

Health, Wellbeing & Diaspora

The lived experience(s) of
TB in a refugee community
in Auckland, New Zealand

Jody Lawrence, PhD Candidate
University of Auckland

Objectives



- To understand the social, political, cultural and economic dimensions of TB in the Auckland Somali population

Somali population profile

- Arrived early 1990's
- Migration streams
 - Refugee quota, family reunification, asylum seeker
- 1,770 Somalis in NZ (2001 Census)
 - Data quality issues
- Concentrated in main urban centres
 - Neighbourhood clusters – Public Housing
- Mixed resettlement experiences

Preliminary Research Findings

- A work in progress!



Denholm, 1999

The TB experience: Emerging Themes

- Pre-migration issues
- Post-migration issues
- Stigma
- The road to wellness



Denholm, 1999

Pre-migration issues - Displacement & loss

- Civil War 1992 – Displacement

Narratives of loss

- Family members – husbands, children
- Health and wellness
- Loss of nationhood / national identity
- History
- Material resources
- Social support and networks
- Social status
- Educational/employment status

Living with loss

“I had to leave. We had to leave all the cars and the houses, everything. We had to take nothing, even no food, nothing. Just walk. When we came to Kenya, you know, the refugee camp, my husband died there. So life was getting really hard. Coming to NZ was good, but I thought you know I don't belong in NZ. I feel you know, my heart is in my country. Because in my country I had big home and big family. Lucky. But NZ, no big family, no big house”

Post-migration issues - Challenges of resettlement

- Economic hardship
- Employment
- Education
- Contracted social networks
- Language
- Dealing with separation
- Visible “other” – Neighbourhood/Political

When asked about the cause of her TB one participant stated,

“Sometimes I’m thinking too much, for example I had the TB. So I believe that TB attack me because I was thinking too much. I was worrying about my family back home a lot. Sometimes I go to the toilet and I just sitting on the toilet but I was thinking of my family. I have got a big family and I can’t afford to fix their problems and I can’t afford to send whatever they want so I was thinking, thinking, thinking a lot”

So what does this mean for TB?

- Multiple layers of disadvantage
 - E.g. Economic – housing overcrowding
- Poor health and wellbeing
- High levels of stress and worry
 - Compromise immune system's ability to contain TB germ
- Influences likelihood of developing TB and the subsequent 'disease experience'

Living with Stigma

- TB continues to be a stigmatised disease
- Difficult to talk about it
- Contributed to reluctance to be interviewed

- Isolation

“People will run away from me”

- Shameful

Jody “And how did your family react”

SM1 “They were sad because I’m the only person, the first person in the family to have this disease”

Jody Who have you told about your TB?

S I haven't told anyone – no-one asked. But people found out. It's a small community.

Jody And did those people act differently towards you?

S Yes of course. They don't want to be close.

Jody And what about other friends?

S I don't have contact with anyone. I don't have any friends.

Jody Is this after you had TB?

S Before and after

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- TB as incurable & equated with certain death
 - “Somebody who has TB, is, like somebody who has AIDS” (Com2)
 - “I thought I was dead, gone and going to hell” (SF2)

Long road to wellness

- Long time between first symptoms and treatment
 - 9 – 12 months
- Extra-pulmonary vs pulmonary
 - Back, lymph nodes, stomach
- Numerous tests and medical appointments
- Hospitalisation

Typical case

- First symptoms - high fever, coughing, vomiting, headaches and lack of energy
- Visit GP (family doctor) – paracetamol
- Repeated GP visits – up to 20
- Very sick
- Chest xray's
- Presentation at Emergency Department
- Diagnosis – extended hospitalisation

- **Curing TB?**

- Compliance – Medication as ‘the only way’
- 9-12 month course
- Long-term effects on health and wellbeing

Conclusion

- Themes
 - Pre-migration issues
 - Post-migration issues
 - Stigma
 - The road to wellness



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