

## TB and HIV stigma compounded by threatened masculinity: implications for TB health-care seeking in Malawi

J. Chikovore,\* G. Hart,<sup>†</sup> M. Kumwenda,<sup>‡§</sup> G. Chipungu,<sup>§</sup> N. Desmond,<sup>¶¶</sup> E. L. Corbett<sup>\*\*</sup>

\*HIV/AIDS, STIs & TB Program, Human Sciences Research Council, Durban, South Africa; <sup>†</sup>School of Life & Medical Sciences, University College London, London, UK; <sup>‡</sup>Malawi Liverpool Wellcome Trust Clinical Research Program, Blantyre, <sup>§</sup>Helse Nord TB Initiative, College of Medicine, Chichiri, Blantyre, Malawi; <sup>¶</sup>Liverpool School of Tropical Medicine, Liverpool, <sup>¶¶</sup>London School of Hygiene and Tropical Medicine, London, UK

### SUMMARY

**SETTING:** Urban Blantyre, Malawi.

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

**DESIGN:** A multi-method qualitative study applying a modified grounded theory approach. Data were gathered from March 2011 to March 2012 from 134 men and women taking part in 1) focus group discussions with community members ( $n = 6$ ) and health care workers ( $n = 2$ ), and 2) in-depth interviews with TB patients ( $n = 20$ , females  $n = 14$ ) and chronic coughers ( $n = 20$ , women  $n = 8$ ). Data were analysed inductively to identify, refine and consolidate, and verify emerging concepts and themes.

**RESULTS:** Two emerging themes highlighting compound stigma in this high human immunodeficiency virus (HIV) prevalence, low-income setting are presented. First, cough or any illness that portended a 'serious' condition were accompanied by portrayals of cough, TB

and HIV as being interchangeable. Chronic coughers and TB patients described their illness in ways that foregrounded bodily decimation and rupture of social life and masculine identity. Second, 'resistance strategies' entailed resisting classification as (seriously) ill by evading or ambivalently approaching health care, or acknowledging the 'ill' status then actively pursuing health-appropriate behaviours, including changing lifestyle or adopting non-normative gender roles.

**CONCLUSIONS:** Managing patients requires 1) going beyond syndromic management based on vital signs and clinical indicators to recognising and intervening on health care-seeking related tensions to retain individuals in care, and 2) understanding and addressing TB stigma as it manifests and affects men and women differently in specific settings.

**KEY WORDS:** health care seeking; qualitative; gender

TUBERCULOSIS (TB) killed 1.8 million people worldwide in 2015, 0.4 million of whom were infected with the human immunodeficiency virus (HIV).<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 is now better realised through national surveys.<sup>1</sup>

The African continent is disproportionately represented in the global TB burden. Africa accounts for 16% of the world's population,<sup>2</sup> but one third of the TB cases that occurred in 2015 were in this continent.<sup>1</sup> Poor living conditions in fast-growing cities and the HIV epidemic have contributed to the resurgence of TB in Africa in recent decades.<sup>3</sup> The scale-up of antiretroviral therapy (ART) services has meanwhile dramatically improved the prospects of eliminating the HIV epidemic in Africa, and has had a major impact on regional TB epidemiology; effective diagnosis and linkage to care has thus become a

public health imperative. However, in 2015, 4.3 million of the world's estimated 10.4 million incident TB cases went unreported.<sup>1</sup> Moreover, in Africa, many people living with HIV (PLHIV) who need HIV treatment fail to access it;<sup>4</sup> only 7% of PLHIV who were eligible for preventive TB 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 gap in health care access disproportionately. As well as constituting the bulk of the 10.4 million incident cases in 2015 (5.9 million males vs. 3.5 million females), male sex is a risk factor for late diagnosis and treatment, and for death while on treatment for both TB and HIV.<sup>8–11</sup> Although the higher burden of TB in males could be due to the higher true incidence of the disease, their well-described poor use of primary health services is likely

Correspondence to: J Chikovore, HIV, AIDS, STIs & Tuberculosis (HAST) Research Program, Human Sciences Research Council, Durban, South Africa 4001. e-mail: [jchikovore@hsrc.ac.za](mailto:jchikovore@hsrc.ac.za)

Article submitted 15 December 2016. Final version accepted 24 April 2017.

a contributing factor.<sup>12,13</sup> A qualitative study was designed to understand the reasons why males with TB remain undiagnosed in the community. This article presents TB-related stigma as it emerged from that study.

