard about it. I don’t care. I don’t because I don’t do a bad thing. This is a disease coming from God. (P12, line 113-114)

Similar to managing problems about self-disclosure, belief in God was a mechanism to deal with sadness, sorrow, anger and anxiety about being diagnosed with tuberculosis. It served as a method to ease accepting the current situation and a way to see possible positive sides of the existing condition. P2 explained it very clearly.

> If it comes, we accept that it is from God. We say there is no need for being sad. That’s why I don’t feel sorrow, I don’t care. My precious God saw it appropriate for me. Maybe that is an opportunity for making us withdrawn from certain things. Maybe that is beneficial (hayırlı). (P2, line 60-63)

3.2.4. Research Question 4: “What are some factors that account for the possible variations in the experiences of persons diagnosed with TB?”

3.2.4.1. Phase of Disease:

A standard tuberculosis treatment includes 4 types of drugs in the first 2 months and 2 in the following 4 months. This treatment is expected to create differences in symptoms and the level of infectiousness. During the first two months, symptom relief and decrease in clinical complaints are seen. This is where patients start to recognize the difference in their bodies. The degree of infectiousness also diminishes as identified with certain methods such as investigating phlegm cultures. So it would not be wrong to categorize the patients in two different groups according to time since diagnosis. The third group includes MDR patients who undergo more intense treatment and longer drug use.

Table 6: Time Since Diagnosis

Time Since Diagnosis	Patient Numbers
0-2 months	1, 2, 3, 5, 8, 10, 11, 14, 20, 22, 23
2-12 or more months	4, 6, 7, 9, 12, 15, 16, 18, 19, 21, 24
MDR	13, 17

Participants who were taking medication for more than 2 months described their relief and changes in their physical symptoms. Table 6 presents the patients according to the time since diagnosis. P4, who was at fourth month of her treatment, mentioned the decrease of drug amount she used and described her orientation to medications. Similarly, P5 explained his physical change in the first months of his treatment and indicated a better physical portrait.

> Now the amount of pills is not that much, it decreased to 5. So, I think my body got used to them. I started to go back to my normal life. (P4, line 147-148)
>
> I was really bad. I could not walk, could not climb up stairs…3 months is over now, it will be 4 months soon. Thank God I'm fine now. I'm using medications, I feel good. (P12, line 14-15)

Besides the reduced physical effects of the illness, there were other changes observed based on the time of the diagnosis. As presented above, self-disclosure is related with social stigma and self-stigmatization. This topic was important for and described by many patients. The interviews of the patients showed that difficulties in self-disclosure reported more by the patients in the early phase of their disease and mentioned less during the later stages. P10 was a patient in treatment for 2 months. He indicated that he did not tell anybody about his illness, including his children and wife.

> No, she doesn't know. She tells me to quit smoking. I mean, she thinks that

> I have difficulties in breathing like asthma. (P10, line 174-175)

Another patient who was diagnosed a week before the interview date described that he did not prefer to tell anyone, that he did not like to talk to anybody. He also added that he found it unnecessary to make disclosures.

> No, I don’t tell anybody. I am not a person who likes chit chatting. I don’t tell anyone. (P22, line 118)

This does not mean that self-disclosure was not a problem after two months of diagnosis, but it could mean that this became less of a problem over time. The reason for this difference could be the difficulties in orientation to the disease; the patients may be trying to get used to the new diagnosis along with physical, social and psychological changes. Also, being exposed to information about the disease might have an impact on reducing their anxiety over time.

Time factor was also mentioned by the patients who did not experience any problems about self-disclosure. P6, who was very comfortable sharing information about his disease did not state any immediate self-disclosure. Although he did not describe it explicitly, it appears that he needed some time to share it with the others.

> After a while, I shared it with all. My family learned my disease, my friends. (P6, line 163)

Furthermore, a doctor mentioned the role of the stage of the disease in the thoughts and relationships of the patients, such that the relief in the bodily complaints seems to be related to the attitudes towards self-disclosure.

> After a while, after the 3rd month, their anxiety diminishes. Because after the second month, they feel better. They accept that things will be alright for them. (D4, line 104-106)

Being informed about the disease seems to an important factor related to self-disclosure and self-stigma. A comparison of patient narratives according to stages of disease shows a difference in psychological and social relief. In addition, although not expressed explicitly, there are descriptions pointing to the importance of information about the disease. When they were asked to comment on the societal view of tuberculosis, some described the difference between ignorant and knowledgeable people, noting better attitudes by the educated people towards the patients. One possibility is that patients' preferences about self-disclosure are also related to their own level of information about the disease. However, a comparison of patient opinions about the perception in society failed to reveal a difference based on the stage of disease. At every stage, patients' opinions varied and approximately similar numbers of patients portrayed negative or more positive perspectives in their environment. So it cannot be concluded that there is a link between self-disclosure and the perception of TB in the society.

The process is more complicated for MDR patients. First of all, self-disclosure problems are mentioned more by these patients. However, similar to all the patients in later phases of the disease, they also experienced contradicting thoughts about it, and they also described selective disclosure. P13 and P17 both talked about the people who were aware of their disease, as well as some who didn't have any information. Their families and others in their close environment were aware of the diagnosis. The reason might be the long process of treatment, which lasts approximately 2 years. So, it could be much more difficult to keep their diagnosis a secret from their environment, especially from people at work. Furthermore, regarding the severity of the symptoms and huge amount of drugs, self-disclosure might be necessary for them.

> I told my family, co-workers, my environment…I mean I told the people I was close with. I told them that I had an inflammation in my lungs. But I said tuberculosis only to those closest to me. (P17, line 92-94)

As can be seen from the description of P17, self-disclosure is based on the emotions and choice of the patient. A patient might disclose to his close family, but might choose not to the others. P17 and P13, both MDR patients, chose to disguise the identity of the disease with some people. They both were concerned about the others, which made self-disclosure process harder for them.

> During the second diagnosis, there were more people who were concerned about me. And I was becoming more upset when I saw them upset. My brother, he was also very disappointed. I didn't tell the second diagnosis to my father. I couldn't. We secretly went to house to take my stuff. (P13, line 376-379)

Both MDR patients showed high levels of self-stigma as reflected by depressive and anxious feelings, isolation, changes in daily routines and concerns around infection. They expressed intensive negative feelings during their interviews. P13 wanted to take a break from the conversation while he was crying and the interviewer stopped the recorder, to make him relax. He cried after the question about others' reaction to his disease.

> They were all so sad. My little sister was influenced so much. That period was very hard for her, because she became lonely…she always wanted to visit hospital (cry). (P13, line 337-338)

He then described the difficulties at the hospital and his negative experiences about other patients, such as seeing people dying, especially the young ones. Here, hospitalization is revealed as another factor related to stigmatization which will be discussed later below.

> Second time…because you try so hard, you recover and move on, while being cautious. People were talking at the hospital. First diagnosis, then the second, then third and it gets more and more intensive. They were talking about the possibility of death. (P13, line 372-375)

Self-worthlessness and loneliness were P13's other negative feelings, and part of his internalized stigma. Furthermore, he portrayed the others as people who have negative attitudes towards the disease, because of lack of information.

> I was really sad. You feel worthless. You become a person that is worth nothing in the eyes of others, that they have to bear with in the same environment. (P13, line 101-102)

> There are lots of people who have no idea about the disease, they think that they can be infected from anything, from glass or plate. (P13, line 107-108)

P17, another MDR patient shared similar experiences about her feelings. She mentioned that she had been suffering from several psychological difficulties including anxiety and depression most of her life and that she was getting psychiatric support after the diagnosis.

> I was feeling worthless; I could not express myself. I thought that I was incapable of doing nothing (line 52-54). I now try to open myself, try to communicate with other people (P17, line 219-220)

She also had problems with her marriage, especially about their sex life. She was not feeling the same, and she described that she was isolating herself from her husband.

> I do not want a sexual relationship with my husband. I don’t know why, but I don’t want it. (P17, line 157)

Overall, MDR patients showed more problems with self-disclosure, self-stigma and portrayed the stigmatizing behavior of the others in the society. They were having psychological difficulties and were having mood fluctuations during their treatment process. The long duration of the treatment, physical symptoms and the attitude of the others seemed to be the major causes of their difficulties.

3.2.4.2. Family History of Tuberculosis:

Table 8: Family History of TB

Family History of TB	Patient Numbers
Yes	2, 6, 7, 11, 15, 17, 18, 21, 22
No	1, 3, 4, 5, 8, 9, 10, 12, 13, 14, 16, 19, 20

Another factor that might influence self-disclosure is the incidence of tuberculosis history in the family, which is presented for each patient in Table 8.

