

Why are the Missing, Missing?

Qualitative Research to establish why the San of Omaheke, Namibia are among the missing TB patients and development of strategies to find them

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Introduction

10 million people develop tuberculosis (TB) annually. One third of these are ‘missing’. Reasons proposed for patients being missed affect all stages of the patient pathway, including problems with diagnosis, treatment and documentation. Finding the missing TB patients is a priority; infected patients will die without treatment, TB will spread in the community, and incomplete treatment causes drug resistance.

The San, an Indigenous population in Southern Africa, experience significant TB problems. They were originally nomadic hunter-gatherers but now endure struggles with poverty, poor health status, marginalisation, discrimination and loss of land. Many San live in Namibia. Namibia has the joint tenth highest TB incidence globally and is one of 30 high TB burden countries identified by the World Health Organisation. It is estimated that there are 2,425 missing patients with TB in Namibia.

Aims

The aim of this research was to investigate reasons why the San of Namibia are among the TB missing and to propose interventions to address this.

Methods

Focus group discussions took place with the San of Omaheke, Namibia. 38 participants were included. They discussed their TB experience, opinions about TB among the San population and their solutions to finding the missing TB patients. Framework analysis of results enabled thematic extraction of relevant findings. Research was based at *The Lifeline Clinic*, an NGO-led primary healthcare clinic providing free healthcare to 3,500 San annually. The nearest hospital is 120km away.

Results

Thematic analysis of the focus group discussions revealed that the San are among the TB missing because they live in remote regions and struggle to reach healthcare; they have incorrect health beliefs and poor TB knowledge; available healthcare standards are often inadequate; and they are affected by their intrinsic personal characteristics including mobility, lack of initiative, different concepts of time and traditional medicine use.

This can be divided into three main themes, as below, with illustrative quotes from participants.

Ability to reach healthcare facilities

‘I was living in Pos 9b. The first day I walked to Pos 9c and slept there. From there I walked to Pos 7 and slept there. Then I got a lift to the clinic the next day’
‘One day I tried but they did not have enough petrol’
‘The child was staying very far from the clinic. They didn’t have money to pay for transport. She died by the side of the road because they couldn’t pay’
‘If someone lives far, they try to phone the clinic. If there’s no signal, the patient dies’

Health-related behaviour and knowledge (including standards of available healthcare)

