Tuberculosis stigma and perceptions in the US-Mexico border

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Abstract

Objective. To examine the experiences and perspectives on the disease and stigma from the vantage point of the persons affected by TB in El Paso, Texas, and Juárez, México to inform research on health-related stigma and interventions. Materials and methods. Semi-structured interviews to study TB-related stigma and the impact on access and healthseeking behaviors with 30 Mexican-origin adults (18 years and older) undergoing TB treatment. Results. Barriers to accessing health services for TB; emotional distress due to their deteriorated physical and emotional condition; reactions ranging from depression, sadness; doubt, anger, and fear of rejection; distancing, fear of contagion, stigma, and feeling of discriminated against, and isolation from loved ones were reported. Conclusion. Stigma associated with TB is a barrier to health care access and to quality of life in tuberculosis management. Stigma adversely shapes the experience of treatment and recovery. Stigma is not a naturally occurring phenomenon, but something created by people and as such it can be "un-done" by those people as part of a collective which comprises society.

Key words: Tuberculosis; health-related stigma; access to health care; US-Mexico border

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Resumen

Objetivo. Examinar las experiencias y perspectivas sobre la infección por tuberculosis (TB) y estigma desde el punto de vista de personas afectadas en El Paso, Texas y Cd. Juárez, México para informar con base en evidencia sobre el estigma relacionado con la salud y las intervenciones. Material y métodos. Aplicación de entrevistas semiestructuradas para investigar el estigma relacionado con la TB y el impacto sobre el acceso y la búsqueda de servicios de salud en 30 adultos de origen mexicano (18 años y mayores) que recibían o recibieron tratamiento de TB. Resultados. Se identificaron barreras al acceso a servicios de salud para la tuberculosis, angustia debido a su deteriorado estado físico y emocional, reacciones que van desde depresión, tristeza, duda, ira y miedo al rechazo, además de distanciamiento, temor al contagio, estigma, sentimiento de discriminación y aislamiento de los seres queridos. Conclusión. El estigma asociado con TB es una barrera al acceso a atención de la salud y calidad de vida en el manejo de la infección. El estigma afecta de manera adversa la experiencia de tratamiento y recuperación. El estigma no es un fenómeno natural, es creado por las personas y como tal se puede abatir por parte de aquellas personas que son parte de un colectivo social.

Palabras clave: tuberculosis; estigma relacionado con la salud; acceso a servicios de salud; frontera mexicano-estadounidense

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Tuberculosis (TB) is a disease resulting from infection $oldsymbol{1}$ by Mycobacterium tuberculosis. It is also a social illness that causes great suffering, a disease of "atrisk populations."1,2 Tuberculosis is a social condition that involves deep emotional experiences, alienation from family members, isolation and stigmatization.^{3,4} Tuberculosis ravages interpersonal connections.⁵ The experience of tuberculosis illustrates that an infectious disease entails more than treatment involving medications. Studies have identified tuberculosis in mummies from Egypt dating back 5 400 years. TB is responsible for the highest number of deaths in human populations produced by a single microbial pathogen.⁷⁻⁹ Worldwide, tuberculosis continues to be a major cause of morbidity, mortality, and disability.¹⁰ Vital individual and social dimensions to addressing tuberculosis include narratives centered on the Persons Affected by TB (PATB), the relationship to family members, school, employment, community, and society.