The relatives with TB diagnosis were siblings, parents, aunts, aunt-in-laws, uncles and grandparents, diagnosed at different times:

> My aunts had the disease. Also my uncles. They experienced it, they even, they stayed in the hospital. (P17, line 229-230)
>
> My sister and my brother they both had tuberculosis. It was 10-20 years ago. Not new. (P21, line 44)

Patients with family histories of tuberculosis reported less difficulty about self-disclosure. Family history of TB seemed to serve a facilitative effect on sharing information about the disease. Seeing, hearing and living with that experience might create a better understating of the problem less self-stigmatizing. P18 told the story of his uncle, which she learned after her diagnosis. She also found out that her father had the same disease when he was a child. Furthermore, she was informed about the disease and got a calming advice from her aunt-in-law.

> My uncle also had tuberculosis. I found out when I was diagnosed. My uncle's wife said that my father also had tuberculosis when he was little…I don't know for sure, but I do know about my uncle. His wife told me not to be afraid and to be careful about my nutrition. (P18, 161-165)

The family of history of tuberculosis also had another effect on the patients. When two group of patients are compared, those with a TB history in the family tended to seek help from health care institutions more quickly. They did not show any hesitation and chose to consult dispensaries or hospitals directly.

> Yes, I first came here. My brother, he was also treated here…his was a resistant type. (line 25) He told me to come here, he advised me. (P2, line 41)
>
> My father, also my aunt. They had tuberculosis. My grandfather was also diagnosed with TB. When I was losing weight, people at home suspected it. (P11, line 23-24)

As seen in his description, knowing a family member with a tuberculosis diagnosis pushed P2 to consult dispensaries. Similarly, P11's physical changes were recognized by his family and they started to think of the possibility of tuberculosis, which then fastened the diagnostic process. These relations are in line with the observations of the doctors.

> Usually people come here with transfer or with a family history of tuberculosis. Coming because of a cough or expecting tuberculosis but not diagnosed with it, these are rare. Frequently people come with the suspicion of the disease, and they react less intensely. (D1, line 41-44)
>
> They have anxieties about being stigmatized. But we give explanations to them and after 1-2 months, they are more relaxed. (D8, line 48-50)

As the doctor describes, having a TB history in family has an impact on the reaction to the diagnosis. Patients who had a diagnosed family member did not define the diagnosis as a shocking experience, or expressed feeling nothing. P6 was one of them.

> I didn't feel anything at the moment. I trust my wife, and I also experienced it with my father. (P6, line 44)
>
> It did not influence me, since my father had the same disease. In my family only my father had this disease, no one else does…it didn't influence me. No, I mean it would be wrong to say no, but it affected me very little. (P6, line 111-112)
>
> I did not allow myself to get pessimistic at the moment. Because this comes from God, you cannot do anything. I did not feel fear. I was calm and continued to take my medications. (P7, line 31-35)

Another doctor shared her observations and thoughts about patients' acceptance of the disease and drew attention to the relation between acceptance and family history of TB. She noted that people having difficulties accepting the diagnosis are more likely to be the ones without any experience about the disease within their family.

> Some do not believe and they say that this a misdiagnosis. They try to underestimate the disease and ask me if medication is necessary. Some reactions are so intense, yes. They don’t accept it and say that they do not have the disease in their family. (D5, line 41-44)

As seen in the narratives of P6 and P7, having information about the disease made the patient feel prepared for its diagnosis and led to different reactions including better coping. P7 mentioned his belief in God and the belief that it was coming from him. Similarly, other patients made comparisons between their disease and that of their relative, and engaged in as downward comparison, as a way to cope with their current situation.

> My brother experienced this disease very intensely. I see my situation as not that bad. He was hospitalized, he lost many things from himself, from his psychology. (P15, line 145-146)

> I remembered my uncle’s wife. We were in primary school. People were talking about her at home…she had died from tuberculosis. (P7, line 159-160)

Furthermore, similar to the findings regarding the comparison of the stages of the patients according to time since diagnosis, there is not a visible connection between the family history of tuberculosis and patients’ views regarding the perception of TB in the society. Three patients thought that there was a negative perception, one declared that the society is uninformed about the disease, another two thought that there is an improvement in the societal beliefs, and the last two noted a variety of opinions according to individuals’ level of education. So, patients did not have a consensus on the perception of TB in the society, even if they shared similar family stories about the disease.

3.2.4.3. Support System:

Patients portrayed their support system in terms of attitudes and behaviors of others. Although lack of support was dominant in the overall picture, there were patients who did feel the presence of the others. Similarly, there were patients who could easily disclose their problems different stigma-related experiences. Support system seemed to be an important factor especially for self-disclosure. Although it is difficult to make a strong connection, it is possible to point to the positive effect of support on self-disclosure. Patients who did experience disappointment about the support of the others seemed to have more difficulties about sharing their disease and those with a better support system who expressed their appreciation about the others, reported fewer issues about self-disclosure. P3 had the support of his wife and his family. Although he could not spend time with his parents due to their advanced age, he noted being grateful for his wife's support several times during the interview. In parallel, he did not have any concern about sharing his disease with the others and declared that everyone was aware of his diagnosis.

> Everyone near us know about my disease. We do not keep it as a secret. Everyone knows. (P3, line 76)

Another patient who did not share major difficulties about self-disclosure described the support from her husband, mother and father. Although she was aware of the possible stigmatizing attitudes of the society, she declared that she did not hesitate to share her disease with anyone.

> My relatives know, it gets heard…I'm fine. I don't care, I don't because I am not doing a bad thing. It is a disease coming from God. (P12, line 113-114)

A positive support system seemed to facilitate easier self-disclosure independently from self-stigma and the perception of tuberculosis in the society. This might mean that no matter what the level of stigma within the patient or in the society, a person can more easily share current problems if they have a good support system.

3.2.4.4. Personal Background:

Patients' personal background seemed to influence their experience of tuberculosis. Especially hospitalization, age, gender and employment status were found to have an influence on creating variance regarding how the diagnosis and the process of tuberculosis treatment were described.

Hospitalization:

Being hospitalized during the treatment of tuberculosis made slight differences in the descriptions of the patients. The hospitalized patients are showed in Table 7.

Table 7: Hospitalization

Hospitalization	Patient Numbers
In-Patient	7, 10, 13, 14, 15, 17, 23, 24
Out-Patient	1, 2, 3, 4, 5, 6, 8, 9, 11, 12, 16, 18, 19, 20, 21, 22,

2 MDR patients were also hospitalized and they showed high levels of self-stigma and stigmatizing behavior from their environment. However, even if they are excluded from the hospitalized group, the group of in-patients appeared to have more difficulty in their experience of the disease. Patients who were treated in the hospital for a while expressed more problems with self-disclosure, with 3 of them even denying their need to share it with other people. The rest were highly selective when they thought about disclosing. P7 was one, and did not inform his family about being treated in the hospital. He also had difficulty being in public areas, and lived in isolation for 3 months.

> I stayed in the hospital for a month. When they called me, I was telling them that I was at home. I continued like that…because I didn't want them to come see me. (P7, line 56-57)

Distinctive from the out-patients, they shared more stories about the stigma in the society and about their negative practices in the hospitals. Different from their experience in the dispensaries, they had complaints about the attitudes of the personnel and their behavior. P13 described his diagnosis with negative feelings and said that he was maltreated by the doctor. Similarly, P14 shared his feelings about being in the hospital and had complaints about the behavior of the doctors and the nurses. He felt the stigmatizing behavior of the people around him and spoke with anger.

> We went to the hospital with my brother. Doctor got me out of the room immediately after looking at the paper. She grabbed two masks from the table and told me to wear it. She was rude…We were not aware of what was happening, but she sent me out. (P13, line 139-142)

> They treat us like bugaboos. Doctors, nurses, they stay away from us. Like negative, uninviting. Sorry, but they act like we are animals. Who are they? What are their manners? They humiliate us. (P14, line 35-38)

Being in the hospital for a long time might relate to higher levels of self-stigma. Patients were seeing various forms of different diseases and facing death. They were hearing the conversations between other patients who were suffering and their families, as well as their reactions. Spending time in an environment full of distress, seemed to influence the emotional states of the patients. P10 described his feelings of being in the hospital as well as the questions in his mind.