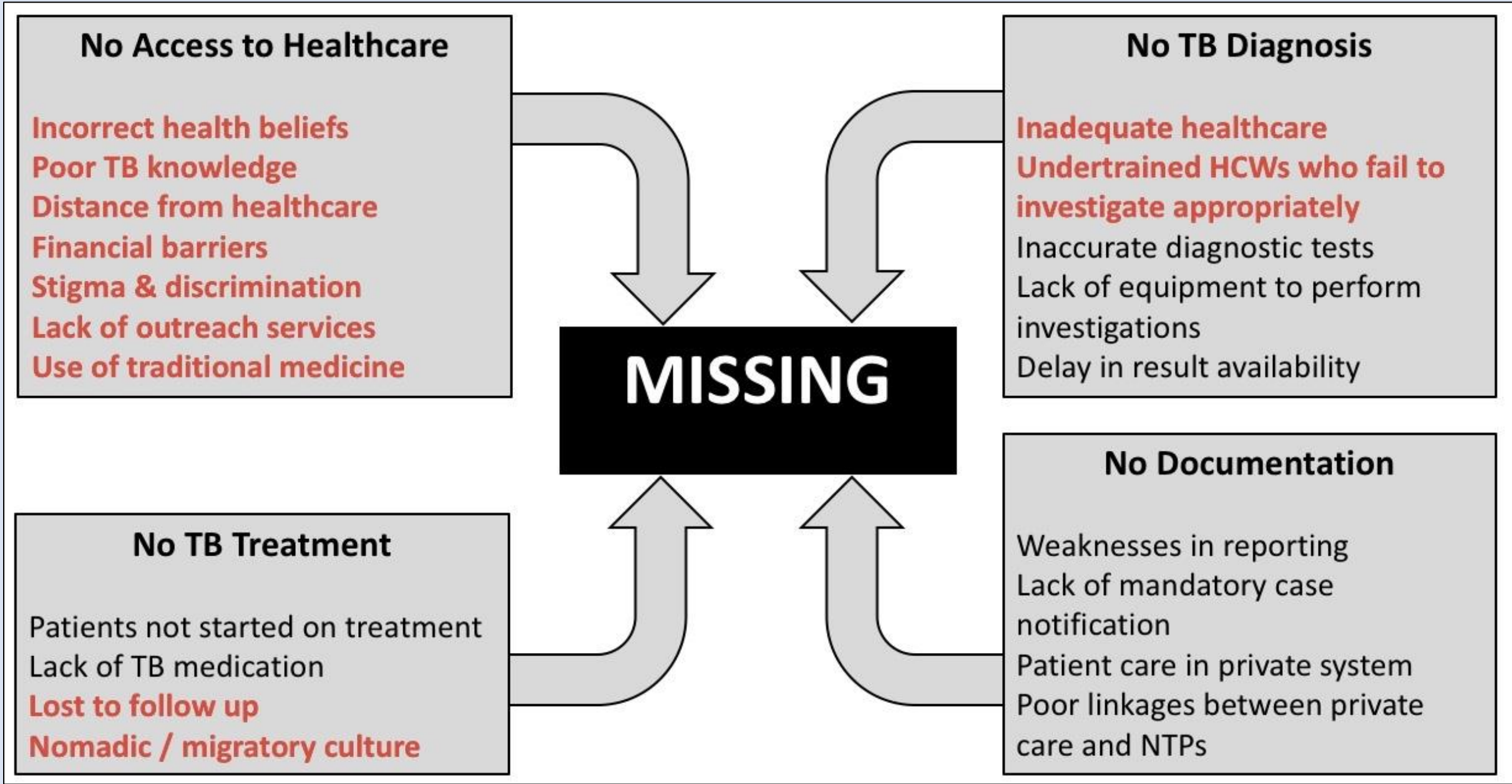
‘TB is caused by burning rubbish’
‘Relapse TB is because people have been bad’
‘I had a cough, sputum, sweats and coughed up blood. I didn’t think I had TB’
‘We try traditional medicine from the bush and you drink it and you cure TB’
‘I always got paracetamol for chest pain. They said the chest was fine and I got sicker and sicker. I only got pain pills’

