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Identification of barriers to tuberculosis care-seeking and co-creation of interventions to improve diagnosis with communities in an informal settlement in Blantyre, Malawi

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3 **Title: Identification of barriers to tuberculosis care-seeking and co-creation of**
4 **interventions to improve diagnosis with communities in an informal settlement**
5 **in Blantyre, Malawi**
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Abstract

Introduction

Men have a higher prevalence of undiagnosed tuberculosis (TB) than women and can spend up to a year longer infectious in the community before receiving treatment. Health outcomes are often worse for people with TB living in informal settlements. This study aimed to understand the barriers to seeking care for TB and co-create interventions to address these barriers.

Methods

We used qualitative research methods including in-depth interviews and participatory workshops. Researchers worked with women and men living in Bangwe, an informal settlement in Blantyre Malawi to develop interventions that reflected their lived realities. The study took place over two phases, in the first phase we undertook interviews with men and women to explore barrier to care seeking, in the second phase we used participatory workshops to co-create interventions to address barriers. In total, 30 interviews were conducted, and 23 participants joined participatory workshops. The team used a thematic content analysis to analysis the data.

Results

We identified three inter-connected thematic areas that shaped men's health TB seeking behaviour: precarious socioeconomic conditions; gendered social norms; and the role of the health system. Insecurity of day labour with no provision for sick leave; pressure to provide for the household and a gendered desire not to appear weak and a severely under-resourced health system all contributed to men delaying care in this context. Identified interventions included improved patient-provider relations within the health-system, improved worker rights and broader social support for households.

Conclusion

Improving men's pathways to care require interventions that address both individual level factors but also the broader social environment including legislation and safety nets for households.

Article summary

Study strengths and limitations

- In-depth interviews provided participants with an opportunity to articulate their individual experiences in their own words.
- Participatory workshops took an art-based approach and used theatre as a research method in conjunction with group discussions, enabling participants to express and then reflect together
- The theatre-based approach allowed for generating new insights and critical understanding through participants embodied participation, allowing them to present their lived realities and to collectively explore them
- We worked separately with men and women before bringing the two groups together, allowing for open discussion of potentially sensitive gender norms and behaviours
- Interventions identified will need to be tested to understand effectiveness co-created interventions

INTRODUCTION

Tuberculosis (TB) is the leading infectious cause of adult death worldwide (1). Approximately 10 million people become ill with TB each year, with a further 1.5 million people die of TB annually (2). Countries in sub-Saharan Africa – like Malawi – have experienced extremely high incidence of TB, driven by generalized HIV epidemics and poverty (3,4). Concerted global action to end the TB pandemic by 2030 has galvanized around key targets, including Target 3.3, of the Sustainable Development Goals (SDGs).

Despite global recognition of the need for urgent action on TB, progress towards meeting global targets remains unacceptably slow. An estimated 3.6 million people are either not diagnosed or reported to national TB programmes each year (5). Intensified efforts to identify, evaluate and implement interventions that reflect the lived realities of affected communities are urgently needed.

Prompt recognition of people with active TB and initiation of effective anti-tuberculosis treatment are vital to improve treatment outcomes and reduce transmission. Studies in many countries indicate significant delays exist in seeking care among people subsequently diagnosed with TB. In Malawi, substantial patient delays have been recorded (6), with severe deterioration in health following a prolonged period of symptoms often preceding health facility presentation (7,8). The direct costs including transport and loss of work days often impacted low income households (9). Social stigma caused by a widely-held perception that a TB diagnosis indicates HIV infection may also lead to delays in health seeking (10).

Men are disproportionately-affected by TB, with the prevalence of undiagnosed infectious TB among men two times higher than among women (11). In Malawi, men spend on average one year longer than women with undiagnosed TB in the community (11) and are likely to be responsible for upwards of two-thirds of all TB transmission events in Africa (12). Improving timely diagnosis of TB is therefore likely to have substantial health benefits for men, women and children.

The substantially higher burden of TB among men compared to women reflects broader patterns of morbidity and mortality data across the world, with women on

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3 average living 4.6 years longer than men (13). These patterns are in part shaped by
4 biological factors. However, the socio-cultural construct of gender also plays an
5 important role in explaining these differences (14). The WHO defines gender as “the
6 roles, behaviours, activities, attributes and opportunities that any society considers
7 appropriate for girls and boys, and women and men. Gender interacts with, but is
8 different from, the binary categories of biological sex” (15). Central to the concern of
9 gender is the hierarchical power relations that shape relationships between different
10 groups of people.
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18 Since the 1990s, critical gender theories have increasingly focused on how gender
19 shapes men’s health and well-being (13,16–18). Connell (2011) suggests that
20 gender has a materialist orientation, understood in terms of practices (what people
21 actually do) rather than what is expected (18). This moves gender beyond being a
22 fixed set of values or norms, to something that is produced and reproduced in
23 everyday practice (18). The theoretical framing of this paper draws on both critical
24 gender theory to understand barriers men’s care seeking for TB with the overall
25 purpose to identify interventions to address these barriers.
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34 **METHODS**

35 ***Study context***

36 Malawi, is considered a low-income country ranking 171st out of 189 countries on the
37 United Nations Development Programme (UNDP) human development index (19).
38 Approximately 80% of Malawi’s population undertake subsistence farming, with
39 maize being the dominant crop. A recent survey by Afrobarometer found that Malawi
40 was one of the most food insecure countries in Africa (20). An estimated 38% of
41 Malawian’s live below the poverty line and 47% of children are stunted (21). In
42 comparison to other countries, urbanisation has been slower in Malawi and a
43 majority of the population (84%) reside in rural areas (22).
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53 This study was situated in Bangwe Township, an informal settlement on the eastern
54 outskirts of Blantyre City, Southern Malawi. The formation of Bangwe dates back to
55 colonial rule, when Native Africans were considered too primitive for urban dwelling.
56 They were instead forced to live on the periphery of the city in townships that were
57 referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas
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3 during the colonial period led to densely over-crowded informal settlements.
4 Following independence in 1964, traditional housing associations were established
5 in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial
6 ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little
7 access to basic amenities. The historical formation continues to shape the lives of
8 residents as access to public services remain extremely limited and overpopulation
9 an ever-growing challenge.
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17 Malawi's health system is pluralistic, with government, private and faith-based
18 organisations providing services. The government sector being the only services
19 provided free at the point of use (25). Primary health centres are important entry
20 points for health service provision, with most TB diagnosis and treatment services
21 being integrated at this level.
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27 ***Study design***

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29 This study aimed to understand barriers and develop interventions to improve
30 pathways to diagnosis and care of TB for men living in an informal settlement in
31 urban Blantyre. We used qualitative study design (in-depth interviews) and
32 participatory workshops (PWs). In-depth interviews were selected because they
33 provided participants with an opportunity to articulate their experiences in their own
34 words (26). PWs took an art-based approach and used theatre as a research
35 method in conjunction with group discussions. To allow for open discussion of
36 potentially sensitive gender norms and behaviours these PWs initially divided groups
37 by gender, working separately with men and women before bringing the two groups
38 together. Drawn from Theatre of the Oppressed (27), Image and Forum theatre
39 techniques were used to facilitate participants to express and then reflect together,
40 with each exercise feeding into the next stage of the workshop (28,29). Drawing on a
41 theatre-based approach allowed for generating new insights and critical
42 understanding through participants embodied participation, allowing them to present
43 their lived realities which could then be collectively explored.
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56 ***Data collection***

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58 Data collection took place between January 2019 until October 2019, using in-depth
59 interviews and participatory workshops. The study team used a short screening tool
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3 to identify women attending the Bangwe Primary Clinic who reported their partners
4 had a persistent cough (defined as a cough lasting more than two weeks). We then
5 asked if they would consent to an interview; following the interview we also asked if
6 they would be happy for us to contact their partners. Interviews were conducted in a
7 private room within the research office in the clinic. We then held participatory
8 workshops over a one-week period, inviting all participants from the in-depth
9 interviews. Not all participants were available, so we used snowballing techniques
10 with our recruited participants to identify men and women living in Bangwe who were
11 willing to participate in the PWs. Following the workshops, we invited participants
12 who hadn't previously been interviewed to attend an interview.
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22 Authors MP and MN conducted the interviews and MP, EM and EMACP facilitated
23 the PWs. Debriefing meetings were held soon after every interview to review
24 emerging findings and identify areas requiring further exploration. All interviews and
25 PW discussions were conducted in the local language (Chichewa) and audio
26 recorded.
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32 ***Data analysis***

34 Data were analysed using a thematic content analysis (30). Audio recordings were
35 transcribed verbatim, translated into English, and imported into NVIVO10 software to
36 facilitate organization and analysis. Transcripts were read and re-read for
37 familiarization. Transcripts were then coded inductively (31). MP and EMACP each
38 coded an initial sample of transcripts, before comparing interpretations, and merging
39 their separately generated coding frames. We used the merged coding frame to
40 code further transcripts, iteratively modifying the frame as new data were analysed.
41 We had frequent debriefing sessions to ensure we agreed with interpretation of the
42 data and analysis summaries.
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51 ***Ethical approval***

53 Participants provided informed consent, either written or witnessed thumbprint.
54 Consent was taken at the start of each interviews and at the start of the week of
55 participatory workshops and reviewed each day with participants. Ethical approval
56 for the study was granted by the University of Malawi College of Medicine and the
57 Liverpool School of Tropical Medicine Research Ethics Committee.
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Funding

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Data sharing

The data supporting results of this study will be available on request from the Malawi Liverpool Wellcome Trust Clinical Research Programme's data department by emailing this address: sdsm@mlw.mw. We do not intend to make the data publicly available because the consent from our participants and approvals from the ethics committees did not cover data sharing.

Patient involvement

Patients were involved in the design of the participatory workshops. The methodology allowed for participants to take the lead and decide on which exercises would be used during the days. We also involved patients in deciding how to disseminate findings.

RESULTS

A total of 11 men and 12 women participated in the participatory workshops and we conducted 30 interviews (15 men and female 15 women) table 1 provides a breakdown of demographic details of participants.

Table 1: participant demographics

We present the results in two sections. The first section explores the barriers men identified as shaping their decision to seek care. In the second section, we explore potential interventions that arose from the qualitative interviews and PWs, including those to address factors at the structural level.

Barriers to health-seeking

From our data we identified three inter-connected thematic areas that shaped men's health seeking behaviour: precarious socioeconomic conditions; gendered social norms; and the role of the health system.

Precarious socioeconomic conditions

One of the central themes throughout the data collection was the high levels of poverty experienced across participants' households. This shaped household survival and in turn constrained the agency that men and women had over prioritising health-seeking. Men and women at times had contrasting views about who was responsible for the survival of the household. Nearly all men saw their labour as vital, but some women also described the key role their businesses played in generating income.

All the participants described economic instability in their households. Most men worked in *ganyu* or casual "piece work" (examples of these roles include moulding or bricklaying, off-loading trucks or ploughing fields). *Ganyu* labour was physically demanding, very poorly paid and rarely secured beyond a single day. Most of the female participants engaged in small business that generated some income, but success depended on accessing capital and profits were often precarious.

In households in Bangwe, managing food insecurity was central to many household decisions. Men argued that insufficient household income constrained their agency to seek care because missing work would lead to short-falls in income and a lack of food. Most participants rented and the pressure to pay rent was often a further of tension. Both men and women, described how stressful – and at times hopeless – the grinding poverty they experienced in their day-to-day lives made them feel. This is represented in the quote below:

It's been a very difficult life because nothing works to our plans. Whatever we do now is just so we have food for the day. When we go to bed, we don't know what tomorrow holds for us, what we are going to eat [...] it's very challenging [...] now is about month end and the landlord will soon be asking for his money. **[Male participant, in-depth interview (IDI)]**

While treatment at the Ministry of Health-operated Bangwe Health Centre was free, men still articulated that seeking care placed an economic burden on the household and the economic instability of relying on casual labour left men and families in

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3 extremely challenging economic situation. For example, visiting the hospital ran the
4 risk of losing income for the day:
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8 The challenge with piece works is you can't go to the hospital when you are
9 unwell because going to the hospital means you won't be able to make
10 money, and if you won't be able to make money, you won't eat [...] So,
11 wondering what you are going to eat if you miss work you go to work despite
12 being sick. If you depend on business for food for the day, it means you have
13 you have to go to town even when you are sick. **[Male participant, IDI]**
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19 Similarly, insecurity of casual employment meant that workers had no formal rights,
20 including no provision for sick leave, *ganyu* workers without legal protection. If men
21 took time off to seek care, they also faced the threat of their work being terminated.
22 In the quote below, the male participant discusses how continual absences due to ill-
23 health could mean a loss of their job.
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29 [...] most companies don't pay you when you miss a day of work. If you are
30 sick and want to go to a clinic, it's very hard for them to allow you time off.
31 You may take a day off on your own without permission, hoping that you will
32 show them a medical report, but most employers don't accept that. They
33 shout at you, insult you, and cut your pay [...] my colleague at work developed
34 a heart failure problem because of being in contact with chemicals. His heart
35 wasn't functioning properly, and every week he would have a day off work.
36 This caused him to have problems with his bosses to a point that they sacked
37 him. **[Male participant, IDI]**
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47 During the PWs with men, the relational aspects of employment were raised by the
48 group. When men did not go to work due to sickness, they described being
49 disciplined by their employers. In one scene, men acted out an exchange between a
50 *bwana* (the boss) and a man requesting time off because they are sick. The *bwana*
51 was extremely rude to the man and told him not to return to work if he went to the
52 hospital. Such restricting labour conditions create barriers to early care-seeking for
53 men with symptoms of TB.
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Gendered social norms

Gendered hierarchies shaped men's well-being and lives in complex ways. Men's decisions around their health were shaped by the precarious economic position of households in Bangwe. However, broader social norms also shaped men's behaviour. Enduring illness and suffering in silence was one-way man could demonstrate strength to himself and others. Men described needing to present as themselves as strong not just in their household and workplace but also to the wider community. These masculine beliefs of stoicism also appeared in perceptions of women as being more vulnerable to sickness and had weaker immunity. The quote below may likely be allegorical, referring to a broader range of illnesses than just a stubbed toe:

[...] I could say his blood is different from mine. When he stumbles so much blood comes out but the toe does not take many days to heal. But when I stumble my toe takes one or two weeks to heal. **[Female participant, IDI]**

Ideas of men being more resilient to illness also appeared to be linked to perceptions about illness and severity. Men described a pattern of waiting and seeing if their condition worsened before they sought care, and only going to formal health care when illness was at an advanced stage. Inability to physically carry on particularly to go to work prompted seek care. Further, if the illness episode continued for a longer period of time, it signalled severity and stimulated decisions about seeking care.