> Your psychology worsens. You see people who come in normal, but end up dying and see their wives who cry for them. You become worse hearing these…And you start to ask, "how did I get that disease? Will I get better? Will I infect my family?" And you feel like an outsider. (P10, line 65-68)

Although hospitalization was a difficult process for the patients, they also described positive memories about the times they spent there. Most of them talked about their relationship with the other patients and remembered their friendship.

> The best part of the disease is the supportive environment in the hospital with the other patients. I still meet with them, since 2007. We meet, talk. (P13, line 163-165)

Age:

Another personal information that was related to differences between the experiences was the age factor. The age distribution of the patients is shown in Table 8.

Table 8: Age

Age	Patient Numbers
18-29	4, 9, 11, 13, 15
30-49	1, 2, 3, 5, 6, 8, 12, 16, 17, 18, 19, 20, 21, 24
50-64	7, 10, 14, 22, 23

Although self-disclosure was a problem for most of the patients, younger participants declared less severe difficulties about sharing their disease with the others. Patients in the age range between 18 and 29 experienced easier self-disclosures with their families, and especially with their mothers and fathers. P4 talked about his mother's presence when he consulted the hospital, and about the availability of his friends during the process.

> I did not tell my friends at the beginning. I told my parents. My mother was with me when I went to doctor. Then, all my friends came with me to the hospital. They learned the diagnosis at that moment. (P4, line 210-213)

Another patient described that he was with one of his closest friends when he first went to a health-care facility. So, the first person who was aware of his disease was a friend. Then, during the process, he decided to tell his family.

> I was with my friend, my closest friend. My parents are divorced, so they did not find out about my diagnosis immediately. I wanted to learn about TB properly and then to tell them. Then I first told my father, and then, my mother. (P9, line 72-74)

The narratives of the younger patients point to the importance of the availability of friends in making self-disclosure. The physical and emotional accessibility of friends could facilitate easier self-disclosure. Also, compared to the older ones, younger patients declared the presence of their parents when being at a consultation at the dispensaries and hospitals. The narratives of the older patients, on the other hand, reflected a different picture. They seemed to be more anxious about sharing their disease with the others. P7 was one of the patients who did not engage in any self-disclosure. His family and relatives were not aware of the diagnosis. When the reasons were asked, he described his worry about his children. He seemed to see himself as a possible burden, and did not want the others to be worried.

> No, I didn’t tell anybody… (line 43) My children do not know of my disease… (line 67) If I tell them, they man come here; they all have their own children, they have jobs. What would they do here? I did not want to inconvenience them. (P7, line 202-204)

Similarly, P10 did not prefer to share his disease with many people. He declared that because they were illiterate, he did not have any support from his family. When the reasons of his non-disclosure were investigated, he said that his parents were too old to understand and to spend time with him. Interestingly, he shared that his wife was not aware of the tuberculosis diagnosis.

> She doesn’t know. She learned about it recently. She knew that I should not smoke…she knew that I had difficulties in breathing, and she now guesses that it is asthma. God knows, I could never guess that I would have tuberculosis. (P10, line 174-176)

We can see the difficulties of older people with their families; particularly their concerns about their children, old parents and husbands and wives. However, it can be speculated that there should be more than that. P10 mentions his differences from his parents by emphasizing their lack of knowledge and education. Self-disclosure might be related to internalized features of tuberculosis that are based on earlier opinions on the disease. As mentioned earlier, some patients described the difference between tuberculosis stigma over the years. When we look at the patients as a function of age, it appears that the older patients might be affected by existence of faulty beliefs towards the disease, coming from older times.

Gender and Employment:

Third and fourth personal factors that might relate to different experiences are gender and employment status. Table 9 shows the distribution of patients according to gender.

Table 9: Gender

Gender	Patient Numbers
Male	1, 2, 3, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 22, 23, 24
Female	4, 15, 17, 18, 19, 20, 21

Self-disclosure problems were mentioned less by the female participants. Five out of 7seven women could share their disease with their family and close friends. Male patients were more inclined to keep their disease a secret from their close relatives and tended to name their situation with another disease such as the flu or problems with other organs. Working actively seems to be an important factor. Table 12 presents the patients according to their employment status.

Table 12: Employment Status

Employment Status	Patient Numbers
Employed	1, 3, 7, 8, 9, 11, 13, 16, 24
Unemployed	2, 4, 5, 6, 10, 12, 14, 15, 17, 18, 19, 20, 21, 22, 23

As can be seen in the table, all women participants are unemployed. However, there are working and non-working male patients in the study. This could be one of the dramatic differences between men and women. Working regularly points to an environment where social contact is necessary. Social contact and exposure to more people in a daily routine might increase the concerns of the tuberculosis patients about the possibility of being stigmatized by a group. Unemployed women might also have contact with their environment, such as their neighbors or family members, but they would stay in their close environment and feel more safe. So, the reason behind different self-disclosure preferences might be related to employment status. In parallel, during the interviews, men talked more about economic issues and their difficulty in managing their monetary problems. A male patient P1 described his concerns about being out of work and about stabilizing his personal economic situation

> I could lose my job. I live in İstanbul, I have nowhere else to go…I put the disease aside; I only think of these, what will I do if I become unemployed…If they discharge me, how can I find a new job. (P1, line 550-553)

Another gender-based difference was about help-seeking behavior. Two patients out of 24 shared that they consulted a psychiatrist after they were diagnosed, and they were both women.

> I am getting psychiatric help at the moment…I thought that I was going to die. They told me to stay apart from my children. I wore a mask, I felt terrible. I thought I should remain distant from other people. (P17, line 70-74)

> My son, he started not to do his homework. He thought that something might happen to me every time, he slept with me, hugged me; he was crying for 15-20 days. I got support…from a psychologist. (P19, line 145-148)

Furthermore, the thoughts of women about the perception of tuberculosis in the society were more negative when compared to the descriptions of the male participants. Five out of 7 women portrayed a society with negative attitudes towards the disease.

> They don’t see it as nice. They don’t see it as good. (P17, line 189)

However, the descriptions of men had a wider range. Study participants included 7 females and 17 males. This could be the reason for a wider range of opinions of the male participants.

DISCUSSION

The themes presented in the results section described the experiences of the patients after being diagnosed with tuberculosis. The main objective of the study was to understand the tuberculosis experiences of the patients with regards to their physical, psychological and social states and stigma-related practices. A general overview of the emergent themes based on the narratives of the patients shows that being diagnosed with tuberculosis is a phenomenon that has an influence first on the patients, then on their environment including the nuclear family, extended family, neighborhood, as well as the whole society. Tuberculosis is a disease which is not only a concern of the patient, but of the wider environment as well since it has social features. Being an infectious disease is its most prominent characteristic, which in fact, makes it difficult to limit its effect to the individual. The concept of stigma is also societal. The experience of having a tuberculosis experience included several components and various stigma-related factors. These issues were present in the narratives of the patients and the doctors and in the focus group discussion with a non-patient group.

While the experience of each patient was unique and different, they also had commonalities. Patients described physical, psychological and social differences that occurred after the diagnosis. These experiences were mainly based on the problems that they encountered during this process. The process of being diagnosed and their reactions to the diagnosis comprised the most detailed part in their descriptions and provided various kinds of information about their current emotional and social state. Their support system, economic relationship related issues with the others were other components of their narratives. Furthermore, they had to face stigma-related experiences such as perception of tuberculosis in society, difficulties about self-disclosure, self-stigma and problems about the treatment process. On the other hand, their coping mechanisms varied as a function of their life circumstances and personal characteristics. It should be noted again that the experiences depended on different mechanisms and aspects of the subgroups of the participants. The particular stage of their disease, having a tuberculosis history in the family, quality of the support system and personal background were some factors that accounted for the variance in their experiences. A closer look at their experiences, ways of coping and factors that lead to differences in those experiences is necessary to draw a better picture about the experience of living with tuberculosis.

4.1. RESEARCH QUESTIONS 1 and 2:

The first research question was asked with the aim to understand the major experiences of the patients after the diagnosis. Three categories emerged as the main themes, and were primarily about the physical, social and psychological changes. Regarding the first question, two points should be emphasized: First, the most described and detailed topic was the process before the diagnosis, issues around it, and the diagnosis itself. Second, despite the differences in the emotional tone of the participants while talking about their experiences, most of them were willing and enthusiastic to share their stories. The second question was about the stigma-related experiences of the patients. During the interviews, some were specifically asked to explain their stigma experiences, while others talked on their own. For the purpose of giving a general overview and drawing relationships between different themes, first two questions are discussed together.