This article draws from the social constructionist paradigm,<sup>14</sup> and mainly from 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, dramatic social, political and economic changes in recent history (including colonial intervention and ongoing globalisation dynamics) have shaped and continue to shape gender and social relations, while simultaneously influencing people's abilities to fulfil 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, post-colonial politics driven by a male elite that touts custodianship of morality and tradition has mobilised against Western influence while emphasising nation-building in a process that at once marginalises 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 male counterparts. Where men are generally absent due to HIV/AIDS (acquired immune-deficiency syndrome), work or divorce, women have limited land rights and shoulder heavy workloads with low returns on agricultural investment; their contribution to national and domestic economies is, however, not acknowledged.<sup>19,23</sup>

The situation of women has nevertheless been the subject of increasing attention globally and in Africa over the last few decades. It should be noted that men were initially overlooked, but later became subjects of research interest with respect to family planning, safe motherhood, HIV/AIDS prevention, and gender-based violence, and largely to lend support to women's situations, as they (men) were considered privileged but also blameworthy. This partly explains why TB policy and research has stressed the vulnerability of women.<sup>24–28</sup> We focus here on the gender-based situation of men and relate this to their increased susceptibility to TB.

## STUDY POPULATION AND METHODS

With a population of 15.8 million, over half of whom lived below the poverty line in 2014, Malawi ranks 173 of 188 countries on the Human Development Index.<sup>29</sup> The country is urbanising rapidly,<sup>30</sup> and informal employment predominates.<sup>31</sup> HIV prevalence and TB incidence are estimated at respectively 9.1% and 193 per 100 000 population.<sup>32</sup> TB case

notification rates during 1995–2013 show consistent overrepresentation of men.<sup>1</sup>

Malawi offers free basic health services at point of care based on a commitment to the principle of a public health approach. Testimony to the effectiveness of this approach is the fact that 61% of PLHIV and over 90% of PLHIV who are TB patients are on ART, 79% of people newly enrolled in HIV care are on anti-tuberculosis treatment, and the TB treatment success rate is 85%.<sup>1</sup> Nevertheless, TB case detection was low, at 43% in 2015.<sup>1</sup> Optimum delivery of health care is hampered by staff shortages and frequent stock-outs of supplies.<sup>33</sup>

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

We solicited the perspectives of chronic cough to learn about or extrapolate views about and responses to TB-suggestive symptoms, as people without close experience of TB may not recognise the symptoms.<sup>36</sup> TB patients were nevertheless interviewed about specific TB disease-related experiences. In-depth interviews were used to elicit privately the experience of cough and TB disease in view of the associated stigma.<sup>36–38</sup> Community FGDs explored general beliefs about cough, health care-seeking, gender roles and health services. HCW FGDs were aimed at obtaining insight into the interaction of the health care system with patients. To avoid deliberately steering the research towards the already conspicuous subject of HIV, participants' HIV status was not asked about, and HIV was not deliberately introduced as a topic during discussions.

The research ethics committees of the Malawi College of Medicine and the Human Sciences Research Council granted full approval of the study.

**Table** Data collection methods, study participants and sample size

Method	Participant category	<i>n</i> (total participants)	Gender
FGD	Health care 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)
In-depth interviews	Newly diagnosed TB patients (mean age 33 years, range 21–70; married patients slightly more than 50%)	20	6 men 14 women
	Chronic coughers (mean age 36 years, range 18–77; balanced in terms of marital status)	20	12 men 8 women

FGD = focus group discussion; TB = tuberculosis.

Data were recorded, transcribed and translated verbatim into English, imported into a NVivo qualitative data analysis program (QRS International, Oss, The Netherlands, 2008), and coded and analysed 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 entailing identifying emerging concepts during the reading of the text. Related codes were grouped together and their source text retrieved and re-read to discern salient dimensions of categories. This procedure 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 themes.

