van der Westhuizen *et al.*
BMC Global and Public Health (2024) 2:66
https://doi.org/10.1186/s44263-024-00097-8

BMC Global and Public Health

RESEARCH **Open Access**

Stigma relating to tuberculosis infection prevention and control implementation in rural health facilities in South Africa — a qualitative study outlining opportunities for mitigation

Helene-Mari van der Westhuizen[2*], Rodney Ehrlich[2], Ncumisa Somdyala[3], Trisha Greenhalgh[1], Sarah Tonkin-Crine[1] and Chris C. Butler[1]

Abstract

Background Tuberculosis (TB) is a stigmatised disease with intersectional associations with poverty, HIV, transmission risk and mortality. The use of visible TB infection prevention and control (IPC) measures, such as masks or isolation, can contribute to stigma.

Methods To explore stigma in this condition, we conducted in-depth individual interviews with 18 health workers and 15 patients in the rural Eastern Cape of South Africa using a semi-structured interview guide and narrative approach. We used reflexive thematic analysis guided by line-by-line coding. We then interpreted these key findings using Link and Phelan's theoretical model of stigma, related this to stigma mitigation recommendations from participants and identified levels of intervention with the Health Stigma and Discrimination Framework.

Results Participants shared narratives of how TB IPC measures can contribute to stigma, with some describing feeling 'less than human'. We found TB IPC measures sometimes exacerbated stigma, for example through introducing physical isolation that became prolonged or through a mask marking the person out as being ill with TB. In this context, stigma emerged from the narrow definition of what mask-wearing symbolises, in contrast with broader uses of masks as a preventative measure. Patient and health workers had contrasting perspectives on the implications of TB IPC-related stigma, with patients focussing on communal benefit, while health workers focussed on the negative impact on the health worker-patient relationship. Participant recommendations to mitigate TB IPC-related stigma included comprehensive information on TB IPC measures, respectful communication between health workers and patients, shifting the focus of TB IPC messages to communal safety (which could draw on *ubuntu*, a humanist framework) and using universal IPC precautions instead of measures targeted at someone with infectious TB.

Conclusions Health facilities may unwittingly perpetuate stigma through TB IPC implementation, but they also have the potential to reduce it. Evoking '*ubuntu*' as an African humanist conceptual framework could provide a novel perspective to guide future TB IPC stigma mitigation interventions, including policy changes to universal IPC precautions.

Keywords Tuberculosis, Stigma, Infection prevention and control, Intervention, Ubuntu

---

*Correspondence:
Helene-Mari van der Westhuizen
helene.vdw@phc.ox.ac.uk
Full list of author information is available at the end of the article

Background

An estimated global total of 10.6 million people developed tuberculosis (TB) disease in 2021 [1]. Yet despite being common, TB remains a stigmatised disease with intersectional associations with poverty, social marginalisation, HIV, transmission risk and the risk of dying due to the disease [2]. Understanding TB stigma and developing mitigation strategies are important components of improving TB prevention and care.

Infection prevention and control (IPC) policies may contribute to actions that could be experienced as stigmatising, for example by isolating those who are believed to be infectious. Both the 1999 and 2019 WHO guidelines on TB IPC caution that stigma is an important implementation consideration, specially also mentioning its relevance to mask wearing [3, 4]. Viewing this through the Health Stigma and Discrimination Framework, this places a focus on healthcare facilities as important spaces where patients may have TB stigma experiences and where there may be observable stigma practices [5].

In a study based in Ghana, a number of examples of discrimination relating to TB IPC in healthcare facilities were identified [6]. Junior members of staff were delegated the care of TB patients, health workers avoided or shortened interactions with TB patients and health workers treated TB patients with contempt by shouting at them. Fear of becoming infected with TB was identified as one of the drivers of the stigma [6]. Pervasive TB stigma can lead to outcomes including being a barrier to seeking a TB diagnosis, hinder commencement of treatment and long-term poorer health outcomes [7].