With more than five decades into the modern era of TB control and more than three decades into the HIV / AIDS epidemic, stigma remains a significant challenge for HIV and TB control programs. Stigma associated with TB has been identified as a major barrier to healthcare and quality of life in TB management. 12-20

Stigma

Stigma is a social process that exists when elements of labeling, stereotyping, separation, loss of status, and discrimination occur in a power situation that allows them. The concept of stigma can be traced to the classical Greek, where it was used to brand outcast groups with a physical and permanent mark of their moral status. The signs were bodily cuts or burns which signified that the bearer was a slave, criminal, traitor, or a blemished person to be avoided especially in public places. Erving Goffman developed what has become the benchmark social theory of the association between stigma and disease. 23-24

Stigma sequelæ

Stigma is recognized to have a major impact on public health. Stigma and its associated discrimination produce social inequality.²⁵⁻²⁷ The forms and intensity of stigma fluctuate (e.g. HIV/AIDS, leprosy, TB, mental health). Stigma is a mechanism of social control that defines social norms and punishes those who deviate. At the heart of stigma lies the "fear" that those who are stigmatized threaten society.

Studies in stigma indicate that it deters people from seeking diagnosis and care and that woman bear

the highest burden of stigma-avoiding behaviors.^{2,17} Stigma is created by ignorance of the disease, myths about how it is transmitted, prejudice, lack of access to services, and irresponsible media reporting. The effects on stigmatized individuals include stress, depression, fear, relationship problems, and loss of employment, reduced education opportunities, and vulnerability to disability.^{1,21,28,29}

Objectives

The study describes the characteristics of participants affected by TB who were undergoing TB treatment in Ciudad Juarez, Mexico and El Paso, Texas; investigates the perceptions and experiences of Mexican-origin individuals affected by TB to illustrate how the TB is experienced and the relationship to health-seeking behaviors; explores the perceived and internalized stigma by the person affected by tuberculosis; and investigates the actual experiences of social stigma and discrimination by persons affected with TB.

Materials and methods

Study design

The investigation was cross-sectional and included quantitative and qualitative methods. Participants were recruited using a convenience sample of 30 Mexicanorigin adults (18 years and older) in Ciudad Juarez, Mexico and El Paso, Texas. The sample consisted of thirty participants based on theoretical sampling, as explained by Patton, 30 receiving treatment for TB at the study locations who met the inclusion criteria. This method of sampling was used because the objective was to develop an understanding of the subjective experience of persons affected by tuberculosis and TB-related stigma. Recruitment of participants was done by health personnel of the TB Program or Clinic staff at the study locations. Participation was voluntary. Once permission was granted by participants, health workers scheduled the interviews with the trained project interviewer. A bilingual semi-structured guide was utilized. Descriptive analysis was done. The qualitative data was analyzed using Milles and Huberman technique using Goffman's theory of stigma^{21,22,24,26-28} by the research team and presented in a PhD dissertation by the primary author.

Study population and setting

The US-Mexico border is an area encompassing 2 000 miles separating the two countries. The El Paso-Ciudad

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Juarez metropolitan area is overwhelmingly Hispanic, Mexican-origin. Low socioeconomic and educational levels, high rates of immigration, and rapid industrial development partly explain the present complexity of the US-Mexico border. These factors affect health and quality of life. Diseases like tuberculosis and HIV on one side of the border directly impact the other side because of the mobility and migration in both directions. Health inequalities exist along the US-Mexico border, especially among minority populations who are vulnerable as a result of low socioeconomic status, lack of health insurance, linguistic and cultural barriers, and limited access to health care.²⁹

The incidence of TB at the border far exceeds national incidence rates in both countries. In 2009, TB rates on each side of the border were 1.8 times their respective national averages according to the Centers for Disease Control and Prevention³¹ and unpublished sources (Castellanos, September 29, 2010).³² Ongoing transmission, prolonged infection, delayed diagnosis, increased mobility, and increased drug-resistance have been documented among persons residing along the US-Mexico border.³³ The criteria for selecting El Paso and Ciudad Juárez included: higher risk for TB, greater prevalence than national rates, limited resource availability, and geographical location on an international border.