## RESULTS

Two emerging themes highlighting a compound stigma in this high HIV prevalence, low-income setting are presented. First, views that cough or any illness portended a ‘serious’ condition were accompanied by portrayals of cough, TB and HIV as being interchangeable. Furthermore, chronic coughers and TB patients described their illness in ways that foregrounded bodily decimation and rupture of social life and masculine identity. Second, ‘resistance strategies’ entailed resisting classification as (seriously) ill through evading or ambivalently approaching health care, or acknowledging an ‘ill’ status then actively pursuing health-appropriate behaviours, including changing lifestyle or adopting non-normative gender roles.

### *Cough, TB, and HIV are treated as interchangeable and collectively held as ‘serious illness’*

Cough, TB, and HIV were generally discussed interchangeably and collectively held as equivalent to or signalling ‘serious illness’. In validation, patients and persons with chronic cough described their experience of the disease 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 years old, chronic cough)

It also emerged that illness disrupted social relationships, causing mental strain in patients. One patient recounted her distress from the treatment she had since 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 behaviour towards you... I feel that the way they’re living with me, I’m not at peace at all ... I’m suffering. (Woman, 26 years old, TB patient)

### *Threat to valued representations of masculinity*

By impeding mobility, especially in a setting in which informal work—which is insecure and lacks social protection—was the primary source of livelihood, illness automatically led to a loss in 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.

Impaired mobility and incapacitation thus threatened the image 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’. As men are often those expected to provide economically for their families in this setting,<sup>41</sup> it is not surprising that during the interview a patient became visibly agitated as he recalled how his family’s well-being had deteriorated dramatically 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 years old, TB patient)

The theme of incapacitation and disrupted ability to work was elaborated further 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 years old, TB patient)

### Resistance strategies

#### *Ambivalence and avoidance in relation to health care-seeking*

Given the prevailing views regarding illness and the descriptions provided by patients of their distress, it is little wonder that health care seeking attracted huge anxiety and ambivalence. Individuals who were ill but were yet to be diagnosed with TB or HIV would wish to know what potentially 'serious' condition they were suffering from, but would be nervous about receiving or even seeking out unpleasant information in the first place. Rumours emphasising the taxing and difficult nature of treatment regimens, and supposedly drastic lifestyle changes that medication necessitated, fuelled 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, socialising, and alcohol appeared to affect and concern men more, which is understandable considering that such behaviours 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 starts shifting and coming up with *plans*.

Anxieties persisted even in TB-diagnosed patients,

for whom further investigations might be required. One confessed to hesitating in undergoing the HIV testing he had been recommended, 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-h, I don't feel so good.

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

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

What also emerges from the quote shown above is that the avoidance of health care, far from being a discrete or abrupt event, is a process laced with tensions and contradictions. Part of the reason for this is that health-care avoidance is intricately tied to the 'performance'<sup>44</sup> of gender, including masculinity. Thus, if health care seeking courts fear, and threatens to emasculate men, men may (actively or possibly subconsciously) 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 health care.<sup>41</sup> It may also involve constructing and reconstructing one's priorities in the ways in which one talks about these to other people,<sup>46</sup> or one's actions and performativity. Both may happen simultaneously and be part of the same process.

Demonstrating the tensions related to the avoidance of health care seeking, possibly as part of performing masculinity—whether through action or language—a 29-year-old patient initially stressed that he had delayed seeking health care 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 a simple cough?'

A comparable phenomenon is when health-system challenges—which are well described for these settings—interact with patient anxieties, with the result that challenges are accentuated in the eyes of patients and the community. More salient challenges in turn heighten anxieties about illness and health care seeking. Participants describe at length below syndromic management by clinic staff, which is often appropriate, but comes across as bewildering to patients, who feel coerced into undergoing unexpected testing and treatment with little explanation, choice or regard to the cause of their ill health.