Results showed that, regardless of the different life stories, all patients suffered from physical complaints before the diagnosis and during the treatment process. The first symptoms of the disease included weight loss, a cough with or without phlegm or blood, difficulty in breathing, loss of appetite and excessive perspiration. Some patients had a single symptom, while others described several which made them go to a hospital or to another health-care facility. As explained in the guidebook of the Ministry of Health, the presence of one or more of these symptoms point to the possible diagnosis of tuberculosis (Özkara et al, 2011). However, there were others who were surprised about their diagnosis since they did not have any symptoms such as the ones explained above. They were diagnosed after their consultation at the dispensaries to obtain a health report for either marriage, job application or insurance. As it is seen in the literature and in guidelines for tuberculosis reports, dispensaries and hospitals in Turkey are responsible for detecting the early signs of the disease (Özkara, Aktaş, Özkan & Ecevit, 2003).

Furthermore, patients described the issues about the large amount of drugs and the related bodily symptoms that they experienced at the beginning and during the early phases of the treatment. These included complaints such as nausea, dizziness, vomiting, and ache and pain in the different areas of the body. In the literature, multi-drug use during the tuberculosis treatment is related with various side effects (Özkara et al, 2003). These effects were explained as relatively low and tolerable, but as needing doctors' attention to control high risk possibilities. Loss of appetite, nausea, stomach ache, joint pain and burning sensation on the feet were seen as minor side effects of the medications. Itchiness, skin eruption, dizziness, hepatitis and visual impairment are the possibilities of major risks (Sevim, 2010). When the results are compared with the literature, it is evident that the descriptions of the patients are in line with the expected results of medication use, and that their complaints can be seen as minor effects of the treatment. Besides the anticipated side effects of the medication use, patients declared their boredom and unwillingness to continue to take their pills. Here the important factor seemed to be the duration of the treatment, which is generally 6 months with different medications. The treatment period is divided into two stages: the beginning period endures approximately 2 months, and the continuum period generally ends in the following 4 months (Özkan, 2010). Results revealed that, considering the long process of the treatment, doctors gave importance to informing the patients about the possible difficulties of long-time drug use, under the control of DOT (Directly Observed Treatment). Both doctors and patients articulated the need for informing and being informed about the process, in order to diminish possible problems. It is important to note that, doctors at the dispensaries were aware of the concept of stigma and its components, and made much effort to avoid any stigmatizing behavior at their work places. Without any exception, their dedication to be helpful to tuberculosis patients, will to ensure a successful treatment, protecting the rights of the patients regarding their well-being were remarkable.

A very recent study by Polat (2017) showed that stigma is related with the infectious nature of the disease, the long duration of the treatment process and the obligatory DOT. The same study also found that the most significant reason behind patient stigmatization is the lack of access to necessary information about the disease and the ongoing process. Although the doctors in the study declared that they were supportive in terms of informing the patients, patients described their concerns about the current procedure. Some of them stated that they did not need any assistance or observation while taking the pills, and most were unhappy about the stigmatizing effects of it. These included being at the health-care facility every single day, at a specific time, signing a paper, and being exposed to people in the neighborhood. The process made the patients vulnerable to public view and was an obstacle for non-disclosure. Similarly, dispensary doctors were aware of the nervousness of their patients, and tried to find different strategies to accommodate them; however, they knew the importance and necessity of the DOT system. The effectiveness of DOT related to the cure of TB is a known fact (Weiss, Ramakrishna & Somma, 2006); however, the stigmatizing side of the system has also been studied in the literature. For example, a study in India explored the reasons behind non-participation to the DOT program and found lack of confidentiality and fear of being stigmatized as the major problems. 28% of the participants were concerned about stigma and they were mostly women (Balasubramanian, Oommen & Samuel, 2000). Another study about DOT revealed that the need to resist disclosure and the effort to hide their disease resulted in a delay in the start of treatment (Morankar, Suryawanshi, Kudale, Patil & Deshmukh, 2000). These findings of this study were in line with the previous findings as indicating the advantageous and non-advantageous sides of this treatment protocol.

There is a considerable amount of research on the quality of life (QoL) of tuberculosis patients conducted in different countries that provides information about the daily lives of the patients. Research showed the significant difference among control and patient groups; physical and psychological aspects of QoL were shown to be the most affected domains, while social was aspect the highest in India (Meera, Nandini & Ingle, 2008). In contrast, another study done in Nigeria, investigating health-related quality of life (HRQOL) of tuberculosis patients showed that physical domain was the least affected one, while environmental aspect was the highest including finance, safety and accessibility to information. Although the current study is not a quantitative one like the others, it can be stated that physical problems and the treatment process are at least as important as other issues such as social and psychological aspects of the disease.

An analysis of the results showed the social and psychological differences and difficulties of the patients. These mainly included the form and quality of the relationship between themselves and others, as well as the reflections of their inner worlds and emotions. A very important topic was the perceived support system. The work of Taşkın (2007) showed that 17.9% of patients indicated a negative pattern in their familial relations and 19.8% of them remarked a decline in the quality of relations with the neighbors. Similar to the literature, but with a higher ratio, one half of the participants declared the lack of support, distant behaviors and negative attitudes of others including family members, neighbors and colleagues. The other half of the patients described their positive experience about their social environment, such as the existence and closeness of the others; and perceiving emotional backing from their parents, siblings and friends. However, there was no strict difference between the two groups. Patients who were appreciating others' support also talked about the being disappointed by the others. This conflictual picture was also in line with the literature. A study about the social stigma in Nicaragua, done with in-depth interviews and focus groups, found two conflicting results. First it showed the presence and support of the close environment of the patients, as well as the presence of the fear of being contaminating and infecting others. Second finding showed that people around tuberculosis patients considered them unlucky and experienced a feeling of mistrust near them, while the patients avoided self-disclosure to inhibit a possible loss of trust and to avoid depression (Macq, Solis, Martinez, Martiny & Dujardin, 2005). One of the possible reason behind the conflictual situations might be the anxiety of infecting others, and the fear of people about being contaminated, which is another result of the current study.

Another reason might be related with another theme of this study, feeling discomfort in others. The discomfort was explained by other's distant behavior and their concerns about being infected and transferring the disease to their own families. When put together, feeling or predicting discomfort in others, seems to be in line with the fear of infecting others, and being infected by the patients, thus in relation with self-stigma. These also provide supportive evidence for the work of Mack et al (2005). This result might show the difficulty in this study of dividing participants into two, as supported and non-supported ones. Interestingly, without a single exception, all patients were happy regarding the support of the dispensaries. This is a result that is difficult to compare with the literature. However, it should be noted that, our study was conducted in the dispensaries of the Tuberculosis Association of Turkey. The procedure, attitudes, skills and the stability of the personnel might be different in other dispensaries that are government run.

Another social concern of the patients was about wearing a mask. Especially during the early stages of the disease, patients had to distance themselves physically from the others, and to wear a mask while with others or in public areas. Wearing a mask had consequences for the patients such as being separated from the others or having another room to sleep due to the concern around infection. In parallel, health-care literature relates different forms of isolation such as psychological or physical, loss of intimacy and contact with mask wearing (Robertson, Hershenfield, Grace & Stewart, 2004). Along with the mask, the isolation and being separated from others, their looks, and observing others distancing themselves were the major concerns of the participants in this study. These were in line with the descriptions in the qualitative work of Dodor (2008) in which wearing mask was related with isolation and feelings of shame. The study of Dodor (2008) also revealed that most of the health-care workers were using the mask and making the patients use it, because of their fear of being infected, as well as the fear of the people in the society. Similarly, during the focus group discussion, the mask was primarily associated with infection. In contrast, this study did not reveal a strong fear of the doctors or personnel in the dispensaries.

Doctors were in consensus about the necessity of using masks for protection, especially in the infectious cases such as MDR patients (Dharmadhikari, Mphahlele, Stoltz, Venter, Methebula, Masotla, Lubbe, Pegano, First, Jensen & Walt, 2012), but in practice they preferred to monitor the contamination with air circulation and ultraviolet lights. So, it must be pointed out that the behavior of the health-care personnel was cautious and most were aware of the possibility of stigmatizing the patients. So, this study did not reveal any deviant exclusionary behavior from the personnel. Another association about the mask was about the diagnosis. Majority of the patients associated the first contact with the mask with when they were diagnosed and talked about their emotions including being upset, shock, anger and acceptance. These emotions were similar to the feelings experienced during the diagnosis, another important theme of the current study. There was a diversity in the reactions, behaviors and emotions of the patients. There were patients who did not accept themselves as diagnosed with tuberculosis, while others described feelings of worry and anxiety through the acceptance process. Mostly, there were feelings of shock, being stunned, but relief was also present. A few patients described feeling nothing, or denied negative feelings. These different reactions are in line with findings of a study in India that assessed the initial reactions of 100 tuberculosis patients to diagnosis and found that majority experienced the situation as negative. The 18% of the patients mentioned being hopeful, 30% were anxious or tense, 26% reported being depressive, %20 could not express their feelings and 6% denied their situation (Eram, Khan, Tamanna, Khan, Khaliq & Abidi, 2006).