[...] if there's ever been a time that I was seriously sick then it is now. Other than this time, I have never been sick to a point where I could just stay indoors. Whenever I am sick, usually it's diarrhoea and it doesn't last, maybe only for 2 days, and I still go to town [...] **[Male participant, IDI]**

The decision to seek medical care was also shaped by the belief in a higher power and a pre-determined path. As one male participant said, "*I will just stay at home; if it's death so be it, it's God's will if I die.*" The fatalistic statement reflects a sense of spirituality that embraces death and illness as God-predestined, and thus disputes the relevance of seeking medical attention.

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3 Some men and women described attending churches where seeking biomedical
4 care violated the doctrine of the church. They reported pastors operating in the area
5 who would heal patients and discourage them from further engagement in bio-
6 medical care. The following quotes demonstrates the complex interactions between
7 church and faith healing shape, and health seeking behaviour.
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12 Pastors tell patients to stop treatment and believe that they will be healed
13 after praying for them. They also tell people not to go to the hospital when sick
14 instead they should just believe [in God]. **[Female participant PW]**
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18 19 **Gendered power relations and the household**

20 The ideas of power and household dynamics were explored in the workshops with
21 women, being asked to make images (still body sculptures) of men who live in
22 Bangwe. The women created images either of men at work or at leisure. This was in
23 contrast to images women made of themselves either performing household work or
24 praying. The images of men alluded to higher literacy levels, access to free time and
25 money either buying alcohol or using their mobile phones. The images created
26 reveal rigid gendered divisions of labour where the man hold both the responsibility
27 to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys
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36 During the workshops, men and womens' decision-making power within the
37 household was often discussed. The centrality of men's power over women, was
38 both overtly, and covertly articulated, with women more financially dependent for
39 their survival and the survival of their children. Women described how their economic
40 dependency left them vulnerable to violence, which could take different forms but
41 included emotional, economic or physical violence. This was initially hard to talk
42 about, and not directly mentioned; but after a role play which featured violent
43 physical responses from husbands that participants began to share the risks they
44 might face. This in itself is indicative of the unspoken power that men often hold.
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52 One aspect we centred discussion was whether women could discuss their
53 husband's health with him, and whether they could suggest taking action, such as
54 going to the clinic to seek treatment for a persistent cough. Both men and women
55 described how the ability to discuss their husband's health and decision-making
56 depended on the dynamics of the relationship. For some women and men, asking
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3 their husband about his health or advising them could lead to angry exchanges, as
4 men perceived taking advice could put them in a weaker position:
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9 [...] You don't have to listen to a woman every time she suggests something
10 to you. Sometimes you have to ignore what she says. If she talks to you
11 [about seeking treatment] and you listen, she doesn't take you seriously or
12 respect you anymore, she puts a 'hedge around you' and commands you at
13 will. Once she commands you, you are no longer respected as a man. So you
14 need to be stubborn a bit, showing you're a man. **[Male participant, IDI]**
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21 Due to the economic dependency of the household, women also articulated their
22 concern about men seeking care and missing work, as this would have a further
23 impact on the family.
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27 If we have children and the husband has been sick maybe for a week, you
28 say this man needs to go and work. Maybe [because] you have gone days
29 without eating and the bodies are weak [...] this happens in families. For
30 instance, my husband may come back from work feeling really sick with body
31 pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay
32 here at home?' [...] **[Female participant, PW]**
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39 However, both male and female groups referred to the changing roles of women in
40 the household in Malawi that were challenging traditional notions of power and
41 household decision-making roles. The increasing number of women in urban
42 Bangwe owning small businesses gave them an independent income and brought
43 greater decision-making power. This is articulated in the quote below:
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48 Women are also making decisions in the household when they have access
49 to finances, but those that are dependent on men easily accept [whatever
50 their male partner decides] **[Female participant, PW]**
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55 **The role of the health system**

56 Previous encounters at the health centre, often left men feeling angry and
57 marginalised. Long waiting times, poor treatment by health care staff and chronic
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3 shortage of medicines drove men to seek delay care or seek out alternatives. Men
4 and women were particularly angry at the treatment they received by clinicians, at
5 best they saw health workers as rude and dismissive and at worst, violent. Examples
6 of the cruel treatment included scoffing or ignoring patients and not allowing patients
7 to explain their illness:
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13 Sometimes doctors are not speaking politely, they are harsh and treat you as
14 though you were not humans. Some of them go out to chat to each other,
15 where they laugh and do things of their own. Like today, as we were collecting
16 drugs, one of them said, "You men are looking at me! You should look down.
17 Why are you looking at me?! Some of you do not bath!" You find people
18 swearing: "I should come here again?!" **[Female participant, IDI]**
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26 The lack of drugs, long waits and short consultations often impacted on men's
27 decision to seek care. Men were unhappy about committing to spending a day going
28 to the clinic when they could buy drugs from the grocery store and return to work.
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33 ...people feel discouraged by what happens at the clinic: "I should go there,
34 climb that hill, just so they can give me Bactrim?" Because you expect to get
35 better treatment when you go there: "I thought they were going to inject me."
36 But they only give you Panadol when you go there. So you say "I just wasted
37 my time last time, it is better that I buy from the shops." **[Female participant,
38 IDI]**
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44 The organisation of the clinic, including specific treatment days and separate lines,
45 particularly for HIV also made men fearful of seeking care, as they were concerned,
46 they would be identified and treated differently in the community. Bangwe health
47 centre is at the top of a steep hill and many participants had to walk long distances
48 and climb a steep hill. If they wanted to use transport this would further impact the
49 household finances:
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55 Sometimes the challenge is transport, you can't walk to the clinic, so you just
56 sit at home. If you have some money, you are able to visit the clinic, because
57 there are lots of minibuses or bicycle taxis out there. **[Male participant, IDI]**
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3 Although, it is important to note some men and women only trusted the government
4 hospitals to provide the correct diagnosis.
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7 [...] the hospital is where you can get a diagnosis of your sickness. Because
8 on your own you might think it is TB yet it's something else showing
9 symptoms of TB. [...] you might be sick and still be unaware of what you are
10 sick with. **[Male partner, IDI]**
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18 **Interventions to improve men's pathways to care**

19 In this section we present findings around interventions identified by participants
20 during the participatory workshop to improve men's pathways to care. The
21 suggestions from participants included: labour rights legislation; patient welfare
22 support system; and drawing on local leadership to encourage men to seek care.
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28 As we have demonstrated above, men's pathways to care are shaped by complex
29 intersecting inequalities, with poverty intersecting with gendered social norms to
30 shape many decisions. Working conditions associated with temporary work –
31 including the absence of sick leave and lack of labour law protections – and the fear
32 of losing vital income and dismissal from work were all important factors in shaping
33 care-seeking behaviour. For these work-related barriers participants proposed
34 improved employment legislations that provided and safeguarded rights for workers.
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42 We feel that the government should provide and stiffen laws against bosses
43 that subject their workers to maltreatment so that if they are found ill-treating
44 the workers they should be punished. Also, the government should ensure
45 that all workers are on medical scheme like MASM, and it should be
46 compulsory that each and every worker should be under a medical
47 scheme **[Male participant, PW]**
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53 Trust in the health system and concerns about the way health practitioners treated
54 patients shaped decisions to seek care. One intervention proposed to address this
55 barrier was the establishment of a reporting system where patients could report their
56 concerns about health care workers. Suggestions made by participants included a
57 toll-free line or a welfare office where patients could report maltreatment.
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5 We're thinking that maybe setting up offices right at the health facility where
6 people could forward their complaints to the senior clinic staff. There should
7 be toll free numbers to call the senior members of staff. The senior staff would
8 then figure out how to help you. The other thing is punishing the doctors,
9 maybe ill-treatment might stop. **[Male participant, PW]**

14 During the workshops, participants described how reliance on faith healing and
15 traditional medicine acted as a barrier to seeking the "right" care. This framing was
16 presented by participants as a problem that needed to be dealt with. This may in
17 part, of been a response to the researchers' positionalities – coming from a well-
18 known health research organisation. Some participants suggested punitive
19 measures, with chiefs imposing fines on people who use non-biomedical services.
20 However, other participants argued that educationally oriented interventions that
21 would foster gradual cultural reforms and adoption of formal health practices and
22 behaviours. One of the suggestions that came out was implementing public
23 awareness campaigns and civic education programmes on health matters.

33 I believe that each one of us have their own traditions. So, we cannot leave
34 something that is deep rooted in our society. Just deciding from nowhere that
35 we have a decree that no one should ever use traditional medicine. I'm
36 thinking of education so that we gradually move away from it [informal health
37 practices] rather than introducing laws. Sometimes that's when people do it
38 more when it's prohibited. While people are using traditional medicine, those
39 that know about modern medicine should with evidence civic educate those
40 that don't know. Then people will on their own start using these helpful
41 methods. Laws are good indeed but sometimes do not work. **[Male
42 participant, PW]**

52 Financial support for seeking medical care commonly emerged as most suitable for
53 addressing the economically related barriers. Opportunities for support included the
54 government and NGO partners as potential sponsors. They felt the money would
55 compensate transport costs and loss of income that people normally incurred when
56 accessing the clinic.

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5 Refunding the money patients spend on transport to the clinic could help with
6 the problem of people not visiting the clinic when they are sick. Like for me
7 today I would not have come had my wife not told me that you were going to
8 refund my transport fee. I was encouraged by the news of the refund... So, if
9 you refund transport, it will help to some degree. **[Male participant, IDI]**

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15 Participants also explored different ways in which communities could establish their
16 own social safety nets without dependence on external support. They considered a
17 village fund where villagers contributed a small amount as one of the ways of
18 organizing safety nets.
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24 [...] encouraging chiefs to set up small funds where all the members of the
25 community contribute K20 even K50 or K100. We can manage that amounts.
26 So when someone is in need we should use the money to get them to the
27 hospital. Rather than waiting for an ambulance from the office. Because
28 sometimes it becomes difficult for the ambulance to come. **[Male participant,**
29 **PW]**

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36 Participants also considered outreach services as an alternative strategy to increase
37 access to healthcare for men, this would take away one of the financial barriers:
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41 Another way would be seeing people in their homes because some don't have
42 means of transport and struggle to get to the clinic. So meeting and speaking
43 to them in their homes might help. **[Male participant, IDI]**