When you present with cough, 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 3-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 by embracing diagnosis and treatment*

A different form of resistance emerged when, despite previous fears about being investigated, patients indicated they tend to receive a confirmed diagnosis and the accompanying anti-tuberculosis treatment well. Patients expressed gratitude for the obvious improvement 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 years old, 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 years 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 female 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 years 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 are you leaving this house (like that); go and have a bath first'—anything, I now obey. (Man, 30 years old, TB patient)

## DISCUSSION

The study was intended to place special emphasis on obtaining male viewpoints. Men comprise the majority of TB patients globally and may contribute disproportionately to TB transmission because of a longer mean duration of infectiousness before diagnosis. The perceptions and experiences of men with regard to health systems have, in general, been given less attention by policy makers than women in the years leading up to the then Millennium Development Goals, with their special focus on maternal and child health. Relatively little was therefore understood of male-specific stigma and barriers to diagnosis and care.

Previous TB research has also been criticised for mostly involving individuals who presented for health care, and targeting the individual level of analysis.<sup>47</sup> There have been growing demands for greater attention to be paid to the 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 highlight TB stigma linked to a combination of 'vulnerability' to debilitating disease, threatened masculinity amid high HIV prevalence, worsening economic conditions and limited social protection. These scenarios imply that seeking health care is accompanied by ambivalence and anxiety.

These data not only add to an emerging body of literature that is drawing focus to the 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> However, studies continue to describe PLHIV on treatment struggling with fears of death, rumours about the side effects of ART, and anxieties related to poverty and unemployment<sup>51</sup> and the threat of transmitting infection.<sup>52</sup> Although they cherish recovery and strive to shed the 'sick identity', PLHIV frequently encounter situations that remind them of their difference and exclude them from society.<sup>53</sup> Similar experiences to the ones described in the present study have been described for TB patients elsewhere,<sup>54,55</sup> thereby underlining the interconnectedness between HIV and TB.

We showed here that although, as reported elsewhere,<sup>56</sup> men accept diagnosis and treatment of TB and almost certainly HIV due to the positive experience from, or in anticipation of, the benefits of treatment, their anxieties and tensions before diagnosis, as related to the desire to socialise and exert control<sup>57,41</sup> or to pressures related to their role as material providers,<sup>41</sup> present a critical barrier to health seeking. However, in the case of HIV, the public health approach used in resource-constrained settings has emphasised retention and monitoring only for ART-eligible individuals.<sup>58</sup> As a result, ART-ineligible individuals are side-lined or provided with only limited counselling although, as our study indicates, they may have several 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. With regard to integration, health care users struggle with algorithms that are aimed at achieving collaborative activities, especially if presenting with cough or a diagnosis of TB leads to HIV testing without an explanation of the rationale.

Mindful of weaknesses in health systems,<sup>59</sup> patient ambivalence or reticence regarding investigations influences how they experience and perceive algorithms. Of particular importance is the mismatch between the medical model of viewing and managing disease (i.e., disease as being putative and manageable largely by applying bio-scientific methods) and patients' perspectives of illness (which are situated within people's experiences as actors at personal, dyadic and group levels).<sup>14,60</sup> The stigma of illness then results from people's experiences and challenges in their social domains, and within the intersection of these domains with health systems that prioritise biomedical understanding and outcomes. Men are already emasculated by economic precarity or physically incapacitated/threatened by illness but are expected to lead material provision for the family.<sup>41</sup> Simultaneously they experience engagement with

health care as being 'un-masculine',<sup>41,57</sup> and the approach used by health systems may be alienating.

## CONCLUSIONS

Managing and prioritising patients who present at health facilities ideally requires services that go beyond syndromic management based on vital signs and clinical indicators to recognising tensions related to health care seeking. It also involves 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 complex interventions built on detailed understanding of its manifestation and form, including its structural determinants, and also how it affects women and men differently in specific settings.

## Acknowledgements

The authors thank the participants; the management and authorities of Blantyre for permission to carry out the study; the District Medical Officer and health managers for permission to access health facilities and records; D Mwale, a research assistant; Professor R Heyderman, former Director of Malawi Liverpool Wellcome (MLW); and the data processing and support staff at the MLW Trust. Funding for this study was received from the Wellcome Trust, London, UK (WT085411MA).

Conflicts of interest: none declared.

