Persisting challenges of ‘landing’ a tuberculosis diagnosis in a high-HIV prevalence setting with universal healthcare: perspectives of patients from urban Blantyre, Malawi

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Background

- TB kills 1.5 million people globally every year; 0.4 million of whom are HIV-infected (WHO, 2015)
- TB had resurged in Africa from a combination of weak health systems, rapid urbanization, poor living conditions in fast-growing cities, and the HIV epidemic (Lonnroth et al, 2009)
- There is currently a steady but slow decline in TB incidence, prevalence and mortality within the African region
- Africa bears a disproportionate share of the global TB burden: it had 28% of cases in 2014 (WHO, 2015), but 14% of the population
- End TB seeks to eliminate TB by 2035,with a key component being identification and treatment of cases early

Background

- The socio-economic burden associated with seeking healthcare for TB exacerbates vulnerability
- End TB seeks to reduce ‘catastrophic’ costs associated with TB disease, and to promote universal health care, including addressing health systems weaknesses
- Some countries have enacted policies that make TB diagnosis and care free.
- Male gender continues to be a risk factor for late diagnosis and treatment (WHO, 2013)

Study aim and setting

- **Aim**: To understand why men delay seeking healthcare for TB.
- Malawi is low-income, with high levels of unemployment and informal work
- Adult national HIV prevalence: 10.6%
- ART coverage 67% -- in 2014
- TB incidence: 163/100,000; 78% diagnosed within a year against the global target of 70%
- Treatment success rate at 85%
- 70% of TB patients are co-infected with HIV
- Case notification: 5000/yr. - 1985 to > 25 000/yr. in early 2000s

Malik 2013; Aggarwal et al 2010; Habitat 2012; WHO. 2014; Chimzizi & Harries 2007

Sampling

Technique	Participant category	N (total participants)	Gender
FGD	Healthcare workers	2 (20)	Mixed sex (3 men and 7 women per group)
	Community members	8 (74)	3 men only FGDs 3 women only FGDs 2- mixed sex FGDs (11 women, 9 men)
IDI	Newly diagnosed TB patients	20	6 men 14 women
	Chronic coughers who reported not having sought formal care	20	12 men 8 women

Theme 1: Interpreting evolving symptoms

- Recognition is neither immediate nor definitive
- Malaria is frequently suspected first
- Healthcare seeking is eclectic
- Internalized ‘knowledge’ from campaigns helps recognize symptoms, but not immediately

‘(If) while chatting with friends I tried to laugh, I’d end up coughing, but not as ‘normal’ people do … This dragged on … maybe 3 months. I’d go 2 weeks without (coughing) … (and) think it’s finished… only to find it had started again. Then I started thinking ‘this has to be a major cough’… seeing it wasn’t stopping and I was losing a lot of weight even while “walking” … I then thought it was malaria. … With that “malaria” I started vomiting … 3 days non-stop. Without eating, I became weak; then I told my child … ‘Tomorrow, take me to hospital’”

“When it started … it was … what one might normally consider to be ‘flu that comes with coughing’… As it continued ...I began to suspect … this should be TB…. . I thought about what’s said about the need to be tested if a cough exceeds certain duration. … I … (was) losing weight.”

(46-yr old woman)

"I like to listen to a certain radio program … It explains how people are 'found' with TB so-and-so. ... As I listened one day… I said to myself, 'these symptoms that these radio guests experience, so they really do happen? … I'm feeling it happening in my body… it feels hot when I'm sleeping, sweating, and during the day, my blood flows very fast … Whenever I am working, I sometimes feel weak'. … It reached a point where one day I said to my *madam,* 'whether I like it or not, this time if I go to *hospital*, I'm going to be admitted."

(55-yr old man)

Theme 2: Health systems challenges encountered

- Failure of equipment to pick disease
- HCW treating for malaria before TB investigations
- Patients being shunted between home and facility as HCWs managed for other diseases than TB
- Patients shuttling between various facilities hoping to obtain more satisfactory care

46-yr old woman

- Visited a facility, was immediately admitted after being determined to be ‘serious’.
- A ‘scan’ yielded ‘no result’, as did her sputum smear.
- Although admitting she had the ‘signs’, clinicians discharged her for lack of proof, and she ‘continued to suffer at home’.
- While contemplating seeking another opinion, an organization tracked her and were surprised that she had been let go.
- They invited her to the hospital, and “pierced me in the bones and extracted some marrow” and immediately ordered treatment initiation.