We use Goffman's seminal conceptualisation of stigma as a physical marking that, within the context of social relations and interaction, reveal the tainted moral status associated with the person [8]. Stigma can be further explored through considering the following: *enacted stigma* which is overt discrimination (for example someone with TB being dismissed from their job) and *felt stigma*, the sense of shame and a fear of encountering enacted stigma (for example someone with TB avoiding contact with other people as they fear they may react with disgust) [9]. This can be further differentiated as *anticipated stigma* (which may be perceived but may or may not become enacted stigma) and *internalised stigma* (feeling shame or blame for having TB disease) [9–11]. Despite receiving prominence in the policy and academic literature, there has been little progress in finding ways in which TB IPC-related stigma can be mitigated [6, 10, 11]. Instead, avoiding the stigma related to mask wearing by people with TB is sometimes cited as a reason for abandoning the use of masks in health facilities [12]. This contributes to the ongoing spread of TB to health workers, patients and visitors — affecting those with underlying health conditions more severely.

When looking at the literature beyond application to TB on the links between infection control measures and stigma, some possible mitigation strategies are identified. In a literature review on the stigmatisation of source isolation (people who have a transmittable infection), Gammon and colleagues found that isolation can be a barrier to contact time with health workers, and that protective equipment can impair communication [13]. They recommended additional training for health workers to mitigate the social and psychological impacts of isolation on patients through increasing social interaction between health workers and patients.

During the COVID-19 pandemic, in some settings, people with Asian heritage wearing masks were stigmatised and treated as carriers of disease [14, 15]. A multi-country meta-ethnography by Tsang and colleagues explored how positive social meanings attached to mask wearing contributed to higher uptake of masks during respiratory epidemics and sustained use outside of epidemic contexts, predominantly in countries in Asia [16]. They observed that positive social identities support the use of mask wearing including associations with solidarity, civic responsibility and scientific modernity. This shifted the meaning of mask wearing from being exclusively for the prevention of a specific disease (such as SARS) to that of offering broader protection against a range of respiratory illnesses, pollution and radiation [17, 18]. This contrasts with the requirement in health facilities that patients with TB wear masks to protect others but no requirement that people who do not have TB wear masks as protective to the wearer. It is likely that in some settings, due to widespread use of masks for COVID-19, mask wearing may have become less stigmatised for TB as well [19, 20].

Nyblade and colleagues suggested an array of intervention strategies to address stigma in health facilities. This included the following: providing information about the stigmatised condition, building skills through interactive learning activities and promoting empowerment, for example by offering counselling for the stigmatised group [7]. Nyblade and colleagues also recommended increasing contact with people who form part of the stigmatised group (for example through rotations in clinical roles for health workers or exposing staff to individuals with the stigmatised condition in non-clinic interactions) and using structural approaches to address stigma through reviewing policies and service integration [7].

Stangl and colleagues, through their Health, Stigma and Discrimination Framework, call on researchers who develop stigma interventions to 'move away from psychological models that see stigma as a thing which individuals impose on others, and instead emphasize, the broader social, cultural, political and economic forces that structure stigma' [5]. They present multiple levels that stigma interventions could focus on, highlighting that a combination of levels should be preferred.

In this study, we aimed to explore (a) the underlying contributors to why TB IPC measures in health facilities in the study context were perceived as stigmatising and (b) how the perspectives of health workers and patients differ regarding the implications of TB IPC associated stigma. (c) We then present participant recommendations for how the stigma associated with TB IPC could be mitigated or overcome.

Methods

Study setting

This qualitative research study was conducted in a rural district of the Eastern Cape of South Africa, the province with the highest TB incidence rate in the country at 692 per 100,000 people [21]. The district has an HIV prevalence of 15.3%, with people with HIV disproportionately affected by transmission of TB in health facilities [19, 22]. The district's high tuberculosis burden is rooted in the contributions of migrant mining labour, racially discriminatory tuberculosis policies during the apartheid government, and a focus on TB treatment as the main intervention, to the neglect of improving social and economic conditions [20].