## References

- 1 World Health Organization. Global tuberculosis report, 2016. WHO/HTM/TB/2016.13. Geneva, Switzerland: WHO, 2016.
- 2 United Nations. World population prospects: the 2015 revisions. New York, NY, USA: United Nations, Department of Economic and Social Affairs, Population Division, 2015.
- 3 Lönnroth K, Jaramillo E, Williams B G, Dye C, Raviglione M. Drivers of tuberculosis epidemics: the role of risk factors and social determinants. *Soc Sci Med* 2009; 68: 2240–2246.
- 4 UNAIDS. The Gap Report. Geneva, Switzerland: UNAIDS, 2014. [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS\\_Gap\\_report\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf). Accessed July 2017.
- 5 Pietersen E, Ignatius E, Streicher E M, et al. Long-term outcomes of patients with extensively drug-resistant tuberculosis in South Africa: a cohort study. *Lancet* 2014; 383: 1230–1239.
- 6 Pooran A, Pietersen E, Davids M, Theron G, Dheda K. What is the cost of diagnosis and management of drug resistant tuberculosis in South Africa? *PLOS ONE* 2013; 8: e54587.
- 7 Klopper M, Warren R M, Hayes C, et al. Emergence and spread of extensively and totally drug-resistant tuberculosis, South Africa. *Emerg Infect Dis* 2013; 19: 449–455.
- 8 Corbett E L, Charalambous S, Moloi V M, et al. Human immunodeficiency virus and the prevalence of undiagnosed tuberculosis in African gold miners. *Am J Respir Crit Care Med* 2004; 170: 673–679.
- 9 Johnson L F, Mossong J, Dorrington R E, et al. Life expectancies of South African adults starting antiretroviral treatment: collaborative analysis of cohort studies. *PLOS MED* 2013; 10: e1001418.
- 10 Mills E J, Bakanda C, Birungi J, et al. Life expectancy of persons receiving combination antiretroviral therapy in low-income

