

TB and HIV stigma compounded by threatened masculinity: the implications for tuberculosis healthcare-seeking in Malawi

*Running head:* TB and HIV stigma compounded by threatened masculinity

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## **ABSTRACT**

*Setting:* Urban Blantyre, Malawi

*Objective:* To understand why men remain undiagnosed with tuberculosis (TB) in the community.

*Design:* A multi-method qualitative study applying a modified grounded theory approach. Data were gathered during March 2011-March 2012 from 134 men and women taking part in focus group discussions with community members (n=6) and healthcare workers (n=2), and in-depth interviews with TB patients (n=20, women=14) and chronic coughers (n=20, women=8). Data were analysed inductively to identify, refine and consolidate, and verify emerging concepts and themes.

*Results:* Two themes are presented. In the first, views that cough or any illness portended a 'serious' condition were accompanied with interchangeable portrayals of cough, TB and HIV, and with chronic coughers' and TB patients' descriptions of their illness foregrounding bodily decimation and rupture of social life and masculine identity. The second, 'resistance strategies', entailed resisting classification as (seriously) ill through evading or ambivalently approaching healthcare, or acknowledging the 'ill' status then actively pursuing health-appropriate behaviors, including changing lifestyle or adopting non-normative gender roles.

*Conclusions:* Managing patients requires going beyond syndromic management based on vital signs and clinical indicators, to recognizing and intervening on healthcare-seeking related tensions so as to keep individuals in care, and understanding and addressing TB stigma as it manifests and affects men and women differently in specific settings.

Key words: healthcare-seeking; qualitative; gender

## INTRODUCTION

Tuberculosis (TB) killed 1.8 million people globally in 2015 of whom 0.4 were HIV-infected<sup>1</sup>. Despite declining case-fatality rates during 2000 - 2015, estimated numbers of TB deaths have increased in recent years as the magnitude of the global burden of undiagnosed TB has become better realized through national surveys<sup>1</sup>.

The African continent is disproportionately represented in the global TB burden; . carrying 16% of the population<sup>2</sup>, it accounted for a third of the TB cases that occurred in 2015<sup>1</sup>. Poor living conditions in fast-growing cities and the HIV epidemic have contributed to TB's resurgence in Africa in recent decades<sup>3</sup>. Scale-up of anti-retroviral therapy (ART) services has meanwhile dramatically improved the prospects of eliminating the African HIV epidemic, and has had a major impact on regional TB epidemiology, with the result effective diagnosis and linkage to care has become a public health imperative. Regrettably, in 2015 4.3 million of the estimated 10.4 million incident TB cases went unreported<sup>1</sup>. Moreover, in Africa, many people living with HIV (PLWH) who need HIV treatment are not accessing it<sup>4</sup>; only 7% of PLWH who were eligible for TB preventive treatment were receiving it in 2015<sup>1</sup>. A further challenge relates to the growth of drug-resistant TB, for which complicated and costly treatment and poorer prognosis especially in HIV-prevalent communities<sup>1,5-7</sup> are likely fuelling stigma and fear of TB disease.

Men experience the healthcare access gap disproportionately. As well as constituting the bulk of the 10.4 million incident cases in 2015 (5.9 million men vs. 3.5 million women), male gender is a risk factor for late diagnosis and treatment, and death while on treatment for both TB and HIV<sup>8-11</sup>. Although the higher burden of TB in men could be due to higher true incidence of disease, men's well-described poor utilization of primary health services is likely a contributing factor<sup>12,13</sup>. A qualitative study was designed to understand the reasons why men remain undiagnosed with TB in the community. This paper presents TB-related stigma as it emerged within the study.

The paper draws from the social constructionist paradigm<sup>14</sup> and mainly gender relational theory which holds that gender is constructed within micro and macro-level processes and dynamics that straddle both space and time<sup>15,16</sup>. In Southern Africa, rapid and drastic social, political and economic changes in recent history, which include colonial intervention and ongoing globalization dynamics, have shaped and continue to shape gender

and social relations, but simultaneously influence people's abilities to fulfill their role expectations. Part of women's well-documented vulnerability was triggered or accentuated within these historical and contemporary dynamics<sup>17-19</sup>. In some countries after independence, a post-colonial politics driven by a male elite that touts custodianship of morality and tradition has mobilized against Western influence while emphasizing nation-building, in a process that simultaneously marginalizes or accords token acknowledgment to femininity<sup>20-22</sup>. In Malawi and the region today, women are less educated, comparatively under-represented in formal employment, and poorer than their men counterparts. Where men are generally absent due to HIV/AIDS, work, or divorce, and women have limited land rights, the women shoulder heavy workloads with low returns on agricultural investment, but their contribution to national and domestic economies is not acknowledged<sup>19,23</sup>.