Data collection

Data sources include in-depth individual interviews with 18 health workers and 15 patients conducted between August 2019 and January 2020 which lasted between 30 and 90 min each. (see Table 1) We recruited participants at one district hospital and four primary care facilities. Sampling was purposive and was from waiting rooms in the health facilities and at staff meetings. We specifically looked to include health workers and patients with key perspectives such as health workers who previously developed occupational TB, patients who have TB currently or had TB before and patients who had had experiences of using a mask while visiting a health facility. It is important to note that some patients with experiences of TB were not asked to wear a mask ($n=3$), and some patient participants who have not had TB also had experiences of being asked to wear a mask when visiting a health facility ($n=2$); this was while being investigated for symptoms of TB. During this study period, the most commonly used type of mask by patients was surgical masks, while health workers used surgical masks or particulate filter respirators. Our sample size was guided by data saturation, which relates to the degree to which new data repeat what was expressed in previous data [23].

Table 1 Participant characteristics

	Health workers	Patients
Age		
Median	33	34
Range	22–56	18–66
Sex		
Male	6	7
Female	12	8
Health worker profession		
Doctor	5	-
Nurse	10	-
Allied health professional	2	-
Support staff (translator)	1	-
Health facility		
District hospital	11	-
Primary care clinic	7	-
Years of work experience		
0–10	12	-
10+	6	-
TB disease		
Drug-sensitive TB	2	9
Drug-resistant TB	0	1
Previously asked to wear a mask when visiting a health facility as part of TB IPC		
Yes	-	9 (7 were patients with experience of TB)
No	-	6 (3 were patients with experience of TB)
Total participants	**18**	**15**

We used a semi-structured interview guide with a narrative approach, which was refined based on pilot testing (see additional file 1 for our interview guide.) Interviews were conducted in *isiXhosa* or English (based on the participant's preference), audio-recorded, transcribed, translated into English where applicable and checked for accuracy by the research team. Interviews were conducted at the preferred site of the participants, which included health facilities, the research centre and homes.

Data analysis

Initial analysis was inductive and grouped according to patient and health worker interviews. We were guided by Braun and Clarke's reflexive thematic analysis, using line-by-line coding led by HvdW with NVivo software [24] (see additional file 2 for our coding tree). We then interpreted the thematic areas relating to TB IPC and stigma in health facilities using Link and Phelan's theoretical model of stigma to identify the contributions of different stigma components and how this relates to mitigation recommendations and identify levels of intervention with the Health Stigma and Discrimination Framework [5, 25]. This study formed part of a broader programme of doctoral research which also includes organisation practices influencing TB IPC implementation and TB IPC in community settings.

Link and Phelan's theoretical model of stigma draws on disability and sociological studies and has five co-occurring components [25]. Two stigma sub-concepts relate to the material properties of a mask and physical implications of TB IPC measures (as *visible label* of having TB and emphasising *separation* between 'us and them'). Two stigma subcomponents relate to TB IPC measures reflecting the stigma associated with having TB more broadly (*loss of status and discrimination* and *stereotyping* of people with TB), and the final component considers the influence of *power* which can relate to stigma practices [26]. Link and Phelan argue for including a focus on how power is asserted through existing socioeconomic inequalities and through differences in class, race, religion or gender. In relation to TB, power can also be asserted through institutions, policies, TB IPC measures, diagnostics and treatment delivery [27]. Another example where power could be expressed is in the doctor-patient relationship, where Shei highlighted that this relational power depends on trust — which the patient trusts that the health worker will use the power asymmetry in an ethical way and make constructive changes in the lives of their patients while treating patients as rational, intelligent, fellow human beings [28].