44 45 46 47 **Discussion**

48
49 In Bangwe, an informal settlement in Blantyre we found high rates of poverty were
50 central to many household decisions around care-seeking. Most participants
51 described the grinding nature of food insecurity left people feeling hopeless and
52 constrained the agency that men and women had to act on ill-health. *Ganyu* labour
53 practices significantly contributed to the economic insecurity that household
54 experienced. Weaknesses in primary health care meant patients faced long waiting
55 times, poor treatment by clinicians and a shortage of drugs. These factors all
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3 contributed to men delaying care until their illness significantly impacted on their live
4 and livelihood. To achieve universal healthcare coverage and impact upon TB
5 epidemics, these complex, intersecting barriers must be addressed together.
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7 Participants developed and defined a set of interventions to address these barriers
8 that should be evaluated in partnership between researchers and community-
9 members.
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15 For urban men living in informal settlements gendered power relations shaped by
16 economic insecurity in the household in turn shaped behaviour. Going to the clinic,
17 was interpreted by men as representing weakness, with the risk of losing
18 employment further exacerbating their precarious position. In most households, men
19 saw themselves as the breadwinner, which furnished them with more decision-
20 making power than women. Women described the heavy domestic labour they
21 carried, which often left them with little leisure time, and which they contrasted with
22 men whom they perceived to have more. Complex power dynamics shaped
23 communication between partners, with women describing how, at times, speaking to
24 their partners about his health could be dangerous for them. But in Bangwe,
25 gendered partnership dynamics were evolving, particularly when women's earnings
26 through their own businesses provided a significant contribution to the household,
27 increasing their power and voice in household decisions.
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39 Drawing on a participatory methodology allowed participants and researchers to
40 work together to co-create interventions. This approach allowed participants to
41 meaningfully engage with researchers developing interventions that addressed their
42 lived realities. Key interventions to address barriers to care seeking identified and
43 developed by PW participants included interventions at the individual level and the
44 broader structural level. At the individual level, interventions included changing
45 behaviour through targeted civic education programmes directed at men to
46 encourage them to seek bio-medical care. At the structural level, interventions
47 included improved labour regulations, including protection from dismissal if men did
48 seek care, and payment of sick leave. The need for somewhere to take their
49 grievances such as the labour office were seen as important to ensure compliance
50 by employers. Safety nets system that supported households when a household
51 member was sick to allow them to seek care was also identified as a priority.
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5 The urgent need to improve primary health care facilities was also identified. The
6 shortages of resources, both human and material, meant that participants faced long
7 waiting periods and a lack of drugs when they did see a clinician. The need for
8 improved communication, as clinicians were seen at times as being rude or abusive
9 to patients during consultations. Participants saw that a service that allowed them to
10 complain about clinicians could provide better accountability for health workers. Men
11 valued confidentiality during their visits to the health centre and proposed reordering
12 of the queue to ensure confidentiality when they sought care. Fear of being
13 associated with HIV services drove some of these concerns, but also queues that
14 allowed men to see male clinicians was also suggested as a way to encourage men
15 to seek care. One suggestion was also to bring services closer to the community, to
16 eliminate the costs of visiting a health centre.
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27 Globally, gender power relations have often afforded men more power and privilege
28 than women, with greater access to education and financial resources. However, this
29 has not translated into better health outcomes. We find strikingly similar accounts
30 from the UK, to Central Asia and Southern Africa of men delaying health care
31 seeking (16,17,32,33) that echoed our own findings. This is also reflected in
32 Chikovore et al (2014 and 2017) which found in urban Blantyre that men's need to
33 be perceived as a strong meant they would delay seeking care. They also found that
34 the association between TB and HIV meant men would delay care seeking due to
35 associated stigma from HIV.
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46 In a review of health outcomes, Sverklik (2011) found that across the globe, people
47 living in informal settlements suffer disproportionately from ill-health throughout their
48 life course. These patterns of ill-health can be observed from birth with cramped and
49 poor quality housing, poor access to water and sanitation and limited access to
50 public services including health care shaping health outcomes (34). We see these
51 social and political configurations present in Bangwe, shaping household decision
52 making. Structural interventions act to change the context in which health is
53 produced and reproduced are gaining greater attention in public health (35). In
54 context of urban Blantyre where weak legislative frameworks leave workers with very
55 few rights require urgent attention.
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In summary, by generating knowledge and understanding with men and women community members in urban Blantyre, Malawi, we identified three inter-connected thematic areas that shaped men's health and TB seeking behaviour, and potentially contribute to high levels of ongoing transmission in these settings: precarious socioeconomic conditions; gendered social norms; and the role of the health system. Insecurity of day labour with no provision for sick leave; pressure to provide for the household and a gendered desire not to appear weak and a severely under-resourced health system all contributed to men delaying care-seeking. Interventions identified and developed by participants included targeted civic education programmes, improved patient-provider relations within the health-system and legislation to ensure worker rights to sick pay, and broader social support for households.

Conflict of interest declaration

The authors declare that there is no conflict of interest.

Author contributions

Author	Contribution/Role in the study
Mackwellings Phiri	Data collection, Analysis, Paper writing
Effie Makepeace	Data collection, Paper review
Margaret Nyali	Data collection and analysis
Moses Kumwenda	Study design, data collection and analysis support
Elizabeth L Corbett	Study design and paper writing
Katherine Fielding	Study design and paper writing
Augustine T Choko	Study design and paper writing
Peter MacPherson	Study design, analysis and paper writing
Eleanor E MacPherson	Led the study, designed, analysed and supported paper writing

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Table 1 participant demographics

Characteristics	Category	Number
Gender	Male	15
	Female	15
Age	18-34years	24
	35 & above years	6
Education	No school or primary level	22
	Secondary level	6
	College level	2

Occupation	Piece work (Brick laying, molding bricks, etc.)	10
	Self-employed (Tailoring, welding/fabrication, painting businesses, etc.)	5
	Petty trading (Selling tomatoes, charcoal, etc.)	12
	No occupation (Looking for job)	3

For peer review only

Research Checklist

#1	<p>Title</p> <p>Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended.</p>	<p>Page 1</p>
#2	<p>Abstract</p> <p>Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions.</p>	<p>Page 2</p>
#3	<p>Introduction</p> <p>Problem formulation</p> <p>Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement.</p>	<p>Pages 4, 5</p>
#4	<p>Purpose or research question</p> <p>Purpose of the study and specific objectives or questions.</p>	<p>Page 6</p>
#5	<p>Methods</p> <p>Qualitative approach and research paradigm</p> <p>Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The</p>	<p>Pages 6, 7</p>

	<p>rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.</p>	
#6	<p>Researcher characteristics and reflexivity</p> <p>Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability.</p>	
#7	<p>Context</p> <p>Setting / site and salient contextual factors; rationale.</p>	<p>Page 5</p>
#8	<p>Sampling strategy</p> <p>How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.</p>	<p>Pages 6, 7</p>
#9	<p>Ethical issues pertaining to human subjects</p>	<p>Page 7</p>

	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	
#10	Data collection methods Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale.	Pages 6, 7
#11	Data collection instruments and technologies Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study.	Page 7
#12	Units of study Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results).	Pages 8, 23
#13	Data processing Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts.	Page 7

#14	<p>Data analysis</p> <p>Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.</p>	Page 7
#15	<p>Techniques to enhance trustworthiness</p> <p>Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.</p>	Page 7
#16	<p>Results/findings</p> <p>Syntheses and interpretation</p> <p>Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.</p>	Pages 8-17
#17	<p>Links to empirical data</p> <p>Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.</p>	Pages 9-17
#18	<p>Discussion</p> <p>Intergration with prior work, implications, transferability and contribution(s) to the field</p>	Pages 17-24

	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field.	
#19	Study strength and Limitations Trustworthiness and limitations of findings.	Page 3
#20	Other Conflicts of interest Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed.	Page 20
#21	Funding Sources of funding and other support; role of funders in data collection, interpretation and reporting.	Page 8
#22	Author contributions Role of each other in the study and their contributions	Page 20

BMJ Open

Improving pathways to care through interventions co-created with communities: a qualitative investigation of mens' barriers to tuberculosis care-seeking in an informal settlement in Blantyre, Malawi

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3 **Title: Improving pathways to care through interventions co-created with**
4 **communities: a qualitative investigation of mens' barriers to tuberculosis care-**
5 **seeking in an informal settlement in Blantyre, Malawi**
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Abstract

Introduction

Men have a higher prevalence of undiagnosed tuberculosis (TB) than women and can spend up to a year longer contributing to ongoing transmission in the community before receiving treatment. Health outcomes are often worse for TB patients living in informal settlements especially men. This study aimed to understand the barriers preventing men from seeking care for TB and co-create interventions to address these barriers.

Methods

We used qualitative research methods including in-depth interviews and participatory workshops. Researchers worked with women and men living in Bangwe, an informal settlement in Blantyre, Malawi to develop interventions that reflected their lived realities. The study took place over two phases, in the first phase we undertook interviews with men and women to explore barrier to care seeking, in the second phase we used participatory workshops to co-create interventions to address barriers and followed up on issues emerging from the workshops with further interviews. In total, 30 interviews were conducted, and 23 participants joined participatory workshops. The team used a thematic analysis to analyse the data.

Results

Three inter-connected thematic areas shaped men's health TB seeking behaviour: precarious socioeconomic conditions; gendered social norms; and constraints in the health system. Insecurity of day labour with no provision for sick leave; pressure to provide for the household and a gendered desire not to appear weak and a severely under-resourced health system all contributed to men delaying care in this context. Identified interventions included improved patient-provider relations within the health-system, improved workers' health rights and broader social support for households.

Conclusion

Improving men's pathways to care requires interventions that consider contextual issues by addressing individual level socioeconomic factors but also broader structural factors of gendered social dynamics and health systems environment.

Article summary

Study strengths and limitations

- In-depth interviews provided participants with an opportunity to articulate their individual experiences in their own words.
- Participatory workshops took an art-based approach and used theatre as a research method in conjunction with group discussions, enabling participants to express and then reflect together
- The theatre-based approach allowed for generating new insights and critical understanding through participants embodied participation, allowing them to present their lived realities and to collectively explore them
- We worked separately with men and women before bringing the two groups together, allowing for open discussion of potentially sensitive gender norms and behaviours
- Interventions identified will need to be tested to understand effectiveness co-created interventions

INTRODUCTION

Tuberculosis (TB) is the leading infectious cause of adult death worldwide (1). Approximately 10 million people become ill with TB each year, with a further 1.5 million people die of TB annually (2). Countries in sub-Saharan Africa – like Malawi – have experienced extremely high incidence of TB, driven by generalized HIV epidemics and poverty (3,4). Concerted global action to end the TB pandemic by 2030 has galvanized around key targets, including Target 3.3, of the Sustainable Development Goals (SDGs).

Despite global recognition of the need for urgent action on TB, progress towards meeting global targets remains unacceptably slow. An estimated 3.6 million people are either not diagnosed or reported to national TB programmes each year (5). Intensified efforts to identify, evaluate and implement interventions that reflect the lived realities of affected communities are urgently needed.

Prompt recognition of people with active TB and initiation of effective anti-tuberculosis treatment are vital to improve treatment outcomes and reduce transmission. Studies in many countries indicate significant delays exist in seeking care among people subsequently diagnosed with TB. In Malawi, substantial patient delays have been recorded (6), with severe deterioration in health following a prolonged period of symptoms often preceding health facility presentation (7,8). The direct costs including transport and loss of work days often impacted low income households (9). Social stigma caused by a widely-held perception that a TB diagnosis indicates HIV infection may also lead to delays in health seeking (10).

Men are disproportionately-affected by TB, with the prevalence of undiagnosed infectious TB among men two times higher than among women (11). In Malawi, men spend on average one year longer than women with undiagnosed TB in the community (11) and are likely to be responsible for upwards of two-thirds of all TB transmission events in Africa (12). Improving timely diagnosis of TB is therefore likely to have substantial health benefits for men, women and children.

The substantially higher burden of TB among men compared to women reflects broader patterns of morbidity and mortality data across the world, with women on

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3 average living 4.6 years longer than men (13). These patterns are in part shaped by
4 biological factors. However, the socio-cultural construct of gender also plays an
5 important role in explaining these differences (14). The WHO defines gender as “the
6 roles, behaviours, activities, attributes and opportunities that any society considers
7 appropriate for girls and boys, and women and men. Gender interacts with, but is
8 different from, the binary categories of biological sex” (15). Central to the concern of
9 gender is the hierarchical power relations that shape relationships between different
10 groups of people.
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18 Since the 1990s, critical gender theories have increasingly focused on how gender
19 shapes men’s health and well-being (13,16–18). Connell (2011) suggests that
20 gender has a materialist orientation, understood in terms of practices (what people
21 actually do) rather than what is expected (18). This moves gender beyond being a
22 fixed set of values or norms, to something that is produced and reproduced in
23 everyday practice (18). The theoretical framing of this paper draws on both critical
24 gender theory to understand barriers men’s care seeking for TB with the overall
25 purpose to identify interventions to address these barriers.
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34 **METHODS**

35 ***Study context***

36 Malawi, is considered a low-income country ranking 171st out of 189 countries on the
37 United Nations Development Programme (UNDP) human development index (19).
38 Approximately 80% of Malawi’s population undertake subsistence farming, with
39 maize being the dominant crop. A recent survey by Afrobarometer found that Malawi
40 was one of the most food insecure countries in Africa (20). An estimated 38% of
41 Malawian’s live below the poverty line and 47% of children are stunted (21). In
42 comparison to other countries, urbanisation has been slower in Malawi and a
43 majority of the population (84%) reside in rural areas (22).
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53 This study was situated in Bangwe Township, an informal settlement on the eastern
54 outskirts of Blantyre City, Southern Malawi. The formation of Bangwe dates back to
55 colonial rule, when Native Africans were considered too primitive for urban dwelling.
56 They were instead forced to live on the periphery of the city in townships that were
57 referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas
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3 during the colonial period led to densely over-crowded informal settlements.
4 Following independence in 1964, traditional housing associations were established
5 in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial
6 ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little
7 access to basic amenities. The historical formation continues to shape the lives of
8 residents as access to public services remain extremely limited and overpopulation
9 an ever-growing challenge. British rule also brought the introduction of urban
10 capitalism changing family configurations and gendered norms (25). There was
11 increasingly nucleated family and a greater dependency of women on their
12 husbands' wage labour. It also physically relocated women away from their land
13 making access to food sources more challenging (26). Today, Malawi ranks 172 out
14 of 189 countries making it one of the most unequal countries in the world (27).