The last few decades have nevertheless seen rising attention to women's situation including on the African continent. Men were initially overlooked but later drew interest mainly in the areas of family planning and safe motherhood, HIV/AIDS prevention, and gender-based violence, primarily to lend support to women's situation because they were considered already privileged and also blameworthy. This partly explains why TB policy and research has stressed vulnerability of women<sup>24-28</sup>. We focus here on the gendered situation of men, and relate this to their increased susceptibility to TB.

## STUDY POPULATION AND METHODS

Malawi is ranked 173/188 on the Human Development Index<sup>29</sup>, and over half of the 15.8 million population lived below the poverty line in 2014. The country is rapidly urbanizing<sup>30</sup>, and has predominantly informal type employment<sup>31</sup>. HIV prevalence and TB incidence are estimated at 9.1% and 193/100 000, respectively<sup>32</sup>. TB case notification rates during 1995-2013 show consistent overrepresentation of men<sup>1</sup>.

Malawi offers basic health services free at point-of-care, based on a commitment to the principle of a 'public health approach'. Testimony to the benefits of this approach includes: 61% of PLWH and over 90% of PLWH who are TB patients are on ART; 79% of people newly enrolled in HIV care are on TB treatment; the TB treatment success rate is 85%<sup>1</sup>. Tuberculosis case detection is nevertheless low, at 43% in 2015<sup>1</sup>. Optimum delivery of healthcare is hampered by staff shortages and frequent stock-outs of supplies<sup>33</sup>.

Fieldwork was carried out in March 2011 – March 2012, in three high-density, low-income localities in urban Blantyre. Methods (focus groups and in-depth interviews) and data sources (TB patients, chronic coughers who had not sought formal care, health workers [HCWs], and ordinary community members) were triangulated<sup>34</sup>, and participants further varied by age and sex<sup>35</sup>, to obtain a more complete picture of the little-known research topic. Patients were identified through TB registers held at local primary health centers, and chronic coughers through cluster enumeration during a related TB/HIV epidemiology study where information had been sought regarding presence in households of cough of  $\geq 3$  weeks' duration. Most participants worked informally, in construction-related trades, or as clothing, vegetable or grocery merchants, repairers/installers of electrical ware, truck or mini-bus operators, and footballers and musicians. The few who were formally employed were a police officer, teacher, health surveillance assistant, and some security guards. Three had stopped working after taking ill. Women were generally younger than their male counterparts. Participant characteristics and methods are shown in Table 1.

We solicited perspectives of chronic cough in order to learn about or extrapolate views about and responses to TB-suggestive symptoms, given that people without close experience of TB may not recognize its symptoms<sup>36</sup>. However, TB patients were interviewed about specific TB disease-related experiences. IDIs sought to elicit privately the experiences of cough and TB disease in view of its associated stigma<sup>36-38</sup>; community FGDs explored

general beliefs about cough, healthcare-seeking, gender roles, and health services; and HCW FGDs sought insights into the healthcare system's interaction with patients. To avoid deliberately steering the research towards the highly salient subject of HIV in this setting, participants' HIV status was not inquired, and HIV was not deliberately introduced as a topic during discussions.

The Malawi College of Medicine and Human Sciences Research Council research ethics committees granted full approval of the study. Data were recorded, transcribed and translated verbatim into English, imported into NVivo Qualitative data analysis program (QRS International Pty Ltd, 2008), and coded and analyzed inductively using a modified grounded theory approach<sup>39,40</sup>. Coding was both deductive and inductive, drawing on questions brought into the study but also involving identifying emerging concepts during reading of text. Related codes were grouped and their source text retrieved and re-read to discern salient dimensions of categories. This was followed by breaking down the categories, and renaming and reconnecting them at more theoretical levels to generate broader themes, while re-reading transcripts to consolidate the emerging themes.

## RESULTS

Two emerging themes illuminate a compound stigma in this high-HIV prevalence low-income setting. In the first, views that cough or any illness portended a ‘serious’ condition were accompanied with interchangeable portrayals of cough, TB and HIV, and with chronic coughers’ and TB patients’ descriptions of their illness that foregrounded bodily decimation and rupture of social life and masculine identity. The second, ‘resistance strategies’, entailed resisting classification as (seriously) ill through evading or ambivalently approaching healthcare, or acknowledging the ‘ill’ status then actively pursuing health-appropriate behaviors, including changing lifestyle or adopting non-normative gender roles.