Research team

The research team was led by HvdW, a clinician-researcher who had previously worked in this setting and who led the health worker interviews. A research assistant (N. S.) who lives in the area and has experiences of receiving care at the health facilities supported recruitment. She received training in qualitative research methods and led the *isiXhosa* interviews (with HvdW taking notes for most of these interviews). We kept detailed journals and had regular debriefing conversations about how our presence including gender (both being female) might influence the responses from participants. We piloted different approaches to conducting the interviews (for example where HvdW would not be present) and found that participants did not focus attention on her as note-taker. Co-investigators provided expertise in occupational health (RE), primary care (CB and TG), behavioural science (STC) and social science (TG) and supported critical discussions of the data collection processes and interpretation.

The reporting of this research has been done according to the COREQ checklist [29] (see additional file 3).

Results

We start by describing the stigma experiences and practices that our participants linked to TB IPC measures in this context. We then contrast health worker and patient perspectives on what implications these stigma experiences have for TB IPC implementation. Finally, we present patient and health worker recommendations on how TB IPC stigma could be mitigated.

Stigma experiences and practices relating to TB IPC in health facilities

Participants felt that mask wearing for source control (protecting others from becoming infected) was a practice that could often lead to someone with TB experiencing stigma.

> *When you look at a person [wearing a mask] you think to yourself that maybe this one has a huge illness which is bigger than mine. Even though a person doesn't eventually say anything, the eye speaks, to see how people see you. – participant 32, male MDR-TB patient, previously asked to wear a mask.*

This description 'the eye speaks' shows how much of this stigma is based on the perceptions of others and how it could be communicated through a glance in a facility's waiting room. It is an intersection between *felt* and *enacted* stigma — the person wearing a mask may anticipate and interpret certain body language from people in the waiting room as stigmatising without this being the intention, but the small gestures could also communicate a message that becomes *enacted* stigma. One participant described how she unobtrusively tried to cover her baby's head with a blanket to protect them from TB when they saw someone who was wearing a mask in a waiting room. Two other participants described trying to move away from a masked person, one saying she will do it in a way not to 'offend the person' which we consider examples of enacted stigma.

This shows how in our study setting a mask was seen as a label of TB and by some as a label of MDR-TB, which through its shared symbolic meaning led to fear of infection being a driver of stigma:

> *[Should I be asked to wear a mask] means that I am infected—I have TB then.—Participant 8, female patient, no previous TB, not asked to wear a mask.*

Yet whether a mask was a valid label for TB was questioned by some health workers, as some of the health facilities included in the study would provide masks for patients with respiratory symptoms while their TB investigations were pending. In our sample, there were also some patients who had TB who were not asked to wear a mask (see Table 1) or patients with MDR-TB who were expected to wear masks irrespective of whether they still posed an infection risk to others.

Isolation was also described as a practice that could lead to experiences of stigma. Patients felt this was both a physical separation but also communicated a reduction in their value, when they were asked to join a different group:

> *What made it hurtful is that I was taken away from other people and be placed alone there. Maybe I was placed with people who had this thing on [wearing a mask]. ... I thought I should persevere. – participant 15, male previous TB patient, asked to wear a mask.*

> *I did not get offended. Because I know the TB disease is contagious. It is a must that you agree when you are put aside because you will infect a lot of people. – participant 5. female patient previous TB, not asked to wear mask.*

The emphasis that this participant places on communal safety is further explored in the "Results" section of this manuscript.

While improving natural ventilation was considered the least stigmatising TB IPC measure, some participants still felt that it could communicate a message of carelessness on the part of health workers:

> *[There are people] hurt by that. "They open [windows], we are cold, and they do not care about us", they would say. I would say "It is so that the disease passes and gets out through that window and door because it will infect you if these doors and windows are closed, you will not be safe".—participant 25, female patient, twice had previous TB, not asked to wear mask.*

Some participants felt the stigma related to infection control measures should be viewed more widely, beyond the experience linked with infection control practices, to the broader experience of being a person who is ill. TB IPC is a painful moment, often at the beginning of a new illness experience, but also symbolises a broader experience of now having a different identity.

