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Conceptions of chronic cough as serious illness in a high HIV prevalence context, and implications for tuberculosis control through men: a study in Blantyre, Malawi

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Tuberculosis as a public health problem

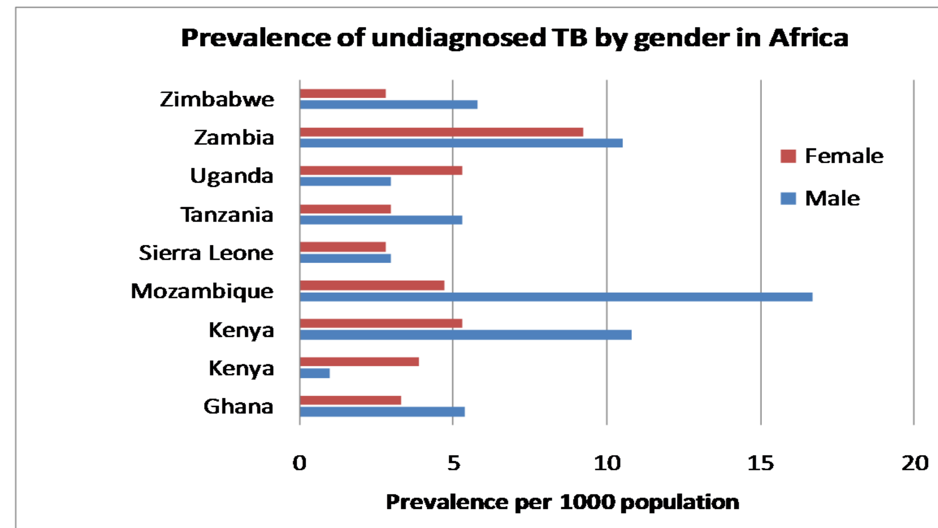
- Globally in 2012, TB was responsible for 8.6 m cases and 1.3 million deaths
- Africa accounts for 27% of global cases but has only 14% of the population
- TB's recent resurgence in Africa is driven by
  - HIV
  - Weak health systems
  - rapid urbanization, and poor living conditions in fast-growing cities

Men socializing in Harare, Zimbabwe

WHO 2013, Lonnroth 2009

Men and tuberculosis

- Men delay seeking healthcare more than women
- They have higher early mortality than women
- Largely in Africa, more men than women remain undiagnosed with disease in the community
- There is limited health research on men in African settings; existing work seeks to improve women's health
- The TB control strategy in use in most settings relies mainly on individuals self-presenting for care at facilities



EU 2013, Corbett et al 2007; Borgdoff et al 2000; Ayles et al 2009, World Bank 2012

Aims of study

- To understand the reasons for high levels of undiagnosed TB among men in the community
- To develop, and explore preferences around, candidate interventions for facilitating men to engage with healthcare

Theoretical context

- **Connell:**
  - "masculinities are patterns of practice by which both men and women, though predominantly men, engage the position of men in a gender order"

- **Social constructionism**
  - historically and culturally specific forms of analysis
  - sees world as constructed through daily interactions
  - there is possibility of multiple creations of the world: 'meanings, values, identities, knowledge, and power are plural, ambiguous, multiform, and even contradictory'

Connell 2010 & 2012; Burr 1995; Courtenay 2000

Research process

- In order to understand this little known but complex topic including its different dimensions, we triangulated data sources and techniques.
- Chronic cough (2 or more weeks) was used as a proxy for TB. We felt that asking directly about TB might yield little regarding health seeking behaviour as TB is often not easily recognisable at lay level.
- However, TB was directly discussed with those that had more direct experience, such as TB patients.

Category of participants	Data collection technique	Sex	No of participants	Total no. of participants
Chronic coughers	IDI (n=20)	Women	13	
		Men	7	20
Recently diagnosed TB patients	IDI (n=20)	Women	8	
		Men	12	20
Community members	FGD (n=8)	Women	40	
		Men	34	74
Health Care Workers	FGD (n=2)	Women	14	
		Men	6	20
Stakeholders	3 day workshop	Women		
		Men		27

Country setting: Malawi

- Low-income, with high levels of unemployment and informal work
- Adult national HIV prevalence: 10.8%
- ART coverage: 69% (based on 2010 guidelines)
- TB incidence: 163/100,000; 78% diagnosed within a year against the global target of 70%
- Treatment success rate: 85%
- 70% of TB patients are co-infected with HIV
- Case notification: 5000/yr. - 1985 to > 25 000/yr. in early 2000s

An informal work setting in one of the study communities

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

Findings

DYNAMICS AND EXPERIENCES AROUND CHRONIC COUGH

Four themes

1. The link drawn between cough and serious illness in a high HIV prevalence setting
2. Fears and ambivalence around seeking healthcare and being investigated for cough
3. Seeming transition from being fearful before to being embracing after diagnosis of TB and initiation of treatment
4. Inverted gender representations and roles

In a high-HIV prevalence setting, chronic cough is linked to illness seen or experienced as serious (cough-TB-HIV-serious illness)

Loss of independence, diminished functioning and regression to helplessness

- *"one then fails to do things one was able to do when well (and) now expects other people to do things for them, like bathing… eating… and yet the person is a grown-up."* (Community men's FGD)

Diminished functioning and the frustration entailed

- *"I used to run up and down with different kinds of businesses … ever since taking ill, I just stay. For a businessperson … everything has just stopped. So my life has become hard… [Participant continues further down] … I am failing to walk and get to my business premise. Even cooking has been hard for me because my body is weak; … washing [laundry] too*"… (46yr old woman, TB patient, not married)

In a high-HIV prevalence setting, chronic cough is linked to illness seen or experienced as serious (cough-TB-HIV-serious illness)

Stress, frustration, and anger as one fails to play designated role of head of family who is in charge and in control.