The authors developed a conceptual framework to facilitate the exploration of TB-related stigma and health seeking behaviors among the respondents. In this framework (figure 1), the authors include the concept of stigma^{23,24,27} TB and HIV / AIDS related stigma^{2,4,34} from an individual's perspectives and from the broader social context. The framework also draws from the findings from the Border Tuberculosis Alliance Project and the Border Voices and Images of TB Project, both directed by the primary author.³⁵

Perceptions and experiences of TB are influenced by demographic, psychological, and socioeconomic factors. Perceived, internalized and actual experiences of stigma are addressed in the conceptual framework with a corresponding series of measures: experiences with TB diagnosis and treatment, co-morbidities, perceptions and attitudes toward TB and stigma, disclosure and perceived support.

Inclusion criteria and sampling methods

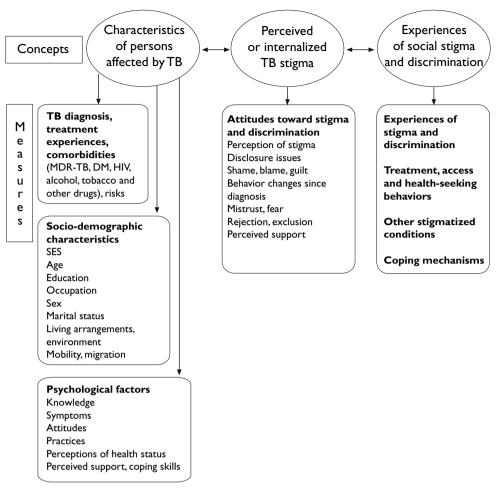
The study consists of a convenience sample of 15 persons of Mexican-origin affected by tuberculosis and in treatment or who completed TB treatment less than six months ago in Ciudad Juarez and 15 from El Paso that met the inclusion criteria. Because of the mobility

of border residents, the heterogeneous nature of the region, and the high prevalence of TB on both sides of the border, the researchers chose to sample the same number of persons affected by TB from each of the two locations. The health personnel (i.e. TB program nurses and physicians) of the health centers (Centros de Salud) of selected locations assisted in identifying respondents from El Paso and Ciudad Juarez. Health workers received an orientation by the investigators on the study aims and were provided with recruitment flyers in both English and Spanish. The sample set (n=30) was constructed according to theoretical sampling, as explained by Patton,³⁰ as a process in which the researcher samples incidents, slices of life, time periods, or people on the basis of their potential manifestation or representation of important theoretical constructs. The sample becomes, by definition and selection, representative of the phenomenon of interest. Theoretical sampling permits elucidation and refinement of the variations in, manifestations of, and meanings of a concept as it is found in the data gathered during fieldwork. Interviews were conducted after informed consent was obtained from participants.

Recruitment

Two health workers from El Paso and two from Ciudad Juarez TB programs prepared a list of persons affected by TB and in treatment at the time of the study. Health workers first contacted the persons affected by TB and secured permission from the participants to have the study interviewers contact them to invite them to participate in the investigation. Eligible participants were recruited by the health personnel of the TB program (El Paso) or the Health Jurisdiction (Ciudad Juárez).

An informed consent was completed at that time and a copy was given to the participant. Only individuals who met the study criteria participated in the interviews. A gift card of \$20 dollars or the equivalent in Mexican pesos was presented to the individuals that participated. Interviews in Juárez were originally scheduled to take place at a Health Center; however most of the facilities were neither optimal nor private. To secure privacy, the most of the interviews in Ciudad Juárez were moved to a community-based organization (i.e. Compañeros) or to the participant's residence. If the interview was conducted at the participant's home, then two interviewers were present. This decision was made by the research team given the elevated risks and violence associated with the violence experienced in that city during the past year. The second interviewer served as an observer. All interviews were conducted in Spanish, with the exception of one in English based on participants' language



Framework draws on the work of Sumartajo^{34,36}

FIGURE 1. TUBERCULOSIS RELATED STIGMA STUDY CONCEPTUAL FRAMEWORK

preference. In El Paso, there was no need to have an interpreter, because the interviewer was bilingual. In El Paso, Texas the majority of interviews were conducted at the TB clinic. A few of the interviews were conducted at the participant's residence because of transportation issues. Each participant was interviewed once.