> *I was afraid of people in that moment they were giving the mask to me. I thought to myself that it means my illness is wrong. [But] my illness shouldn't affect other people, I thought I should endure the mask. What was making me feel embarrassed was continually coming to the hospital. Everyone seeing me going from the hospital carrying the pills. That causes so much embarrassment for me. But then I would think that there is nothing they [the people looking strangely at me] are going to do for me, my health is here [at the hospital].- participant 15, male patient, previous TB, asked to wear a mask.*

This participant links his experience of receiving a mask to the shame of being seen to visit the health facility or carrying tablets — which is broader than being ashamed to have TB. He felt ashamed to be an ill person, because in this context for his age group and gender it has the intersectional stigma of being connotated to having HIV.

Patients and health workers think differently about the implications of TB IPC-associated stigma for health facilities

While in our dataset health workers and patients broadly agreed that TB IPC measures in health facilities can be stigmatising to patients, they had contrasting perspectives on the implications. In facilities where masks and respirators were commonly used, health workers perceived patients to oppose TB IPC measures, but that they 'endured' it as part of receiving care. It was interesting that none of the health workers we interviewed considered patients to value TB IPC for communal safety. In facilities where masks and respirators were not commonly used, health workers said making a patient feel 'dehumanised' through TB IPC measures contradicted the underlying values of empathy, respect and establishing a therapeutic relationship. One health worker described disregarding the use of respirators to show they care for patients above their own needs:

> *Patient care and outcome at the end of the day is more important than PPE. – participant 29. Mamele hospital, female doctor.*

Health workers described being concerned that TB stigma would deter patients from coming for care at the facility in the future and would also cause patients who wear masks in facilities to be stigmatised in the community. In a different clinic, a health worker wearing a respirator as personal protective equipment was seen to be stigmatising to patients:

> *The [patient] asked me, "Sister, why are you all wearing a mask and we're not wearing them? Sister, are we disgusting you?" They felt like they were dirty. So [we] stopped wearing them. – participant 6, Aphiwe clinic, female nurse.*

Yet in contrast with these health worker perceptions and despite their own strongly felt stigma, patients did not perceive stigma as a reason to discontinue mask wearing, instead of focussing on the protection offered by masks, emphasising that having TB is transient, and that the health of health workers is important. This was similar for patients who were asked to move to an isolation area — they mentioned trusting the health facility to make a recommendation in the communal best interest.

The overwhelming majority of patient participants described the use of masks as a way to protect other people but also the wearer. One participant who had undergone TB diagnostic tests multiple times saw wearing a mask as a process that she could initiate when arriving at a facility and did not view it to be stigmatising:

> *I would wear it without any problem. If I have a fever perhaps, when I walk in, let's say I am coughing, I ask for it as I get out of the nursing area, because I don't know what I have. I will know only when my results are back. I have no problem [wearing a mask]. – participant 14, female patient, no previous TB, asked to wear a mask.*

These findings contrasted with health worker views that patients did not understand why masks were being used and who simply used masks when they were told to do so. This contrast is interesting, because many of the health workers and patients form part of the same community and share a similar cultural background. This suggests that there may be additional underlying differences in the way that health workers and patients conceptualise mask wearing. For example, one participant articulated both the benefit and discomfort:

> *[When I was asked to wear a mask] there was no problem because I know that I have a certain sickness so I should not infect the next person. When I am to speak to another person I have to wear it. I noticed that they were looking at me. It was their first time to see what I was wearing. I asked myself whether these people looked at me for what reason? I was given a mask and they were not given one, so I did feel like my heart was hurting, but a little. Not much. – Participant 21, male patient, currently has TB, asked to wear a mask.*

While some health workers focussed on their duty to care for an individual patient, the patient participants emphasised collectivism and the importance of communal safety. Health workers viewed TB IPC as interfering with their work, instead of being part of their work.

