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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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Title: 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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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

average living 4.6 years longer than men (13). These patterns are in part shaped by biological factors. However, the socio-cultural construct of gender also plays an important role in explaining these differences (14). The WHO defines gender as "the roles, behaviours, activities, attributes and opportunities that any society considers appropriate for girls and boys, and women and men. Gender interacts with, but is different from, the binary categories of biological sex" (15). Central to the concern of gender is the hierarchical power relations that shape relationships between different groups of people.

Since the 1990s, critical gender theories have increasingly focused on how gender shapes men's health and well-being (13,16–18). Connell (2011) suggests that gender has a materialist orientation, understood in terms of practices (what people actually do) rather than what is expected (18). This moves gender beyond being a fixed set of values or norms, to something that is produced and reproduced in everyday practice (18). The theoretical framing of this paper draws on both critical gender theory to understand barriers men's care seeking for TB with the overall purpose to identify interventions to address these barriers.

METHODS

Study context

Malawi, is considered a low-income country ranking 171st out of 189 countries on the United Nations Development Programme (UNDP) human development index (19). Approximately 80% of Malawi's population undertake subsistence farming, with maize being the dominant crop. A recent survey by Afrobarometer found that Malawi was one of the most food insecure countries in Africa (20). An estimated 38% of Malawian's live below the poverty line and 47% of children are stunted (21). In comparison to other countries, urbanisation has been slower in Malawi and a majority of the population (84%) reside in rural areas (22).

This study was situated in Bangwe Township, an informal settlement on the eastern outskirt of Blantyre City, Southern Malawi. The formation of Bangwe dates back to colonial rule, when Native Africans were considered too primitive for urban dwelling. They were instead forced to live on the periphery of the city in townships that were referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas

during the colonial period led to densely over-crowded informal settlements. Following independence in 1964, traditional housing associations were established in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little access to basic amenities. The historical formation continues to shape the lives of residents as access to public services remain extremely limited and overpopulation an ever-growing challenge.

Malawi's health system is pluralistic, with government, private and faith-based organisations providing services. The government sector being the only services provided free at the point of use (25). Primary health centres are important entry points for health service provision, with most TB diagnosis and treatment services being integrated at this level.

Study design

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

Data collection

Data collection took place between January 2019 until October 2019, using in-depth interviews and participatory workshops. The study team used a short screening tool

to identify women attending the Bangwe Primary Clinic who reported their partners had a persistent cough (defined as a cough lasting more than two weeks). We then asked if they would consent to an interview; following the interview we also asked if they would be happy for us to contact their partners. Interviews were conducted in a private room within the research office in the clinic. We then held participatory workshops over a one-week period, inviting all participants from the in-depth interviews. Not all participants were available, so we used snowballing techniques with our recruited participants to identify men and women living in Bangwe who were willing to participate in the PWs. Following the workshops, we invited participants who hadn't previously been interviewed to attend an interview.

Authors MP and MN conducted the interviews and MP, EM and EMACP facilitated the PWs. Debriefing meetings were held soon after every interview to review emerging findings and identify areas requiring further exploration. All interviews and PW discussions were conducted in the local language (Chichewa) and audio recorded.

Data analysis

Data were analysed using a thematic content analysis (30). 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 (31). 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.

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

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

extremely challenging economic situation. For example, visiting the hospital ran the risk of losing income for the day:

> The challenge with piece works is you can't go to the hospital when you are unwell because going to the hospital means you won't be able to make money, and if you won't be able to make money, you won't eat […] So, wondering what you are going to eat if you miss work you go to work despite being sick. If you depend on business for food for the day, it means you have you have to go to town even when you are sick. **[Male participant, IDI]**

Similarly, insecurity of casual employment meant that workers had no formal rights, including no provision for sick leave, *ganyu* workers without legal protection. If men took time off to seek care, they also faced the threat of their work being terminated. In the quote below, the male participant discusses how continual absences due to ill-health could mean a loss of their job.

> […] most companies don't pay you when you miss a day of work. If you are sick and want to go to a clinic, it's very hard for them to allow you time off. You may take a day off on your own without permission, hoping that you will show them a medical report, but most employers don't accept that. They shout at you, insult you, and cut your pay […] my colleague at work developed a heart failure problem because of being in contact with chemicals. His heart wasn't functioning properly, and every week he would have a day off work. This caused him to have problems with his bosses to a point that they sacked him. **[Male participant, IDI]**

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

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. In ability 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.

Some men and women described attending churches where seeking biomedical care violated the doctrine of the church. They reported pastors operating in the area who would heal patients and discourage them from further engagement in bio-medical care. The following quotes demonstrates the complex interactions between church and faith healing shape, and health seeking behaviour.

> Pastors tell patients to stop treatment and believe that they will be healed after praying for them. They also tell people not to go to the hospital when sick instead they should just believe [in God]. **[Female participant PW]**

Gendered power relations and the household

The ideas of power and household dynamics were explored in the workshops with women, being asked to make images (still body sculptures) of men who live in Bangwe. The women created images either or men at work or at leisure. This was in contrast to images women made of themselves either performing household work or praying. The images of men alluded to higher literacy levels, access to free time and money either buying alcohol or using their mobile phones. The images created reveal rigid gendered divisions of labour where the man hold both the responsibility to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys

During the workshops, men and womens' decision-making power within the household was often discussed. The centrality of men's power over women, was both overtly, and covertly articulated, with women more financially dependent for their survival and the survival of their children. Women described how their economic dependency left them vulnerable to violence, which could take different forms but included emotional, economic or physical violence. This was initially hard to talk about, and not directly mentioned; buy after a role play which featured violent physical responses from husbands that participants began to share the risks they might face. This in itself is indicative of the unspoken power that men often hold.

One aspect we centred discussion was whether women could discuss their husband's health with him, and whether they could suggest taking action, such as going to the clinic to seek treatment for a persistent cough. Both men and women described how the ability to discuss their husband's health and decision-making depended on the dynamics of the relationship. For some women and men, asking

their husband about his health or advising them could lead to angry exchanges, as men perceived taking advice could put them in a weaker position:

> […] You don't have to listen to a woman every time she suggests something to you. Sometimes you have to ignore what she says. If she talks to you [about seeking treatment] and you listen, she doesn't take you seriously or respect you anymore, she puts a 'hedge around you' and commands you at will. Once she commands you, you are no longer respected as a man. So you need to be stubborn a bit, showing you're a man. **[Male participant, IDI]**

Due to the economic dependency of the household, women also articulated their concern about men seeking care and missing work, as this would have a further impact on the family.