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26 Malawi's health system is pluralistic, with government, private and faith-based
27 organisations providing services. The government sector being the only services
28 provided free at the point of use (28). Primary health centres are important entry
29 points for health service provision, with most TB diagnosis and treatment services
30 being integrated at this level.
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36 ***Study design***

37 This study aimed to understand barriers and develop interventions to improve
38 pathways to diagnosis and care of TB for men living in an informal settlement in
39 urban Blantyre. We used qualitative study design (in-depth interviews) and
40 participatory workshops (PWs). In-depth interviews (IDIs) were selected because
41 they provided participants with an opportunity to articulate their experiences in their
42 own words (29). PWs took an art-based approach and used theatre as a research
43 method in conjunction with group discussions. To allow for open discussion of
44 potentially sensitive gender norms and behaviours these PWs initially divided groups
45 by gender, working separately with men and women before bringing the two groups
46 together. Drawn from Theatre of the Oppressed (30), Image and Forum theatre
47 techniques were used to facilitate participants to express and then reflect together,
48 with each exercise feeding into the next stage of the workshop (31,32).
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Data collection

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3 Data collection took place between January 2019 until October 2019, using in-depth
4 interviews and participatory workshops. The study team used a short screening tool
5 to identify women attending the Bangwe Primary Clinic who reported their partners
6 had a persistent cough (defined as a cough lasting more than two weeks). We then
7 asked if they would consent to an interview; following the interview we also asked if
8 they would be happy for us to contact their partners. Eleven women and 10 men
9 participated in the initial interviews; we stopped interviews when no themes arose.
10 After analysing the data from the interviews and themes relating to mens' treatment
11 barriers had been identified, we held participatory workshops to further discuss the
12 barriers and to identify and prioritise potential interventions to these barriers. PWs
13 happened over a one-week period, with each day split into five hourly discussion
14 sessions. We invited all participants from the in-depth interviews to join the
15 workshops, but nine were not available. So, we used snowballing techniques with
16 our recruited participants to identify men and women living in Bangwe who were
17 willing to participate in the PWs. Following the workshops, we invited participants
18 who hadn't previously been interviewed to attend an interview. Median (IQR) ages by
19 sex for the 30 study participants were 34 (23-42) years for women and 37 (26.5-
20 62.5) years for men. Interviews were conducted in a private room within the research
21 office in the clinic and lasted between one hour and 45 minutes. All interviews and
22 PW discussions were conducted in the local language (Chichewa) and audio
23 recorded.
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41 The research team comprised of two Malawian (one female master's student and
42 one male researcher employed by the Research Institute who sponsored the study)
43 and two white British women both from the UK. Our levels of education, sex,
44 economic position and race (in the case of EM and EMACP) are likely to have
45 shaped our interactions with the participants. MP interviewed some of the female
46 participants and were a mixed team when we conducted the female workshops. As a
47 research team, we all have significant experience of conducting research (3 of the 4
48 researchers with more than 10 years each). Following each interview and at the end
49 of each day of the participatory workshops, we held debriefing sessions. During
50 these sessions we reviewed emerging findings and identifying areas requiring further
51 exploration. We also focused on how participants responded to the questions and
52 whether we may have influenced this.
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Data analysis

Data were analysed using a thematic analysis (33). Audio recordings were transcribed verbatim, translated into English, and imported into NVIVO10 software to facilitate organization and analysis. Transcripts were read and re-read for familiarization. Transcripts were then coded inductively (34). MP and EMACP each coded an initial sample of transcripts, before comparing interpretations, and merging their separately generated coding frames. We used the merged coding frame to code further transcripts, iteratively modifying the frame as new data were analysed. We had frequent debriefing sessions to ensure we agreed with interpretation of the data and analysis summaries (35).

Ethical approval

Participants provided informed consent, either written or witnessed thumbprint. Consent was taken at the start of each interviews and at the start of the week of participatory workshops and reviewed each day with participants. Ethical approval for the study was granted by the University of Malawi College of Medicine and the Liverpool School of Tropical Medicine Research Ethics Committee.

Funding

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Data sharing

The data supporting results of this study will be available on request from the Malawi Liverpool Wellcome Trust Clinical Research Programme's data department by emailing this address: sdsm@mlw.mw. We do not intend to make the data publicly available because the consent from our participants and approvals from the ethics committees did not cover data sharing.

Patient involvement

Patients were involved in the design of the participatory workshops. The methodology allowed for participants to take the lead and decide on which exercises

would be used during the days. We also involved patients in deciding how to disseminate findings.

RESULTS

A total of 11 men and 12 women participated in the participatory workshops and we conducted 30 interviews (15 men and female 15 women) table 1 provides a breakdown of demographic details of participants.

Table 1: participant demographics

Characteristics	Category	Number
Gender	Male	15
	Female	15
Age	18-34years	15
	35 & above years	15
Education	No school or primary level	22
	Secondary level	6
	College level	2
Occupation	Piece work (Brick laying, molding bricks, etc.)	10
	Self-employed (Tailoring, welding/fabrication, painting businesses, etc.)	5
	Petty trading (Selling tomatoes, charcoal, etc.)	12
	No occupation (Looking for job)	3

We present the results in two sections. The first section explores the barriers men identified as shaping their decision to seek care. In the second section, we explore potential interventions that arose from the qualitative interviews and PWs, including those to address factors at the structural level. Table 2 provides a summary of the study findings.

Table 2: summary of study findings

Barriers to health-seeking

- Precarious economic conditions:
 - Household economic instability including poverty and lack of money for food and for paying children school fees
 - Difficult working conditions including work with no paid sick leave and the risk of losing income if visit the clinic and stay out of work
- Gendered social norms
 - Masculine ideas of stoicism that men should be strong and perceiving help-seeking as a sign of weakness resulted in delayed or no treatment seeking at all
 - Social expectations of men as household providers meant that men prioritised work over their health
- Constraints within the health system
 - Previous experience of drug stockouts meant that people tended to rely on other sources of medication such as visiting private clinics or buying from pharmacies or groceries
 - Poor provider-patient relations including harsh treatment by staff also discouraged people from visiting the clinic
 - Long distances to the clinic and long waiting times at the clinic were also attributed to why people did not visit the clinic

Interventions to improve men's pathways to care

- Labour legislation
 - The need for labour laws that protect casual workers' health rights, for example providing them with paid leave entitlements
- Patient welfare support
 - Introducing hospital audit systems for policing providers' behaviours towards patients, including a toll-free line or a welfare office where maltreatment can be reported
- Engaging local leadership
 - Working with village chiefs through developing and enforcing by laws that promote formal health utilization and discourage non-biomedical practices such as faith and traditional healing
- Health and civic education

- Implementing public awareness campaigns and health education programmes to facilitate cultural reforms and uptake of formal health

Barriers to health-seeking

From our data we identified three inter-connected thematic areas that shaped men's health seeking behaviour: precarious socioeconomic conditions; gendered social norms; and constraints in the health system.

Precarious socioeconomic conditions

One of the central themes throughout the data collection was the high levels of poverty experienced across participants' households. This shaped household survival and in turn constrained the agency that men and women had over prioritising health-seeking. Men and women at times had contrasting views about who was responsible for the survival of the household. Nearly all men saw their labour as vital, but some women also described the key role their businesses played in generating income.

All the participants described economic instability in their households. Most men worked in *ganyu* or casual "piece work" (examples of these roles include moulding or bricklaying, off-loading trucks or ploughing fields). *Ganyu* labour was physically demanding, very poorly paid and rarely secured beyond a single day. Most of the female participants engaged in small business that generated some income, but success depended on accessing capital and profits were often precarious.

In households in Bangwe, managing food insecurity was central to many household decisions. Men argued that insufficient household income constrained their agency to seek care because missing work would lead to short-falls in income and a lack of food. Most participants rented and the pressure to pay rent was often a further of tension. Both men and women, described how stressful – and at times hopeless – the grinding poverty they experienced in their day-to-day lives made them feel. This is represented in the quote below:

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3 It's been a very difficult life because nothing works to our plans. Whatever we
4 do now is just so we have food for the day. When we go to bed, we don't
5 know what tomorrow holds for us, what we are going to eat [...] it's very
6 challenging [...] now is about month end and the landlord will soon be asking
7 for his money. **[Male participant, IDI018]**
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14 While treatment at the Ministry of Health-operated Bangwe Health Centre was free,
15 men still articulated that seeking care placed an economic burden on the household
16 and the economic instability of relying on casual labour left men and families in
17 extremely challenging economic situation. For example, visiting the hospital ran the
18 risk of losing income for the day:
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25 The challenge with piece works is you can't go to the hospital when you are
26 unwell because going to the hospital means you won't be able to make
27 money, and if you won't be able to make money, you won't eat [...] So,
28 wondering what you are going to eat if you miss work you go to work despite
29 being sick. If you depend on business for food for the day, it means you have
30 you have to go to town even when you are sick. **[Male participant, IDI019]**
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36 Similarly, insecurity of casual employment meant that workers had no formal rights,
37 including no provision for sick leave, *ganyu* workers without legal protection. If men
38 took time off to seek care, they also faced the threat of their work being terminated.
39 In the quote below, the male participant discusses how continual absences due to ill-
40 health could mean a loss of their job.
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46 [...] most companies don't pay you when you miss a day of work. If you are
47 sick and want to go to a clinic, it's very hard for them to allow you time off.
48 You may take a day off on your own without permission, hoping that you will
49 show them a medical report, but most employers don't accept that. They
50 shout at you, insult you, and cut your pay [...] my colleague at work developed
51 a heart failure problem because of being in contact with chemicals. His heart
52 wasn't functioning properly, and every week he would have a day off work.
53 This caused him to have problems with his bosses to a point that they sacked
54 him. **[Male participant017, IDI]**
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5 During the PWs with men, the relational aspects of employment were raised by the
6 group. When men did not go to work due to sickness, they described being
7 disciplined by their employers. In one scene, men acted out an exchange between a
8 *bwana* (the boss) and a man requesting time off because they are sick. The *bwana*
9 was extremely rude to the man and told him not to return to work if he went to the
10 hospital. Such restricting labour conditions create barriers to early care-seeking for
11 men with symptoms of TB.
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17 18 19 **Gendered social norms**

20 Gendered hierarchies shaped men's well-being and lives in complex ways. Men's
21 decisions around their health were shaped by the precarious economic position of
22 households in Bangwe. However, broader social norms also shaped men's
23 behaviour. Enduring illness and suffering in silence was one-way man could
24 demonstrate strength to himself and others. Men described needing to present as
25 themselves as strong not just in their household and workplace but also to the wider
26 community. These masculine beliefs of stoicism also appeared in perceptions of
27 women as being more vulnerable to sickness and had weaker immunity. The quote
28 below may likely be allegorical, referring to a broader range of illnesses than just a
29 stubbed toe:
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38 [...] I could say his blood is different from mine. When he stumbles so much
39 blood comes out but the toe does not take many days to heal. But when I
40 stumble my toe takes one or two weeks to heal. **[Female participant, IDI011]**
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43 Ideas of men being more resilient to illness also appeared to be linked to perceptions
44 about illness and severity. Men described a pattern of waiting and seeing if their
45 condition worsened before they sought care, and only going to formal health care
46 when illness was at an advanced stage. Inability to physically carry on particularly to
47 go to work prompted seek care. Further, if the illness episode continued for a longer
48 period of time, it signalled severity and stimulated decisions about seeking care.
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56 [...] if there's ever been a time that I was seriously sick then it is now. Other
57 than this time, I have never been sick to a point where I could just stay
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3 indoors. Whenever I am sick, usually it's diarrhoea and it doesn't last, maybe
4 only for 2 days, and I still go to town [...] **[Male participant, ID1009]**
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8 **Use of alternative medicine to biomedical care**

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10 The decision to seek medical care was also shaped by the belief in a higher power
11 and a pre-determined path. As one male participant said, "*I will just stay at home; if*
12 *it's death so be it, it's God's will if I die.*" The fatalistic statement reflects a sense of
13 spirituality that embraces death and illness as God-predestined, and thus disputes
14 the relevance of seeking medical attention.
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20 Some men and women described attending churches where seeking biomedical
21 care violated the doctrine of the church. They reported pastors operating in the area
22 who would heal patients and discourage them from further engagement in bio-
23 medical care. The following quotes demonstrates the complex interactions between
24 church and faith healing shape, and health seeking behaviour.
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30 Pastors tell patients to stop treatment and believe that they will be healed
31 after praying for them. They also tell people not to go to the hospital when sick
32 instead they should just believe [in God]. **[Female participant PW005]**
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38 Further, participants also discussed people diagnosing and treating illness using
39 traditional techniques, and cited dependence on traditional healing as preventing
40 people from utilising formal health services.
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45 Another problem that stops people from visiting the hospital is belief in
46 traditional medicine. There are people that trust traditional medicine and
47 oppose seeking treatment from the hospital. **[Male participant, PW003]**
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51 **Gendered power relations and the household**