### **Cough, TB, and HIV held interchangeable and collectively considered ‘serious illness’**

Cough, TB, and HIV were generally discussed interchangeably and collectively held as equivalent to or signaling ‘serious illness. In validation, patients and chronic coughers described their disease experience as entailing bodily decimation and extreme pain.

If I wake up in the night from heavy coughing ... I can continue coughing for a long while ... This manner of coughing just shows that my body is what... not okay; it’s really sick ... coughing by day and by night. (Man, 30-yr old, chronic cougher)

It further emerged that illness disrupted social relationships causing mental strain in patients. A patient recounted her ‘suffering’ from the treatment she had begun receiving from her family members.

This suffering in the home ... [chuckles]... You see, when there’s a problem in the home, you notice a change in people’s behavior towards you... I feel that the way they’re living with me, I’m not at peace at all ... I’m suffering. (Woman, 26-yr old, TB patient)

### **Threat to valued masculinity representations**

By impeding mobility especially in this setting where informal work – which is insecure and lacks social protection –was the primary source of livelihood, illness automatically led to loss of income. A 46-year old widowed TB patient and ‘businessperson’ who was living with and providing for a six-member family lamented “*taking care of this entire family alone*” and juggling her children’s and the entire family’s needs and wants. No longer able to tend her business or perform her usual chores, she remarked that “*Everything*

*has simply stalled; life has become hard... I can't even walk to my business premises ... let alone cook because my body is just weak".*

Impended mobility and incapacitation thus threatened the images of what constitutes normal and competent adulthood. Men in a community FGD derisively remarked that an adult person who was unwell had to "...wait for others to do things for them ... bathing... eating... yet they are a grown-up." With men often those expected to provide economically for their families in this setting<sup>41</sup>, it was of little surprise that during interview a patient became visibly agitated as he recalled how his family's well-being had drastically deteriorated with his illness.

Just to say, 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 has been disturbed ... this is not the way we eat, no. ... I don't eat the way I used to! (Man, 30-yr old, TB patient)

The theme of incapacitation and disrupted ability to work was elaborated on by another patient:

This cough which has attacked me this time, truly speaking.... I can't say I still work the way I used to. If a *customer* comes ... (with) large notes ... it gets very difficult especially if they are rushing and require *change* quickly. What I do in those cases is, if a child is passing by, even one that I don't know, I send them to fetch the *change* for me ... or I simply tell the *customer*, "Take and bring the money later". (Man, 30-yr old, TB patient)

## **Resistance strategies**

### *Ambivalence and avoidance in relation to healthcare-seeking*

Given the prevailing views regarding illness, and descriptions provided by patients of their suffering, it is little wonder healthcare-seeking attracted huge anxiety and ambivalence. Individuals who were ill but not yet TB- (or HIV-) diagnosed would wish to know what potentially 'serious' condition they were suffering from, but be nervous about receiving or even seeking out in the first place unpleasant information. Rumors emphasizing the taxing and difficult nature of treatment regimens, and supposedly drastic lifestyle changes that medication necessitated, fueled the ambivalence.



We hear they'll tell you at the *hospital* (health facility) that once you start medication, you must stop some things ... smoking... alcohol... Some say no more hot pepper... and in the home men and women must sleep separately... we don't know whether this is true. (Woman, mixed-sex community FGD)

Abstinence from sex, socializing, and alcohol appeared to affect and concern men more, which is understandable considering that these behaviors are among those most strongly associated with manhood<sup>42,43</sup>. The following exchange occurred during a mixed-sex community FGD.

**Man:** For some, it's said, like 'once you're taking the drug, you shouldn't do this and that' [laughter], so they (men) say 'there's no way I'm ever going to manage that'...

**Woman:** When a (male) smoker or drinker is diagnosed with TB, the duration that he must take the drug seems too long, so he starting shifting and coming up with *plans*.

Anxieties persisted even in TB-diagnosed patients, for whom further investigations might be required. One confessed to dithering over an HIV test that had been recommended for him, and instead self-assessing his health by feeling and examining his body.

... You won't be entirely *free* (to test). ... Because, for me, if I compare how I was before to how I am feeling now -- maybe because of that anxiety ... a-a-h, I don't feel so good.

(I: How?) I am just anxious [laughing].