> If we have children and the husband has been sick maybe for a week, you say this man needs to go and work. Maybe [because] you have gone days without eating and the bodies are weak […] this happens in families. For instance, my husband may come back from work feeling really sick with body pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay here at home?' […] **[Female participant, PW]**

However, both male and female groups referred to the changing roles of women in the household in Malawi that were challenging traditional notions of power and household decision-making roles. The increasing number of women in urban Bangwe owning small businesses gave them an independent income and brought greater decision-making power. This is articulated in the quote below:

> Women are also making decisions in the household when they have access to finances, but those that are dependent on men easily accept [whatever their male partner decides] **[Female participant, PW]**

The role of the health system

Previous encounters at the health centre, often left men feeling angry and marginalised. Long waiting times, poor treatment by health care staff and chronic

shortage of medicines drove men to seek delay care or seek out alternatives. Men and women were particularly angry at the treatment they received by clinicians, at best they saw health workers as rude and dismissive and at worst, violent. Examples of the cruel treatment included scoffing or ignoring patients and not allowing patients to explain their illness:

> Sometimes doctors are not speaking politely, they are harsh and treat you as though you were not humans. Some of them go out to chat to each other, where they laugh and do things of their own. Like today, as we were collecting drugs, one of them said, "You men are looking at me! You should look down. Why are you looking at me?! Some of you do not bath!" You find people swearing: "I should come here again?!" **[Female participant, IDI]**

The lack of drugs, long waits and short consultations often impacted on men's decision to seek care. Men were unhappy about committing to spending a day going to the clinic when they could buy drugs from the grocery store and return to work.

> …people feel discouraged by what happens at the clinic: "I should go there, climb that hill, just so they can give me Bactrim?" Because you expect to get better treatment when you go there: "I thought they were going to inject me." But they only give you Panadol when you go there. So you say "I just wasted my time last time, it is better that I buy from the shops." **[Female participant, IDI]**

The organisation of the clinic, including specific treatment days and separate lines, particularly for HIV also made men fearful of seeking care, as they were concerned, they would be identified and treated differently in the community. Bangwe health centre is at the top of a steep hill and many participants had to walk long distances and climb a steep hill. If they wanted to use transport this would further impact the household finances:

> Sometimes the challenge is transport, you can't walk to the clinic, so you just sit at home. If you have some money, you are able to visit the clinic, because there are lots of minibuses or bicycle taxis out there. **[Male participant, IDI]**

Although, it is important to note some men and women only trusted the government hospitals to provide the correct diagnosis.

> […] the hospital is where you can get a diagnosis of your sickness. Because on your own you might think it is TB yet it's something else showing symptoms of TB. […] you might be sick and still be unaware of what you are sick with. **[Male partner, IDI]**

Interventions to improve men's pathways to care

In this section we present findings around interventions identified by participants during the participatory workshop to improve men's pathways to care. The suggestions from participants included: labour rights legislation; patient welfare support system; and drawing on local leadership to encourage men to seek care.

As we have demonstrated above, men's pathways to care are shaped by complex intersecting inequalities, with poverty intersecting with gendered social norms to shape many decisions. Working conditions associated with temporary work – including the absence of sick leave and lack of labour law protections – and the fear of losing vital income and dismissal from work were all important factors in shaping care-seeking behaviour. For these work-related barriers participants proposed improved employment legislations that provided and safeguarded rights for workers.

> We feel that the government should provide and stiffen laws against bosses that subject their workers to maltreatment so that if they are found ill-treating the workers they should be punished. Also, the government should ensure that all workers are on medical scheme like MASM, and it should be compulsory that each and every worker should be under a medical scheme **[Male participant, PW]**

Trust in the health system and concerns about the way health practitioners treated patients shaped decisions to seek care. One intervention proposed to address this barrier was the establishment of a reporting system where patients could report their concerns about health care workers. Suggestions made by participants included a toll-free line or a welfare office where patients could report maltreatment.

> We're thinking that maybe setting up offices right at the health facility where people could forward their complaints to the senior clinic staff. There should be toll free numbers to call the senior members of staff. The senior staff would then figure out how to help you. The other thing is punishing the doctors, maybe ill-treatment might stop. **[Male participant, PW]**

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

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

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

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

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

> […] encouraging chiefs to set up small funds where all the members of the community contribute K20 even K50 or K100. We can manage that amounts. So when someone is in need we should use the money to get them to the hospital. Rather than waiting for an ambulance from the office. Because sometimes it becomes difficult for the ambulance to come. **[Male participant, PW]**

Participants also considered outreach services as an alternative strategy to increase access to healthcare for men, this would take away one of the financial barriers:

> Another way would be seeing people in their homes because some don't have means of transport and struggle to get to the clinic. So meeting and speaking to them in their homes might help. **[Male participant, IDI]**

Discussion

In Bangwe, an informal settlement in Blantyre we found high rates of poverty were central to many household decisions around care-seeking. Most participants described the grinding nature of food insecurity left people feeling hopeless and constrained the agency that men and women had to act on ill-health. *Ganyu* labour practices significantly contributed to the economic insecurity that household experienced. Weaknesses in primary health care meant patients faced long waiting times, poor treatment by clinicians and a shortage of drugs. These factors all

contributed to men delaying care until their illness significantly impacted on their live and livelihood. To achieve universal healthcare coverage and impact upon TB epidemics, these complex, intersecting barriers must be addressed together. Participants developed and defined a set of interventions to address these barriers that should be evaluated in partnership between researchers and community-members.

For urban men living in informal settlements gendered power relations shaped by economic insecurity in the household in turn shaped behaviour. Going to the clinic, was interpreted by men as representing weakness, with the risk of losing employment further exacerbating their precarious position. In most households, men saw themselves as the breadwinner, which furnished them with more decision-making power than women. Women described the heavy domestic labour they carried, which often left them with little leisure time, and which they contrasted with men whom they perceived to have more. Complex power dynamics shaped communication between partners, with women describing how, at times, speaking to their partners about his health could be dangerous for them. But in Bangwe, gendered partnership dynamics were evolving, particularly when women's earnings through their own businesses provided a significant contribution to the household, increasing their power and voice in household decisions.

