



The Social Determinants Underlying Tuberculosis Diagnostic Delay: A Qualitative Study

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Introduction

Early detection and diagnosis of TB remains a major global priority for tuberculosis control efforts. Low case detection and delays in treatment initiation contribute to increased community transmission of TB, severity of individual infection, and risk of mortality.

We aimed to investigate the social determinants contributing to diagnostic delay in Lima and Callao, Peru. We compared data collected from persons diagnosed with TB, their family members, and health care personnel working in the National TB Program to gain an individual, community, and health-system level understanding of this phenomenon.

Methods

Design: A qualitative research study using semi-structured interviews for persons diagnosed with TB (aged ≥ 18 years) and their family members and focus groups for health care personnel.

Procedures: Data were collected from 19 districts of Lima and Callao, Peru. Semi-structured interviews with persons diagnosed with TB (n=105) and their family members (n=61) focused on health-seeking behaviors and community perceptions of TB.

Focus groups (n=7) were conducted with health-care personnel working in the National TB Program.

Analysis: Data from the interviews and focus groups were transcribed and then analyzed using a grounded theory approach. First, interviews and focus groups were reviewed to identify emerging themes and concepts. A list of codes was then created to organize information provided by participants. A fully coded analysis of all transcripts was completed and used to create a conceptual framework of factors contributing to diagnostic delay.

Results

The median number of days between onset of symptoms and the clinic visit that led to the first positive diagnostic sputum sample in the National TB Program was 57. As their first health-seeking behavior, persons diagnosed with TB were significantly more likely to self-medicate with pharmaceutical medicines and/or natural medicines than consult formal health care providers (65% vs 35%; $z=4.35$, $p<0.001$). Interview and focus group data were separated conceptually into five categories that directly or indirectly contributed to diagnostic delay of TB disease.

Table 1: Results of Interviews and Focus Group Discussions

Concept	Illustrating Quotes	Description
Previous Knowledge and Experience with Illness	"I thought TB was for people who did not eat, for the vagabonds that didn't look after their things." (Male Patient, Interview)	Prior to diagnosis, most persons diagnosed with TB had at least heard of the existence of a disease called TB. There was variable information however, on its causes and the details of treatment.
	"I guess that, if there was a percentage, 70% don't know [about treatment for TB]." (Family Member, Interview)	
	"The whole world knows that if you have TB you leave your sputum for free and they give you your medicine for free." (Family Member, Interview)	
Material Resources and Available Social Support	"[I waited] because of work...there was no time. I returned in the night from my job, around 8:30 and at this time the health posts are not open." (Male Patient, Interview)	Economic restraint was strongly reported as a reason for delayed healthcare-seeking behavior. Persons diagnosed with TB who had available social support reported seeking care at professional medical facilities more quickly.
	"In the month of April I started to feel a little sick and I was coughing frequently and my mom got worried and made me go to the hospital for an appointment." (Female Patient, Interview)	
Threshold of Symptom Severity	"The cough made my chest hurt. I couldn't take it...I started to feel pain behind in my back. I had fever and my body hurt. My fever was too high." (Male Patient, Interview)	It was noted that most persons diagnosed with TB sought care from a physician after ill health prevented them from conducting daily activities, were noted as extremely abnormal, or persisted for an unusually extended period of time.
	"Some delay, some wait, coughing, and they come when it doesn't pass with any pills and they start to vomit blood..." (Health Care Worker, Focus Group)	
Health Seeking Behaviors	"It was for a throat infection. Every day I took different pills because I was going to different pharmacies and they told me I was sick in the throat...I thought it would pass in the night and the next day it came back...At this time I didn't have health insurance and I didn't have time [to go to the doctor]." (Female Patient, Interview)	Overwhelmingly, persons diagnosed with TB and their family members held general distrust in the public health care system. Persons diagnosed with TB were found to seek care at public health posts only after exhausting all other healthcare options. These options included: self-medicating, using natural medicine, and seeking care with privately-funded physicians.
	"The majority come with one month of symptoms – they thought it was something normal or they went to the pharmacies or did what their mother, sister, grandmother told them to do. When the symptoms persist they go to a private professional and since he doesn't have much experience he says upper respiratory infection. And then they continue hurting and then finally go to the public health post when a lot of time has passed." (Health Care Worker, Focus Group)	
Community and Health System Response to TB Disease	"If you have tuberculosis...you feel like a source of infection and the people are going to, they are going to reject you..." (Male Patient, Interview) "I had a patient and I asked him, why did you abandon treatment? He said the nurse left him the pills on the table and then everyone disappeared, everyone left running... The patient said: why am I going to come here if they treat me bad, if I feel bad? A TB patient has low self-esteem, and with the treatment we give him it gets worse..." (Health Care Worker, Focus Group).	It was universally agreed that persons diagnosed with tuberculosis faced discrimination by the public and in health posts.