(I: Why?) ... Well, because of that TB issue. (Man, 24-yr old, TB patient)

What also emerges from the above quote is that avoidance of healthcare, far from being a discrete or abrupt event, is a process laced with tensions and contradictions. Part of the reason for this is that healthcare avoidance is intricately tied to the 'performance'<sup>44</sup> of gender including masculinity. Thus, if healthcare-seeking courts fear, and thus threatens to emasculate men, men may (actively or possibly sub-consciously) embark on a 'flight from the feminine'<sup>45</sup>, whereby they would rank it lower than other obligations and time demands. The 'performance' may involve devoting maximum time to working, effectively leaving little room for healthcare<sup>41</sup>. It may also involve constructing and reconstructing one's priorities through the way one talks about them to other people<sup>46</sup>, or through actions and performativity. Both may happen simultaneously and be part of the same process.

Demonstrating the tensions related to avoiding healthcare possibly as part of performing masculinity – whether through action or language – a 29-year old patient initially stressed that he had delayed seeking healthcare because of time constraints, before immediately elaborating that he had also been afraid.

... There wasn't time, yeah. At that time, there wasn't ... really was just exactly that: the time to go to the *hospital* (health facility) ... and then also not having the courage to say, "I must test". *Uh uh!* (No!) Instead, I'd keep telling myself "what I have here is simple cough?"

A comparable phenomenon is when health systems' challenges – which are well described for these settings – interact with patients' anxieties, with the result the challenges are accentuated in the eyes of patients and the community. More salient challenges in turn heighten anxieties about illness and seeking healthcare. Below, participants are describing at length syndromic management by clinic staff, which is often appropriate, but comes across as bewildering to patients who feel coerced into having unexpected tests and treatments with little explanation, choice, or regard for their own perspectives relating to the cause of their ill-health.

When you present coughing, don't expect they'll test you just for that ... they'll test for that *and* other things. ... To them it's not mere cough. Maybe you haven't washed blankets in a while ... or sleep on a mud floor ... things that make a cough fail to heal fast ... You go with a three-month cough, they don't look at where you're from, but just the period. And they say maybe it is HIV/AIDS, and want to investigate you for that... (Man, mixed-sex community FGD)

Once you are admitted, before they release you, you're told to have your blood tested. So you can't run away ... even if you didn't plan it in your mind ... You can't even say you just came to receive the drug for cough and nothing more. You can't be saved. (Woman, mixed-sex community FGD)

They say, 'Would you like an AIDS test?' And you agree – on your own.... But once they test you, they'll have results for anything ... Not even that they do the test once -- maybe they will *take* (draw) another two *bottles* (tubes) ... We all know malaria is tested on a *glass* [slide]... what then is the use of that extra *bottle*? [Laughter] (Woman, mixed-sex community FGD)

*Resisting illness and emasculation through embracing diagnosis and treatment*

A different form of resistance emerged when, despite prior fears about being investigated, patients indicated they tend to receive well a confirmed diagnosis and the accompanying TB treatment. Patients expressed gratitude for the obvious improvements in their health, and for having been helped to avert worse outcomes.

... Before, I never used to know peace ... whenever I tried to sleep, I would start coughing ... and then I would have to sit up ... And there was the breathlessness... So I am very glad ... (the diagnosis) happened while I was still strong... and I could take the drug and not be severely weakened from taking it ... (Otherwise) I would have grown thin. (Man, 55-yr old man, TB patient)

... If you were diagnosed while still looking fit, would you be stressed? While still this strong and healthy... and still living in your home, moving about and doing chores! (Woman, 26-yr old, TB patient)

Demonstrating an enthusiasm to safeguard their health, male patients described shedding habits such as alcohol use and smoking, and focusing on adhering properly so they could live to care for their families. Some also described shifting from initially trying to manage their health problems alone to starting to embrace or even solicit psychosocial support from other people, including women relations and other family members.

If I don't set my alarm ... my family dash over, 'Dad it's medication time!'... In the past that would have triggered hell: 'you are forcing me to take medicine, what for!' Because I was still feeling good in the body... and could say, 'Well, what even if I skipped a day?' (Man, 30-yr old, TB patient)

Another participant described how he was now submitting to his wife, as she stepped in to support him with his medication.