Another social aspect of the consequences of the disease was related to work and finances. Most patients had to quit their jobs after being diagnosed, and some had difficulties when they tried to go back. The industry they were in, their job definition and position, being a worker or owning their own business were the factors related to these difficulties. The attitudes from colleagues at work were not very welcoming for most of them, but there were several participants who were happy with the behavior of their co-workers and bosses. Few of them reported having an advantage about being their own boss, so that they did not feel themselves obliged to continue working. The study again showed a diversity in the area of economics. In the literature, the relationship of tuberculosis and economic problems was high among low SES and was linked with a higher risk of tuberculosis, regarding the possibilities of malnutrition, pollution or drug use (Narasimhan, Wood, MacIntyre & Mathai, 2013). Also, tuberculosis itself has an impact on patients' economic situations and becomes an economic burden for the patient and his family during the treatment process. Although the availability of free drugs is helpful, quitting work seems like a major problem for most patients and families (Long et al, 2001).

Besides the physical, social and psychological changes described above, the perception of tuberculosis in the society was another crucial theme of the study. Participants were asked to comment on the opinions of other people and two main groups of opinions emerged: The first group portrayed a negative picture and believed that tuberculosis was seen as a bad and strange. They interpreted this as having to do with lack of knowledge and misconceptions about the disease. The second group had a more positive picture and talked about the presence of different opinions, ranging from nice and tolerant to negative. Several patients in this group also mentioned the lack of knowledge.

In parallel, the focus group discussion showed the associations about tuberculosis; most participants discussed being uninformed about the disease and guessed that it no longer existed. Their other associations were fear-provoking phenomena such Turkish movies, spitting blood, mask, infectiousness and dying. Fear and threat are related with stigma in the literature. As a basic survival system, human being are fearful of the unknown or death related concepts of the infectious diseases (Strangor & Crandall, 2000). The importance of the existence of threat heightens when infectious diseases are concerned, because individuals feel a threat, or "peril" which empowers the stigmatizing attributes and behaviors towards the sick people (Jones et al, 1984). Different from our current results, a focus group work done in Kenya showed that people were aware of the existence of tuberculosis; however, because of their lack of information about the details of the disease it was perceived as a dangerous, highly infectious and serious disease (Liefooghe et al, 1997).

The threat is not only prevalent in the society, but also in the inner worlds of the patients. The results showed that the threat perception in the social environment got internalized by most of patients and negative associations were assumed as real. Emotional changes such as feeling of depression, anxiety, loneliness and low self-esteem were experienced during the process. The work of Akpınar & Kayhan (2013) showed that tuberculosis patients scored high on anxiety and depression . Another study in Turkey found a moderate level of anxiety and depression among tuberculosis patients that pointed to the need for psychological support (Polat & Ergüney, 2012). The literature shows that internalized stigma is one of the sources feelings of shame and guilt that eventually leads to diminishing self-worth and self-esteem, which might result in depression and anxiety (Baral, Karki & Newell, 2007). However, in our country, these findings were not examined in the context of self-stigma.

The current study showed that other components of self-stigma were isolation, fear of infecting others and making changes in the daily lives. A qualitative study in Nepal, proposed fear of infecting others and isolation as a result of self-stigma of the tuberculosis patients (Baral, Karkı & Newell, 2007). Similarly, the participants of this study described their concerns around infection, especially to their loved ones, which isolated from the community. The changes in daily routines such as separating utensils and dishes in the house, as well as their rooms, or excessive cleaning were in order to protect their families. It should be noted that fear of infection and isolation to some extend could be legitimized with medical reasons; however, it is known that (excluding the MDR cases) patients with TB are free of infection after two weeks of drug use (Özkan, 2010). However, our results and the literature show a longer duration of isolation in various studies conducted in different countries including Mexico City, Vietnam and India (Long et al, 2000, Arthur & Linda, 1992).

A last, but a major issue of the patients was about self-disclosure. Most reported feeling the hesitation of sharing their disease with the others. Some kept it as a secret from their families, and some preferred to share it with certain people. The reasons were mostly about mistrust, creating a bad reputation and misperception. They also did not want to make their families them feel anxious or sad. There were patients who preferred to rename their disease as another one, such as the cold, the flu or osteolysis. However, there were few others who did not have any concern about self-disclosure. They reported their belief in God, so they were not responsible for the diagnosis, which made them feel more at ease about informing the others. A quantitative study done in Turkey showed that 60.9% of the patients did not inform their friends, and 66% of them did not share their diagnosis with their colleagues with the fear of being marginalized (Özol, Koçak, Çoşkunol & Egemen, 2005). In parallel, the work of Arıkan, Kuruğlu, Berel, Oral, Ekim, Köktürk & Levent (2000) found that 24% of the patients kept their diagnosis as a secret from everyone except their close family, 20% reported that they shared it when necessary, and 16% shared with those who needed to be protected considering the risk of contamination.

4.2. RESEARCH QUESTION 3:

The third question aimed to understand the coping mechanisms and preferred strategies of the patients after being diagnosed with tuberculosis. Patients preferred certain mechanism to adjust psychologically to the stress of the disease and stigma. The results revealed five main mechanisms: selective disclosure, isolation, distraction, humor and religion.

As explained above, self-disclosure was a difficult and problematic process, and was a part of stigma and stigma-related experiences of the patients. However, selective-disclosure was also a mechanism for protecting the self from the possible threat of the others, since the outer world is full of bad reputation, negative associations and discrimination for most of them. Isolation is a similar result of a stigmatizing experience; however, it has a also protective nature. Whether these strategies are selected on purpose and their effectiveness can be discussed. Folkman & Lazarus (1980) proposed two major strategies of coping: problem-focused and emotion-focused. These two forms of coping provide the management of stress and reduce of the anxiety. It is also known that coping mechanisms can involve engagement or disengagement (approach or avoidance) depending on the situation and the person (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001). However, the strategies or attempts to control stress might not be as effective as the person wills (Scheier, 1986). So, selective disclosure and isolation can be seen as non-effective strategies, since they do not involve a task, or positive connotations. Besides, distraction from one’s emotions is considered as a coping skill in the work of Moos and Tsu (1997).

Furthermore, these strategies might also be understood in line with the need for control. As proposed in the work of Compas et al (2001), gaining control over a stressful event is a way to cope with the current problem. Primary control is over one’s environment and the reactions of others, whereas secondary control is more about regulating emotions. Selective-disclosure and isolation might be mechanisms to have control over the environment, wherein the feeling of control is very lowered for the cases of tuberculosis patients. Since it is very difficult and even impossible for them to control the stigmatizing behavior of the others, controlling their own behavior and isolating oneself might serve as a protection. Furthermore, isolation can be seen as a part of avoidance coping for the stigmatized individual, since it is a form of social and physical withdrawal from a stressful atmosphere. A person might try to avoid stigmatizing environments; however if he or she cannot control them, total social isolation might occur (Miller & Kaiser, 2001).

Distraction as another mechanism was described by patients in different forms. They tried to shift emotional or behavioral attention from the main stressor, which might be the disease or the stigma, to something else. These included focusing on another disease rather than tuberculosis, overwork and preferring not to quit one’s job during difficult times, doing physical activities such as walking, and adapting new healthy behaviors in terms of nutrition and bodily health. Since there are many different opinions and proposed strategies in the coping literature, distraction can be discussed through various lenses. Earlier studies show distraction as an avoidance mechanism and thus useless or maladaptive for reducing stress (Conner-Smith, Compas, Wadsworth, Thomsen & Saltzman, 2000). However, more recent research has evaluated distraction as a form of engagement strategy, and several studies showed its effectiveness on diminishing obsessive or intrusive thinking during a stressful time period. Distraction, rather than suppression might be more beneficial for the stigmatized individuals (Miller & Kaiser, 2001). So, distracting thoughts and the behaviors of the tuberculosis patients might work at a certain level to decrease their stress about the burden of the disease and social stigma.

