The Experience of Receiving a Tuberculosis Diagnosis: A Qualitative Exploration

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Tuberculosis, stigma, psychosocial effects, quality of life, coping

Abstract

This study aimed to investigate the psycho-social experiences of individuals with a tuberculosis diagnosis and to explore processes related to stigma and coping in this context. Towards this aim, in-depth interviews were conducted with 24 adults who had received pulmonary tuberculosis diagnosis at different dispensaries in İstanbul, and who were in different stages of treatment. The data was analyzed using Thematic Analysis and the MAXQDA software. The findings were organized under 1) Psychosocial effects of receiving a tuberculosis diagnosis, 2) Coping, and 3) Factors that account for the differences in the experiences. Findings are discussed in the light of existing literature and strengths and limitations of the current study as well as recommendations for future research are presented. In line with the literature, issues related to interpersonal relationships and finances were the most salient matters that came to fore and were interwoven with accounts of stigma related experiences such as fear of infecting others, interpersonal distancing and difficulties with self-disclosure. As expected, availability of social support was an important stress buffer. That the reported responses by others were not exclusively stigmatizing, and that attempts at sympathy and care were also observed support the findings of previous research in Turkey that has found recipients of TB to be moderately stigmatized by others. Arguments are made both for the need to educate the public to reduce societal stigma, as well as for psychosocial interventions with individuals with TB diagnosis based on possible predictors of the differences in experiences with the illness.

Tüberküloz Teşhisi Almış Olma Deneyimi: Kalitatif Bir İnceleme

Anahtar kelimeler
Tüberküloz, damgalanma, psikososyal etkiler; hayat kalitesi, başa çıkma

Öz

Bu araştırmanın amacı tüberküloz tanısı almış olan bireylerin psiko-sosyal deneyimlerini incelemek, bu bağlamda da damgalanma ve başa çıkma süreçlerini anlamaya çalışmaktır. Çalışma kapsamında İstanbul'da tüberküloz tanısı almış ve tedavi sürecinin farklı aşamalarında olan 24 yetişkin birey ile derinlemesine görüşmeler yapılmıştır. Veriler Tematik Analiz adımlarını takip ederek ve MAXQDA yazılımı kullanarak analiz edilmiştir. Bulgular üç ana tema altında toplanmıştır: 1) Tüberküloz tanısı almanın psikososyal etkileri, 2) Başa çıkma, ve 3) Deneyimlerdeki olası farklılaşmayı açıklayan unsurlar. Bulgular varolan alanyazını çerçevesinde tartışılmış, araştırmanın güçlü yönleri ve sınırlılığı belirtilmiş ve gelecek çalışmalar için öneriler paylaşılmıştır. Literatürle uyumlu olarak, kişilerarası ilişkiler ve maddi konularda yaşanan sıkıntılar en belirgin sorunlar olarak, ve başkalarını enfekte etme kaygısı, insanlardan uzak durma ve açılma ile ilgili zorluklar gibi stigmayla da ilişkilenerek öne çıkmaktadır. Bekleneceği gibi, sosyal desteğin varlığı da önemli bir unsur olmaktadır. Başkalarından alınan tepkilerin sadece stigmatize edici olmayışı ve anlayış esirgeme de içerebiliyor olması Türkiye'de daha önce yapılan çalışmalarda TB tanısı almış bireylere yönelik stigmanın orta düzeyde bulunduğu saptaması ile de uygundur. Hem toplumsal stigmayı azaltıcı eğitimlerin, hem de TB tanısı almış ve hastalığı farklı deneyimleyebilen bireylere yönelik psikososyal müdahalelerin faydası olabileceğine dikkat çekilmektedir.

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Tuberculosis (TB) is among the top 10 causes of death and the leading cause from a single infectious agent. In 2019, approximately 10 million people became ill with TB worldwide, and a total of 1.2 million died from it. (World Health Organization [WHO], 2020). TB is a curable and preventable illness, but for those who are diagnosed, it has negative effects not just on physical health, but on psychological, social and economic well being as well. TB has been found to affect many domains of quality of life (QoL), including general health perceptions, somatic sensations, psychological health, spiritual well-being, and physical, social and role functioning, accompanied also with social stigmatization, isolation, medication burden, long duration of therapy, sexual dysfunction, financial loss, and fear (Hansel, Wu, Chang, & Diette, 2004). A recent review points particularly to the role of reduced work capacity, social stigmatization, and psychological issues on patients' worsened QoL (Aggarwal, 2019). Thus, the aim of the present study was to explore the experiences of individuals with a TB diagnosis, particularly in relation to stigma and coping.