On a descriptive level, these findings indicate a mismatch between what health workers perceive patients to feel and what patients described in the interviews. Yet to explore and understand stigma, it is also important to consider how power is exerted and how this may intersect with trust. Examples of power that we specifically looked for in our data set was the asymmetrical power relationship between health worker and patient (which relies on the health worker's expertise to provide the care and services patient needs), through the power that medicine holds as institution (with medical jargon and training) or by looking at the contextual power of an organisation (a clinic in a rural area being the only facility that provides care). The most pertinent example was during our interviews, when asked for recommendations that could be presented to health workers, some patients described being unwilling to engage with health workers on TB IPC. They described this as being willing to 'submit' to the treatment they receive and suggested that it would be a sign of not trusting health workers' expertise to provide their opinion.

Some of the health workers also mentioned that they felt the influence of race and educational privilege in this rural context on how willing patients are to communicate about TB IPC:

> *I'm the white doctor. I never get opposition. I never get resistance. I never get people that say "I refused. I'm not going to wear it [the mask]". I don't get people that challenge me. I don't get people that question me. Perhaps they want say something but they're just too scared to say it. – participant 4, Mamele Hospital, female doctor.*

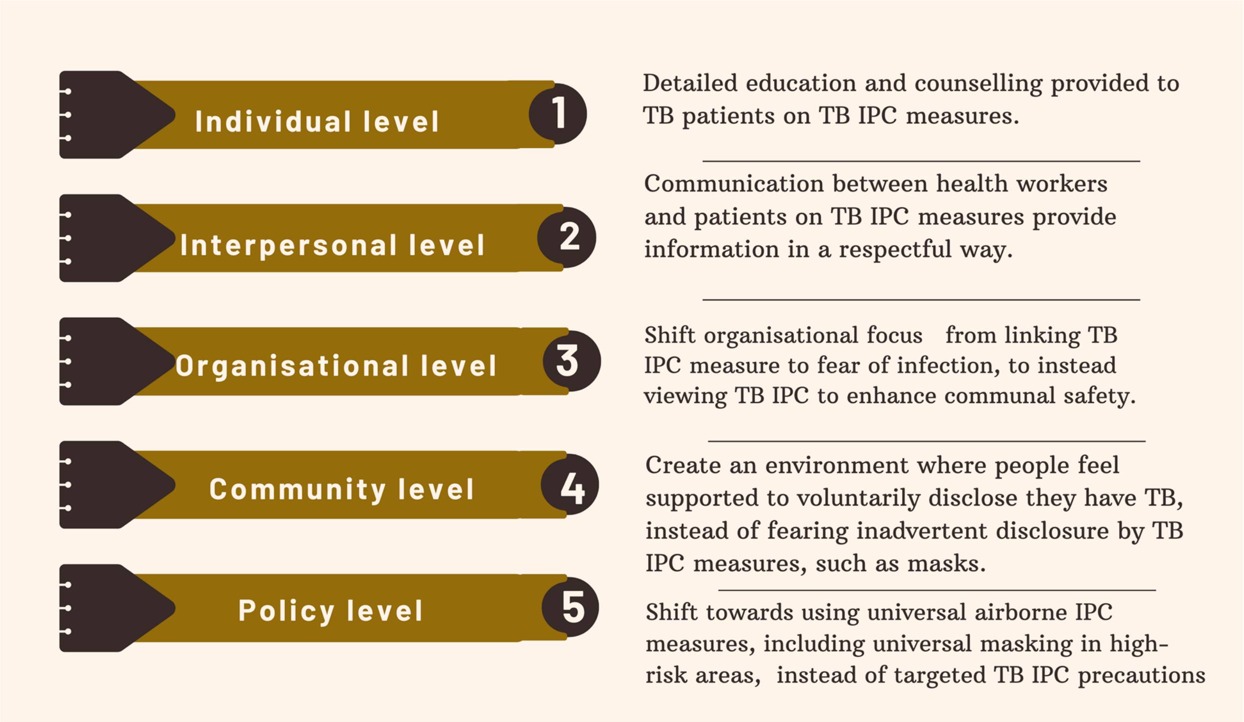
However, many of the health workers come from the same community as the patients. One nurse recommended that through having more discussions about TB and TB IPC, it would be possible to reach a shared understanding and increase the motivation of health workers to make preventative efforts:

> *We can move and we can educate—we are from this communities—we live with these people. And we have information about TB, but [what is lacking is] a will. And to talk with them and make sense with them so that they can understand. Mostly people understand but they need motivation to start doing something to prevent TB. – participant 7, Aphiwe Clinic, male nurse, manager.*

Encouraging communication between health workers and patients on TB IPC preferences may be one way to engage with these power dynamics and ensure both perspectives are heard.