Drawing on a participatory methodology allowed participants and researchers to work together to co-create interventions. This approach allowed participants to meaningfully engage with researchers developing interventions that addressed their lived realities. Key interventions to address barriers to care seeking identified and developed by PW participants included interventions at the individual level and the broader structural level. At the individual level, interventions included changing behaviour through targeted civic education programmes directed at men to encourage them to seek bio-medical care. At the structural level, interventions included improved labour regulations, including protection from dismissal if men did seek care, and payment of sick leave. The need for somewhere to take their grievances such as the labour office were seen as important to ensure compliance by employers. Safety nets system that supported households when a household member was sick to allow them to seek care was also identified as a priority.

The urgent need to improve primary health care facilities was also identified. The shortages of resources, both human and material, meant that participants faced long waiting periods and a lack of drugs when they did see a clinician. The need for improved communication, as clinicians were seen at times as being rude or abusive to patients during consultations. Participants saw that a service that allowed them to complain about clinicians could provide better accountability for health workers. Men valued confidentiality during their visits to the health centre and proposed reordering of the queue to ensure confidentiality when they sought care. Fear of being associated with HIV services drove some of these concerns, but also queues that allowed men to see male clinicians was also suggested as a way to encourage men to seek care. One suggestion was also to bring services closer to the community, to eliminate the costs of visiting a health centre.

Globally, gender power relations have often afforded men more power and privilege than women, with greater access to education and financial resources. However, this has not translated into better health outcomes. We find strikingly similar accounts from the UK, to Central Asia and Southern Africa of men delaying health care seeking (16,17,32,33) that echoed our own findings. This is also reflected in Chikovore et al (2014 and 2017) which found in urban Blantyre that men's need to be perceived as a strong meant they would delay seeking care. They also found that the association between TB and HIV meant men would delay care seeking due to associated stigma from HIV.

In a review of health outcomes, Sverklik (2011) found that across the globe, people living in informal settlements suffer disproportionately from ill-health throughout their life course. These patterns of ill-health can be observed from birth with cramped and poor quality housing, poor access to water and sanitation and limited access to public services including health care shaping health outcomes (34). We see these social and political configurations present in Bangwe, shaping household decision making. Structural interventions act to change the context in which health is produced and reproduced are gaining greater attention in public health (35). In context of urban Blantyre where weak legislative frameworks leave workers with very few rights require urgent attention.

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

Research Checklist

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

	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.	
#6	**Researcher characteristics and reflexivity** 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.	
#7	**Context** **Setting / site and salient contextual factors; rationale.**	Page 5
#8	**Sampling strategy** How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.	Pages 6, 7
#9	**Ethical issues pertaining to human subjects**	Page 7

	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	**Data analysis** 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.	Page 7
#15	**Techniques to enhance trustworthiness** Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.	Page 7
#16	**Results/findings** **Syntheses and interpretation** Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	Pages 8-17
#17	**Links to empirical data** Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	Pages 9-17
#18	**Discussion** **Intergration with prior work, implications, transferability and contribution(s) to the field**	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

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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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Title: 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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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 mens' 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

average living 4.6 years longer than men (13). These patterns are in part shaped by biological factors. However, the socio-cultural construct of gender also plays an important role in explaining these differences (14). The WHO defines gender as "the roles, behaviours, activities, attributes and opportunities that any society considers appropriate for girls and boys, and women and men. Gender interacts with, but is different from, the binary categories of biological sex" (15). Central to the concern of gender is the hierarchical power relations that shape relationships between different groups of people.

Since the 1990s, critical gender theories have increasingly focused on how gender shapes men's health and well-being (13,16–18). Connell (2011) suggests that gender has a materialist orientation, understood in terms of practices (what people actually do) rather than what is expected (18). This moves gender beyond being a fixed set of values or norms, to something that is produced and reproduced in everyday practice (18). The theoretical framing of this paper draws on both critical gender theory to understand barriers men's care seeking for TB with the overall purpose to identify interventions to address these barriers.

METHODS

Study context

Malawi, is considered a low-income country ranking 171st out of 189 countries on the United Nations Development Programme (UNDP) human development index (19). Approximately 80% of Malawi's population undertake subsistence farming, with maize being the dominant crop. A recent survey by Afrobarometer found that Malawi was one of the most food insecure countries in Africa (20). An estimated 38% of Malawian's live below the poverty line and 47% of children are stunted (21). In comparison to other countries, urbanisation has been slower in Malawi and a majority of the population (84%) reside in rural areas (22).

This study was situated in Bangwe Township, an informal settlement on the eastern outskirt of Blantyre City, Southern Malawi. The formation of Bangwe dates back to colonial rule, when Native Africans were considered too primitive for urban dwelling. They were instead forced to live on the periphery of the city in townships that were referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas

during the colonial period led to densely over-crowded informal settlements. Following independence in 1964, traditional housing associations were established in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little access to basic amenities. The historical formation continues to shape the lives of residents as access to public services remain extremely limited and overpopulation an ever-growing challenge. British rule also brought the introduction of urban capitalism changing family configurations and gendered norms (25). There was increasingly nucleated family and a greater dependency of women on their husbands' wage labour. It also physically relocated women away from their land making access to food sources more challenging (26). Today, Malawi ranks 172 out of 189 countries making it one of the most unequal countries in the world (27).

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

Study design

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

Data collection

Data collection took place between January 2019 until October 2019, using in-depth interviews and participatory workshops. The study team used a short screening tool to identify women attending the Bangwe Primary Clinic who reported their partners had a persistent cough (defined as a cough lasting more than two weeks). We then asked if they would consent to an interview; following the interview we also asked if they would be happy for us to contact their partners. Eleven women and 10 men participated in the initial interviews; we stopped interviews when no themes arose. After analysing the data from the interviews and themes relating to mens' treatment barriers had been identified, we held participatory workshops to further discuss the barriers and to identify and prioritise potential interventions to these barriers. PWs happened over a one-week period, with each day split into five hourly discussion sessions. We invited all participants from the in-depth interviews to join the workshops, but nine were not available. So, we used snowballing techniques with our recruited participants to identify men and women living in Bangwe who were willing to participate in the PWs. Following the workshops, we invited participants who hadn't previously been interviewed to attend an interview. Median (IQR) ages by sex for the 30 study participants were 34 (23-42) years for women and 37 (26.5-62.5) years for men. Interviews were conducted in a private room within the research office in the clinic and lasted between one hour and 45 minutes. All interviews and PW discussions were conducted in the local language (Chichewa) and audio recorded.