Data collection

The research team consisted of two investigators from each study location (University of Texas at El Paso, Universidad Autónoma de Ciudad Juarez), two health practitioners (Jurisdicción Sanitaria No. II, City of El Paso Tuberculosis Program) and two experienced interviewers from Programa Compañeros. The researchers viewed and field tested the instrument for linguistic and cultural appropriateness. The method used to collect

the data consisted of a single semi-structured interview with each of the study participants. The interview guide contained closed and open-ended questions. The conceptual variables of the instrument consisted of: 1) Socio-demographic, general characteristics and household data; 2) Tuberculosis diagnosis; 3) Knowledge of TB; 4) Psychosocial factors related to TB; 5) Attitudes and health-seeking practices related with TB and treatment; 6) Awareness of TB and information resources; 7) Attitudes about perceived stigma or internalized stigma related to TB; and 8) Perceptions of TB and stigma.

Analysis of the data

The interviews ranged from 60 to 70 minutes. The interviews were digitally audio taped with the participant's

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permission in writing, transcribed immediately and in the language in which the interview was conducted and not translated to English. Transcriptions were done by two experienced professionals. The transcripts were then read and confirmed by two of the research members. No identifying data were recorded about participants. Only codes were used and participants were assured that confidentiality would be maintained. Analysis of the data was done in several stages throughout the study. The first stage consisted of computing the descriptive statistical analysis including means and categorical data as percentages (%) (n). Qualitative data were entered into Word and all audio digital recordings of interviews were encrypted. These files were than transcribed using Naturally Speaking 9 Recorder software.³⁷

The second stage was a more rigorous process of analyzing the content for the emergence of new categories and sub-categories. Code themes were developed and analysis was completed using qualitative descriptive as designed by Miles & Huberman.²⁸ Codes or themes were grouped and mapped using the TB stigma conceptual framework (i.e. perceived stigma, internalized social stigma, meaning and experiences with TB), which was developed using Goffman's theory of stigma.^{23,24} This analysis was done by the authors and a third researcher from the Universidad Autónoma de Ciudad Juarez. The third and final stage involved synthesizing the findings to look for patterns and relationships to create a better understanding of TB and TB-related stigma from the perspective of the persons with TB.

The recurring themes of the study include: issues with TB diagnosis (lack of timely diagnosis), experience with treatment, delays in accessing medical care for TB, awareness of TB information resources, and attitudes about TB-related stigma and discrimination. The University of Texas at El Paso provided ethical oversight through its Institutional Review Board.

Results

Characteristics of participants

In total 30 participants were interviewed in the two locations. Table I shows the characteristics of all of respondents.

Health care practices

Tuberculosis diagnosis: severe symptoms prompted treatment

When asked about their TB diagnosis, the prevailing idea was that there were a series of barriers they encountered when accessing health care services for TB.

Table I

SOCIO-DEMOGRAPHIC PROFILE OF STUDY PARTICIPANTS

CIUDAD JUAREZ MEXICO AND EL PASO TEXAS.

AUGUST 2009

Category (n)*	Characteristic	Number (Percent)
Sex (30)	Female	13 (43)
	Male	17 (56)
Age (30)	20-30	11 (36)
	31-50	10 (33)
	51> (96 yrs.)	9 (30)
Marital status (30)	Single	13 (43)
	Common Law/Married	13 (43)
	Other(Divorced,Widow)	4 (13)
Last year of school completed (29)	< 6 years	7 (23)
	6th-8th years	14 (46)
	9th and more	8 (26)
Occupation (30)	Informal	12 (40)
	Formal	I (3.3)
	Unemployed	4 (13)
	Disabled	4 (13)
	Retired	I (3.3)
	Home	7 (23)
Employment (13)	Regular	10 (33)
	Occasional	3 (10)
Income (18)	Yes	15 (50)
	No	3 (10)
Native of (30)	México (Juárez 16)	26 (86)
	USA (El Paso 2)	4 (13)
Currently living in (30)	México	15 (50)
	USA	15 (50)
Frequency of border crossings (24)	Weekly	2 (6.6)
	Monthly	7 (23)
	Does not cross	15 (50)
Home ownership (30)	Yes	7 (23)
	No	23 (76)