Originally identified by Goffman (1963), the conceptualization of stigma has become increasingly multidisciplinary (Link & Phelan, 2003). Empirical research has differentiated between 'internalized' or self-stigma, 'anticipated' stigma, and 'experienced' stigma (Craig, Daftary, Engel, O'Driscoll, & Ioannaki, 2016; Sommerland et al., 2017). Stigma has come to be seen as a social determinant of health, particularly in terms of delay in seeking health care and adherence to treatment. Yet, as shown in a systematic review of research on TB stigma published between 2006-2016, unlike stigma related to HIV, TB related stigma has not been a major focus of study in low incidence countries (Craig, et al., 2016). Most people appear to lack accurate information about the transmission of TB bacteria and about its treatment and cure, which has been found to increase stigma and particularly self-stigma (Baral, Karki & Newell, 2007; Dimitrova, Balabanova, Atun, & Coker, 2006; Eastwood & Hill, 2004; Gibson, Cave, Doering, Oritz, & Harms, 2005; Liefooghe, Baliddawa, Kipruto, Vermeire, & De Munynck, 1997; Long, Johansson, Diwan, & Winkvist, 2001; Sengupta et al., 2006).

A qualitative review of 30 studies that explored the experiences of having TB or having a family member with TB, considered psychosocial stigma in relation to stereotyping, exclusion, rejection, devaluation, status loss or blaming of an individual or family due to having TB. Three major themes were identified in this research: isolation, whether experienced as withdrawal or being shunned, shame, and fear of the physical and social consequences of having TB (Juniarti & Evans, 2011). This synthesis of research once again demonstrated the prevalent ignorance about TB and the myths surrounding it, as well as the need for education at the individual, family, and the community levels where TB is endemic.

It is also the case that stigma may not be the only response to a deviant or an undesirable condition such as illness or crime. In an integrative theory of mental representations of deviant conditions, Dijker and Koomen (2007) propose that other people's responses to deviance are a function of the type of deviance (passive/dependent vs active/threatening, dangerous, controllable vs uncontrollable) as well as on perceivers' personality, situational, cultural and historical factors. In their two dimensional classification supported by multidimensional scaling analysis on social distance rankings of different deviant conditions, TB, as a contagious disease that is largely not under the control of the individual, appears to fit the category of active-uncontrollable deviance.

Research in Turkey has been primarily quantitative, linking TB diagnosis negatively with QoL, and positively with symptoms of depression and anxiety (Özkurt et al., 2000; Polat & Ergüney, 2012; Taşkın & Olgun, 2010; Ünalan, Baştürk, & Ceyhan, 2008). A relatively recent study found a greater number of stress symptoms, more ineffective coping skills and lower life satisfaction among a group of TB patients when compared with a control group (Ulubayram & Durak Batıgün, 2016). Studies using the Stigma Scale for Patients with Tuberculosis (SSPT) Sert, 2010) have found individuals with a TB diagnosis to be somewhat moderately stigmatized, with stigmatization being higher among men, low SES and non-disclosing participants (Açıkel & Pakyüz, 2015; Bayraktar & Khorshtd, 2017; Öztürk, 2013; Şimşek, Özmen, & Çetinkaya, 2016). In an explorative study (Aslan, Altıntaş, Emri, & Ulaşlı 2004) on self evaluations of TB patients in a reference sanatorium, 91.8% found TB to be a socially troubling disease compared to 76.3% who found AIDS to be so. Financial problems, loneliness and hospitalization were the major sources of difficulties in their lives.

The present study is the first qualitative exploration of individuals who have received a TB diagnosis. The purpose of the study was to understand the psycho-social experiences of individuals with TB diagnosis in Turkey, especially in relation to stigma, the dynamics behind it, its consequences, as well as the mechanisms used to cope with both the illness and the stigma.

Method

Participants

Participants were recruited by convenience sampling from 8 tuberculosis dispensaries located in different parts of İstanbul, including Üsküdar, Beykoz, Kartal, Ümraniye, Kadıköy, Pendik, Taksim and Şehremini. 24 individuals (17 men, 7 women) with a TB diagnosis participated in individual in-depth interviews. The sample met the following criteria: (a) having the TB diagnosis, (b) the diagnosis 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. The age range was 21 to 64 (M=39,8), 11 of 24 (heterosexual) participants were married; 15 had a job; 9 had no personal income, 11 had a lower-class income (including minimum wage) and 4 had upper-middle class income.

Procedure

Ethics approval for the study was obtained from the University Ethics Review Board. Each potential participant was briefly informed about the study by the head doctor and asked to come to the dispensary if they volunteered to participate. Interviews were conducted in a private room at each dispensary. All participants were asked to give written consent. The interviews were audiotaped with the participants' consent, transcribed verbatim, and assigned fictive names. All patients were first asked to fill a demographic form.