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53 The ideas of power and household dynamics were explored in the workshops with
54 women, being asked to make images (still body sculptures) of men who live in
55 Bangwe. The women created images either of men at work or at leisure. This was in
56 contrast to images women made of themselves either performing household work or
57 praying. The images of men alluded to higher literacy levels, access to free time and
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3 money either buying alcohol or using their mobile phones. The images created
4 reveal rigid gendered divisions of labour where the man hold both the responsibility
5 to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys
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10 During the workshops, men and women's decision-making power within the
11 household was often discussed. The centrality of men's power over women, was
12 both overtly, and covertly articulated, with women more financially dependent for
13 their survival and the survival of their children. Women described how their economic
14 dependency left them vulnerable to violence, which could take different forms but
15 included emotional, economic or physical violence. This was initially hard to talk
16 about, and not directly mentioned; but after a role play that featured violent physical
17 responses from husbands, participants began to share the risks they might face.
18 This in itself is indicative of the unspoken power that men often hold.
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26 One aspect we centred discussion was whether women could discuss their
27 husband's health with him, and whether they could suggest taking action, such as
28 going to the clinic to seek treatment for a persistent cough. Both men and women
29 described how the ability to discuss their husband's health and decision-making
30 depended on the dynamics of the relationship. For some women and men, asking
31 their husband about his health or advising them could lead to angry exchanges, as
32 men perceived taking advice could put them in a weaker position:
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41 [...] You don't have to listen to a woman every time she suggests something
42 to you. Sometimes you have to ignore what she says. If she talks to you
43 [about seeking treatment] and you listen, she doesn't take you seriously or
44 respect you anymore, she puts a 'hedge around you' and commands you at
45 will. Once she commands you, you are no longer respected as a man. So you
46 need to be stubborn a bit, showing you're a man. **[Male participant, ID1024]**
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53 Due to the economic dependency of the household, women also articulated their
54 concern about men seeking care and missing work, as this would have a further
55 impact on the family.
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3 If we have children and the husband has been sick maybe for a week, you
4 say this man needs to go and work. Maybe [because] you have gone days
5 without eating and the bodies are weak [...] this happens in families. For
6 instance, my husband may come back from work feeling really sick with body
7 pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay
8 here at home?' [...] **[Female participant, PW011]**
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14 However, both male and female groups referred to the changing roles of women in
15 the household in Malawi that were challenging traditional notions of power and
16 household decision-making roles. The increasing number of women in urban
17 Bangwe owning small businesses gave them an independent income and brought
18 greater decision-making power. This is articulated in the quote below:
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23 Women are also making decisions in the household when they have access
24 to finances, but those that are dependent on men easily accept [whatever
25 their male partner decides] **[Female participant, PW015]**
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31 **Constraints in the health system**

32 Previous encounters at the health centre, often left men feeling angry and
33 marginalised. Long waiting times, poor treatment by health care staff and chronic
34 shortage of medicines drove men to seek delay care or seek out alternatives. Men
35 and women were particularly angry at the treatment they received by clinicians, at
36 best they saw health workers as rude and dismissive and at worst, violent. Examples
37 of the cruel treatment included scoffing or ignoring patients and not allowing patients
38 to explain their illness:
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46 Sometimes doctors are not speaking politely, they are harsh and treat you as
47 though you were not humans. Some of them go out to chat to each other,
48 where they laugh and do things of their own. Like today, as we were collecting
49 drugs, one of them said, "You men are looking at me! You should look down.
50 Why are you looking at me?! Some of you do not bath!" You find people
51 swearing: "I should come here again?!" **[Female participant, IDI001]**
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3 The lack of drugs, long waits and short consultations often impacted on men's
4 decision to seek care. Men were unhappy about committing to spending a day going
5 to the clinic when they could buy drugs from the grocery store and return to work.
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10 ...people feel discouraged by what happens at the clinic: "I should go there,
11 climb that hill, just so they can give me Bactrim?" Because you expect to get
12 better treatment when you go there: "I thought they were going to inject me."
13 But they only give you Panadol when you go there. So you say "I just wasted
14 my time last time, it is better that I buy from the shops." **[Female participant,
15 IDI013]**
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21 The organisation of the clinic, including specific treatment days and separate lines,
22 particularly for HIV also made men fearful of seeking care, as they were concerned,
23 they would be identified and treated differently in the community. Bangwe health
24 centre is at the top of a steep hill and many participants had to walk long distances
25 and climb a steep hill. If they wanted to use transport this would further impact the
26 household finances:
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32 Sometimes the challenge is transport, you can't walk to the clinic, so you just
33 sit at home. If you have some money, you are able to visit the clinic, because
34 there are lots of minibuses or bicycle taxis out there. **[Male participant,
35 IDI024]**
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40 Although, it is important to note some men and women only trusted the government
41 hospitals to provide the correct diagnosis.
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44 [...] the hospital is where you can get a diagnosis of your sickness. Because
45 on your own you might think it is TB yet it's something else showing
46 symptoms of TB. [...] you might be sick and still be unaware of what you are
47 sick with. **[Male participant, IDI008]**
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52 53 54 **Interventions to improve men's pathways to care**

55 In this section we present findings around interventions identified by participants
56 during the participatory workshop to improve men's pathways to care. The
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3 suggestions from participants included: labour rights legislation; patient welfare
4 support system; and drawing on local leadership to encourage men to seek care.
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8 As we have demonstrated above, men's pathways to care are shaped by complex
9 intersecting inequalities, with poverty intersecting with gendered social norms to
10 shape many decisions. Working conditions associated with temporary work –
11 including the absence of sick leave and lack of labour law protections – and the fear
12 of losing vital income and dismissal from work were all important factors in shaping
13 care-seeking behaviour. For these work-related barriers participants proposed
14 improved employment legislations that provided and safeguarded rights for workers.
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22 We feel that the government should provide and stiffen laws against bosses
23 that subject their workers to maltreatment so that if they are found ill-treating
24 the workers they should be punished. Also, the government should ensure
25 that all workers are on medical scheme like MASM, and it should be
26 compulsory that each and every worker should be under a medical
27 scheme [Male participant, PW002]
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33 Trust in the health system and concerns about the way health practitioners treated
34 patients shaped decisions to seek care. One intervention proposed to address this
35 barrier was the establishment of a reporting system where patients could report their
36 concerns about health care workers. Suggestions made by participants included a
37 toll-free line or a welfare office where patients could report maltreatment.
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44 We're thinking that maybe setting up offices right at the health facility where
45 people could forward their complaints to the senior clinic staff. There should
46 be toll free numbers to call the senior members of staff. The senior staff would
47 then figure out how to help you. The other thing is punishing the doctors,
48 maybe ill-treatment might stop. [Male participant, PW006]
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53 During the workshops, participants described how reliance on faith healing and
54 traditional medicine acted as a barrier to seeking the "right" care. This framing was
55 presented by participants as a problem that needed to be dealt with. This may in
56 part, of been a response to the researchers' positionalities – coming from a well-
57 known health research organisation. Some participants suggested punitive
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3 measures, with chiefs imposing fines on people who use non-biomedical services.
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5 However, other participants argued that educationally oriented interventions that
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7 would foster gradual cultural reforms and adoption of formal health practices and
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9 behaviours. One of the suggestions that came out was implementing public
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11 awareness campaigns and civic education programmes on health matters.
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14 I believe that each one of us have their own traditions. So, we cannot leave
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16 something that is deep rooted in our society. Just deciding from nowhere that
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18 we have a decree that no one should ever use traditional medicine. I'm
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20 thinking of education so that we gradually move away from it [informal health
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22 practices] rather than introducing laws. Sometimes that's when people do it
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24 more when it's prohibited. While people are using traditional medicine, those
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26 that know about modern medicine should with evidence civic educate those
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28 that don't know. Then people will on their own start using these helpful
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30 methods. Laws are good indeed but sometimes do not work. **[Male
31
32 participant, PW004]**

33
34 Financial support for seeking medical care commonly emerged as most suitable for
35
36 addressing the economically related barriers. Opportunities for support included the
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38 government and NGO partners as potential sponsors. They felt the money would
39
40 compensate transport costs and loss of income that people normally incurred when
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42 accessing the clinic.

43
44 Refunding the money patients spend on transport to the clinic could help with
45
46 the problem of people not visiting the clinic when they are sick. Like for me
47
48 today I would not have come had my wife not told me that you were going to
49
50 refund my transport fee. I was encouraged by the news of the refund... So, if
51
52 you refund transport, it will help to some degree. **[Male participant, IDI002]**

53
54 Participants also explored different ways in which communities could establish their
55
56 own social safety nets without dependence on external support. They considered a
57
58 village fund where villagers contributed a small amount as one of the ways of
59
60 organizing safety nets.

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3 [...] encouraging chiefs to set up small funds where all the members of the
4 community contribute K20 even K50 or K100. We can manage that amounts.
5 So when someone is in need we should use the money to get them to the
6 hospital. Rather than waiting for an ambulance from the office. Because
7 sometimes it becomes difficult for the ambulance to come. **[Male participant,**
8 **PW002]**
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15 Participants also considered outreach services as an alternative strategy to increase
16 access to healthcare for men, this would take away one of the financial barriers:
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20 Another way would be seeing people in their homes because some don't have
21 means of transport and struggle to get to the clinic. So meeting and speaking
22 to them in their homes might help. **[Male participant, IDI002]**
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27 Discussion

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29 Our study which drew on qualitative and participatory research methods and found
30 care seeking decisions for men were shaped by gender power relations which
31 intersected with economic instability within the household and insecure employment.
32 Food insecurity was a significant and ongoing concern for all household members,
33 but for men their gendered roles and viewing themselves as providers within the
34 household were preformed through significant delays in care seeking. Family
35 structures often meant that women depended on men's labour and speaking to them
36 directly about care-seeking was challenging. Urban capitalism, which was introduced
37 by the British colonial rulers reconfigured family structures and increased women's
38 reliance on men's wage labour. Employment rights were very weak, and left men
39 with little opportunity to take sick leave to visit the clinic. Weaknesses and
40 constraints within the health system further exacerbated men's delays in seeking
41 treatment.
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53 Drawing on a participatory methodology allowed participants and researchers to
54 work together to co-create interventions. Key interventions to address barriers to
55 care seeking identified and developed by PW participants included interventions at
56 the individual level and the broader structural level. At the individual level,
57 interventions included changing behaviour through targeted civic education
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3 programmes directed at men to encourage them to seek bio-medical care. At the
4 structural level, interventions included improved labour regulations, including
5 protection from dismissal if men did seek care, and payment of sick leave. The need
6 for somewhere to take their grievances such as the labour office were seen as
7 important to ensure compliance by employers. Safety nets system that supported
8 households when a household member was sick to allow them to seek care was also
9 identified as a priority.
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17 The Gender Inequality Index (GII), demonstrates that Malawi is very unequal country
18 with men favoured in a range of indicators. Men are afforded more power and
19 privilege than women, with greater access to education and financial resources.
20 However, this has not translated into better health outcomes. This reflects global
21 trends from UK, to Central Asia and Southern Africa of men delaying health care
22 seeking (16,17,36,37) that echoed our own findings. In the literature on TB, findings
23 from ethnographic research undertaken in Khayelitsha Cape Town, which found a
24 range of factors shaped men's care and adherence to treatment, lack of food and
25 economic constraints were identified reflecting those found in our study (38). In
26 Kenya, ethnographic work found that treatment seeking was delayed by individual
27 (39), social-cultural and structural factors. Chikovore et al (2014 and 2017) in urban
28 Blantyre that men's need to be perceived as strong meant they would delay seeking
29 care. They also found that the association between TB and HIV meant men would
30 delay care seeking due to associated stigma from HIV.
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43 In a review of health outcomes, Sverklik (2011) found that across the globe, people
44 living in informal settlements suffer disproportionately from ill-health throughout their
45 life course. These patterns of ill-health can be observed from birth with cramped and
46 poor quality housing, poor access to water and sanitation and limited access to
47 public services including health care shaping health outcomes (40). We see these
48 social and political configurations present in Bangwe, shaping household decision
49 making. Structural interventions act to change the context in which health is
50 produced and reproduced are gaining greater attention in public health (41). In
51 context of urban Blantyre where weak legislative frameworks leave workers with very
52 few rights require urgent attention. At present, TB control in Malawi predominantly
53 depends on men and women presenting at the clinic with symptoms and then being
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3 referred for treatment. This approach is leading to men delaying care seeking. Our
4 findings and interventions speak to the need for interventions, not only to strengthen
5 health systems and community-based TB active case finding interventions but also
6 to intervene to address upstream factors including providing support for men to take
7 time off work.”
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13 **Study limitations**

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15 The study had a number of limitations. Firstly, there were limitations to the way
16 participants were identified and recruited. By recruiting participants through
17 screening women at Bangwe clinic we may only have included those groups who
18 had the economic means to visit the clinic and may have missed poorer and groups
19 that were more difficult to recruit. Secondly, we were not able to include all
20 participant from the first phase of the study into the next phase and included
21 additional participants through snowballing. The iterative nature of the two-stage
22 approach was to allow participants time to reflect on the study questions, by only
23 including some of the participants in the second stage this may have meant
24 participants were more inhibited in what they shared.
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34 In summary, by generating knowledge and understanding with community members
35 in urban Blantyre, Malawi, we identified three inter-connected thematic areas that
36 shaped men’s health and TB seeking behaviour, and potentially contribute to high
37 levels of ongoing transmission in these settings: precarious socioeconomic
38 conditions; gendered social norms; and constraints in the health system. Insecurity
39 of day labour with no provision for sick leave; pressure to provide for the household
40 and a gendered desire not to appear weak and a severely under-resourced health
41 system all contributed to men delaying care-seeking. Interventions identified and
42 developed by participants included targeted civic education programmes, improved
43 patient-provider relations within the health-system and legislation to ensure worker
44 rights to sick pay, and broader social support for households.
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54 **Conflict of interest declaration**