Inherent San personal attributes and characteristics

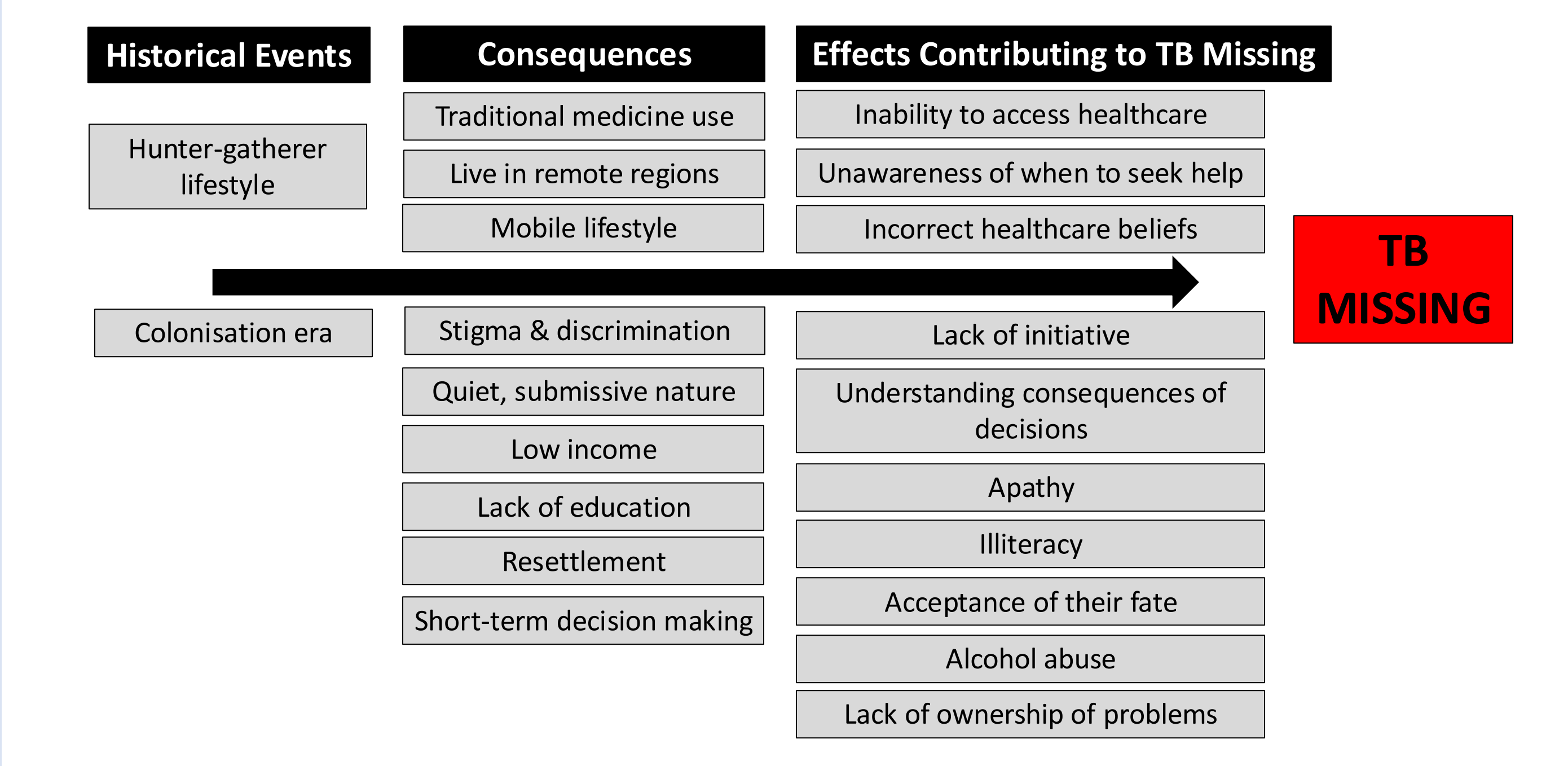
‘I’m too shy to go to the clinic’
‘The hospital nurses are sometimes mean to us. The cleaners shout and say we should go outside, because we’re San’
‘Someone will get TB, then they move and get TB again. They infect the family again. People far away aren’t treated. They infect mobile people’
‘I felt better in hospital and then went home. I stopped the pills and started drinking alcohol and became sick again’

Discussion

WHO have divided the reasons why TB patients are missing into 4 categories, as demonstrated below. The reasons affecting the San of Namibia identified during this research are highlighted in red.



It is apparent that some are missing ‘because they are San’. There are wide-ranging sociocultural factors contributing to this fact. They face problems intrinsically related to their cultural heritage, with effects from their previous hunter-gatherer lifestyle and further effects from the trauma of colonisation. This is outlined in the figure below:



Interventions

Five medium-term interventions are proposed to prevent the San being among the TB missing, based on these findings:

- 1) Ensure that all TB patients receive appropriate financial support;
- 2) A community health education programme;
- 3) Increased National TB Programme support during treatment;
- 4) A San Community Health Worker scheme
- 5) Amending the Namibian TB guidelines to include chest pain as a possible TB symptom.

Conclusions

When a San individual develops TB, they lack the education to understand the symptoms, and they have incorrect health beliefs. They struggle to reach healthcare facilities. Available healthcare standards can be poor and there may be San-related stigma. Some San remain mobile, increasing exposure to untreated patients. When combined with their inherent personality traits, some resulting from their hunter-gatherer past and some from subsequent marginalisation, and their acceptance that dying from TB is the norm, they become part of the TB missing. Cultural stereotyping must be avoided; the San are among the TB missing due to external factors beyond their control that have caused structural violence secondary to their cultural heritage.