As described above, stress is mainly linked with anxiety and depression, whereas humor stands like a buffer between stress and negative emotions of an individual (Abel, 2002). The literature shows the physical correlates of humor such as muscle relaxation, positive mood excretion and reduced pain (Deaner & McConatha, 1993). Besides the physical and hormonal effects, humor has an impact on psychological status as supporting the cognitive appraisal of the individuals, and can work as a coping mechanism (Kuiper & Martin, 1998). During the interviews, there were patients who made jokes, laughed, smiled at emotional moments. These patients made jokes on a stressful topic such as death, discrimination or hurtful moments. Humor may be their attempt to control and balance their negative emotions with a positive one. It is also known that humor has an effect on balancing the cognitive perspective and on providing a better psychological state in response to a real or perceived threat (Abel, 2002). Similarly, the work of Rim (1988) showed the correlation between humor and minimization, reversal and seeing the positive side of the events. Moreover, the use of humor has an impact on social relationships. The study by Nezlek and Derks (2001) which investigated the social interactions of the revealed humor as coping method for stress and as a means for empowering the connection and interaction with the others. It can be concluded that the use of humor is helpful for reducing the stress of the tuberculosis patients, and for making them feel less vulnerable to the difficult stigmatizing process.

As another strategy, religious beliefs and belief in fate were also described. A few patients believed that the disease came from God, that there is no need to rebel against it. Interestingly, these were the patients who talked about death and worst possibilities of the disease. So, their powerful religious beliefs were helpful to cope with intrusive or negative thoughts and emotions during the treatment process. In the literature, there are studies showing the positive impact of spirituality on HIV/AIDS (Kendall, 1994) and cancer patients (Johnson & Spilka, 1991) as a useful coping mechanism. Moreover, there are others showing the link between religiosity and various physical illnesses, neurological problems and mental disorders. It is known that the existence of an important chronic or infectious disease influences the emotional well-being of the patients. Religious beliefs, or having a powerful connection with spirituality support the individual by providing hope, reminding the meaning of life and a sense of control (Koenig, Larson & Larson, 2001). These are in line with the descriptions of patients with TB. They reported feeling free from being guilty, worthless, sad or anxious during the diagnosis and the ongoing process. However, similar to other mechanisms, the permanence of the effects are questionable, since patients also provided negative emotions while talking about other areas on their disease.

4.3. RESEARCH QUESTION 4:

The purpose of the fourth question was to understand the possible factors that might be responsible for the variations in the experiences of tuberculosis patients. Results showed four main factors: phase of disease, family history of tuberculosis, support system and demographical information.

Regarding the long duration of the tuberculosis treatment, including 2 months of initial phase and 4 months of the continuum phase, a comparison was made between three group of patients (Özkan, 2010). Those who were during the initial phase, continuum phase and MDR patients. MDR patients were separated, because of the different process of their treatment that influences the time of symptom relief, progression and developments (Tahaoğlu, 2010). As would be medically expected (Özkan, 2010), patients who were during the continuum period described the relief of symptoms, as well as their relaxation after the diminishing amount of pills. Physical symptoms are examined in relation with the quality of life (QoL) in the literature. Similar to this study, a study about QoL made a comparison of three stages of the disease: before treatment, at the second month and at the sixth month. Results showed a significant increase in the QoL of the patients after their second month of treatment.

Our results showed that, besides the physical differences among groups, there were other areas which might create slight differences among patients. First, the difficulties about self-disclosure were more mentioned by the patients at the initial phase of the treatment. Although self-disclosure was also a concern of the patients at other phases, the intensity seemed more in the initial phase. The self-disclosure process was more complicated for MDR patients, just like their treatment, and they had difficult times sharing their diagnosis with other people. The reason for these differences might be related with the symptom relief and empowerment of the health-related quality of life which are related with the levels of anxiety and depression (Johnson, Jones, Seidenberg & Hermann, 2004). A study conducted in South Africa, showed a relationship between self-disclosure and perceived stigma. Patients preferred to make a disclosure when they did not feel the possibility of stigmatization, and when they felt trust, safety and need for others (Zolowere, Manda, Panulo & Muula, 2008). In contrast, the current study did not find significant difference among groups, in terms of their perception about the society's belief on tuberculosis or stigmatizing behavior. Moreover, similar to the findings of Zolowere and colleagues (2008), it can be argued that patients during the early stages of the disease and MDR patients required more support from their environment and family for them to self disclose. MDR patients showed more signs of self-stigma, when compared to other patients, including the changes in emotional states such as anxiety and depression, isolation, changes in daily routine and fear of infecting others.

The high level of self-stigma of these patients might be another reason for their difficulty in self-disclosure. A study in Kathmandu found that patients during the intensive treatment, such as the beginning phase had experienced more stigma compared to others (Aryal, Badhu, Pandey, Bhandari, Khatiwoda, Khatiwada & Giri, 2012). The same study also showed that having a history of TB diagnosis had an impact on high levels of stigma, which is the case for MDR patients. Also, the long duration of the treatment process, mood fluctuations, difficulties in family and attitude of the others seemed to be in relation with their concerns. Due to lack of information in the literature, the results cannot be compared to other tuberculosis research, however it can be argued that non-disclosure was a way to protect the boundary between oneself and the others, to protect oneself from being stigmatized or losing the possibility of getting support (Greene, 2000).

The second factor was the family history of tuberculosis including siblings, parents, aunts, aunt-in-laws, uncles and grandparents. Although patients described different stories about their family stories including tuberculosis diagnosis, a commonality was about self-disclosure. Patients who had a tuberculosis experience of a family member could engage more easily in self-disclosure. This might be because of observing or hearing the same disease in the past, which could diminish the stigmatizing attitudes towards the disease. Having lived with that experience in the past might create a better understating of the problem and an environment that was more informative about the symptoms of the disease. This was in contrast with the current information in the literature. The work in Kathmandu, showed that patients who had family histories of tuberculosis showed higher levels of stigma (Aryal et al, 2012). The contradicting results might be related with the cross-national differences in the treatment and attitudes towards tuberculosis, and about the methodological differences among studies; the work Aryal et al was on the assessment of stigma with quantitative measures, whereas the current results are based on qualitative descriptions of self-disclosure. As mentioned above, self-disclosure and perceived stigma were not seen as being related in the current study. Another study on beliefs and knowledge about tuberculosis done with non-patients, showed that having a family history of TB, had an impact on reduced levels of stigma (Westaway, 1989). So it might be argued that, a family experience with the same disease could generate a better understanding of tuberculosis which in fact lowers the stigma, which, in turn, might result in lowering self-stigma or feeling more comfortable when sharing with the other family members.

Another effect of having a tuberculosis history in the family was about the help-seeking behavior of the patients. Patients who had a family member with the same disease tended to seek help from health institutions more quickly and easily. They were not inclined towards relating their symptoms to other diseases, but chose to consult dispensaries or hospitals directly. Some were able to make a guess about the possibility of tuberculosis. Literature shows that delays in diagnosis or treatment of tuberculosis cases are related with the lack of information of the people and low awareness about the disease (Storla, Yimer & Bjune, 2008). It can be argued that awareness of tuberculosis increases with family history, which might in fact result in quicker help-seeking behavior. Similarly, another study in Malawi showed that delay in care seeking behavior in tuberculosis patients, was connected with two major factors: lack of education and not knowing a person with TB (Salaniponi, Harries, Banda, Kangombe, Mphasa, Mwale, Upindi, Nyirenda, Banerjee & Boeree, 2000).

The results showed that one's support system was another factor in the differences among the experiences of tuberculosis patients, especially about the issues around self-disclosure. Mostly, patients who described being supported by family or friends reported less problems about self-disclosure and were relatedly more comfortable about sharing their diseases. On the other hand, patients who were mostly disappointed by the behavior of the others did emphasize more problems about trust and engaging in self disclosure. Interestingly, other themes such as self-stigma and perception of TB in the society, did not show a relationship with the support system. This could mean that no matter the level of stigma within the patient or in the society, a person would share the current problem with the existence of a good support system.

The importance of a support system and perceived support is explained in the stigma literature by Goffman. As explained before, a feeling of safety is important for a stigmatized group of people. They tend to keep a distance between them and the others, and diminish time spent with them, in order to prevent providing personal information (Goffman, 1963). The work of Zolowere et al (2008) is in line with the results as showing the importance of feelings of safety, trust and need of the others for making self-disclosure.