- *"It's like being head of family and sick … like, it's been complicated. So, ever since, how we eat is changing compared to in the past… My means of getting money changed … (and) this is not the way we eat, no. … I don't eat the way I used to."* (30yr old man, TB patient, married)

Fears and ambivalence then penetrate and shape experiences of seeking healthcare

Fear is visible in narratives that are simultaneously punctuated with inconsistency:

- *“there wasn’t time. Yeah. At that time, there wasn’t … really just that – the time to go to the hospital (health facility) --- … and then also not having the courage to say ‘I should test’. Umm umm! Instead I’d tell myself ‘What I have is a mere cough?’”* (29yr old man, TB patient)

Fear

- *“… it’s like you don’t get to be that free (open to getting tested). Yeah, as for me, the way I was at first compared to now -- maybe because of that anxiety … a-ah, I don’t feel all that well. Mmm (Yes).. . (Interviewer: What do you mean?) I just happen to be anxious [laughing]. Yeah (Interviewer: Why so?) … well, about that TB issue.*” (24yr old man, TB patient)

Fears and ambivalence then penetrate and shape experiences of seeking healthcare

Although accounts describe health systems as being coercive and poorly communicating algorithms, the theme of fear endures

- *“Whatever you’re thinking, when you go to the hospital that’s what happens. They ask, ‘Would you be interested in an AIDS test?’ So you agree - on your own… they don’t force you. But once they test you, they will have results for anything … Because they are testing the content of your blood, the infection that can be there. Not even that they do the test once - maybe they will take other two bottles, a separate pipe. For malaria, we all know it’s tested on a glass… so what’s the use of that extra sample…?”* [Laughter] **(Woman in community mixed sex FGD)**

- *“once you get admitted, before they release you, you’re told to have your blood tested. So you can’t run away from having your blood tested. You can’t run away even if you didn’t plan in your mind on getting tested. You can’t even say you just came to receive the drug for cough and nothing more. You can’t be saved. This means they’ll test your blood so they see how you are.”* **(Woman in community mixed sex FGD)**

Embracing treatment following a positive TB diagnosis

- *“I was very pleased (to be diagnosed) … I’d had no peace in these last days… Whenever I tried to sleep and started to cough … I had to sit up ... then it would momentarily cease … And then the breathlessness... So I was very happy … (the diagnosis) happened while I’m still strong… I could take the drug and not be weakened from taking it … (otherwise) I might still be coughing and have grown thin.”* **(55yr old man, TB patient, married)**

- *“… If you are diagnosed when looking fit, would you be stressed? While still this strong and healthy… still at home and moving about and doing work”* **(26yr old woman, TB patient, married)**

Embracing treatment following a positive TB diagnosis

- *"… [Being diagnosed with TB] is a big thing … I now refrain from the worldly things that I was doing… I can't drink beer ... I don't smoke … I used to drink bad (sic) but they said to refrain. … I had wanted to stop … but had no specific reason …. Now they told me I should take care of my family; I'm very happy…"* **(30yr old man, TB patient)**

- *"… right now, just the perfect life… so good; no stress… seeing I was instructed on how to take the medicine; there is no day that I've missed or deviated. Things seem to be going okay and I do see improvement."* **(IDI, 21-yr. male TB patient)**

Inverted gender representations and relations

- *"... the papers (treatment documents) … (my sister) said, 'I'll keep these. … and whenever you are left say with 3, 4 (tablets), I'll go or if need be force you to go, or simply remind you'. … This really encourages me. ... she even says, 'don't worry, TB was only a problem in the past … nowadays people are being cured."* **(21yr old man, TB patient, unmarried)**

- *"Upon receiving the medication and instructions … on the way home my wife told me 'this is your chance, now you can be chaste' … (Participant continued later)… Whatever she tells me … for example, 'you will not leave this house, you should first go and have a bath', I obey"* **(IDI, 30-yr male married TB patient)**.

Conclusions

- Men have been neglected in health research, partly because they are considered more powerful and advantaged than women.
- The alternative roles and images portrayed for men in this study need to be made more visible.
- The seeming shift from fear before investigation and diagnosis to embrace and acceptance afterwards indicates a need for greater effort in drawing people into care and retaining them even in earlier phases of illness.
- The public health approach, used to manage HIV in resource limited settings, however invests more counselling and treatment effort in people with low CD4 counts, thus neglecting those not yet tested or qualifying for treatment.
- This may explain the well documented rapid drop out of care reported early in the care cascade.
- Care and counselling for TB and HIV should attend to different needs based on stage in the care continuum.
- Ultimately, interventions must, to the extent possible, assume complex forms.

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