Figure 1: Conceptual framework of Diagnostic Delay

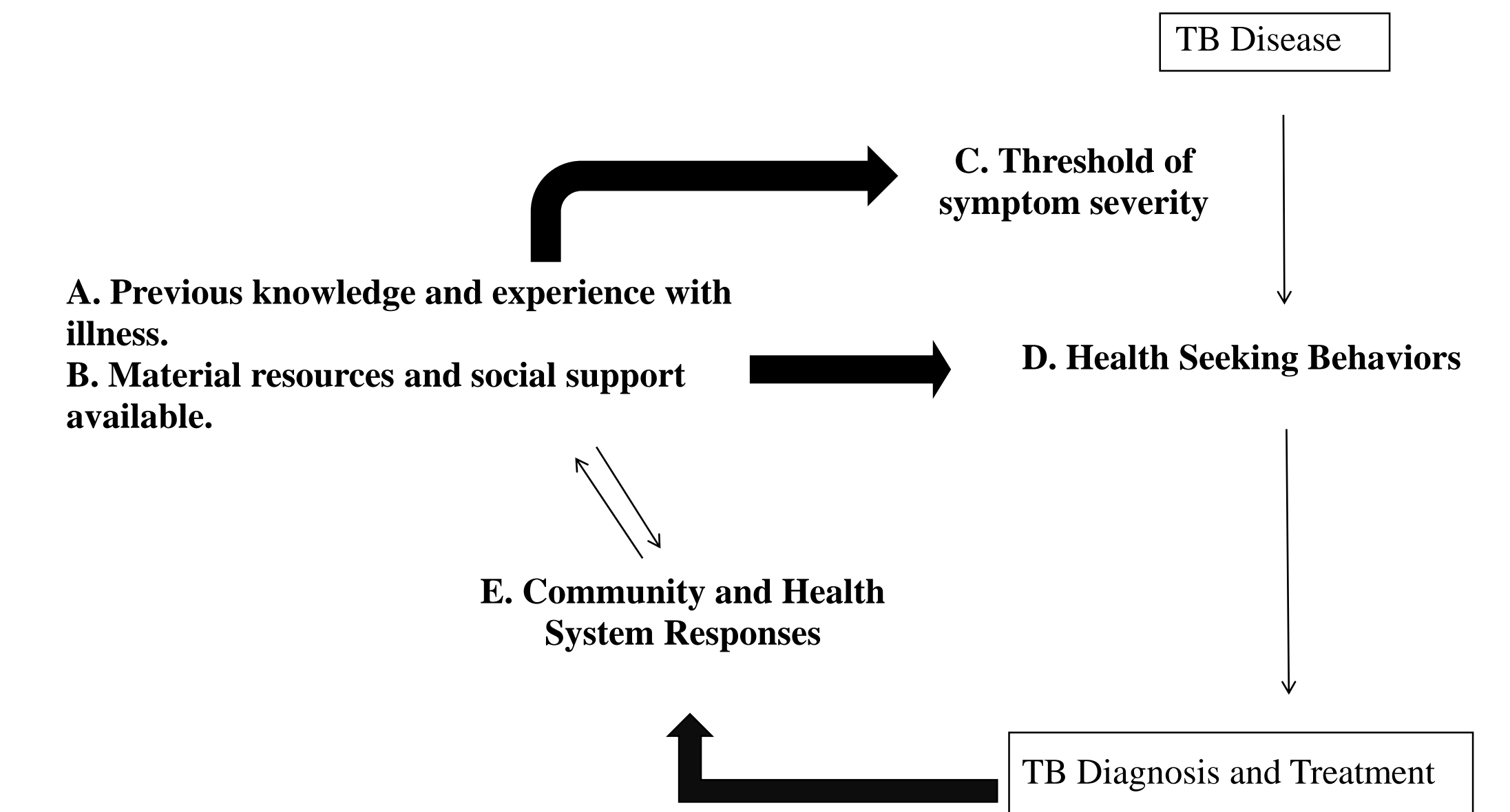
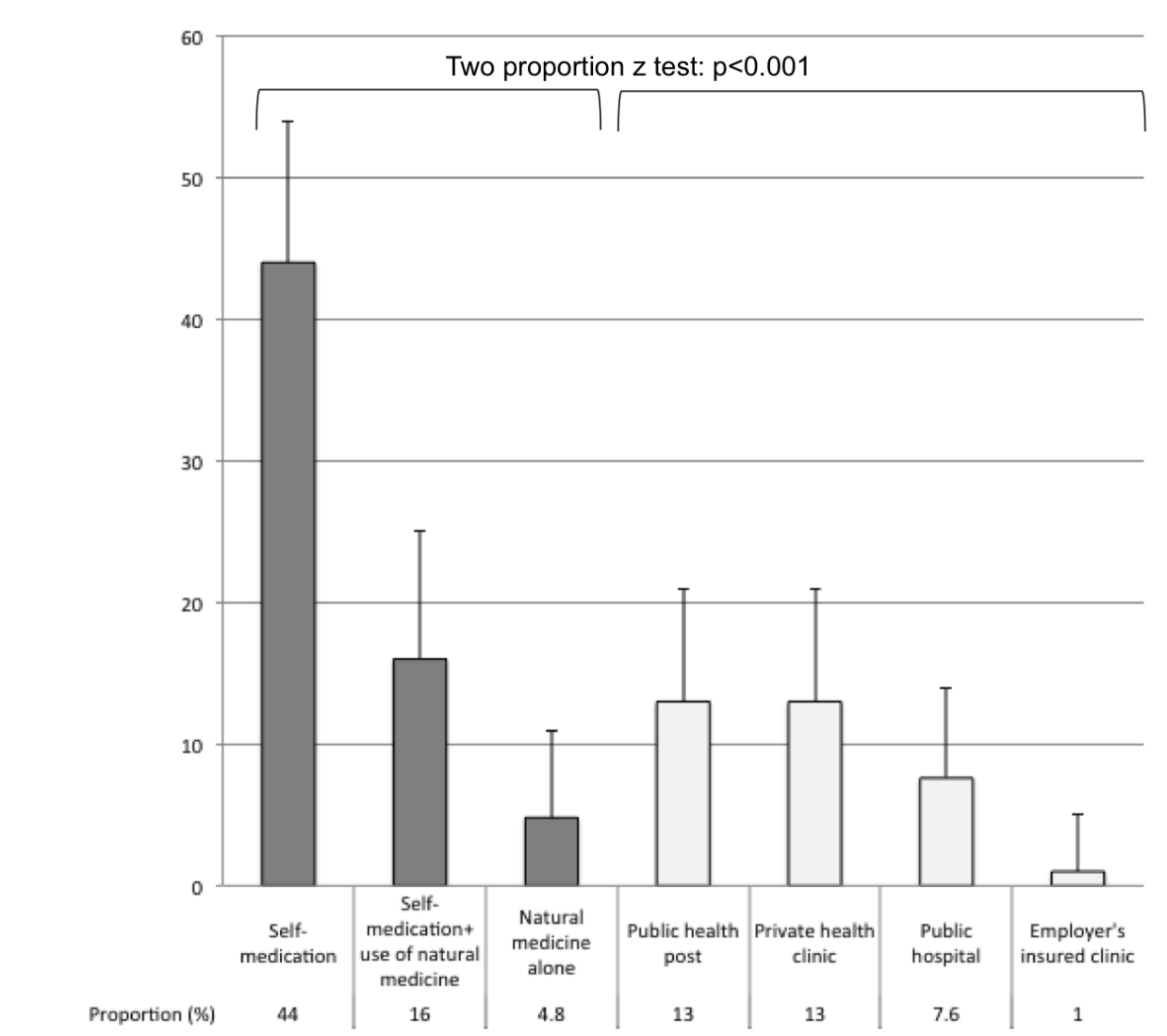
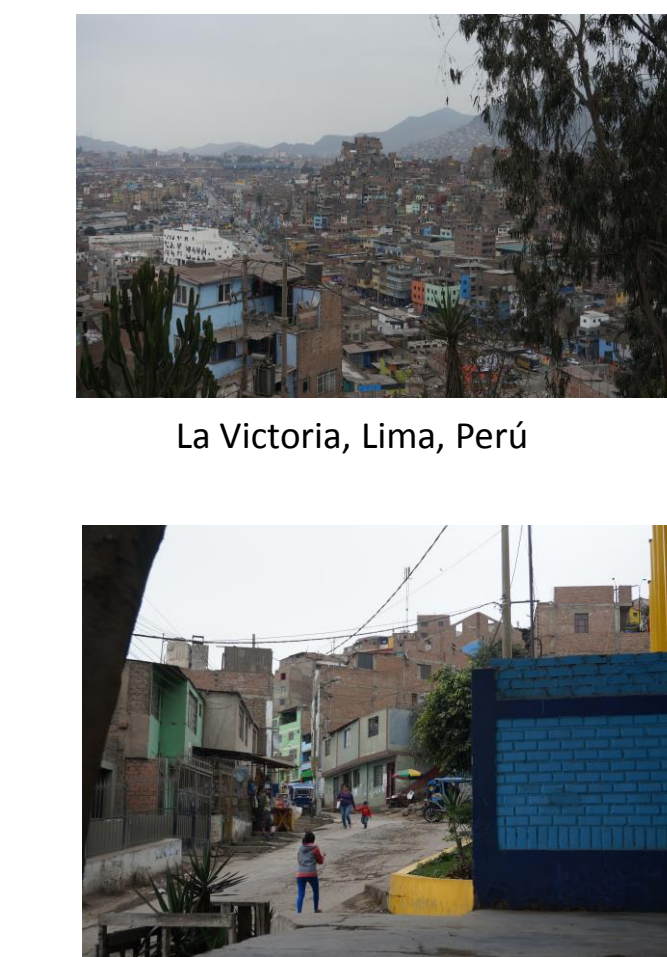


Figure 2: First Health Seeking Behaviors conducted by persons diagnosed with TB. Error bars represent 95% CIs.



Conclusions

Diagnostic delays were frequent and prolonged and our research findings have implications for TB control efforts in Perú and other resource-constrained settings. The development and/or improvement of policies that address and help reduce diagnostic delays are urgently needed.

We found that persons diagnosed with TB, their family members, and healthcare providers stated that when individuals reach a threshold of symptom severity, they address their health with the least time-consuming, most economically feasible, and well-known healthcare option available to them. TB case-finding strategies should therefore, be targeted at the most widely used of these options, demonstrated as self-medication in our research. Additionally, more material and human resources are needed in health clinics to conduct these strategies and address the multilevel social determinants of health identified in this study.