Data Analysis

The interviews were analyzed with 'Thematic Analysis Method' (Braun & Clarke, 2006). The primary researcher took field notes during the interviews, so as to be able to capture their mood and attitude. The interviews were transcribed and coded using the computer assisted software MAXQDA. Six steps of Thematic Analysis suggested by Braun and Clarke (2006) were followed during the analysis. Coding started with close and systematic reading of the text. Secondly, general categories of information were identified. Meaningful units were selected and labeled with relevant categories. All throughout, memos were used with the aim to specify links or associations in the data. Subcategories were then assigned, after making multiple readings of the raw material. Using the specific segments and wordings of the participants, "in vivo" codes were also used. Some segments were coded with more than one code, and some segments were not coded if they were not relevant to the aim of the study. Continuous reading of the material led to grouping of lower level categories under larger ones and a revision and reduction of the initial codes. Lastly, these categories were elevated to more general themes. Two investigators coded several transcripts separately until there was agreement on the codes that were used. The core categories were set by consensus.

Results

Research Questions

In this section the emerging themes from the interviews will be presented. These themes will be organized according to the research questions below.

1) What are the major psychosocial experiences of the participants after getting the TB diagnosis and undergoing treatment? How are these experiences related to stigma?

2) What are the main coping strategies of the participants?

3) What are some factors that account for the possible variations in the experiences of persons diagnosed with TB?

Psycho-social effects of being receiving a tuberculosis diagnosis

Reaction to the diagnosis

The psychological effect of receiving a diagnosis came up right away in the interview. Hearing the diagnosis of TB was tough. "*I could not accept it; you can't embrace it at the beginning. Like I don't have an illness. Like how can I be sick at this age, there must be a mistake. (P16, male, age 32)* "*Tuberculosis? What was that? My mind was frozen. I even lost my way home… I was alone, my mind was blocked. Okay, tuberculosis, tuberculosis I said." (P18, female, age 33)*

They also questioned the causes of TB and tried to understand why they were sick. Some of them perceived the illness as given by God. "*I mean, of course I was a bit worried, suffering. Why I asked, I am 60 years old, why did God give me something like this. (P10, male, age 63)*

This belief had a soothing effect. *"I did not let myself get pessimistic 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, male, age 55)*

Once diagnosed, participants mentioned loneliness, fatigue, and difficulty in social interactions. "*You start to listen to patient songs. Maybe you know those from the past, but after the illness, it starts to catch your attention. You then try to relate the songs to yourself. Then you are better able to understand loneliness… (P1, male, age 43)*. Feelings related to difficulties with interpersonal relations included anger, intolerance and lack of willingness for sexual activity.*" I stayed away from my husband…I was staying away from having sex with him…I couldn't feel like having sex." (P17, female, age 41) "The illness made me so angry. I mean, I don't know whether it made me angry, or ruined my psychology. After the diagnosis, I became unable to tolerate anything. (P2, male, age 30)* Some offered suggestions for similar others in their situation: "*I want tuberculosis departments established in hospitals…they keep dispensaries separate, and it becomes a burden for the patients. It should be in the hospitals. I want that; not for myself, but for the others." (P19, female, age 39)*

Worries about other people's feelings and well-being were common. Eighteen participants were preoccupied with the possibility of infecting someone and talked about urging their contacts to get themselves checked. "*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, male, age 34)*

Depending on personal characteristics, resources and aspects of the social environment, some chose to physically stay away from others. Half of the participants mentioned being isolated from others at different phases of their illness. They reported having separated their rooms at home, spending time alone by themselves and minimizing their interactions with their community.

> I started to keep my distance from everything…I was far away from society; I was going straight home after work…this way I felt more comfortable. (P7, male, age 55)
>
> 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 to take it off. But I could feel their sadness. Which is why, I was always in my room alone. (P4, female, age 26).
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> I arranged a private room for myself, in order to be far away from the others. I slept and woke up there for 2 months…during these months I continued my life apart from my children and husband. When I saw people's reactions, 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 the bathroom and speaking to the water. (P19, female, age 39)

It is known that the infectious stage 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 anxiety and distress. "*I didn't want to be in public areas. I could infect others. I didn't want to be near them, and to make them nervous. That's why I stayed at the hospital for 2 months. When people called me and asked me where I was, I didn't tell them. "(P7, male, age 55)* Concerns about infecting others were associated with the feeling of guilt. "*I am a fatalist and a believer. Anything can happen to me, it doesn't matter. But I don't want to hurt anyone… then I feel guilty." (P1, male, age 43)*

While the other half did not make an explicit explicit reference to isolating themselves, most mentioned keeping a distance from other people.