A final, but an important factor that might be related with differences among tuberculosis patients is personal background information. First of all, having the experience of hospitalization made a slight difference among self-disclosure and perceived stigma. Hospitalization process exposed patients to new and difficult material such as death and stigmatizing behavior, which resulted in difficulties in sharing their disease with the others. In-patients shared more stories from their own lives, when talking about societal stigma and they were unhappy about the behavior of staff in the hospitals. In line with the results, the work of Barnhoorn and Adriaanse (1992) that compared non-compliant and compliant patients found that patients were feelings threat, insecurity and discomfort in the hospitals, caused by the behavior of the others. The discomfort and lack of sense of belonging might be correlated with feelings of discrimination and stigma of the patients. Another study showed that, patients were expecting rejection and discrimination among their relatives, after the discharge from the hospital (Rubel & Garro, 1992). Besides the negative aspects of hospitalization, some patients were positive about the time spent there, mentioning the relationships between other patients, and the long-lasting friendships. These findings were in contrast with the literature (Chang, Wu, Hansel & Diette, 2004), which may have to do with cultural and institutional factors that might be different in various countries.

Age, gender and employment were the factors that had an influence on the experiences of the patients. The current study showed that younger patients had fewer concerns and difficulties about self-disclosure, while older ones were describing more difficulties about sharing their disease. This difference seemed to be related to young people's need for their parents or living with them, as well as being in the hospital with their mothers and fathers on the day of diagnosis. Similarly, the work of Bilge and Çam (2010) about the stigma towards mental illness, noted the correlation between younger age and low levels of stigma. Furthermore, there are studies comparing of patients' quality of life (QoL) according to age.. The work of Chamla (2004) found better rates of QoL of younger patients when compared to older patients, similar to the results of the work of Guo, Marra, Moadebi, Elwood & Fitzgerald (2008). However, another study conducted in Turkey, showed no relation between gender, age and QoL of the hospitalized tuberculosis patients, but a significant difference in terms of income, education, support system and life conditions (Duyan, Kurt, Aktaş, Duyan & Kulkul, 2005).

Considering gender, the current study showed that men were more inclined to have self-disclosure problems. They preferred to keep their disease as a secret or renamed tuberculosis when necessary. In literature, generally women are related with higher stigma rates and lower self-disclosure (Sert, 2010; Dhingra & Khan, 2010). However, there are other studies that found no significant difference between men and women in terms of the rate of stigmatization (Açıkel & Pakyüz, 2015), or showed higher stigma rates and longer delays in treatment among men (Berisha, Zheki, Zadzhmi, Gashi, Hokha & Begoli, 2009). The higher level of concerns of men about self-disclosure might be caused by their their economic anxieties. Economic burden after the tuberculosis diagnosis seemed as a problem for both male and female participants of the study by Long and colleagues (2001), but their worries were different; while females were more concerned about the well-being of their children and felt themselves as a caregiver, males were more anxious about providing income to the household. Relatedly, employment might be the reason behind the difference among men and women, since all the women participants in the study were unemployed.

4. 4. LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH:

This study was important as being the first qualitative study about the experiences of the tuberculosis patients in Turkey. By using a qualitative method and inductive analysis, experiences of the patients could be investigated deeply. The relatively large size of the sample provided a variety of patients and afforded comparative analysis of each theme. The interviews with the doctors and the focus group discussion with a non-clinical sample supported the results of the data from the patients, and provided different perspectives. Furthermore, conducting the study in different locations of İstanbul, strengthened the variety of the participants.

Although, the recruitment of participants was made from different dispensaries in various location in İstanbul, this was a limitation of the study. It would be better for future studies to also add participants from secondary health-care facilities such as public or private hospitals. This would widen the generalizability of the results. The similarity of the approaches of the doctors might be because of collecting information only from primary health-care facilities. This might also be the reason for the patients' satisfaction with the doctors, since the process is different in the hospitals when compared to dispensaries. Dispensaries are places wherein doctors are only responsible for tuberculosis, while the doctors at hospitals are diagnosing and treating other diseases. Furthermore, the dispensaries were those related with the İstanbul Tuberculosis Association. Other dispensaries of the government could be included in the study. Another limitation was the difference between the percentages of male and female participants. The information was collected from a sample of 70.8% men and 28.2% women. The ratios could be made to be more approximate to the distribution of TB diagnosis in the country, which in 2014 was 58.4% men and 41.6% women in İstanbul (İlter, 2016).

Furthermore, methodological issues could be cited among the limitations of the research. Conducting face-to-face interviews in a single meeting, might have influenced the amount and quality of the information given by the participants. Conducting several meetings might be more powerful for creating a trust relationship, in order to gain deeper knowledge. However, despite the short meeting time, participants seemed open and ready to share their inner worlds. Another point about the methodology was the convenience sampling method. This method could have created a bias, since participants were called by the doctors of the dispensaries. In addition, participants were double-checked to ensure that they met study criteria and that they were willing to participate. One last limitation is about the lack of literature on the topic. Restricted amount of research done in Turkey, impeded the possibility for discussing the material in a broader context.

In future studies, researchers might recruit participants from different areas, including hospitals, dispensaries and other health-care facilities. It might be important to have a more balanced ratio of men and women, in order to do a valid comparison between them. In order to eliminate self-selection bias of the doctors, the researcher could wait and collect data from the DOT facility, which would also reveal the participation rates of the patients. Before conducting the interviews, patients can be visited in the dispensaries to make a social contact and to instill the sense of trust, in order to provide a secure base for the meetings. Or, two meetings can be arranged, which may provide time for the researcher to read and work on the initial interview and to add on important additional questions. For instance, as discussed above, experience of having a tuberculosis diagnosis and the following process is crucial for the patients. In future research, collecting information on the thoughts, attitudes and associations about the disease of the patients, before the diagnosis could be helpful. Furthermore, qualitative and quantitative methods can be combined to understand the stigma-related experiences of the patients, which would help to make accurate comparisons of the sub-groups and understand the reasons behind various experiences.

CONCLUSION

This study aimed to gain a deep understanding about the diagnosis of tuberculosis. It focused on the experiences of tuberculosis patients along with the concept of stigma and stigma-related phenomena in their daily lives. The main objective was to gain a better understanding of the diagnosis experience and the following period and to demonstrate the factors associated with the process through the lenses of the patients. Considering the lack of qualitative research on the topic, especially in Turkey, the study was designed to provide in-depth understanding of the topic. Interviews with doctors working in the dispensaries and a focus group discussion with a non-clinical sample were conducted in order to collect different opinions about the same disease from a diversity of participants. Individual interviews with 24 tuberculosis patients provided the major information of the study and interviews with 8 doctors supported the main findings. Outcomes of the focus group conversation strengthened the findings of the patients and doctors.

Findings provided information on different areas of the lives of the participants. First, results showed that tuberculosis patients experienced differences in the physical, social and psychological levels. Second, participants had stigma-related experiences including perception of tuberculosis in society, self-stigma, self-disclosure and problems about Directly-Observed Treatment (DOT). Third, patients used coping mechanisms such as selective disclosure, isolation, distraction, information seeking, humor and religion. Lastly, time since diagnosis, family history of TB, support system and demographical information emerged as the factors influencing the differences among experiences. Overall, results indicate the need for psychosocial support of the tuberculosis patients as well as a need to educate the public. Moreover, health-care policies need to be reviewed regarding the stigma-related experiences of the patients.

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APPENDICES

APPENDIX A

Informed Consent Form for Patients

(In Turkish)

Bilgilendirilmiş Onam Formu

Sayın Katılımcı;

Bu çalışma, İstanbul Bilgi Üniversitesi Klinik Psikoloji Yüksek Lisans Programı öğrencisi olan Sena Karslıoğlu tarafından Prof. Dr. Hale Bolak Boratav'ın danışmanlığında, tüberküloz teşhisi almış bireylerin, bu teşhisi aldıktan sonraki deneyimlerini anlamak amacıyla yüksek lisans tezi kapsamında yürütülmektedir.

Görüşmeye katılım gönüllüdür. Görüşme için bir saatinizi ayırmanız istenmektedir. Öncelikle yaşınız, doğum yeriniz, medeni haliniz ve eğitim durumunuz gibi kısa soruları cevapladıktan sonra tüberküloz teşhis almış olmakla ilgili düşünceleriniz, duygularınız ve deneyimleriniz konuşulacaktır.

Görüşmeler kasede alınacaktır. Görüşme sırasında dilediğiniz zaman kaydın durdurulmasını isteyebilirsiniz. Görüşme başlamadan önce, görüşme sırasında veya sonrasında, istediğiniz takdirde zaman soru sorabilirsiniz.