The research team comprised of two Malawian (one female master's student and one male researcher employed by the Research Institute who sponsored the study) and two white British women both from the UK. Our levels of education, sex, economic position and race (in the case of EM and EMACP) are likely to have shaped our interactions with the participants. MP interviewed some of the female participants and were a mixed team when we conducted the female workshops. As a research team, we all have significant experience of conducting research (3 of the 4 researchers with more than 10 years each). Following each interview and at the end of each day of the participatory workshops, we held debriefing sessions. During these sessions we reviewed emerging findings and identifying areas requiring further exploration. We also focused on how participants responded to the questions and whether we may have influenced this.

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

This study was funded by the MRC/DFID/Wellcome Joint Global Trials Scheme with the grant number MR/R019762/1.

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:

> 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, IDI018]**

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 extremely challenging economic situation. For example, visiting the hospital ran the risk of losing income for the day:

> The challenge with piece works is you can't go to the hospital when you are unwell because going to the hospital means you won't be able to make money, and if you won't be able to make money, you won't eat […] So, wondering what you are going to eat if you miss work you go to work despite being sick. If you depend on business for food for the day, it means you have you have to go to town even when you are sick. **[Male participant, IDI019]**

Similarly, insecurity of casual employment meant that workers had no formal rights, including no provision for sick leave, *ganyu* workers without legal protection. If men took time off to seek care, they also faced the threat of their work being terminated. In the quote below, the male participant discusses how continual absences due to ill-health could mean a loss of their job.

> […] most companies don't pay you when you miss a day of work. If you are sick and want to go to a clinic, it's very hard for them to allow you time off. You may take a day off on your own without permission, hoping that you will show them a medical report, but most employers don't accept that. They shout at you, insult you, and cut your pay […] my colleague at work developed a heart failure problem because of being in contact with chemicals. His heart wasn't functioning properly, and every week he would have a day off work. This caused him to have problems with his bosses to a point that they sacked him. **[Male participant017, IDI]**

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

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, IDI011]**

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. In ability 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, IDI009]**

Use of alternative medicine to biomedical care

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.

Some men and women described attending churches where seeking biomedical care violated the doctrine of the church. They reported pastors operating in the area who would heal patients and discourage them from further engagement in bio-medical care. The following quotes demonstrates the complex interactions between church and faith healing shape, and health seeking behaviour.

> Pastors tell patients to stop treatment and believe that they will be healed after praying for them. They also tell people not to go to the hospital when sick instead they should just believe [in God]. **[Female participant PW005]**

Further, participants also discussed people diagnosing and treating illness using traditional techniques, and cited dependence on traditional healing as preventing people from utilising formal health services.

> Another problem that stops people from visiting the hospital is belief in traditional medicine. There are people that trust traditional medicine and oppose seeking treatment from the hospital. **[Male participant, PW003]**

Gendered power relations and the household

The ideas of power and household dynamics were explored in the workshops with women, being asked to make images (still body sculptures) of men who live in Bangwe. The women created images either or men at work or at leisure. This was in contrast to images women made of themselves either performing household work or praying. The images of men alluded to higher literacy levels, access to free time and

money either buying alcohol or using their mobile phones. The images created reveal rigid gendered divisions of labour where the man hold both the responsibility to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys

During the workshops, men and womens' decision-making power within the household was often discussed. The centrality of men's power over women, was both overtly, and covertly articulated, with women more financially dependent for their survival and the survival of their children. Women described how their economic dependency left them vulnerable to violence, which could take different forms but included emotional, economic or physical violence. This was initially hard to talk about, and not directly mentioned; but after a role play that featured violent physical responses from husbands, participants began to share the risks they might face. This in itself is indicative of the unspoken power that men often hold.

One aspect we centred discussion was whether women could discuss their husband's health with him, and whether they could suggest taking action, such as going to the clinic to seek treatment for a persistent cough. Both men and women described how the ability to discuss their husband's health and decision-making depended on the dynamics of the relationship. For some women and men, asking their husband about his health or advising them could lead to angry exchanges, as men perceived taking advice could put them in a weaker position:

> […] You don't have to listen to a woman every time she suggests something to you. Sometimes you have to ignore what she says. If she talks to you [about seeking treatment] and you listen, she doesn't take you seriously or respect you anymore, she puts a 'hedge around you' and commands you at will. Once she commands you, you are no longer respected as a man. So you need to be stubborn a bit, showing you're a man. **[Male participant, IDI024]**

Due to the economic dependency of the household, women also articulated their concern about men seeking care and missing work, as this would have a further impact on the family.

> If we have children and the husband has been sick maybe for a week, you say this man needs to go and work. Maybe [because] you have gone days without eating and the bodies are weak […] this happens in families. For instance, my husband may come back from work feeling really sick with body pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay here at home?' […] **[Female participant, PW011]**

However, both male and female groups referred to the changing roles of women in the household in Malawi that were challenging traditional notions of power and household decision-making roles. The increasing number of women in urban Bangwe owning small businesses gave them an independent income and brought greater decision-making power. This is articulated in the quote below:

> Women are also making decisions in the household when they have access to finances, but those that are dependent on men easily accept [whatever their male partner decides] **[Female participant, PW015]**

Constraints in the health system

Previous encounters at the health centre, often left men feeling angry and marginalised. Long waiting times, poor treatment by health care staff and chronic shortage of medicines drove men to seek delay care or seek out alternatives. Men and women were particularly angry at the treatment they received by clinicians, at best they saw health workers as rude and dismissive and at worst, violent. Examples of the cruel treatment included scoffing or ignoring patients and not allowing patients to explain their illness:

> Sometimes doctors are not speaking politely, they are harsh and treat you as though you were not humans. Some of them go out to chat to each other, where they laugh and do things of their own. Like today, as we were collecting drugs, one of them said, "You men are looking at me! You should look down. Why are you looking at me?! Some of you do not bath!" You find people swearing: "I should come here again?!" **[Female participant, IDI001]**

The lack of drugs, long waits and short consultations often impacted on men's decision to seek care. Men were unhappy about committing to spending a day going to the clinic when they could buy drugs from the grocery store and return to work.

> …people feel discouraged by what happens at the clinic: "I should go there, climb that hill, just so they can give me Bactrim?" Because you expect to get better treatment when you go there: "I thought they were going to inject me." But they only give you Panadol when you go there. So you say "I just wasted my time last time, it is better that I buy from the shops." **[Female participant, IDI013]**

The organisation of the clinic, including specific treatment days and separate lines, particularly for HIV also made men fearful of seeking care, as they were concerned, they would be identified and treated differently in the community. Bangwe health centre is at the top of a steep hill and many participants had to walk long distances and climb a steep hill. If they wanted to use transport this would further impact the household finances:

> Sometimes the challenge is transport, you can't walk to the clinic, so you just sit at home. If you have some money, you are able to visit the clinic, because there are lots of minibuses or bicycle taxis out there. **[Male participant, IDI024]**

Although, it is important to note some men and women only trusted the government hospitals to provide the correct diagnosis.