Deciding to self disclose about a condition that is infectious is not easy. Most participants reported having difficulties with self disclosure. Each participant had a different story about with whom and how they shared news about their illness. The major reason for selective disclosure was mistrust. "*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 card." (P2, male, age 30).* A second reason was not wanting to see their families worried. "*No, I didn't tell anybody, only my sister…because I didn't want them to be sad. My mother's psychology was not good, she had just lost her sister"(P5, male, age 45).* A third reason was related to the awareness of stigma in the society. *"I can guess what they will assume about me, I heard. I was seeing a foreign woman…so they may think that I had problems with hygiene … so I didn't tell anybody and stayed away. (P1, male, age 43)*

Concern about others' possible reactions to TB made some participants choose to use other names for their illness, such as the flu, osteolysis or the cold. "*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, male, age 55).*

The number of participants who reported no hesitation or problem about self disclosure was small. One person saw the illness as given from God and did not have negative associations about it "*My relatives know, they've heard about it. The neighborhood learned. I don't care; I don't because I am not doing anything bad. It's an illness coming from God. (P12, male, age 48)* Another mentioned a disconnection with the others and lacked a need for self-disclosure. *"I don't find it necessary to tell. No one asks, and I don't tell." (P22, male, age 51)*

When participants described their relationships with others following their diagnosis, most portrayed worn out or poor relationships. Thirteen out of twenty four reported a lack of emotional support from other people, noting their negative beliefs and attitudes as well as distant behavior. People's questions about both the illness and the possibility of infection aroused negative feelings as the participants perceived the questions as disappointing. "*They say 'it is contagious, we have to stay 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 illness". (P19, female, age 39)*

Some participants noted that there was no one who was there for them. Self-isolation was also reported. "*Strictly speaking I did not get any support, because I live alone. Anyway, I do not see many people. (P24, male, age 39)* Others reported receiving support from some people, but not from others. "*No one in the family supported me. Because of their lack of knowledge, my family did not support me. My friends were there for me, my neighbors supported me".(P10, male, age 63)*

Examples were shared of either encountering or anticipating discomfort by others. 8 participants described their experience in detail. "*I had a boyfriend. He knew my illness…Then his sister heard about 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." (P15, female, age 22)* Some stated that they could feel others' negative sentiments, such as coldness and repulsion. "*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 coldness." (P13, male, age 27)* Another participant shared her belief that if she disclosed her illness, others would talk about it behind her back. "*When people ask, I do not disclose about my illness… I don't want to, I don't because I know their nature. They are not tight-lipped. They will talk around… They are bad." (P20, female, age 45)*

Wearing a mask

Wearing a mask, common particularly during the early stages of TB, also invited social difficulties for at least half of the participants. A participant shared his experience wearing a mask for the first time in a hospital. "*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, male, age 27)* Two other participants described their first contact with the mask in the hospital. One person expressed being upset and in shock. "*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*." *(P18, female, age 33)* Another expressed feeling angry when first being told to wear a mask. "*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*." *(P2, male, age 30)*

Issues related to work and finances

The diagnosis of TB confronted participants with economic problems as well. Two participants expressed the advantage of having their own job and company. But, if they were employed by others, they had to quit their jobs, and not all were welcomed back. One participant noted that being infectious kept her from her job and reduced the possibility of finding another job in the future. "*I could lose my job. I live in İstanbul, I have nowhere else to go …If they discharge me, how can I find a new job? They will ask for reports about my health… I don't know." (P1, male, age 43)* "*There is no contagious situation at present... But still, you can't work. You have an illness; you are still taking medication. Everyone is cautious." (P4, female, age 26)*

Perception of TB in society

Participants were also asked directly what they thought was the perception of TB in the society. Nine painted a negative picture, mentioning people's exclusionary behavior and their wrong beliefs about the illness. "*They see it bad, very bad, they find it weird. They think that it is bad, like it will infect them immediately…This is the society. Ignorant." (P12, male, age 48)* Such false beliefs are seen as caused by lack of accurate knowledge about TB, "*Their prejudice is so strong. They don't know even know the name and the place of the illness. They don't know the mechanism of infection. They think that it is a lifelong illness… 'half man', that's what they say." (P13, male, age 27)*

Another five participants portrayed a society in which different opinions and beliefs exist, and linked accurate knowledge with a better understanding of the illness. Three participants argued that TB is no longer perceived as a threat in the society, also relating this to lack of knowledge; thinking that TB no longer exists in the country today might be another source of people's stigmatizing behavior toward what is considered such as a rare condition.