Semi-structured interviews (n=30) and $\ensuremath{^*}$ is the number of actual responses provided

One barrier was not having the financial means to pay for medical care and the lack of health insurance coverage. Participants described the problems associated with tuberculosis prior to treatment as multiple. Interviewees referenced a myriad of TB symptoms like: cough with phlegm, cough with blood, fever, weight loss, muscle aches, difficulty breathing, weakness and fatigue. Most of the participants reported that they experienced symptoms associated with TB for months (6-24 months) before they received treatment.

Participants displayed signs and symptoms of emotional and psychological distress due to their deteriorated physical and emotional condition. Ten of the participants had or have a relative (in some cases more than one) with tuberculosis. In some cases, their relatives had died from tuberculosis. In addition there were several participants that associated TB with being poor, filthy and dirty.

I was 11 years old when we moved to another house... they put my father in the sanatorium, that place was very ugly and I remember that we went to see him... it was very sad. We were alone here (US), we didn't know anyone, they were very difficult times. My two uncles died of that (TB)... ... I thought only dirty people got that disease... I have that type of TB which they said is in the lymph nodes...I don't know how I got it; I do not go to those dirty places. (Female, 52)

Treatment experiences and support received

Most participants received some informal support during their treatment. The primary types of support provided by their family and friends during treatment included moral and psychological support, financial help, and physical support.

... economically and they help me with the kids (family)... they fed them, the bathe them, dress them and take them to school and my husband even stopped working to take care of me. (Female, 26)

The majority of participants were not offered professional support services during their treatment. Treatment for TB focused on the administration of the medications, laboratory, X-ray services and medical consults. Of the four participants who were offered some type of professional support services, all, with the exception of one, received a food basket and a referral to the Seguro Popular Program in Mexico (national public health insurance program).

All of the participants knew that tuberculosis was curable and that adherence to the medication regimen and completing the treatment are the two requirements for cure. Nonetheless, two participants in Juárez abandoned their first TB treatment. In addition, two

individuals developed MDR – an indication of incorrect treatment or misdiagnosis.

Attitudes toward tuberculosis and stigma

Vulnerabilities and tuberculosis

Perceptions were mixed on how susceptible people are to contract TB. Responses on who could get TB included: anyone (18), only drug users and alcoholics (11), persons with other health conditions like diabetes or malnutrition (14), persons living with HIV/AIDS, and (4), children and seniors.

The perception of the risk of getting infected with TB before their diagnosis was low. Reasons cited included: did not think that tuberculosis exists (a disease of the past), had no chronic cough, felt healthy, received the vaccine (BCG) in México as a child, and TB is a disease of the poor, homeless, or malnourished.

Because I went around places where probably... and the thing is that TB what we have seen now is what I tell me husband... I tell him, you see... it can happen even to decent people, not only poor people, the ones who come from ugly places I tell him, I keep my house clean but TB came anyway, and I wasn't like in bars. (Female, 34)

Reactions when diagnosed with tuberculosis

Reactions people had when diagnosed with tuberculosis ranged from depression, sadness (over what would happen to them); doubt (about getting cured), anger (over how they were infected), and fear of rejection (spouse, family, peers and losing job). Some participants tried to hide the TB diagnosis from other persons. Some participants felt hurt when they were asked to sleep separately from their family during the illness. Others could not hold, hug or kiss their children. Some participants lost earnings during their treatment and two lost their jobs. They were told they could no longer work because of their condition and the risk of infecting others