> […] the hospital is where you can get a diagnosis of your sickness. Because on your own you might think it is TB yet it's something else showing symptoms of TB. […] you might be sick and still be unaware of what you are sick with. **[Male participant, IDI008]**

Interventions to improve men's pathways to care

In this section we present findings around interventions identified by participants during the participatory workshop to improve men's pathways to care. The

suggestions from participants included: labour rights legislation; patient welfare support system; and drawing on local leadership to encourage men to seek care.

As we have demonstrated above, men's pathways to care are shaped by complex intersecting inequalities, with poverty intersecting with gendered social norms to shape many decisions. Working conditions associated with temporary work – including the absence of sick leave and lack of labour law protections – and the fear of losing vital income and dismissal from work were all important factors in shaping care-seeking behaviour. For these work-related barriers participants proposed improved employment legislations that provided and safeguarded rights for workers.

> We feel that the government should provide and stiffen laws against bosses that subject their workers to maltreatment so that if they are found ill-treating the workers they should be punished. Also, the government should ensure that all workers are on medical scheme like MASM, and it should be compulsory that each and every worker should be under a medical scheme **[Male participant, PW002]**

Trust in the health system and concerns about the way health practitioners treated patients shaped decisions to seek care. One intervention proposed to address this barrier was the establishment of a reporting system where patients could report their concerns about health care workers. Suggestions made by participants included a toll-free line or a welfare office where patients could report maltreatment.

> We're thinking that maybe setting up offices right at the health facility where people could forward their complaints to the senior clinic staff. There should be toll free numbers to call the senior members of staff. The senior staff would then figure out how to help you. The other thing is punishing the doctors, maybe ill-treatment might stop. **[Male participant, PW006]**

During the workshops, participants described how reliance on faith healing and traditional medicine acted as a barrier to seeking the "right" care. This framing was presented by participants as a problem that needed to be dealt with. This may in part, of been a response to the researchers' positionalities – coming from a well-known health research organisation. Some participants suggested punitive

measures, with chiefs imposing fines on people who use non-biomedical services. However, other participants argued that educationally oriented interventions that would foster gradual cultural reforms and adoption of formal health practices and behaviours. One of the suggestions that came out was implementing public awareness campaigns and civic education programmes on health matters.

> I believe that each one of us have their own traditions. So, we cannot leave something that is deep rooted in our society. Just deciding from nowhere that we have a decree that no one should ever use traditional medicine. I'm thinking of education so that we gradually move away from it [informal health practices] rather than introducing laws. Sometimes that's when people do it more when it's prohibited. While people are using traditional medicine, those that know about modern medicine should with evidence civic educate those that don't know. Then people will on their own start using these helpful methods. Laws are good indeed but sometimes do not work. **[Male participant, PW004]**

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

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

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

> […] encouraging chiefs to set up small funds where all the members of the community contribute K20 even K50 or K100. We can manage that amounts. So when someone is in need we should use the money to get them to the hospital. Rather than waiting for an ambulance from the office. Because sometimes it becomes difficult for the ambulance to come. **[Male participant, PW002]**

Participants also considered outreach services as an alternative strategy to increase access to healthcare for men, this would take away one of the financial barriers:

> Another way would be seeing people in their homes because some don't have means of transport and struggle to get to the clinic. So meeting and speaking to them in their homes might help. **[Male participant, IDI002]**

Discussion

Our study which drew on qualitative and participatory research methods and found care seeking decisions for men were shaped by gender power relations which intersected with economic instability within the household and insecure employment. Food insecurity was a significant and ongoing concern for all household members, but for men their gendered roles and viewing themselves as providers within the household were preformed through significant delays in care seeking. Family structures often meant that women depended on men's labour and speaking to them directly about care-seeking was challenging. Urban capitalism, which was introduced by the British colonial rulers reconfigured family structures and increased women's reliance on men's wage labour. Employment rights were very weak, and left men with little opportunity to take sick leave to visit the clinic. Weaknesses and constraints within the health system further exacerbated men's delays in seeking treatment.

Drawing on a participatory methodology allowed participants and researchers to work together to co-create interventions. Key interventions to address barriers to care seeking identified and developed by PW participants included interventions at the individual level and the broader structural level. At the individual level, interventions included changing behaviour through targeted civic education

programmes directed at men to encourage them to seek bio-medical care. At the structural level, interventions included improved labour regulations, including protection from dismissal if men did seek care, and payment of sick leave. The need for somewhere to take their grievances such as the labour office were seen as important to ensure compliance by employers. Safety nets system that supported households when a household member was sick to allow them to seek care was also identified as a priority.

The Gender Inequality Index (GII), demonstrates that Malawi is very unequal country with men favoured in a range of indicators. Men are afforded more power and privilege than women, with greater access to education and financial resources. However, this has not translated into better health outcomes. This reflects global trends from UK, to Central Asia and Southern Africa of men delaying health care seeking (16,17,36,37) that echoed our own findings. In the literature on TB, findings from ethnographic research undertaken in Khayelitsha Cape Town, which found a range of factors shaped men's care and adherence to treatment, lack of food and economic constraints were identified reflecting those found in our study (38). In Kenya, ethnographic work found that treatment seeking was delayed by individual (39), social-cultural and structural factors. Chikovore et al (2014 and 2017) in urban Blantyre that men's need to be perceived as strong meant they would delay seeking care. They also found that the association between TB and HIV meant men would delay care seeking due to associated stigma from HIV.

In a review of health outcomes, Sverklik (2011) found that across the globe, people living in informal settlements suffer disproportionately from ill-health throughout their life course. These patterns of ill-health can be observed from birth with cramped and poor quality housing, poor access to water and sanitation and limited access to public services including health care shaping health outcomes (40). We see these social and political configurations present in Bangwe, shaping household decision making. Structural interventions act to change the context in which health is produced and reproduced are gaining greater attention in public health (41). In context of urban Blantyre where weak legislative frameworks leave workers with very few rights require urgent attention. At present, TB control in Malawi predominantly depends on men and women presenting at the clinic with symptoms and then being

referred for treatment. This approach is leading to men delaying care seeking. Our findings and interventions speak to the need for interventions, not only to strengthen health systems and community-based TB active case finding interventions but also to intervene to address upstream factors including providing support for men to take time off work."