Coping

Social support

A major advantage as participants tried to cope with their illness was social support. Eleven out of twenty-four talked about the emotional support from their family and friends, and their appreciation. "*You can see true lovers, true friends. I had friends who came over, even though I had a mask on my face. We even took a picture together (laugh)." (P1, male, age 43)* "*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. The most important thing was his words". (P4, female, age 26)*

Individuals from school, work place and health care settings were reported as caring and compassionate. "*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: warmed food was provided 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, male, age 27)"* "*Thank god my boss is not…He talked with me, asked how it was going. Also the company doctor called me frequently. I guess it was because of the attitudes of my boss." (P1, male, age 43)*

Without exception, all 24 participants appreciated the emotional and informative support of the dispensary staff during the treatment process. "*First comes the support of my mother. Then comes the* *support from the staff and the doctor here. Their care was more than enough, just like my mother's. We gave up; we were the ones who had the illness, but they never, never gave up." (P15, female, age 22)*

Selective self-disclosure due to uncertainty about social support was a way to cope with stress, while keeping others safe and avoiding stigmatization. Eighteen participants reported that they chose who to disclose to. *"Because they would label me and try to put a distance, for themselves and their children… I think it was to protect myself…It might be for protection. A kind of defense." (P17, female, age 41)*

Distraction, humor, religiosity

Distraction is a way to shift attention to something else, rather than focusing on the current problem. In the case of TB, some participants preferred to distract themselves emotionally and behaviorally in different ways. Five participants described that they were not fully concentrated on TB. "*I don't do anything for myself. Only, I don't get obsessed with the illness. I know that it will pass… and since I have diabetes, I focus my attention on that. That's what I give importance to, not TB. "(P11, male, age 26)* A dew described physical activities as habits that were developed after the diagnosis. "*My first aim was to stand up. I did not get out of the house in the first two months. I was walking in the garden. I walked, walked." (P6, male, age 47)*

Nine participants preferred making jokes or funny statements about their current states. They laughed at emotional moments during the interviews, or talked about making jokes about their illness. "*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 distress us." (P3, male, age 48)* One woman had been suffering from family problems for a long time and was looking quite emotional. While she was using a common expression used in Turkish about having TB, she smiled. This could be seen as a moment where sadness, anger or distress was replaced by humour. "*I told him that he had finally done it to me. "Look you did it all together; I became a TB" I said. They used to say, 'you made me TB', that's what I said." (P18, female, age 33)*

Half of the participants expressed their faith and asserted their belief that the illness came from God. Powerful religious belief served as a mechanism to regulate participants' concerns about the illness and thoughts about death. They mentioned the worst possibilities about the end of the illness and indicated an acceptance. "*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 with that." (P1, male, age 43)* "*Everyone heard about it. I don't care. I don't because I'm not doing anything bad. This is an illness coming from God." (P12, male, age 48)* "*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 sad, I don't care. My precious God saw it as appropriate for me." (P2, male, age 30)*

Factors that account for the differences in the experiences

In this study, an attempt was also made to identify those factors that might account for the differences in the experiences of the participants. The analysis pointed to various factors: Phase of illness, family history of TB, hospitalization, age, and gender. A standard TB treatment protocol includes 4 types of drugs in the first 2 months and 2 in the following 4 months. This treatment is expected to reduce symptoms and the level of infectiousness. Participants who had been on medication for more than 2 months described their relief and changes in their physical symptoms and reported less difficulty with self-disclosure. "*Now* *the number of pills is not as many, it has decreased to 5. So, I think my body got used to them. I've started to go back to my normal life." (P4, female, age 26; 4th month)* The initial difficulties in orienting to the illness including the diagnosis, as well as the physical, social and psychological changes may account for this difference. Also, exposure to information about the illness might serve to reduce their anxiety over time.

Participants with family histories of TB reported less difficulty about self-disclosure. Family history of TB seemed to make it somewhat easier to react to the diagnosis, to share information about the illness, to seek help more quickly and without hesitation. "*My uncle also had tuberculosis… His wife told me not to be afraid and to be careful about my nutrition." (P18, female, age 33)* "*Yes, I first came here. My brother, he was also treated here…his was a resistant type. He told me to come here, he advised me. "(P2, male, age 30)* "*I didn't feel anything at the moment. I trust my wife, and I had also experienced it (TB) with my father."(P6, male, age 47)* Having seen, heard and lived with that experience might have served to reduce self-stigmatizing.

Being hospitalized during the treatment of TB also made slight differences in the descriptions of the participants. Participants 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. Distinctive from the out-participants, 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 hospital staff and their behavior. "*We went to the hospital with my brother. Doctor got me out of the room immediately after looking at the papers. 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, male, age 27)"* Staying in the hospital for a long time, seeing various forms of different illnesses might have resulted in higher levels of self-stigma and anticipated stigma.

Although self-disclosure was a problem for most of the participants, younger participants reported less difficulty. Participants in the age range between 18 and 29 experienced easier self-disclosure with their families, and especially with their mothers and fathers. The narratives of the younger participants pointed to the importance of the physical and emotional availability of friends in facilitating self-disclosure. "*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, female, age 26)* The narratives of the older participants reflected more anxiety about sharing their illness with others. "*No, I didn't tell anybody… My children do not know of my illness… If I tell them, they may come here; they all have their own children, they have jobs. What would they do here?" (P7, male, age 55)* It is also possible that the older participants might have been more strongly influenced by the beliefs towards the illness in the earlier days.