...horrible, I cried and cried and cried until I could not cry anymore. I was very depressed and I didn't stop every day from crying... the doctor was the only one who encouraged me, he was the only one. Crying and crying, and I didn't touch my kids, I tried to tell them don't kiss me until the doctor explained to me, and I started living my life like before. (Female, 48)

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Attitudes toward stigma and discrimination related to tuberculosis

Attitudes about stigma and discrimination were explored using a semi-structured guide. The majority of the subjects indicated that a person with TB experiences rejection and is feared as a source of infection. A majority also agreed that a person with TB is often treated by others differently. Only a few of the interviewees indicated that the society treats them normally.

The stigmatization of TB and HIV / AIDS continued to be associated with beliefs that TB is linked primarily to poverty and addiction. The correlation of having TB with being 'dirty' or 'filthy' was cited as reasons why stigma is so real.

... people who don't know anything about it (TB), well, the treatment is bad, they are like afraid, like they were sick with HIV also they don't want to have anything to do with people because they think that with a handshake or some other thing they are going to be infected. (Female, 28)

Until now the doctors have treated me very well, they have not rejected me; everything is OK but outside the people reject you a lot... they discriminate, they don't want to greet you, they think you are going to infect them; that's very sad. (Male, 45)

The majority of the participants who experienced stigma expressed it as distancing, fear of contagion, losing job, and feeling discriminated against, isolation from loved ones, and the perception that a person with TB is 'filthy'. Most participants indicated that a person with tuberculosis was treated negatively and experienced rejection by others and felt isolated during treatment. Most reported feeling "useless." Some participants indicated that they became sad, depressed, humiliated or angry.

... I started crying from the depression, crying and overprotecting my kids from myself. I didn't drink in the same cups, I withdrew as much as I could, I was watching TV with them, I never went to bed with them for fear of speaking to them in their face, the first days after I got the information... I didn't sleep with them. (Female, 24)

Some received support from their spouse or a family member and they did not report as much distress as those who felt little or no support during their treatment. Most participants received support from family members throughout their illness.

I have felt less of myself. Sometimes you stigmatize yourself. One feels bad. I don't like being with a lot of people, I feel better when I'm by myself, besides. I haven't gotten used to being like this in the chair (wheelchair). (Male, 22)

Some respondents indicated that during the time they were isolated or in quarantine, they felt very lonely. They had few or no visitors and the special measures taken to avoid contamination were difficult to live with. The physical and emotional demarcation of space was challenging for them. This can make the distancing and separation very difficult.

Views on stigma and strategies to mitigate stigma

A majority of respondents identified the following negative impacts of stigma related to TB: 1) low self-esteem and morale, 2) depression and sadness, 3) fear of casual transmission, and 4) shame and guilt. Among the determinants of stigma associated with HIV / AIDS and TB is the general public's incorrectly perceived fear of infection through casual contact. The perception of moral judgment and biases seem to be stronger for persons living with HIV / AIDS than TB, perhaps because of the sexual nature of HIV transmission. However, moralism plays a strong role in TB stigma as well.

To mitigate stigma and discrimination associated with TB, we asked participants what could be done by health workers, family, and members of society.

Health care workers

There was consensus by the respondents that the primary responsibility that health care workers have was to treat the person affected by TB with dignity and to offer concise information on causes, treatment, adverse effects of medication, and the dangers of interrupting treatment, transmission, and prevention of tuberculosis. The majority of the participants indicated that if information on TB were given to the patient, the family, and the community at large through mass media and presentations, TB would stop being viewed as negative and perhaps people could stop being afraid of the person with TB. Every respondent identified the distribution and dissemination of accurate information as the most important effort that health workers can make to eliminate the stigma associated with TB. Ensuring privacy and confidentiality was identified as an important issue. Respondents also indicated that psychological counseling or support services should be provided.