55 The authors declare that there is no conflict of interest.
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60 **Author contributions**

Author	Contribution/Role in the study
Mackwellings Phiri	Data collection, Analysis, Paper writing
Effie Makepeace	Data collection, Paper review
Margaret Nyali	Data collection and analysis
Moses Kumwenda	Study design, data collection and analysis support
Elizabeth L Corbett	Study design and paper writing
Katherine Fielding	Study design and paper writing
Augustine T Choko	Study design and paper writing
Peter MacPherson	Study design, analysis and paper writing
Eleanor E MacPherson	Led the study, designed, analysed and supported paper writing

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For peer review only

Research Checklist

#1	<p>Title</p> <p>Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended.</p>	<p>Page 1</p>
#2	<p>Abstract</p> <p>Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions.</p>	<p>Page 2</p>
#3	<p>Introduction</p> <p>Problem formulation</p> <p>Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement.</p>	<p>Pages 4, 5</p>
#4	<p>Purpose or research question</p> <p>Purpose of the study and specific objectives or questions.</p>	<p>Page 6</p>
#5	<p>Methods</p> <p>Qualitative approach and research paradigm</p> <p>Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The</p>	<p>Pages 6, 7</p>

	<p>rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.</p>	
#6	<p>Researcher characteristics and reflexivity</p> <p>Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability.</p>	
#7	<p>Context</p> <p>Setting / site and salient contextual factors; rationale.</p>	<p>Page 5</p>
#8	<p>Sampling strategy</p> <p>How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.</p>	<p>Pages 6, 7</p>
#9	<p>Ethical issues pertaining to human subjects</p>	<p>Page 7</p>

	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	
#10	<p>Data collection methods</p> <p>Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale.</p>	Pages 6, 7
#11	<p>Data collection instruments and technologies</p> <p>Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study.</p>	Page 7
#12	<p>Units of study</p> <p>Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results).</p>	Pages 8, 23
#13	<p>Data processing</p> <p>Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts.</p>	Page 7

#14	<p>Data analysis</p> <p>Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.</p>	Page 7
#15	<p>Techniques to enhance trustworthiness</p> <p>Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.</p>	Page 7
#16	<p>Results/findings</p> <p>Syntheses and interpretation</p> <p>Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.</p>	Pages 8-17
#17	<p>Links to empirical data</p> <p>Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.</p>	Pages 9-17
#18	<p>Discussion</p> <p>Intergration with prior work, implications, transferability and contribution(s) to the field</p>	Pages 17-24

	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field.	
#19	Study strength and Limitations Trustworthiness and limitations of findings.	Page 3
#20	Other Conflicts of interest Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed.	Page 20
#21	Funding Sources of funding and other support; role of funders in data collection, interpretation and reporting.	Page 8
#22	Author contributions Role of each other in the study and their contributions	Page 20

BMJ Open

Improving pathways to care through interventions co-created with communities: a qualitative investigation of mens' barriers to tuberculosis care-seeking in an informal settlement in Blantyre, Malawi

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3 **Title: Improving pathways to care through interventions co-created with**
4 **communities: a qualitative investigation of mens' barriers to tuberculosis care-**
5 **seeking in an informal settlement in Blantyre, Malawi**
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Abstract

Introduction

Men have a higher prevalence of undiagnosed tuberculosis (TB) than women and can spend up to a year longer contributing to ongoing transmission in the community before receiving treatment. Health outcomes are often worse for TB patients living in informal settlements especially men. This study aimed to understand the barriers preventing men from seeking care for TB and co-create interventions to address these barriers.

Methods

We used qualitative research methods including in-depth interviews and participatory workshops. Researchers worked with women and men living in Bangwe, an informal settlement in Blantyre, Malawi to develop interventions that reflected their lived realities. The study took place over two phases, in the first phase we undertook interviews with men and women to explore barrier to care seeking, in the second phase we used participatory workshops to co-create interventions to address barriers and followed up on issues emerging from the workshops with further interviews. In total, 30 interviews were conducted, and 23 participants joined participatory workshops. The team used a thematic analysis to analyse the data.

Results

Three inter-connected thematic areas shaped men's health TB seeking behaviour: precarious socioeconomic conditions; gendered social norms; and constraints in the health system. Insecurity of day labour with no provision for sick leave; pressure to provide for the household and a gendered desire not to appear weak and a severely under-resourced health system all contributed to men delaying care in this context. Identified interventions included improved patient-provider relations within the health-system, improved workers' health rights and broader social support for households.

Conclusion

Improving men's pathways to care requires interventions that consider contextual issues by addressing individual level socioeconomic factors but also broader structural factors of gendered social dynamics and health systems environment.

Article summary

Study strengths and limitations

- In-depth interviews provided participants with an opportunity to articulate their individual experiences in their own words.
- Participatory workshops took an art-based approach and used theatre as a research method in conjunction with group discussions, enabling participants to express and then reflect together
- The theatre-based approach allowed for generating new insights and critical understanding through participants embodied participation, allowing them to present their lived realities and to collectively explore them
- We worked separately with men and women before bringing the two groups together, allowing for open discussion of potentially sensitive gender norms and behaviours
- Interventions identified will need to be tested to understand effectiveness co-created interventions

INTRODUCTION

Tuberculosis (TB) is the leading infectious cause of adult death worldwide (1). Approximately 10 million people become ill with TB each year, with a further 1.5 million people die of TB annually (2). Countries in sub-Saharan Africa – like Malawi – have experienced extremely high incidence of TB, driven by generalized HIV epidemics and poverty (3,4). Concerted global action to end the TB pandemic by 2030 has galvanized around key targets, including Target 3.3, of the Sustainable Development Goals (SDGs).

Despite global recognition of the need for urgent action on TB, progress towards meeting global targets remains unacceptably slow. An estimated 3.6 million people are either not diagnosed or reported to national TB programmes each year (5). Intensified efforts to identify, evaluate and implement interventions that reflect the lived realities of affected communities are urgently needed.

Prompt recognition of people with active TB and initiation of effective anti-tuberculosis treatment are vital to improve treatment outcomes and reduce transmission. Studies in many countries indicate significant delays exist in seeking care among people subsequently diagnosed with TB. In Malawi, substantial patient delays have been recorded (6), with severe deterioration in health following a prolonged period of symptoms often preceding health facility presentation (7,8). The direct costs including transport and loss of work days often impacted low income households (9). Social stigma caused by a widely-held perception that a TB diagnosis indicates HIV infection may also lead to delays in health seeking (10).

Men are disproportionately-affected by TB, with the prevalence of undiagnosed infectious TB among men two times higher than among women (11). In Malawi, men spend on average one year longer than women with undiagnosed TB in the community (11) and are likely to be responsible for upwards of two-thirds of all TB transmission events in Africa (12). Improving timely diagnosis of TB is therefore likely to have substantial health benefits for men, women and children.

The substantially higher burden of TB among men compared to women reflects broader patterns of morbidity and mortality data across the world, with women on

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3 average living 4.6 years longer than men (13). These patterns are in part shaped by
4 biological factors. However, the socio-cultural construct of gender also plays an
5 important role in explaining these differences (14). The WHO defines gender as “the
6 roles, behaviours, activities, attributes and opportunities that any society considers
7 appropriate for girls and boys, and women and men. Gender interacts with, but is
8 different from, the binary categories of biological sex” (15). Central to the concern of
9 gender is the hierarchical power relations that shape relationships between different
10 groups of people.
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18 Since the 1990s, critical gender theories have increasingly focused on how gender
19 shapes men’s health and well-being (13,16–18). Connell (2011) suggests that
20 gender has a materialist orientation, understood in terms of practices (what people
21 actually do) rather than what is expected (18). This moves gender beyond being a
22 fixed set of values or norms, to something that is produced and reproduced in
23 everyday practice (18). The theoretical framing of this paper draws on both critical
24 gender theory to understand barriers men’s care seeking for TB with the overall
25 purpose to identify interventions to address these barriers.
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34 **METHODS**

35 ***Study context***

36 Malawi is considered a low-income country ranking 171st out of 189 countries on the
37 United Nations Development Programme (UNDP) human development index (19).
38 Approximately 80% of Malawi’s population undertake subsistence farming, with
39 maize being the dominant crop. A recent survey by Afrobarometer found that Malawi
40 was one of the most food insecure countries in Africa (20). An estimated 38% of
41 Malawian’s live below the poverty line and 47% of children are stunted (21). In
42 comparison to other countries, urbanisation has been slower in Malawi and a
43 majority of the population (84%) reside in rural areas (22).
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53 This study was situated in Bangwe Township, an informal settlement on the eastern
54 outskirts of Blantyre City, Southern Malawi. The formation of Bangwe dates back to
55 colonial rule, when Native Africans were considered too primitive for urban dwelling.
56 They were instead forced to live on the periphery of the city in townships that were
57 referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas
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3 during the colonial period led to densely over-crowded informal settlements.
4 Following independence in 1964, traditional housing associations were established
5 in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial
6 ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little
7 access to basic amenities. The historical formation continues to shape the lives of
8 residents as access to public services remain extremely limited and overpopulation
9 an ever-growing challenge. British rule also brought the introduction of urban
10 capitalism changing family configurations and gendered norms (25). There was
11 increasingly nucleated family and a greater dependency of women on their
12 husbands' wage labour. It also physically relocated women away from their land
13 making access to food sources more challenging (26). Today, Malawi ranks 172 out
14 of 189 countries making it one of the most unequal countries in the world (27).

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26 Malawi's health system is pluralistic, with government, private and faith-based
27 organisations providing services. The government sector being the only services
28 provided free at the point of use (28). Primary health centres are important entry
29 points for health service provision, with most TB diagnosis and treatment services
30 being integrated at this level.
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36 **Study design**

37 This study aimed to understand barriers and develop interventions to improve
38 pathways to diagnosis and care of TB for men living in an informal settlement in
39 urban Blantyre. We used qualitative study design (in-depth interviews) and
40 participatory workshops (PWs). In-depth interviews (IDIs) were selected because
41 they provided participants with an opportunity to articulate their experiences in their
42 own words (29). PWs took an art-based approach and used drew on Theatre of the
43 Oppressed (TO) as a research method in conjunction with group discussions. TO is
44 a participatory theatre making methodology developed by Augusto Boal (30,31)
45 which includes techniques such as Image Theatre and Forum theatre. In our study,
46 games and exercises were used to break down barriers between participants and
47 the research team, before using Image Theatre. Participants made still images with
48 their bodies to explore gender norms, experiences of sickness and healthcare, which
49 were then discussed as a group. The process continued by developing role plays
50 and finally a Forum Theatre performance for the study team which demonstrated
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3 some of the challenges of men seeking healthcare, and gave opportunities for the
4 audience to suggest and try out different solutions onstage. To allow for open
5 discussion of potentially sensitive gender norms and behaviours these PWs initially
6 divided groups by gender, working separately with men and women before bringing
7 the two groups together to make the performance.
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13 **Data collection**

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15 Data collection took place between January 2019 until October 2019, using in-depth
16 interviews and participatory workshops. The study team used a short screening tool
17 to identify women attending the Bangwe Primary Clinic who reported their partners
18 had a persistent cough (defined as a cough lasting more than two weeks). We then
19 asked if they would consent to an interview; following the interview we also asked if
20 they would be happy for us to contact their partners. Eleven women and 10 men
21 participated in the initial interviews; we stopped interviews when no further themes
22 arose. After analysing the data from the interviews and themes relating to men's
23 treatment barriers had been identified, we held participatory workshops to further
24 discuss the barriers and to identify and prioritise potential interventions to these
25 barriers. PWs happened over a one-week period, with each day split into five hourly
26 discussion sessions. We invited all participants from the in-depth interviews to join
27 the workshops, but nine were not available. So, we used snowballing techniques
28 with our recruited participants to identify men and women living in Bangwe who were
29 willing to participate in the PWs. Following the workshops, we invited participants
30 who hadn't previously been interviewed to attend an interview. Median (IQR) ages by
31 sex for the 30 study participants were 34 (23-42) years for women and 37 (26.5-
32 62.5) years for men. Interviews were conducted in a private room within the research
33 office in the clinic and lasted between one hour and 45 minutes. All interviews and
34 PW discussions were conducted in the local language (Chichewa) and audio
35 recorded.
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53 The research team comprised of two Malawian (one female master's student and
54 one male researcher employed by the Research Institute who sponsored the study)
55 and two white British women both from the UK. Our levels of education, sex,
56 economic position and race (in the case of EM and EMACP) are likely to have
57 shaped our interactions with the participants. MP interviewed some of the female
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3 participants and were a mixed team when we conducted the female workshops. As a
4 research team, we all have significant experience of conducting research (3 of the 4
5 researchers with more than 10 years each). Following each interview and at the end
6 of each day of the participatory workshops, we held debriefing sessions. During
7 these sessions we reviewed emerging findings and identifying areas requiring further
8 exploration. We also focused on how participants responded to the questions and
9 whether we may have influenced this.
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17 **Data analysis**

18 Data were analysed using a thematic analysis (32). Audio recordings were
19 transcribed verbatim, translated into English, and imported into NVIVO10 software to
20 facilitate organization and analysis. Transcripts were read and re-read for
21 familiarization. Transcripts were then coded inductively (33). MP and EMACP each
22 coded an initial sample of transcripts, before comparing interpretations, and merging
23 their separately generated coding frames. We used the merged coding frame to
24 code further transcripts, iteratively modifying the frame as new data were analysed.
25 We had frequent debriefing sessions to ensure we agreed with interpretation of the
26 data and analysis summaries (34).
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36 **Ethical approval**

37 Participants provided informed consent, either written or witnessed thumbprint.
38 Consent was taken at the start of each interviews and at the start of the week of
39 participatory workshops and reviewed each day with participants. Ethical approval
40 for the study was granted by the University of Malawi College of Medicine and the
41 Liverpool School of Tropical Medicine Research Ethics Committee.
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48 **Funding**

49 This study was funded by the MRC/DFID/Wellcome Joint Global Trials Scheme with
50 the grant number MR/R019762/1.
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55 **Data sharing**

56 The data supporting results of this study will be available on request from the Malawi
57 Liverpool Wellcome Trust Clinical Research Programme's data department by
58 emailing this address: sdsm@mlw.mw. We do not intend to make the data publicly
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available because the consent from our participants and approvals from the ethics committees did not cover data sharing.