Five out of the seven women were able to share their illness with their family and close friends, whereas the men were more inclined to keep their illness a secret from their close relatives and tended to name their condition with another illness such as the flu or problems with other organs. Another gender-based difference was about help-seeking behavior. Two participants, both women, shared that following their diagnosis, they consulted a psychiatrist: "*I am getting psychiatric help at the moment…I thought that I was going to die... I wore a mask, I felt terrible. I thought I should stay away from other people." (P17, female, age 41)* That said, just as in the comparisons based on the stage of illness, the family history of TB tuberculosis, data based on comparisons based on experience of hospitalization, age and gender, though pointing to certain trends, remained tentative.

Discussion

The main objective of the study was to understand the psychosocial experiences of individuals diagnosed with tuberculosis (TB). A general overview of the data shows that being diagnosed with tuberculosis is a phenomenon that has an influence first on the participants, then on their social environment including family and friends, neighbors, the workplace and the larger society. As an infectious illness that carries stigma, TB has social features and has implications that go beyond the individual patient.

While the story of each participant was unique and different, narratives also had common features. Participants' accounts of psychosocial experiences following the diagnosis were essentially based on the problems that they encountered during this process. Interpersonal relationships and economic issues were the most salient matters that came to fore and were interwoven with accounts of stigma-related experiences such as observation of the perception of TB in society and difficulties with self-disclosure and self-stigma. A closer look at their experiences, ways of coping and factors that may explain the differences in those experiences is necessary to draw a better picture about the experience of living with TB.

From a social-psychological perspective, social support emerged as a pivotal issue. Half of the participants, more than in a previous study in Turkey (Taşkın & Olgun, 2010) declared lacking social support. That said, it is difficult to differentiate between who received support and who did not. Participants who appreciated some people's support also talked about being disappointed by others, a pattern also noted in a study about social stigma in Nicaragua (Macq, Solis, Martinez, Martiny & Dujardin, 2005). The fear of infecting others and self-stigma seemed to predict feeling or anticipating discomfort in others.

Another social concern was about wearing a mask. Especially during the early stages of the illness, participants had to distance themselves physically from the others, and to wear a mask around other people. In parallel, health-care literature relates physical and psychological isolation and lack of intimacy and contact with mask wearing (Dodor, Neal, Kelly, 2008; Robertson, Hershenfield, Grace, & Stewart, 2004).

Work and finances constituted another major area of concern. The relationship between TB and economic problems has been reported to be high among people of low SES who are also more vulnerable to malnutrition, pollution and drug use (Narasimhan, Wood, MacIntyre, & Mathai, 2013). Also, TB itself has an impact on participants' economic situation. Most participants had to quit their jobs after being diagnosed, some had difficulties going back, and a few noted the advantage of being their own boss.

While one group of participants portrayed a negative picture in terms of the perception of TB in the society, another group presented a more positive one. The results showed that the threat perception in the social environment became internalized by most participants. Emotional changes such as feeling of depression, anxiety, loneliness and low self-esteem were typical. A study in Turkey found a moderate level of anxiety and depression among TB patients that pointed to the need for psychological support (Polat & Ergüney, 2012). Research shows that internalized stigma is one of the sources of feelings of shame and guilt that eventually leads to diminishing self-worth and self-esteem, which might result in depression and anxiety (Baral et al., 2007).

The current study showed that other components internalized stigma were isolation and fear of infecting others. A qualitative study of TB patients in Nepal, proposed fear of infecting others and isolation as a result of self-stigma (Baral et al., 2007). Similarly, the participants of this study described their concerns around infection especially of their loved ones, which led to their isolation. It should be noted that although fear of infection and isolation to some extent could be legitimized with medical reasons, it is known that (excluding the MDR cases) participants with TB are free of infection after two weeks of drug use (Özkan, 2010). However, our results as well as studies in various countries including Mexico, Vietnam and India indicate a longer duration of isolation (Rubel & Garro, 1992; Long et al, 2001).

Also related to stigma was the issue of self-disclosure. Previous studies in Turkey have shown that between 24 to 66% of people studied have kept their diagnosis secret from other people (Arıkan et al., 2000; Özol, Koçak, Çoşkunol & Egemen, 2005). Most participants reported feeling hesitant about sharing their illness with others. Some kept it as a secret from their families, while others preferred to share it with only certain people. The reasons were mostly about mistrust, creating a bad reputation and concern about their families feelings. However, there were few others whose belief in God made them feel less personally responsible and more at ease about self-disclosure. Our findings are in line with other research that finds feelings of safety, trust, and need for others to be important facilitators of self-disclosure (Zolowere, Manda, Panulo & Muula (2008.)