Study limitations

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

In summary, by generating knowledge and understanding with 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 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-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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Research Checklist

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

	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.	
#6	**Researcher characteristics and reflexivity** 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.	
#7	**Context** **Setting / site and salient contextual factors; rationale.**	Page 5
#8	**Sampling strategy** How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.	Pages 6, 7
#9	**Ethical issues pertaining to human subjects**	Page 7

	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	**Data analysis** 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.	Page 7
#15	**Techniques to enhance trustworthiness** Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.	Page 7
#16	**Results/findings** **Syntheses and interpretation** Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	Pages 8-17
#17	**Links to empirical data** Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	Pages 9-17
#18	**Discussion** **Intergration with prior work, implications, transferability and contribution(s) to the field**	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
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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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Title: 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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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 mens' 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

average living 4.6 years longer than men (13). These patterns are in part shaped by biological factors. However, the socio-cultural construct of gender also plays an important role in explaining these differences (14). The WHO defines gender as "the roles, behaviours, activities, attributes and opportunities that any society considers appropriate for girls and boys, and women and men. Gender interacts with, but is different from, the binary categories of biological sex" (15). Central to the concern of gender is the hierarchical power relations that shape relationships between different groups of people.

Since the 1990s, critical gender theories have increasingly focused on how gender shapes men's health and well-being (13,16–18). Connell (2011) suggests that gender has a materialist orientation, understood in terms of practices (what people actually do) rather than what is expected (18). This moves gender beyond being a fixed set of values or norms, to something that is produced and reproduced in everyday practice (18). The theoretical framing of this paper draws on both critical gender theory to understand barriers men's care seeking for TB with the overall purpose to identify interventions to address these barriers.

METHODS

Study context

Malawi is considered a low-income country ranking 171st out of 189 countries on the United Nations Development Programme (UNDP) human development index (19). Approximately 80% of Malawi's population undertake subsistence farming, with maize being the dominant crop. A recent survey by Afrobarometer found that Malawi was one of the most food insecure countries in Africa (20). An estimated 38% of Malawian's live below the poverty line and 47% of children are stunted (21). In comparison to other countries, urbanisation has been slower in Malawi and a majority of the population (84%) reside in rural areas (22).

This study was situated in Bangwe Township, an informal settlement on the eastern outskirt of Blantyre City, Southern Malawi. The formation of Bangwe dates back to colonial rule, when Native Africans were considered too primitive for urban dwelling. They were instead forced to live on the periphery of the city in townships that were referred to as Native Land Trusts (23,24). Mass migration from rural to urban areas

during the colonial period led to densely over-crowded informal settlements. Following independence in 1964, traditional housing associations were established in Native Land Trusts of Blantyre, including Bangwe (23,24). Reflecting colonial ideologies, Native Land Trusts, remained underdeveloped, overcrowded with little access to basic amenities. The historical formation continues to shape the lives of residents as access to public services remain extremely limited and overpopulation an ever-growing challenge. British rule also brought the introduction of urban capitalism changing family configurations and gendered norms (25). There was increasingly nucleated family and a greater dependency of women on their husbands' wage labour. It also physically relocated women away from their land making access to food sources more challenging (26). Today, Malawi ranks 172 out of 189 countries making it one of the most unequal countries in the world (27).

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

Study design

This study aimed to understand barriers and develop interventions to improve pathways to diagnosis and care of TB for men living in an informal settlement in urban Blantyre. We used qualitative study design (in-depth interviews) and participatory workshops (PWs). In-depth interviews (IDIs) were selected because they provided participants with an opportunity to articulate their experiences in their own words (29). PWs took an art-based approach and used drew on Theatre of the Oppressed (TO) as a research method in conjunction with group discussions. TO is a participatory theatre making methodology developed by Augusto Boal (30,31) which includes techniques such as Image Theatre and Forum theatre. In our study, games and exercises were used to break down barriers between participants and the research team, before using Image Theatre. Participants made still images with their bodies to explore gender norms, experiences of sickness and healthcare, which were then discussed as a group. The process continued by developing role plays and finally a Forum Theatre performance for the study team which demonstrated

some of the challenges of men seeking healthcare, and gave opportunities for the audience to suggest and try out different solutions onstage. To allow for open discussion of potentially sensitive gender norms and behaviours these PWs initially divided groups by gender, working separately with men and women before bringing the two groups together to make the performance.

Data collection

Data collection took place between January 2019 until October 2019, using in-depth interviews and participatory workshops. The study team used a short screening tool to identify women attending the Bangwe Primary Clinic who reported their partners had a persistent cough (defined as a cough lasting more than two weeks). We then asked if they would consent to an interview; following the interview we also asked if they would be happy for us to contact their partners. Eleven women and 10 men participated in the initial interviews; we stopped interviews when no further themes arose. After analysing the data from the interviews and themes relating to men's' treatment barriers had been identified, we held participatory workshops to further discuss the barriers and to identify and prioritise potential interventions to these barriers. PWs happened over a one-week period, with each day split into five hourly discussion sessions. We invited all participants from the in-depth interviews to join the workshops, but nine were not available. So, we used snowballing techniques with our recruited participants to identify men and women living in Bangwe who were willing to participate in the PWs. Following the workshops, we invited participants who hadn't previously been interviewed to attend an interview. Median (IQR) ages by sex for the 30 study participants were 34 (23-42) years for women and 37 (26.5-62.5) years for men. Interviews were conducted in a private room within the research office in the clinic and lasted between one hour and 45 minutes. All interviews and PW discussions were conducted in the local language (Chichewa) and audio recorded.

The research team comprised of two Malawian (one female master's student and one male researcher employed by the Research Institute who sponsored the study) and two white British women both from the UK. Our levels of education, sex, economic position and race (in the case of EM and EMACP) are likely to have shaped our interactions with the participants. MP interviewed some of the female

participants and were a mixed team when we conducted the female workshops. As a research team, we all have significant experience of conducting research (3 of the 4 researchers with more than 10 years each). Following each interview and at the end of each day of the participatory workshops, we held debriefing sessions. During these sessions we reviewed emerging findings and identifying areas requiring further exploration. We also focused on how participants responded to the questions and whether we may have influenced this.

Data analysis

Data were analysed using a thematic analysis (32). 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 (33). 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 (34).

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

This study was funded by the MRC/DFID/Wellcome Joint Global Trials Scheme with the grant number MR/R019762/1.