Paylaştığınız bilgiler gizli tutulacak, araştırma içinde sözlerinizden alıntı yapmak gerektiği yerlerde isminiz kesinlikle gizli tutulacak ve farklı isimler verilecektir. Sadece bütün görüşmelerden çıkacak ortak sonuçlar araştırmanın sonunda bir araya getirilmek suretiyle diğer araştırmacılarla paylaşılabilir.

Eğer bu araştırmaya katılmak istiyorsanız lütfen aşağıda "Bu formu okudum ve araştırmaya katılmayı kabul ediyorum" yazısının altındaki yeri imzalayın. Dilerseniz bu formun bir kopyasını saklayabilirsiniz.

Görüşme boyunca istediğiniz anda görüşmeyi kesebilir, araştırmadan çekilebilirsiniz. Zaman ayırdığınız ve araştırmaya verdiğiniz değerli katkılarınız için teşekkür ederiz.

Çalışma hakkında daha fazla bilgi almak için Bilgi Üniversitesi Klinik Psikoloji

Yüksek Lisans Programı öğrencisi Sena Karslıoğlu (Tel: 536 760 51 10; e-posta: sekarslioglu@ku.edu.tr) veya Prof. Dr. Hale Bolak Boratav (e-posta: hale.boratav@bilgi.edu.tr) ile iletişim kurabilirsiniz.

Bu bilgilendirilmiş olur belgesini okudum ve anladım. Çalışmaya katılmayı kabul ediyor ve bu onam belgesini kendi hür irademle imzalıyorum. Araştırmacı saklamam için bu belgenin bir kopyasını bana teslim etmiştir.

BU FORMU OKUDUM VE ARAŞTIRMAYI KABUL EDİYORUM

Katılımcının Adı-Soyadı ve İmzası: ___________________________

APPENDIX B

Informed Consent Form For Doctors

(In Turkish)

Bilgilendirilmiş Onam Formu

Sayın Katılımcı;

Bu çalışma, İstanbul Bilgi Üniversitesi Klinik Psikoloji Yüksek Lisans Programı öğrencisi olan Sena Karslıoğlu tarafından Prof. Dr. Hale Bolak Boratav'ın danışmanlığında, tüberküloz teşhisi almış bireylerin, bu teşhisi aldıktan sonraki deneyimlerini anlamak amacıyla yüksek lisans tezi kapsamında yürütülmektedir.

Görüşmeye katılım gönüllüdür. Görüşme için bir saatinizi ayırmanız istenmektedir. Öncelikle yaşınız, doğum yeriniz, medeni haliniz ve eğitim durumunuz gibi kısa soruları cevapladıktan sonra tüberküloz teşhisi almış olan olgularla ilgili düşünceleriniz ve deneyimleriniz konuşulacaktır.

Görüşmeler kasede alınacaktır. Görüşme sırasında dilediğiniz zaman kaydın durdurulmasını isteyebilirsiniz. Görüşme başlamadan önce, görüşme sırasında veya sonrasında, istediğiniz takdirde zaman soru sorabilirsiniz.

Paylaştığınız bilgiler gizli tutulacak, araştırma içinde sözlerinizden alıntı yapmak gerektiği yerlerde isminiz kesinlikle gizli tutulacak ve farklı isimler verilecektir. Sadece bütün görüşmelerden çıkacak ortak sonuçlar araştırmanın sonunda bir araya getirilmek suretiyle diğer araştırmacılarla paylaşılabilir.

Eğer bu araştırmaya katılmak istiyorsanız lütfen aşağıda "Bu formu okudum ve araştırmaya katılmayı kabul ediyorum" yazısının altındaki yeri imzalayın. Dilerseniz bu formun bir kopyasını saklayabilirsiniz.

Görüşme boyunca istediğiniz anda görüşmeyi kesebilir, araştırmadan çekilebilirsiniz. Zaman ayırdığınız ve araştırmaya verdiğiniz değerli katkılarınız için teşekkür ederiz.

Çalışma hakkında daha fazla bilgi almak için Bilgi Üniversitesi Klinik Psikoloji Yüksek Lisans Programı öğrencisi Sena Karslıoğlu (Tel: 536 760 51 10; e-posta:

sekarslioglu@ku.edu.tr) veya Prof. Dr. Hale Bolak Boratav (e-posta: hale.boratav@bilgi.edu.tr) ile iletişim kurabilirsiniz.

Bu bilgilendirilmiş olur belgesini okudum ve anladım. Çalışmaya katılmayı kabul ediyor ve bu onam belgesini kendi hür irademle imzalıyorum. Araştırmacı saklamam için bu belgenin bir kopyasını bana teslim etmiştir.

BU FORMU OKUDUM VE ARAŞTIRMAYI KABUL EDİYORUM

Katılımcının Adı-Soyadı ve İmzası: ____________________________

APPENDIX C

Demographic Questionnaire

(In Turkish)

Demografik Bilgi Formu

Katılımcı no:

Adınız ve Soyadınız:

Doğum Tarihiniz / Yeriniz:

Cinsiyetiniz: ☐ Kadın ☐ Erkek

Medeni Durumunuz: ☐ Evli ☐ Bekar

Eğitim Durumunuz: ☐ Yok

☐ İlköğretim

☐ Lise

☐ Üniversite

☐ Yüksek Lisans / Doktora

Çalışma Durumunuz: ☐ Çalışıyorum ☐ Çalışmıyorum

Aylık Ortalama Geliriniz: ☐ 0 TL

☐ 1 - 1000 TL

☐ 1000 – 3000 TL

☐ 3000 TL ve üzeri

APPENDIX C

Interview Questions

(In Turkish)

Soru Formu

1. Tüberküloz teşhisini ne zaman ve nasıl aldığınızı anlatabilir misiniz?

2. Tüberküloz teşhisi aldıktan sonra hayatınızda neler değiştiğini anlatabilir misiniz?

Probe 1: (gelen konu başlıklarına göre) …dan bahsettiniz. Teker teker ele alırsak…konusunda neler hissetiniz? Nasıl bir şeydi? Neden oldu sizce? Siz bu durumlar karşısında neler yaptınız?

Probe 2: (eğer gelmezse) a) Teşhisi aldıktan sonra iş hayatınız nasıldı? b) Aile içindeki deneyimleriniz nasıldı? c) Sosyal çevrenizde, örneğin arkadaşlarınızla, komşularınızla ilgili deneyimleriniz nasıl gelişti) d) Çalıma hayatınızda değişiklikler oldu mu? Bu sizin için nasıl bir deneyimdi? Neler hissettiniz? Bu durum karşısında neler yaptınız?

3. Bugünkü hayatınızda etiketlenme deneyimini yaşıyor musunuz?

Probe 1: Bu anlattıklarınızdan anlıyorum ki … gibi konular temelde gözüküyor. Teker teker ele alırsak … konusunu biraz daha anlatabilir misiniz? Nasıl bir deneyimdi sizin için? Nasıl hissediyorsunuz? Bu durum karşısında neler yapıyorsunuz? Sizce bunlar işe yarıyor mu?

4. Genel olarak düşündüğünüzde bu durumla başa çıkmanızda size yardımcı olan başka neler var?

Probe: Sadece kendinizi düşünürseniz, sizce hangi yönleriniz ya da yanlarınız başa çıkmanızda yardımcı oluyor?

ETİK KURUL DEĞERLENDİRME SONUCU/RESULT OF EVALUATION BY THE ETHICS COMMITTEE

(Bu bölüm İstanbul Bilgi Üniversitesi İnsan Araştırmaları Etik Kurul tarafından doldurulacaktır /This section to be completed by the Committee on Ethics in research on Humans)

Başvuru Sahibi / Applicant: Sena Karslıoğlu

Proje Başlığı / Project Title: Tüberküloz Teşhisi Alma Deneyimşi ve Sosyal Damgalama: Niteliksel Bir Araştırma

Proje No. / Project Number: 2017-20024-05

1.	Herhangi bir değişikliğe gerek yoktur / There is no need for revision	XX
2.	Ret/ Application Rejected Reddin gerekçesi / Reason for Rejection	

Değerlendirme Tarihi / Date of Evaluation: 9 Şubat 2017

Kurul Başkanı / Committee Chair

Doç Dr. Itır Erhart

Üye / Committee Member

Prof. Dr. Aslı Tunç

Üye / Committee Member

Prof. Dr. Hale Bolak

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