- countries: a cohort analysis from Uganda. *Ann Intern Med* 2011; 155: 209–216.
- 11 Borgdorff M, Nagelkerke N, Dye C, Nunn P. Gender and tuberculosis: a comparison of prevalence surveys with notification data to explore sex differences in case detection. *Int J Tuberc Lung Dis* 2000; 4: 123–132.
  - 12 Malcher G. The state of men's health in Europe. *BMJ* 2011; 343: d7054.
  - 13 Moynihan C. Theories in health care and research: theories of masculinity. *BMJ* 1998; 317: 1072–1075.
  - 14 Brown P. Naming and framing: the social construction of diagnosis and illness. *J Health Soc Behav* 1995; 34–52.
  - 15 Connell R. Gender, health and theory: conceptualizing the issue, in local and world perspective. *Soc Sci Med* 2012; 74: 1675–1683.
  - 16 Jørgensen M W, Phillips L J. *Discourse analysis as theory and method*. Thousand Oaks, CA, USA: Sage, 2002.
  - 17 Berry S. Access, control and use of resources in African agriculture: an introduction. *Africa* 1989; 59: 1–5.
  - 18 Ampofo A A, Beoku-Betts J, Njambi WN, Osirim M. Women's and gender studies in English-speaking sub-Saharan Africa: a review of research in the social sciences. *Gender Soc* 2004; 18: 685–714.
  - 19 Chikovore J. Gender power dynamics in sexual and reproductive health. A qualitative study in Chiredzi District, Zimbabwe. Umeå, Sweden: Umeå University, 2004.
  - 20 Chow E P, Chen L, Jing J, et al. HIV disease burden and related risk behaviours among men who have sex with men in Yuxi Prefecture, Yunnan Province, China: 2010–2011. *AIDS Behav* 2013; 17: 2387–2394.
  - 21 Obbo C. HIV transmission and control in Uganda. In: ten Brummelhuis H, Herddt G, eds. *Culture and sexual risk: anthropological perspective on AIDS*. New York, NY, USA: Routledge, 1995: pp 79–795.
  - 22 Reddy V, Sandfort T. Researching MSM1 in South Africa: some preliminary notes from the frontlines of a hidden epidemic. *Feminist Africa* 11 2008: 29–54.
  - 23 Ngwira N. Gender and poverty reduction in Malawi. Paper presented at the United Nations Department of Economic and Social Affairs Expert Group Meeting, 7 December 2010, New York, NY, USA.
  - 24 Johansson E, Long N, Diwan V, Winkvist A. Gender and tuberculosis control: perspectives on health seeking behaviour among men and women in Viet Nam. *Health Policy* 2000; 52: 33–51.
  - 25 Thorson A, Diwan V K. Gender inequalities in tuberculosis: aspects of infection, notification rates, and compliance. *Curr Opin Pulm Med* 2001; 7: 165–169.
  - 26 Eastwood S, Hill P. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *Int J Tuberc Lung Dis* 2004; 8: 70–75.
  - 27 Needham D M, Foster S D, Tomlinson G, Godfrey-Faussett P. Socio-economic, gender and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. *Trop Med Int Health* 2001; 6: 256–259.
  - 28 Cambanis A, Yassin M A, Ramsay A, Bertel Squire S, Arbide I, Cuevas L E. Rural poverty and delayed presentation to tuberculosis services in Ethiopia. *Trop Med Int Health* 2005; 10: 330–335.
  - 29 United Nations Development Programme. *Human development report 2015*. New York, NY, USA: UNDP, 2015.
  - 30 United Nations Habitat. *Malawi: urban housing sector profile*. Nairobi, Kenya: UN, 2010.
  - 31 Aggarwal A, Hofmann C, Phiri A. *A study on informal apprenticeship in Malawi*. Geneva, Switzerland: International Labour Organisation, 2010.
  - 32 UNAIDS. *HIV and AIDS Estimates (2015)*. Geneva, Switzerland: UNAIDS, 2015. <http://www.unaids.org/en/regionscountries/countries/malawi>. Accessed July 2017.
  - 33 Oxfam. *The right choices: achieving universal health coverage in Malawi*. Oxford, UK: Oxfam, 2016.
  - 34 Sandelowski M. Triangles and crystals: on the geometry of qualitative research. *Res Nursing Health* 1995; 18: 569–574.
  - 35 Lincoln Y, Guba E. *Naturalistic inquiry*. Newbury Park, CA, USA: Sage, 1985.
  - 36 Ngamvithayapong J, Winkvist A, Diwan V. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS* 2000; 14: 1413–1419.
  - 37 Bond V, Nyblade L. The importance of addressing the unfolding TB HIV stigma in high HIV prevalence settings. *J Commun Applied Soc Psychol* 2006; 16: 452–461.
  - 38 Godfrey-Faussett P, Kaunda H, Kamanga J, et al. Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *Int J Tuberc Lung Dis* 2002; 6: 796–805.
  - 39 Strauss A L, Corbin J M. *Basics of qualitative research*. Vol 15. Newbury Park, CA, USA: Sage, 1990.
  - 40 Charmaz K. *Constructing grounded theory*. Thousand Oaks, CA, USA: Sage, 2014.
  - 41 Chikovore J, Hart G, Kumwenda M, Chipungu G A, Corbett L. 'For a mere cough, men must just chew Conjex, gain strength, and continue working': the provider construction and tuberculosis care-seeking implications in Blantyre, Malawi. *Glob Health Action* 2015; 8: 26292.
  - 42 Brown J, Sorrell J, Raffaelli M. An exploratory study of constructions of masculinity, sexuality and HIV/AIDS in Namibia, Southern Africa. *Cult Health Sex* 2005; 7: 585–598.
  - 43 De Visser R O, Smith J A. Alcohol consumption and masculine identity among young men. *Psychol nd Health* 2007; 22: 595–614.
  - 44 Butler J. Bodily inscriptions, performative subversions. In: Warhol-Down R, Price Herndl D. *Feminisms redux: an anthology of literary theory and criticism*. New Brunswick, NJ, USA: Rutgers University Press, 2009: pp 465–476.
  - 45 Kimmel M S. Masculinity as homophobia: Fear, shame, and silence in the construction of gender identity. In: Brod H, Kaufman M, eds. *Research on men and masculinities: theorizing masculinities*. Thousand Oaks, CA, USA: Sage, 2004: 119–141.
  - 46 Reddy V, Butler J. Troubling genders, subverting identities: interview with Judith Butler. *Agenda* 2004; 18: 115–123.
  - 47 Chaudoir S R, Earnshaw V A, Andel S. 'Discredited' versus 'discreditable': understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic Appl Soc Psychol* 2013; 35: 75–87.
  - 48 Simwaka B N, Bello G, Banda H, Chimzizi R, Squire B S, Theobald S J. The Malawi national tuberculosis programme: an equity analysis. *Int J Equity Health* 2007; 6: 24.
  - 49 Farmer P. Introducing ARVs in resource-poor settings: expected and unexpected challenges and consequences. Paper presented at the XIV International AIDS Conference, 7–12 July 2002, Barcelona, Spain.
  - 50 McGrath J W, Winchester M S, Kaawa-Mafigiri D, et al. Challenging the paradigm: anthropological perspectives on HIV as a chronic disease. *Med Anthropol* 2014; 33: 303–317.
  - 51 Goudge J, Ngoma B. Exploring antiretroviral treatment adherence in an urban setting in South Africa. *J Public Health Policy* 2011; 32 (Suppl 1): S52–S64.
  - 52 Mattes D. Caught in transition: the struggle to live a 'normal' life with HIV in Tanzania. *Med Anthropol* 2014; 33: 270–287.
  - 53 Beckmann N. Responding to medical crises: AIDS treatment, responsabilisation and the logic of choice. *Anthropol Med* 2013; 20: 160–174.
  - 54 Daftary A, Padayatchi N. Social constraints to TB/HIV healthcare: accounts from coinfecting patients in South Africa. *AIDS Care* 2012; 24: 1480–1486.