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:

> 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, IDI018]**

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 extremely challenging economic situation. For example, visiting the hospital ran the risk of losing income for the day:

> The challenge with piece works is you can't go to the hospital when you are unwell because going to the hospital means you won't be able to make money, and if you won't be able to make money, you won't eat […] So, wondering what you are going to eat if you miss work you go to work despite being sick. If you depend on business for food for the day, it means you have you have to go to town even when you are sick. **[Male participant, IDI019]**

Similarly, insecurity of casual employment meant that workers had no formal rights, including no provision for sick leave, *ganyu* workers without legal protection. If men took time off to seek care, they also faced the threat of their work being terminated. In the quote below, the male participant discusses how continual absences due to ill-health could mean a loss of their job.

> […] most companies don't pay you when you miss a day of work. If you are sick and want to go to a clinic, it's very hard for them to allow you time off. You may take a day off on your own without permission, hoping that you will show them a medical report, but most employers don't accept that. They shout at you, insult you, and cut your pay […] my colleague at work developed a heart failure problem because of being in contact with chemicals. His heart wasn't functioning properly, and every week he would have a day off work. This caused him to have problems with his bosses to a point that they sacked him. **[Male participant017, IDI]**

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

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, IDI011]**

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. In ability 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, IDI009]**

Use of alternative medicine to biomedical care

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.

Some men and women described attending churches where seeking biomedical care violated the doctrine of the church. They reported pastors operating in the area who would heal patients and discourage them from further engagement in bio-medical care. The following quotes demonstrates the complex interactions between church and faith healing shape, and health seeking behaviour.

> Pastors tell patients to stop treatment and believe that they will be healed after praying for them. They also tell people not to go to the hospital when sick instead they should just believe [in God]. **[Female participant PW005]**

Further, participants also discussed people diagnosing and treating illness using traditional techniques, and cited dependence on traditional healing as preventing people from utilising formal health services.

> Another problem that stops people from visiting the hospital is belief in traditional medicine. There are people that trust traditional medicine and oppose seeking treatment from the hospital. **[Male participant, PW003]**

Gendered power relations and the household

The ideas of power and household dynamics were explored in the workshops with women, being asked to make images (still body sculptures) of men who live in Bangwe. The women created images either or men at work or at leisure. This was in contrast to images women made of themselves either performing household work or praying. The images of men alluded to higher literacy levels, access to free time and money either buying alcohol or using their mobile phones. The images created reveal rigid gendered divisions of labour where the man hold both the responsibility to provide for the family, but also the freedom to enjoy leisure time in ways he enjoys

During the workshops, men and womens' decision-making power within the household was often discussed. The centrality of men's power over women, was both overtly, and covertly articulated, with women more financially dependent for their survival and the survival of their children. Women described how their economic dependency left them vulnerable to violence, which could take different forms but included emotional, economic or physical violence. This was initially hard to talk about, and not directly mentioned; but after a role play that featured violent physical responses from husbands, participants began to share the risks they might face. This in itself is indicative of the unspoken power that men often hold.

One aspect we centred discussion was whether women could discuss their husband's health with him, and whether they could suggest taking action, such as going to the clinic to seek treatment for a persistent cough. Both men and women described how the ability to discuss their husband's health and decision-making depended on the dynamics of the relationship. For some women and men, asking their husband about his health or advising them could lead to angry exchanges, as men perceived taking advice could put them in a weaker position:

> […] You don't have to listen to a woman every time she suggests something to you. Sometimes you have to ignore what she says. If she talks to you

> [about seeking treatment] and you listen, she doesn't take you seriously or respect you anymore, she puts a 'hedge around you' and commands you at will. Once she commands you, you are no longer respected as a man. So you need to be stubborn a bit, showing you're a man. **[Male participant, IDI024]**

Due to the economic dependency of the household, women also articulated their concern about men seeking care and missing work, as this would have a further impact on the family.

> If we have children and the husband has been sick maybe for a week, you say this man needs to go and work. Maybe [because] you have gone days without eating and the bodies are weak […] this happens in families. For instance, my husband may come back from work feeling really sick with body pains, but if you ask him if he'll go to work, he says, 'I will go, should I just stay here at home?' […] **[Female participant, PW011]**

However, both male and female groups referred to the changing roles of women in the household in Malawi that were challenging traditional notions of power and household decision-making roles. The increasing number of women in urban Bangwe owning small businesses gave them an independent income and brought greater decision-making power. This is articulated in the quote below:

> Women are also making decisions in the household when they have access to finances, but those that are dependent on men easily accept [whatever their male partner decides] **[Female participant, PW015]**

Constraints in the health system

Previous encounters at the health centre, often left men feeling angry and marginalised. Long waiting times, poor treatment by health care staff and chronic shortage of medicines drove men to seek delay care or seek out alternatives. Men and women were particularly angry at the treatment they received by clinicians, at best they saw health workers as rude and dismissive and at worst, violent. Examples of the cruel treatment included scoffing or ignoring patients and not allowing patients to explain their illness:

> Sometimes doctors are not speaking politely, they are harsh and treat you as though you were not humans. Some of them go out to chat to each other, where they laugh and do things of their own. Like today, as we were collecting drugs, one of them said, “You men are looking at me! You should look down. Why are you looking at me?! Some of you do not bath!” You find people swearing: “I should come here again?!” **[Female participant, IDI001]**

The lack of drugs, long waits and short consultations often impacted on men’s decision to seek care. Men were unhappy about committing to spending a day going to the clinic when they could buy drugs from the grocery store and return to work.

> …people feel discouraged by what happens at the clinic: “I should go there, climb that hill, just so they can give me Bactrim?” Because you expect to get better treatment when you go there: “I thought they were going to inject me.” But they only give you Panadol when you go there. So you say “I just wasted my time last time, it is better that I buy from the shops.” **[Female participant, IDI013]**

The organisation of the clinic, including specific treatment days and separate lines, particularly for HIV also made men fearful of seeking care, as they were concerned, they would be identified and treated differently in the community. Bangwe health centre is at the top of a steep hill and many participants had to walk long distances and climb a steep hill. If they wanted to use transport this would further impact the household finances:

> Sometimes the challenge is transport, you can’t walk to the clinic, so you just sit at home. If you have some money, you are able to visit the clinic, because there are lots of minibuses or bicycle taxis out there. **[Male participant, IDI024]**

Although, it is important to note some men and women only trusted the government hospitals to provide the correct diagnosis.

> […] the hospital is where you can get a diagnosis of your sickness. Because on your own you might think it is TB yet it’s something else showing

symptoms of TB. […] you might be sick and still be unaware of what you are sick with. **[Male participant, IDI008]**

Interventions to improve men's pathways to care

In this section we present findings around interventions identified by participants during the participatory workshop to improve men's pathways to care. The suggestions from participants included: labour rights legislation; patient welfare support system; and drawing on local leadership to encourage men to seek care.