After receiving medication and instructions ... on the way home, my wife said 'this is your chance now to be chaste' ... Whatever she tells me, for example 'no way you're leaving this house (like that); go and have a bath first' -- anything, I now obey. (Man, 30yr old, TB patient)

## DISCUSSION

This study was intended to place special emphasis on obtaining perspectives of men, who comprise the majority of TB patients globally, and may contribute disproportionately to TB transmission because of longer mean durations of infectiousness before diagnosis. Perceptions and experiences of men with regard to health systems have, in general, been afforded less attention by policy-makers in comparison to their women equivalent in the years leading up to the then MDGs, with their special focus on maternal and child health, and so relatively little is understood of male-specific stigma and barriers to diagnosis and care. Prior TB research has also been criticised for mostly involving individuals who presented for healthcare, and targeting the individual level of analysis<sup>47</sup>. Notably, demands are growing to urge that more attention is paid to structural and social determinants of TB disease and the ways in which TB disease exacerbates poverty at individual, household, and community levels<sup>48</sup>. The accounts detailed here from a diverse group of participants illuminate a form of TB stigma that is linked to a combination of ‘vulnerability’ to debilitating disease and threatened masculinity amid high HIV prevalence, worsening economic precarity, and limited social protection, and which implied that seeking healthcare is accompanied with ambivalence and anxiety.

These data then not only add to an emerging body of literature that is drawing focus to structural determinants of TB and related health-seeking behaviour; they also shed light on the role and manifestation of stigma, at a time when ART is transforming the TB and HIV public health landscape. An underlying assumption has been that the transformation of HIV into a ‘chronic and manageable’<sup>49</sup> condition will drive reduction in stigma as individuals ‘resume normal activities and ... live without physical markers of illness’<sup>50</sup>:306. However, studies continue to describe PLWH on treatment struggling with fears of death, rumors about side-effects of ART, and anxieties related to poverty and joblessness<sup>51</sup> and the threat of passing infection<sup>52</sup>. Even though they cherish recovery and strive to shed the ‘sick identity’, PLWH frequently encounter situations that remind them of their difference, and exclude them<sup>53</sup>. Parallel experiences have been described for TB patients<sup>54,55</sup>, including those in the present study, underlining the interconnectedness between the two conditions.

We show here that even though, as reported elsewhere<sup>56</sup>, men embrace the diagnosis and treatment of TB and almost certainly HIV due to the positive experience or anticipation of benefits from treatment, their anxieties prior to diagnosis present a critical barrier to

health-seeking. However, in the case of HIV, the public health approach used in resource-constrained settings has emphasized retention and monitoring only for ART-eligible individuals<sup>57</sup>. As a result, ART-ineligible individuals are sidelined or given only limited counseling although, as this study indicates, they may have a number of anxieties. For TB, the equivalent issue relates to the period of time between being identified as having presumptive TB and having completed a sufficient number of steps of the sometimes prolonged diagnostic algorithm, the details of which are usually not shared with the patient, to enable initiation of treatment. Integration-wise, healthcare users struggle with algorithms that are aimed at achieving collaborative activities, especially when presentation with a cough, or diagnosis with TB, prompts HIV testing without explanation of the rationale.

Mindful of the significance of health system weaknesses, patients' ambivalence or reticence regarding investigations evidently influences how they experience and perceive algorithms. Particularly important is the disjuncture between the medical model of viewing and managing disease (one that sees disease as putative and manageable largely by applying bio-scientific techniques) and patients' perspectives of illness (which are situated within people's experiences as actors at personal, dyadic, and group levels, who are pursuing normative role expectations and representations)<sup>14,58</sup>. The stigma of illness then results from people's experiences and challenges within their social domains, and additionally, from the intersection of these social domains with health systems that prioritize biomedical understandings and outcomes. For men, who are already emasculated by economic precarity or are physically incapacitated or threatened by illness, the approach used by health systems may be alienating.

## **Conclusions**

Managing and prioritizing patients who present at health facilities ideally requires services that go beyond syndromic management based on vital signs and clinical indicators, to recognizing healthcare-seeking related tensions, and strengthening some of the psychosocial and mental health aspects of counselling, as a means of keeping individuals, including those not yet due for procedures or treatment, in contact with health services. In addition, addressing TB stigma requires combination and complex interventions built around detailed understandings of its manifestation and form, including its structural determinants and also how it affects women and men differently, in specific settings.

### **Competing interests**

The authors declare that they have no competing interests.

### **Authors' contributions**

JC, GH, ELC conceived and designed the study; MK collected data under supervision from JC, ELC, and ND; JC and MK analyzed the data with contributions from ELC, ND, and GH; JC drafted the manuscript; ALL contributed intellectually to revision of the manuscript.

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Table 1: Data collection techniques, study participants and sample size

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 (age range 21-70, mean age 33; slight majority married)	20	6 men 14 women
	Chronic coughers (age range 18-77; mean age 36; balanced by marital status)	20	12 men 8 women