- 55 Peltzer K, Naidoo P, Matseke G, Louw J, Mchunu G, Tutshana B. Prevalence of post-traumatic stress symptoms and associated factors in tuberculosis (TB), TB retreatment and/or TB-HIV co-infected primary public health-care patients in three districts in South Africa. *Psychol Health Med* 2013; 18: 387–397.
- 56 Campbell C, Skovdal M, Madanhire C, Mugurungi O, Gregson S, Nyamukapa C. ‘We, the AIDS people...’: how antiretroviral therapy enables Zimbabweans living with HIV/AIDS to cope with stigma. *Am J Public Health* 2011; 101: 1004–1010.
- 57 Mavhu W, Dauya E, Bandason T, et al. Chronic cough and its association with TB–HIV co-infection: factors affecting help-seeking behaviour in Harare, Zimbabwe. *Trop Med Int Health* 2010; 15: 574–579.
- 58 Tayler-Smith K, Zachariah R, Massaquoi M, et al. Unacceptable attrition among WHO stages 1 and 2 patients in a hospital-based setting in rural Malawi: can we retain such patients within the general health system? *Trans R Soc Trop Med Hyg* 2010; 104: 313–319.
- 59 Kumwenda M, Desmond N, Hart G, et al. Treatment-seeking for tuberculosis-suggestive symptoms: a reflection on the role of human agency in the context of universal health coverage in Malawi. *PLOS ONE* 2016; 11: e0154103.
- 60 Kellett A J. Healing angry wounds: the roles of apology and mediation in disputes between physicians and patients. *Spec Law Dig Health Care (Mon)* 1989; 10: 7–27.



## RÉSUMÉ

**CONTEXTE :** Métropole de Blantyre, Malawi.

**OBJECTIF :** Comprendre pourquoi les hommes atteints de tuberculose (TB) restent non diagnostiqués dans la communauté.

**SCHEMA :** Une étude qualitative à méthodes multiples appliquant une approche modifiée de la théorie à base empirique. Les données ont été rassemblées entre mars 2011 et mars 2012 auprès de 134 hommes et femmes ayant participé à 1) des discussions en groupe focal avec des membres de la communauté ( $n=6$ ) et des personnels de santé ( $n=2$ ); et 2) des entretiens approfondis avec des patients TB ( $n=20$ ; femmes,  $n=14$ ) et des patients atteints de toux chronique ( $n=20$ ; femmes,  $n=8$ ). Les données ont été analysées de manière inductive afin d'identifier, de raffiner et de consolider, et de vérifier les concepts et thèmes émergents.