As we have demonstrated above, men's pathways to care are shaped by complex intersecting inequalities, with poverty intersecting with gendered social norms to shape many decisions. Working conditions associated with temporary work – including the absence of sick leave and lack of labour law protections – and the fear of losing vital income and dismissal from work were all important factors in shaping care-seeking behaviour. For these work-related barriers participants proposed improved employment legislations that provided and safeguarded rights for workers.

We feel that the government should provide and stiffen laws against bosses that subject their workers to maltreatment so that if they are found ill-treating the workers they should be punished. Also, the government should ensure that all workers are on medical scheme like MASM, and it should be compulsory that each and every worker should be under a medical scheme **[Male participant, PW002]**

Trust in the health system and concerns about the way health practitioners treated patients shaped decisions to seek care. One intervention proposed to address this barrier was the establishment of a reporting system where patients could report their concerns about health care workers. Suggestions made by participants included a toll-free line or a welfare office where patients could report maltreatment.

We're thinking that maybe setting up offices right at the health facility where people could forward their complaints to the senior clinic staff. There should be toll free numbers to call the senior members of staff. The senior staff would

then figure out how to help you. The other thing is punishing the doctors, maybe ill-treatment might stop. **[Male participant, PW006]**

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

I believe that each one of us have their own traditions. So, we cannot leave something that is deep rooted in our society. Just deciding from nowhere that we have a decree that no one should ever use traditional medicine. I'm thinking of education so that we gradually move away from it [informal health practices] rather than introducing laws. Sometimes that's when people do it more when it's prohibited. While people are using traditional medicine, those that know about modern medicine should with evidence civic educate those that don't know. Then people will on their own start using these helpful methods. Laws are good indeed but sometimes do not work. **[Male participant, PW004]**

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

Refunding the money patients spend on transport to the clinic could help with the problem of people not visiting the clinic when they are sick. Like for me today I would not have come had my wife not told me that you were going to

> refund my transport fee. I was encouraged by the news of the refund… So, if you refund transport, it will help to some degree. **[Male participant, IDI002]**

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

> […] encouraging chiefs to set up small funds where all the members of the community contribute K20 even K50 or K100. We can manage that amounts. So when someone is in need we should use the money to get them to the hospital. Rather than waiting for an ambulance from the office. Because sometimes it becomes difficult for the ambulance to come. **[Male participant, PW002]**

Participants also considered outreach services as an alternative strategy to increase access to healthcare for men, this would take away one of the financial barriers:

> Another way would be seeing people in their homes because some don't have means of transport and struggle to get to the clinic. So meeting and speaking to them in their homes might help. **[Male participant, IDI002]**

Discussion

Our study which drew on qualitative and participatory research methods and found care seeking decisions for men were shaped by gender power relations which intersected with economic instability within the household and insecure employment. Food insecurity was a significant and ongoing concern for all household members, but for men their gendered roles and viewing themselves as providers within the household were preformed through significant delays in care seeking. Family structures often meant that women depended on men's labour and speaking to them directly about care-seeking was challenging. Urban capitalism, which was introduced by the British colonial rulers reconfigured family structures and increased women's reliance on men's wage labour. Employment rights were very weak, and left men with little opportunity to take sick leave to visit the clinic. Weaknesses and

constraints within the health system further exacerbated men's delays in seeking treatment.

Drawing on a participatory methodology allowed participants and researchers to work together to co-create interventions. Key interventions to address barriers to care seeking identified and developed by PW participants included interventions at the individual level and the broader structural level. At the individual level, interventions included changing behaviour through targeted civic education programmes directed at men to encourage them to seek bio-medical care. At the structural level, interventions included improved labour regulations, including protection from dismissal if men did seek care, and payment of sick leave. The need for somewhere to take their grievances such as the labour office were seen as important to ensure compliance by employers. Safety nets system that supported households when a household member was sick to allow them to seek care was also identified as a priority.

The Gender Inequality Index (GII), demonstrates that Malawi is very unequal country with men favoured in a range of indicators. Men are afforded more power and privilege than women, with greater access to education and financial resources. However, this has not translated into better health outcomes. This reflects global trends from UK, to Central Asia and Southern Africa of men delaying health care seeking (16,17,35,36) that echoed our own findings. In the literature on TB, findings from ethnographic research undertaken in Khayelitsha Cape Town, which found a range of factors shaped men's care and adherence to treatment, lack of food and economic constraints were identified reflecting those found in our study (37). In Kenya, ethnographic work found that treatment seeking was delayed by individual (38), social-cultural and structural factors. Chikovore et al (2014 and 2017) in urban Blantyre that men's need to be perceived as strong meant they would delay seeking care. They also found that the association between TB and HIV meant men would delay care seeking due to associated stigma from HIV.

In a review of health outcomes, Sverklik (2011) found that across the globe, people living in informal settlements suffer disproportionately from ill-health throughout their life course. These patterns of ill-health can be observed from birth with cramped and

poor quality housing, poor access to water and sanitation and limited access to public services including health care shaping health outcomes (39). We see these social and political configurations present in Bangwe, shaping household decision making. Structural interventions act to change the context in which health is produced and reproduced are gaining greater attention in public health (40). In context of urban Blantyre where weak legislative frameworks leave workers with very few rights require urgent attention. At present, TB control in Malawi predominantly depends on men and women presenting at the clinic with symptoms and then being referred for treatment. This approach is leading to men delaying care seeking. Our findings and interventions speak to the need for interventions, not only to strengthen health systems and community-based TB active case finding interventions but also to intervene to address upstream factors including providing support for men to take time off work."

Study limitations

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

In summary, by generating knowledge and understanding with 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 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-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

References

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Research Checklist

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

	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.	
#6	**Researcher characteristics and reflexivity** 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.	
#7	**Context** **Setting / site and salient contextual factors; rationale.**	Page 5
#8	**Sampling strategy** How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale.	Pages 6, 7
#9	**Ethical issues pertaining to human subjects**	Page 7

	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	**Data analysis** 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.	Page 7
#15	**Techniques to enhance trustworthiness** Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale.	Page 7
#16	**Results/findings** **Syntheses and interpretation** Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory.	Pages 8-17
#17	**Links to empirical data** Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings.	Pages 9-17
#18	**Discussion** **Intergration with prior work, implications, transferability and contribution(s) to the field**	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