Patient involvement

Patients were involved in the design of the participatory workshops. The methodology allowed for participants to take the lead and decide on which exercises would be used during the days. We also involved patients in deciding how to disseminate findings.

RESULTS

A total of 11 men and 12 women participated in the participatory workshops and we conducted 30 interviews (15 men and female 15 women) table 1 provides a breakdown of demographic details of participants.

Table 1: participant demographics

Characteristics	Category	Number
Gender	Male	15
	Female	15
Age	18-34years	15
	35 & above years	15
Education	No school or primary level	22
	Secondary level	6
	College level	2
Occupation	Piece work (Brick laying, molding bricks, etc.)	10
	Self-employed (Tailoring, welding/fabrication, painting businesses, etc.)	5
	Petty trading (Selling tomatoes, charcoal, etc.)	12
	No occupation (Looking for job)	3

We present the results in two sections. The first section explores the barriers men identified as shaping their decision to seek care. In the second section, we explore potential interventions that arose from the qualitative interviews and PWs, including those to address factors at the structural level. Table 2 provides a summary of the study findings.

Table 2: summary of study findings

Barriers to health-seeking

- Precarious economic conditions:
 - Household economic instability including poverty and lack of money for food and for paying children school fees
 - Difficult working conditions including work with no paid sick leave and the risk of losing income if visit the clinic and stay out of work
- Gendered social norms
 - Masculine ideas of stoicism that men should be strong and perceiving help-seeking as a sign of weakness resulted in delayed or no treatment seeking at all
 - Social expectations of men as household providers meant that men prioritised work over their health
- Constraints within the health system
 - Previous experience of drug stockouts meant that people tended to rely on other sources of medication such as visiting private clinics or buying from pharmacies or groceries
 - Poor provider-patient relations including harsh treatment by staff also discouraged people from visiting the clinic
 - Long distances to the clinic and long waiting times at the clinic were also attributed to why people did not visit the clinic

Interventions to improve men's pathways to care

- Labour legislation
 - The need for labour laws that protect casual workers' health rights, for example providing them with paid leave entitlements
- Patient welfare support

- Introducing hospital audit systems for policing providers' behaviours towards patients, including a toll-free line or a welfare office where maltreatment can be reported
- Engaging local leadership
 - Working with village chiefs through developing and enforcing by laws that promote formal health utilization and discourage non-biomedical practices such as faith and traditional healing
- Health and civic education
 - Implementing public awareness campaigns and health education programmes to facilitate cultural reforms and uptake of formal health

Barriers to health-seeking

From our data we identified three inter-connected thematic areas that shaped men's health seeking behaviour: precarious socioeconomic conditions; gendered social norms; and constraints in the health system.

Precarious socioeconomic conditions

One of the central themes throughout the data collection was the high levels of poverty experienced across participants' households. This shaped household survival and in turn constrained the agency that men and women had over prioritising health-seeking. Men and women at times had contrasting views about who was responsible for the survival of the household. Nearly all men saw their labour as vital, but some women also described the key role their businesses played in generating income.

All the participants described economic instability in their households. Most men worked in *ganyu* or casual "piece work" (examples of these roles include moulding or bricklaying, off-loading trucks or ploughing fields). *Ganyu* labour was physically demanding, very poorly paid and rarely secured beyond a single day. Most of the female participants engaged in small business that generated some income, but success depended on accessing capital and profits were often precarious.

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3 In households in Bangwe, managing food insecurity was central to many household
4 decisions. Men argued that insufficient household income constrained their agency
5 to seek care because missing work would lead to short-falls in income and a lack of
6 food. Most participants rented and the pressure to pay rent was often a further of
7 tension. Both men and women, described how stressful – and at times hopeless –
8 the grinding poverty they experienced in their day-to-day lives made them feel. This
9 is represented in the quote below:
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17 It's been a very difficult life because nothing works to our plans. Whatever we
18 do now is just so we have food for the day. When we go to bed, we don't
19 know what tomorrow holds for us, what we are going to eat [...] it's very
20 challenging [...] now is about month end and the landlord will soon be asking
21 for his money. **[Male participant, IDI018]**
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28 While treatment at the Ministry of Health-operated Bangwe Health Centre was free,
29 men still articulated that seeking care placed an economic burden on the household
30 and the economic instability of relying on casual labour left men and families in
31 extremely challenging economic situation. For example, visiting the hospital ran the
32 risk of losing income for the day:
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38 The challenge with piece works is you can't go to the hospital when you are
39 unwell because going to the hospital means you won't be able to make
40 money, and if you won't be able to make money, you won't eat [...] So,
41 wondering what you are going to eat if you miss work you go to work despite
42 being sick. If you depend on business for food for the day, it means you have
43 you have to go to town even when you are sick. **[Male participant, IDI019]**
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50 Similarly, insecurity of casual employment meant that workers had no formal rights,
51 including no provision for sick leave, *ganyu* workers without legal protection. If men
52 took time off to seek care, they also faced the threat of their work being terminated.
53 In the quote below, the male participant discusses how continual absences due to ill-
54 health could mean a loss of their job.
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3 [...] most companies don't pay you when you miss a day of work. If you are
4 sick and want to go to a clinic, it's very hard for them to allow you time off.
5 You may take a day off on your own without permission, hoping that you will
6 show them a medical report, but most employers don't accept that. They
7 shout at you, insult you, and cut your pay [...] my colleague at work developed
8 a heart failure problem because of being in contact with chemicals. His heart
9 wasn't functioning properly, and every week he would have a day off work.
10 This caused him to have problems with his bosses to a point that they sacked
11 him. **[Male participant017, IDI]**

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20 During the PWs with men, the relational aspects of employment were raised by the
21 group. When men did not go to work due to sickness, they described being
22 disciplined by their employers. In one scene, men acted out an exchange between a
23 *bwana* (the boss) and a man requesting time off because they are sick. The *bwana*
24 was extremely rude to the man and told him not to return to work if he went to the
25 hospital. Such restricting labour conditions create barriers to early care-seeking for
26 men with symptoms of TB.
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34 ***Gendered social norms***

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36 Gendered hierarchies shaped men's well-being and lives in complex ways. Men's
37 decisions around their health were shaped by the precarious economic position of
38 households in Bangwe. However, broader social norms also shaped men's
39 behaviour. Enduring illness and suffering in silence was one-way man could
40 demonstrate strength to himself and others. Men described needing to present as
41 themselves as strong not just in their household and workplace but also to the wider
42 community. These masculine beliefs of stoicism also appeared in perceptions of
43 women as being more vulnerable to sickness and had weaker immunity. The quote
44 below may likely be allegorical, referring to a broader range of illnesses than just a
45 stubbed toe:
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53 [...] I could say his blood is different from mine. When he stumbles so much
54 blood comes out but the toe does not take many days to heal. But when I
55 stumble my toe takes one or two weeks to heal. **[Female participant, IDI011]**
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3 Ideas of men being more resilient to illness also appeared to be linked to perceptions
4 about illness and severity. Men described a pattern of waiting and seeing if their
5 condition worsened before they sought care, and only going to formal health care
6 when illness was at an advanced stage. Inability to physically carry on particularly to
7 go to work prompted seeking care. Further, if the illness episode continued for a longer
8 period of time, it signalled severity and stimulated decisions about seeking care.
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15 [...] if there's ever been a time that I was seriously sick then it is now. Other
16 than this time, I have never been sick to a point where I could just stay
17 indoors. Whenever I am sick, usually it's diarrhoea and it doesn't last, maybe
18 only for 2 days, and I still go to town [...] **[Male participant, ID1009]**
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24 **Use of alternative medicine to biomedical care**

25 The decision to seek medical care was also shaped by the belief in a higher power
26 and a pre-determined path. As one male participant said, "*I will just stay at home; if*
27 *it's death so be it, it's God's will if I die.*" The fatalistic statement reflects a sense of
28 spirituality that embraces death and illness as God-predestined, and thus disputes
29 the relevance of seeking medical attention.
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36 Some men and women described attending churches where seeking biomedical
37 care violated the doctrine of the church. They reported pastors operating in the area
38 who would heal patients and discourage them from further engagement in bio-
39 medical care. The following quotes demonstrate the complex interactions between
40 church and faith healing shape, and health seeking behaviour.
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46 Pastors tell patients to stop treatment and believe that they will be healed
47 after praying for them. They also tell people not to go to the hospital when sick
48 instead they should just believe [in God]. **[Female participant PW005]**
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53 Further, participants also discussed people diagnosing and treating illness using
54 traditional techniques, and cited dependence on traditional healing as preventing
55 people from utilising formal health services.
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3 Another problem that stops people from visiting the hospital is belief in
4 traditional medicine. There are people that trust traditional medicine and
5 oppose seeking treatment from the hospital. **[Male participant, PW003]**
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10 **Gendered power relations and the household**

11 The ideas of power and household dynamics were explored in the workshops with
12 women, being asked to make images (still body sculptures) of men who live in
13 Bangwe. The women created images either of men at work or at leisure. This was in
14 contrast to images women made of themselves either performing household work or
15 praying. The images of men alluded to higher literacy levels, access to free time and
16 money either buying alcohol or using their mobile phones. The images created
17 reveal rigid gendered divisions of labour where the man hold both the responsibility
18 to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys
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27 During the workshops, men and women's decision-making power within the
28 household was often discussed. The centrality of men's power over women, was
29 both overtly, and covertly articulated, with women more financially dependent for
30 their survival and the survival of their children. Women described how their economic
31 dependency left them vulnerable to violence, which could take different forms but
32 included emotional, economic or physical violence. This was initially hard to talk
33 about, and not directly mentioned; but after a role play that featured violent physical
34 responses from husbands, participants began to share the risks they might face.
35 This in itself is indicative of the unspoken power that men often hold.
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44 One aspect we centred discussion was whether women could discuss their
45 husband's health with him, and whether they could suggest taking action, such as
46 going to the clinic to seek treatment for a persistent cough. Both men and women
47 described how the ability to discuss their husband's health and decision-making
48 depended on the dynamics of the relationship. For some women and men, asking
49 their husband about his health or advising them could lead to angry exchanges, as
50 men perceived taking advice could put them in a weaker position:
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58 [...] You don't have to listen to a woman every time she suggests something
59 to you. Sometimes you have to ignore what she says. If she talks to you
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3 [about seeking treatment] and you listen, she doesn't take you seriously or
4 respect you anymore, she puts a 'hedge around you' and commands you at
5 will. Once she commands you, you are no longer respected as a man. So you
6 need to be stubborn a bit, showing you're a man. **[Male participant, IDI024]**
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12 Due to the economic dependency of the household, women also articulated their
13 concern about men seeking care and missing work, as this would have a further
14 impact on the family.
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18 If we have children and the husband has been sick maybe for a week, you
19 say this man needs to go and work. Maybe [because] you have gone days
20 without eating and the bodies are weak [...] this happens in families. For
21 instance, my husband may come back from work feeling really sick with body
22 pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay
23 here at home?' [...] **[Female participant, PW011]**
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30 However, both male and female groups referred to the changing roles of women in
31 the household in Malawi that were challenging traditional notions of power and
32 household decision-making roles. The increasing number of women in urban
33 Bangwe owning small businesses gave them an independent income and brought
34 greater decision-making power. This is articulated in the quote below:
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39 Women are also making decisions in the household when they have access
40 to finances, but those that are dependent on men easily accept [whatever
41 their male partner decides] **[Female participant, PW015]**
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45 **Constraints in the health system**