**RÉSULTATS :** Deux thèmes émergents illustrant une stigmatisation aggravée dans ce contexte à haute prévalence de l'infection par le virus de l'immunodéficience humaine (HIV) et à faible revenu sont présentés. Dans le premier exemple, les points de vue selon lesquels la toux ou toute maladie présageait un problème « sérieux » ont été accompagnés de

descriptions de toux, de TB et de VIH considérés comme interchangeable. De plus, les touseurs chroniques et les patients TB ont décrit leur maladie d'une manière qui met au premier plan la dégradation du corps et la rupture de la vie sociale et de l'identité masculine. Le deuxième, « stratégies de résistance », consiste à résister à être classé comme (gravement) malade en s'évadant ou en ayant une approche ambivalente des soins de santé ou en reconnaissant le statut de « malade » et en adoptant ensuite activement des comportements favorables à la santé, comme un changement de mode de vie, ou en adoptant des rôles de genre non normatifs.

**CONCLUSION :** La prise en charge des patients requiert d'abord d'aller au-delà d'une prise en charge syndromique basée sur les signes vitaux et les indicateurs cliniques, de reconnaître les tensions liées à la recherche de soins et d'intervenir pour y remédier de manière à retenir les individus en traitement; ensuite elle nécessite de comprendre et d'affronter la stigmatisation TB, car elle se manifeste et affecte les hommes et les femmes différemment dans des contextes spécifiques.

## RESUMEN

**MARCO DE REFERENCIA:** La zona urbana de Blantyre, en Malawi.

**OBJETIVO:** Comprender la razón por la cual persisten en la comunidad hombres con tuberculosis (TB) no diagnosticada.

**MÉTODO:** Fue este un estudio cualitativo de métodos múltiples, en el cual se aplicó una técnica modificada de muestreo teórico. De marzo del 2011 a marzo del 2012 se recogieron datos de 134 hombres y mujeres que participaron en 1) sesiones en grupo con miembros de la comunidad ( $n=6$ ) y profesionales de salud ( $n=2$ ); y 2) entrevistas exhaustivas a pacientes con diagnóstico de TB ( $n=20$ , de los cuales 14 eran mujeres) y personas que referían tos crónica ( $n=20$ ; ocho mujeres). Se practicó un análisis inductivo de los datos a fin de reconocer, afinar y consolidar y verificar los conceptos y los temas que surgieron.

**RESULTADOS:** En el artículo se presentan dos temas que surgieron, que aportaban información sobre una estigmatización combinada en este entorno con alta prevalencia de la infección por el virus del inmunodeficiencia humana (VIH) y bajos ingresos. En el primero, puntos de vista según los cuales la tos o cualquier enfermedad que presagia una 'afección' grave se asocia con descripciones en las cuales la tos, la TB y la

infección por el VIH son intercambiables. Además, los tosedores crónicos y los pacientes con TB describen su enfermedad en términos que ponen en primer plano la aniquilación del cuerpo, la ruptura de la vida social y la identidad masculina. El segundo tema, 'las estrategias de resistencia', implicaban ya fuese el rechazo de su clasificación como enfermos (graves) mediante la evasión de la atención de salud o su ambivalencia al buscarla o el reconocimiento del estado de 'enfermo', seguido luego de comportamientos activos favorables a la salud, incluso con modificación del estilo de vida o la adopción de roles en función del género que no son convencionales.

**CONCLUSIONES:** La atención integral de los pacientes exige, en primer lugar, sobrepasar el tratamiento sindrómico orientado por los signos vitales y los marcadores clínicos, con el objeto de reconocer las tensiones que rodean la búsqueda de atención de salud e intervenir sobre ellas, de manera que las personas sigan acudiendo a los servicios; y en segundo lugar, comprender y abordar la estigmatización asociada con la TB y el mecanismo por el cual afecta de manera diferente a los hombres y las mujeres en determinados entornos.