Theoretical work on coping has distinguished between two major strategies as problem versus emotion-focused (Folkman & Lazarus (1980) and approach/engagement versus avoidance/disengagement (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001). Isolation or disengagement, as an avoidance and emotion focused coping can be another mechanism for self-protection (Miller & Kaiser, 2001). Whether these strategies are selected on purpose and their effectiveness are a matter of debate. On the one hand, selective disclosure and isolation can be seen as non-effective strategies, since they do not involve problem solving; a previous study in Turkey had found non-disclosing individuals to experience more stigma (Bayraktar & Khorshtd, 2017). But non-disclosure can also be seen as a mechanism to exercise control over the environment. Since it is not possible for the patients to control the stigmatizing behavior of others, controlling their own behavior might serve a protective function.

Participants also talked about their attempts to distract emotional or behavioral attention from the main stressor, which might be the illness, the stigma, or something else. As an avoidance mechanism, distraction has been found to be useless or maladaptive for reducing stress (Conner-Smith, Compas, Wadsworth, Thomsen & Saltzman, 2000). However, other research has evaluated distraction, as opposed to suppression, as a form of engagement strategy, effective on diminishing obsessive or intrusive thinking during a stressful time (Miller & Kaiser, 2001).

When confronting a real or perceived threat, humor may be an attempt to control and balance negative emotions with positive ones, a buffer between stress and negative emotions (Abel, 2002; Nezlek & Derks, 2001). Participants' use of humor during the interviews is an example. Similarly, religious beliefs and belief in fate were also helpful in coping with intrusive or negative thoughts and emotions during the treatment process. Studies show the positive impact of spirituality on individuals with HIV/AIDS (Kendall, 1994) and cancer patients (Johnson & Spilka, 1991) as a useful coping mechanism. Religious beliefs and having a powerful connection with spirituality support the individual by providing them with hope and reminding them of the meaning of life (Koenig, Larson & Larson, 2001).

In most of the narratives, stigma related experiences were quite salient. As it has been suggested before, the most significant reason behind stigmatization by others was be the lack of information about the different aspects of the illness (Polat, 2017). That said, participants' reports mostly included examples of internalized and anticipated stigma, as compared to experienced stigma (Daftary, Engel, O'Driscoll, & Ioannaki, 2016; Sommerland et al., 2017).

Dijker and Koomen (2007) make the argument that different 'deviant conditions' activate different motivational mechanisms (fight or flight vs care), and acknowledge room for positive responses in response to deviance. For example, on the one hand, TB, as a contagious disease that is largely not under the control of the individual, but that poses a threat to other people appears to fit the category of active-uncontrollable deviance, eliciting fear; but, it can also be argued that "as an illness that does not entail intentional or pre-meditated attack on others and their resources, it also fits the category of passive-uncontrollable deviance, arousing responses such as tenderness, protection and pity" (p. 65). As such, TB, like AIDS, may be in the category of what the authors identify as a 'complex deviant condition' (p. 91), containing both active-because contagious-, and passive-because suffering and dependence on the help of others- elements, resulting in varying responses in terms of social distancing from the person.

The same authors also address the question of how individuals with a deviant condition cope with their condition as well as with other people's negative reactions and stigmatization. In this context, whether to reveal or conceal one's condition may present a dilemma. As in previous research, individuals in our study often chose close others to disclose their condition. Responses by others are expected to affect the well being and coping of individuals with a TB diagnosis. It can be argued that, overall, the reported responses by others in this study were mixed, and not exclusively stigmatizing, and that attempts at care and sympathy were also observed.

The factors that might be responsible for the variations in the experiences of TB patients were revealed as follows: phase of illness, family history of TB, and personal background information. Although self-disclosure was a concern in all phases, appeared to be strongest in the initial phase. Reports of heightened experience of stigma during the period of intensive treatment at the beginning have been found in previous research as well (Aryal et al., 2012). It can be argued that participants during the early stages of the illness participants required more support from their social environment in order to be able to engage in self-disclosure.

The second possible differentiating factor was the family history of TB. Participants who had an incidence of TB in the family were better able to in self-disclose. Observing or hearing about the same illness in the past can diminish the stigmatizing attitudes towards the illness. This was in contrast with the work in Kathmandu, which showed that participants who had family histories of TB showed higher levels of stigma (Aryal et al, 2012). These contradicting results might be related with the cross-national differences in the treatment and attitudes towards TB, and the differences in methodology. In the current study, self-disclosure and perceived stigma did not seem to be connected. Another study on non-patients' beliefs and knowledge about TB showed that having a family history of TB, reduced the level of stigma (Westaway, 1989). So, it might be argued that, a family experience with the same illness could generate a better understanding of TB, which might result in lowering self-stigma. These participants also tended to seek help from health institutions more quickly and more willingly. Previous research shows that delays in diagnosis or treatment of TB is connected with lack of information and lower awareness about the illness (Storla, Yimer, & Bjune, 2008). It can be argued that awareness of TB increases with family history, which might in fact result in quicker help-seeking behavior.