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47 Previous encounters at the health centre, often left men feeling angry and
48 marginalised. Long waiting times, poor treatment by health care staff and chronic
49 shortage of medicines drove men to seek delay care or seek out alternatives. Men
50 and women were particularly angry at the treatment they received by clinicians, at
51 best they saw health workers as rude and dismissive and at worst, violent. Examples
52 of the cruel treatment included scoffing or ignoring patients and not allowing patients
53 to explain their illness:
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3 Sometimes doctors are not speaking politely, they are harsh and treat you as
4 though you were not humans. Some of them go out to chat to each other,
5 where they laugh and do things of their own. Like today, as we were collecting
6 drugs, one of them said, “You men are looking at me! You should look down.
7 Why are you looking at me?! Some of you do not bath!” You find people
8 swearing: “I should come here again?!” **[Female participant, IDI001]**
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16 The lack of drugs, long waits and short consultations often impacted on men’s
17 decision to seek care. Men were unhappy about committing to spending a day going
18 to the clinic when they could buy drugs from the grocery store and return to work.
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23 ...people feel discouraged by what happens at the clinic: “I should go there,
24 climb that hill, just so they can give me Bactrim?” Because you expect to get
25 better treatment when you go there: “I thought they were going to inject me.”
26 But they only give you Panadol when you go there. So you say “I just wasted
27 my time last time, it is better that I buy from the shops.” **[Female participant,
28 IDI013]**
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34 The organisation of the clinic, including specific treatment days and separate lines,
35 particularly for HIV also made men fearful of seeking care, as they were concerned,
36 they would be identified and treated differently in the community. Bangwe health
37 centre is at the top of a steep hill and many participants had to walk long distances
38 and climb a steep hill. If they wanted to use transport this would further impact the
39 household finances:
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45 Sometimes the challenge is transport, you can’t walk to the clinic, so you just
46 sit at home. If you have some money, you are able to visit the clinic, because
47 there are lots of minibuses or bicycle taxis out there. **[Male participant,
48 IDI024]**
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53 Although, it is important to note some men and women only trusted the government
54 hospitals to provide the correct diagnosis.
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57 [...] the hospital is where you can get a diagnosis of your sickness. Because
58 on your own you might think it is TB yet it’s something else showing
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3 symptoms of TB. [...] you might be sick and still be unaware of what you are
4 sick with. **[Male participant, IDI008]**
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10 **Interventions to improve men's pathways to care**

11 In this section we present findings around interventions identified by participants
12 during the participatory workshop to improve men's pathways to care. The
13 suggestions from participants included: labour rights legislation; patient welfare
14 support system; and drawing on local leadership to encourage men to seek care.
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20 As we have demonstrated above, men's pathways to care are shaped by complex
21 intersecting inequalities, with poverty intersecting with gendered social norms to
22 shape many decisions. Working conditions associated with temporary work –
23 including the absence of sick leave and lack of labour law protections – and the fear
24 of losing vital income and dismissal from work were all important factors in shaping
25 care-seeking behaviour. For these work-related barriers participants proposed
26 improved employment legislations that provided and safeguarded rights for workers.
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34 We feel that the government should provide and stiffen laws against bosses
35 that subject their workers to maltreatment so that if they are found ill-treating
36 the workers they should be punished. Also, the government should ensure
37 that all workers are on medical scheme like MASM, and it should be
38 compulsory that each and every worker should be under a medical
39 scheme **[Male participant, PW002]**
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45 Trust in the health system and concerns about the way health practitioners treated
46 patients shaped decisions to seek care. One intervention proposed to address this
47 barrier was the establishment of a reporting system where patients could report their
48 concerns about health care workers. Suggestions made by participants included a
49 toll-free line or a welfare office where patients could report maltreatment.
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55 We're thinking that maybe setting up offices right at the health facility where
56 people could forward their complaints to the senior clinic staff. There should
57 be toll free numbers to call the senior members of staff. The senior staff would
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3 then figure out how to help you. The other thing is punishing the doctors,
4 maybe ill-treatment might stop. **[Male participant, PW006]**
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7 During the workshops, participants described how reliance on faith healing and
8 traditional medicine acted as a barrier to seeking the “right” care. This framing was
9 presented by participants as a problem that needed to be dealt with. This may in
10 part, of been a response to the researchers’ positionalities – coming from a well-
11 known health research organisation. Some participants suggested punitive
12 measures, with chiefs imposing fines on people who use non-biomedical services.
13 However, other participants argued that educationally oriented interventions that
14 would foster gradual cultural reforms and adoption of formal health practices and
15 behaviours. One of the suggestions that came out was implementing public
16 awareness campaigns and civic education programmes on health matters.
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26 I believe that each one of us have their own traditions. So, we cannot leave
27 something that is deep rooted in our society. Just deciding from nowhere that
28 we have a decree that no one should ever use traditional medicine. I’m
29 thinking of education so that we gradually move away from it [informal health
30 practices] rather than introducing laws. Sometimes that’s when people do it
31 more when it’s prohibited. While people are using traditional medicine, those
32 that know about modern medicine should with evidence civic educate those
33 that don’t know. Then people will on their own start using these helpful
34 methods. Laws are good indeed but sometimes do not work. **[Male**
35 **participant, PW004]**
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45 Financial support for seeking medical care commonly emerged as most suitable for
46 addressing the economically related barriers. Opportunities for support included the
47 government and NGO partners as potential sponsors. They felt the money would
48 compensate transport costs and loss of income that people normally incurred when
49 accessing the clinic.
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55 Refunding the money patients spend on transport to the clinic could help with
56 the problem of people not visiting the clinic when they are sick. Like for me
57 today I would not have come had my wife not told me that you were going to
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3 refund my transport fee. I was encouraged by the news of the refund... So, if
4 you refund transport, it will help to some degree. **[Male participant, IDI002]**
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8 Participants also explored different ways in which communities could establish their
9 own social safety nets without dependence on external support. They considered a
10 village fund where villagers contributed a small amount as one of the ways of
11 organizing safety nets.
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17 [...] encouraging chiefs to set up small funds where all the members of the
18 community contribute K20 even K50 or K100. We can manage that amounts.
19 So when someone is in need we should use the money to get them to the
20 hospital. Rather than waiting for an ambulance from the office. Because
21 sometimes it becomes difficult for the ambulance to come. **[Male participant,**
22 **PW002]**
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29 Participants also considered outreach services as an alternative strategy to increase
30 access to healthcare for men, this would take away one of the financial barriers:
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34 Another way would be seeing people in their homes because some don't have
35 means of transport and struggle to get to the clinic. So meeting and speaking
36 to them in their homes might help. **[Male participant, IDI002]**
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41 Discussion

42 Our study which drew on qualitative and participatory research methods and found
43 care seeking decisions for men were shaped by gender power relations which
44 intersected with economic instability within the household and insecure employment.
45 Food insecurity was a significant and ongoing concern for all household members,
46 but for men their gendered roles and viewing themselves as providers within the
47 household were preformed through significant delays in care seeking. Family
48 structures often meant that women depended on men's labour and speaking to them
49 directly about care-seeking was challenging. Urban capitalism, which was introduced
50 by the British colonial rulers reconfigured family structures and increased women's
51 reliance on men's wage labour. Employment rights were very weak, and left men
52 with little opportunity to take sick leave to visit the clinic. Weaknesses and
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3 constraints within the health system further exacerbated men's delays in seeking
4 treatment.
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8 Drawing on a participatory methodology allowed participants and researchers to
9 work together to co-create interventions. Key interventions to address barriers to
10 care seeking identified and developed by PW participants included interventions at
11 the individual level and the broader structural level. At the individual level,
12 interventions included changing behaviour through targeted civic education
13 programmes directed at men to encourage them to seek bio-medical care. At the
14 structural level, interventions included improved labour regulations, including
15 protection from dismissal if men did seek care, and payment of sick leave. The need
16 for somewhere to take their grievances such as the labour office were seen as
17 important to ensure compliance by employers. Safety nets system that supported
18 households when a household member was sick to allow them to seek care was also
19 identified as a priority.
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30 The Gender Inequality Index (GII), demonstrates that Malawi is very unequal country
31 with men favoured in a range of indicators. Men are afforded more power and
32 privilege than women, with greater access to education and financial resources.
33 However, this has not translated into better health outcomes. This reflects global
34 trends from UK, to Central Asia and Southern Africa of men delaying health care
35 seeking (16,17,35,36) that echoed our own findings. In the literature on TB, findings
36 from ethnographic research undertaken in Khayelitsha Cape Town, which found a
37 range of factors shaped men's care and adherence to treatment, lack of food and
38 economic constraints were identified reflecting those found in our study (37). In
39 Kenya, ethnographic work found that treatment seeking was delayed by individual
40 (38), social-cultural and structural factors. Chikovore et al (2014 and 2017) in urban
41 Blantyre that men's need to be perceived as strong meant they would delay seeking
42 care. They also found that the association between TB and HIV meant men would
43 delay care seeking due to associated stigma from HIV.
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56 In a review of health outcomes, Sverklik (2011) found that across the globe, people
57 living in informal settlements suffer disproportionately from ill-health throughout their
58 life course. These patterns of ill-health can be observed from birth with cramped and
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3 poor quality housing, poor access to water and sanitation and limited access to
4 public services including health care shaping health outcomes (39). We see these
5 social and political configurations present in Bangwe, shaping household decision
6 making. Structural interventions act to change the context in which health is
7 produced and reproduced are gaining greater attention in public health (40). In
8 context of urban Blantyre where weak legislative frameworks leave workers with very
9 few rights require urgent attention. At present, TB control in Malawi predominantly
10 depends on men and women presenting at the clinic with symptoms and then being
11 referred for treatment. This approach is leading to men delaying care seeking. Our
12 findings and interventions speak to the need for interventions, not only to strengthen
13 health systems and community-based TB active case finding interventions but also
14 to intervene to address upstream factors including providing support for men to take
15 time off work.”

27 **Study limitations**

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29 The study had a number of limitations. Firstly, there were limitations to the way
30 participants were identified and recruited. By recruiting participants through
31 screening women at Bangwe clinic we may only have included those groups who
32 had the economic means to visit the clinic and may have missed poorer and groups
33 that were more difficult to recruit. Secondly, we were not able to include all
34 participant from the first phase of the study into the next phase and included
35 additional participants through snowballing. The iterative nature of the two-stage
36 approach was to allow participants time to reflect on the study questions, by only
37 including some of the participants in the second stage this may have meant
38 participants were more inhibited in what they shared.

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41 In summary, by generating knowledge and understanding with community members
42 in urban Blantyre, Malawi, we identified three inter-connected thematic areas that
43 shaped men's health and TB seeking behaviour, and potentially contribute to high
44 levels of ongoing transmission in these settings: precarious socioeconomic
45 conditions; gendered social norms; and constraints in the health system. Insecurity
46 of day labour with no provision for sick leave; pressure to provide for the household
47 and a gendered desire not to appear weak and a severely under-resourced health
48 system all contributed to men delaying care-seeking. Interventions identified and
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developed by participants included targeted civic education programmes, improved patient-provider relations within the health-system and legislation to ensure worker rights to sick pay, and broader social support for households.

Conflict of interest declaration

The authors declare that there is no conflict of interest.

Author contributions

Author	Contribution/Role in the study
Mackwellings Phiri	Data collection, Analysis, Paper writing
Effie Makepeace	Data collection, Paper review
Margaret Nyali	Data collection and analysis
Moses Kumwenda	Study design, data collection and analysis support
Elizabeth L Corbett	Study design and paper writing
Katherine Fielding	Study design and paper writing
Augustine T Choko	Study design and paper writing
Peter MacPherson	Study design, analysis and paper writing
Eleanor E MacPherson	Led the study, designed, analysed and supported paper writing

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References

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Research Checklist

#1	<p>Title</p> <p>Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended.</p>	<p>Page 1</p>
#2	<p>Abstract</p> <p>Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions.</p>	<p>Page 2</p>
#3	<p>Introduction</p> <p>Problem formulation</p> <p>Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement.</p>	<p>Pages 4, 5</p>
#4	<p>Purpose or research question</p> <p>Purpose of the study and specific objectives or questions.</p>	<p>Page 6</p>
#5	<p>Methods</p> <p>Qualitative approach and research paradigm</p> <p>Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The</p>	<p>Pages 6, 7</p>

	<p>rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.</p>	
#6	<p>Researcher characteristics and reflexivity</p> <p>Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability.</p>	
#7	<p>Context</p> <p>Setting / site and salient contextual factors; rationale.</p>	<p>Page 5</p>
#8	<p>Sampling strategy</p> <p>How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.</p>	<p>Pages 6, 7</p>
#9	<p>Ethical issues pertaining to human subjects</p>	<p>Page 7</p>

	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues.	
#10	<p>Data collection methods</p> <p>Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale.</p>	Pages 6, 7
#11	<p>Data collection instruments and technologies</p> <p>Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study.</p>	Page 7
#12	<p>Units of study</p> <p>Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results).</p>	Pages 8, 23
#13	<p>Data processing</p> <p>Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts.</p>	Page 7

#14	<p>Data analysis</p> <p>Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale.</p>	Page 7
#15	<p>Techniques to enhance trustworthiness</p> <p>Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.</p>	Page 7
#16	<p>Results/findings</p> <p>Syntheses and interpretation</p> <p>Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.</p>	Pages 8-17
#17	<p>Links to empirical data</p> <p>Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.</p>	Pages 9-17
#18	<p>Discussion</p> <p>Intergration with prior work, implications, transferability and contribution(s) to the field</p>	Pages 17-24

	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field.	
#19	Study strength and Limitations Trustworthiness and limitations of findings.	Page 3
#20	Other Conflicts of interest Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed.	Page 20
#21	Funding Sources of funding and other support; role of funders in data collection, interpretation and reporting.	Page 8
#22	Author contributions Role of each other in the study and their contributions	Page 20