Family members

The single most important thing that families could do according to the respondents was to be informed about tuberculosis, its forms of transmission, prevention, treatment, and cure. In addition, family members could offer moral support, be patient, and learn how to think more positively about the disease. In addition, family members should avoid rejecting the person affected with TB. The majority of the respondents stated that family members should be accepting of the persons with TB and avoid isolating them or making them feel guilty.

Persons affected with tuberculosis

The three most important actions that persons affected by tuberculosis could do to eliminate stigma and discrimination were: 1) to take and adhere to treatment, 2) get cured, and 3) avoid exposing others to the disease. In addition, the person could help the family and other members of society be informed about the condition and dispel myths in order to stop feelings of being marked or singled out as a result of the TB. Using a personal story, encouraging persons at risk to get tested for TB, talking with persons affected by TB, and encouraging them to complete treatment were identified as actions to help mitigate discrimination. A small number of participants indicated that there was nothing that could be done to eliminate discrimination. Some participants were unable to verbalize the change they would like, and their feelings of "guilt" led them to conclude that maybe they deserved being stigmatized.

Discussion

Being diagnosed with TB can create isolation, discrimination and guilt. There was evidence of perceived and enacted stigma toward a person with TB. The majority of the participants experienced rejection and were feared as a source of infection. The stigmatization of TB continues to be associated with beliefs that TB is linked primarily with poverty, homelessness and addiction.^{1,13} Most participants reported feeling stigmatized as a result of their disease. Respondents reported negative impacts of stigma such as low self-esteem, poor morale, depression and sadness, fear of causal transmission, shame, and guilt. This replicates similar findings in Ecuador and Thailand. 10,15 Results of studies in other countries also reveal similar patterns.³⁸ This could subsequently contribute to the psychosocial effects on persons with TB which resulted in low self-esteem and withdrawal from society.

Also of importance are the positive impacts of stigma that respondents reported. These included over-

coming the disease and rejection and fostering a positive attitude about life and how to care for one's health. For some participants, the experience of living with TB was said to have made them "stronger" emotionally and helped them to have a "more positive outlook on life." This suggests that stigmatized individuals may overcome adversities associated with stigma and illness as an empowering process (positive stigma or resilience) as opposed to solely a depleting coping mechanism. ³⁹ How to deflect negative consequences of TB and TB-related stigma were not explored in the present study. Research and investigations should focus not only on identifying the factors that lead individuals to be harmed by stigma and stress, but also the factors that help individuals to protect and overcome stigmas. ^{39,40,41}

This study contributes to the understanding of several aspects of TB and TB-related stigma, particularly the knowledge and health-seeking behaviors among persons with TB in the El Paso and Ciudad Juarez border region. It documents information on the experiences of persons with TB. The findings cannot be directly generalized to the whole population of the El Paso and Juarez border region in view of its diversity and the asymmetry of the two communities. The findings were considered reliable as the interviews used the same instruments.

Implications for future research

Future research can explore health-related stigma and health-seeking behaviors among other groups like migrants and immigrants. By conducting subsequent indepth interviews of stigma with persons with TB, health care providers can assist in improving the health seeking behaviors of persons affected by TB. The findings of the study suggest that there is a need to understand the roots of misconceptions about TB and to address the lack of knowledge about TB. Persons need to recognize the symptoms of TB early so that diagnoses and treatment can be initiated promptly.

Conclusion

Much of the focus of research related to stigma revolves around social and cognitive aspects of the disease. The result has been that proposed actions to overcome stigma focus on the changes needed at an individual level. This approach has led to "blaming the victim" by leaving it up to the individuals affected to resolve their own situation. In order to move beyond this approach, an analysis of what the social and structural conditions leading to stigmatization of individuals is necessary. Through our analysis of the factors in which stigmatized individuals live, stigma can be understood as a designa-

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tion assigned to individuals rather than being within the person. This focus acknowledges that stigma is not naturally occurring, but something created by people and as such it can be reversed.

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