"I went to the *hospital* … was given *malaria* treatment… but progressively deteriorated to even failing to walk by myself… I finished the *LA* dose and realized I had started coughing... After a month, I came to the *hospital* here at the hall… They took my sputum, but said I didn't have disease. Seeing I continued to cough, I returned and was then referred to Q.E.C.H. … There I did the test and so I was diagnosed and started on treatment."

(31-year old woman)

"It started like *malaria* … after suffering for a month … I went to the hospital and was told it was *malaria*. I was tested but it was not found. … Now I have moved to three places … after which I just said: I should go to Queens … at Queens I had a blood test… I was then told to go to 'your community (hospital) … I came here in the morning and was given the bottles…"

(26-year old woman)

"… the cough would start, and go for a week, and maybe I'd go to the *hospital* to collect some medicine. They would give me that drug for a cough, *Amoxicillin, Panadol*, whatsoever, maybe a bottle (of medicine); once I would finish it up, the cough also ceased, to start all over again a month or so later. And it would be like whenever I am sleeping … the sheets would get wet, sweat all over. And I would feel very hot. … Every time at mid-night … my *madam* (wife) would have to change sheet … So maybe 4 or maybe 5 months passed."

(**55-yr old TB man**)

29-year man

- Took 3 weeks to report at HCF; 1 year to be diagnosed
- 4 negative sputum tests; eventually had an X-ray.
- Was skeptical about X-ray result: “It was the (same) doctor who always gave *Amoxicillin*”
- Frequently purchased over-the-counter drugs between consultations until he was diagnosed
- Did not welcome doctor’s advice to be tested for HIV

Theme 3: Contesting HCW decisions

"… When I was seen, it was on a Sunday. I returned the following Sunday, but still did not get to start treatment … Realizing treatment was not coming, I came back and used a drug bought from the grocery shops. … It didn't help … My sister-in-law scolded me for using drugs not supplied at the hospital, so I went back to the Central hospital, and informed the doctor who also shouted at me so much. I tried to explain that they should not send me back, because should they do … well, there was nothing I was going to do. He understood me, and I was given some medicine. But my leg had swollen. I told him that having come back and forth, my leg was swelling … although not painful, but I am failing to walk, I said."

(32-year old man)

30-year old man

- Upon starting coughing, he went to and was admitted at a hospital for 3 days
- He improved but cough resumed 2 weeks later with loss of appetite and pain when breathing; he purchased own medication;
- Was disappointed about spending a lot of money, but also 'they' were not agreeing to take sputum off his non-productive cough.
- Suspecting bewitchment, he consulted a THP; his headache ceased, but the cough continued.
- "… Because I never knew TB … I was just delaying myself, going here, going there; had I taken one route, I wouldn't have taken long to receive medicine."

30-year old man

- He returned to the HCF, was given take-home *Bactrim* and *Panadol* and instructed to supply sputum at another HCF

- Now coughing and vomiting, and 'feeling hot when sleeping at night' but still with no productive cough, he says:

> "I wanted to force matters, that maybe they should just do an x-Ray … examine me to see what is going wrong here in the ribs."

- Meanwhile, they called to inform him sputum tubes had stocked out."

30-year old man

"But even as I took the medicine, I was wondering inside about this coughing that was not ceasing, which was being said to be TB but I had heard that if one coughed for 2 weeks, they should go for examination; but as for me, I was now into months.// I came to see that, if at all I have been disgruntled after having been told that the bottles are not available.// Therefore I did not even want to go back ./But now, when I came to have the pain on the other side, then said: I would rather go there, last time it was this other side hurting, and now this side too./ … now it is now two sides aching./ … I said: no, and I rushed and came here where I was assisted."

30-year man with two children

- The process of taking his sputum was complicated:

  "When I went to leave (the sputum), I was told that the time to do that had gone, you are late, go and throw that away... I went to throw the last bottle... They told me to start the process again on Monday…"

- Because he was having problems with eating and with vomiting, it being a Wednesday, the 'next Monday' he had told to come back was too far for him

Closing thoughts

- The existing TB management model carries an expectation that symptomatic individuals present for healthcare.
- These findings indicate that such reporting does not translate into an ‘efficient’ and ‘easy’ pathway to diagnosis for patients.
- Delay in diagnosis occurs due to patient-related factors, health system-related factors, and interaction of both
- Poverty, malaria endemicity, and high HIV prevalence also affect the process of diagnosing patients
- IEC can continue to build on a subconscious awareness base that can be called on to ‘decode’ evolving symptoms
- The implementation of universal health coverage in Malawi is longstanding, and noble, but encounters a number of challenges (Abiiro et al 2014)

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