Another factor that might be related with differences among TB patients is personal background information. Hospitalization experience made a slight difference in self-disclosure and perceived stigma. Exposure to new and difficult material such as death and stigmatizing behavior of the health care staff may have resulted in difficulties in sharing their illness with the others. In a study by Barnhoorn & Adriaanse (1992) non-compliant patients were found to experience stronger feelings of threat, insecurity and discomfort caused by the hospital staff. In the present study, hospitalization experience may have heightened feelings of discrimination and stigma. That said, some participants were positive about the time spent there, describing long-lasting friendships among the patients.

Age and gender also had an influence on the experiences of the participants. Younger participants had fewer concerns and difficulties about self-disclosure, supporting the finding of a correlation between younger age and low levels of stigma towards mental illness (Bilge & Çam, 2010). Considering gender, the current study showed men to be more inclined to have problems with self-disclosure. The literature on gender, stigma and self-disclosure, is mixed (Açıkel & Pakyüz, 2015; Berisha et. al, 2009; Dhingra & Khan, 2010; Sert, 2010). Men's higher level of concerns self-disclosure in this study might be caused by their economic anxieties. A study by Long et al. (2001), showed that while women were more concerned about the well-being of their children as care givers, men were more anxious about providing for their households. As all the women participants in the study were unemployed, employment status might be the reason behind this gender difference.

Conclusions: Strength, limitations and suggestions for future research

This study was important for being the first qualitative study about the experiences of the TB participants in Turkey. The relatively large size of the sample recruited from diverse locations allowed for relative heterogeneity of participants and afforded the possibility of comparative analysis. It was noteworthy that all participants drew attention to the fact that the experience of being treated at a dispensary was a very important advantage. Indeed, physicians who work at TB dispensaries are very dedicated to their work and do their best to support their patients against stigmatization. Based on an earlier study in a reference sanatorium that showed an overwhelming majority of the TB patients as evaluating their condition as a socially troubling one (Aslan, Altıntaş, Emri, & Ulaşlı 2004), it is possible that the participants in our study experienced a more favorable treatment context. Another strength of the study was and attempt to delineate the factors that account for the differences in the experiences of the individuals diagnosed with TB.

One limitation of the study is that it was conducted exclusively in TB dispensaries. Future studies should include participants from secondary health-care facilities such as public or private hospitals to increase the generalizability of the findings. Another limitation of the study was that the sample was overwhelmingly men, with 70.8% men and 28.2% women. In future research, it would be good to approximate the distribution of TB diagnosis in the country, which in 2015 was 56.5% men and 43.5% women in İstanbul (Halk Sağlığı Genel Müdürlüğü, 2017). Finally, participants' thoughts, attitudes and associations about this illness prior to the diagnosis were not explored in this study, and it would be helpful to do so in future studies.

Participants seemed open and ready to share their experiences during the interview. That said, interviews in a single meeting might have limited the amount and quality of the information obtained. Also, the convenience sampling technique may have created a bias, since the participants were contacted by the doctors of the dispensaries asking for if they would volunteer to participate. Finally, scarcity of research done in Turkey with TB patients impeded the possibility of discussing the material in a broader context.

A review of the studies on TB pointed to the lack of information on how QoL changes with treatment and cure, and particularly the scarcity of studies on the long-term psychological effects of TB and/or TB treatment (Chang, Wu, Hansel & Diette, 2004). Two such studies showed improvements in perceived HRQoL of TB patients with treatment progression (Mthiyane et al., 2016; Saleem, Malik, Ghulam, Ahmed, & Hamidah, 2018). Our findings also suggest that information gathered in longitudinal research on the effects and course of both the illness and treatment on QoL might benefit both patients and providers. Also, as suggested by previous researchers (Ulubayram & Batıgün, 2016), integrating psycho-educational sessions on stress management and effective coping into the treatment process may be beneficial to the patients.

Finally, it seems like there is still need for work towards reducing TB related stigma. Problematizing its continuing pervasiveness, a systematic literature review of research published between 1950 and 2015 was conducted to assess the effectiveness of interventions aimed at reducing stigma in patients, health care providers, care givers and the wider community, (Sommerland et. al, 2017), and was able to identify only seven studies that provided reliable information on the effectiveness of such interventions. The evidence from this study as well as other research suggests that support groups as well as a concerted effort to improve knowledge and attitudes in the community can make some difference in reducing anticipated and internalized stigma. Our results similarly indicate the need for psychosocial support of the TB patients as well as a need to educate the public. Moreover, health-care policies need to be reviewed towards reducing the still existing stigma in the society.

Conflict of Interest Statement

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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