Four recommendations from patients and health workers on mitigating the stigma associated with TB IPC in health facilities

We asked participants how the stigma associated with TB IPC in health facilities could be mitigated or



Detailed education and counselling provided to TB patients on TB IPC measures.

Communication between health workers and patients on TB IPC measures provide information in a respectful way.

Shift organisational focus from linking TB IPC measure to fear of infection, to instead viewing TB IPC to enhance communal safety.

Create an environment where people feel supported to voluntarily disclose they have TB, instead of fearing inadvertent disclosure by TB IPC measures, such as masks.

Shift towards using universal airborne IPC measures, including universal masking in high-risk areas, instead of targeted TB IPC precautions

Fig. 1 Summary of participant recommendations for multi-level, TB IPC stigma intervention targets

overcome. We first present an overview of how participant recommendations link with the multiple levels of possible stigma interventions, based on the Health Stigma and Discrimination Framework in Fig. 1. We then elaborate on these recommendations in Table 2 and the text by providing illustrative quotes and identifying the stigma subcomponent that the recommendation focusses on, through drawing on Link and Phelan.

An underlying principle of the recommendations presented in Table 2 is that destigmatising TB IPC does not involve omitting the preventative measures but rather paying closer attention to the way TB IPC measures are being communicated and used.

Several participants conceptualised this by asking to be spoken to 'in a human way'. This contrasts with earlier descriptions of having TB, experiencing stigma and feeling like they were less than human.

> *What I would advise [health workers] is that you must be polite to people, because a person is a person through other people [a Nguni proverb, often used to describe the meaning of 'ubuntu']. So, maybe they are a nurse, but they work with people, if the people aren't there, there is nothing they will work with, so they must treat them well. – participant 20, male TB patient, previously asked to wear a mask.*

This participant suggests looking at 'ubuntu' as a way to understand how TB IPC measures should be adapted to emphasise interconnectedness and a shared sense of humanity, which contrasts with the separation, discrimination and disempowerment that Link and Phelan described as subcomponents of stigma (discussed in Table 2). In addition to this, it also introduces the community as point of focus, where people's wellbeing is interdependent and challenges the idea that the health facility is separate and should have interventions only targeted towards it.

Several participants pointed out that visible infection control measures, due to its symbolic meaning, disclose to others that a person has TB. One approach already outlined above would be to change the symbolic meaning of these measures. A different approach would be to create an environment where people are comfortable to disclose that they have TB, which would in turn reduce the stigma associated with TB, and visible TB IPC measures.

> *TB doesn't only attack the poor [people]. [When I tell this to patients] they say, "No, sister. No." I say, "Yes, I'm the one who has [had] TB before, but now my TB is cured. I took treatment regularly and I'm well." That's why I counsel them because I just took that sickness from her to me. Patients must know that this is everyone's disease. – participant 13, Mamele Hospital, female nurse, previous TB.*

Table 2 Patient and health worker recommendations for implementing TB IPC while mitigating TB stigma

Recommendation	Illustrative quote	Stigma subcomponent that is targeted
1. **Provide detailed TB IPC information to patients** Provide detailed descriptions and explanations about why TB IPC is important and how it works	'The nurse should first explain because there are those who will be offended. For example, it is raining, and it is cold and then they suddenly open the windows. They should explain that "We are opening the windows so that we do not infect one another with TB. For us to be in optimal health, we must open these windows, so that the air that we breathe will not remain inside where we are, so that it will go away through the windows."' – participant 11, Female patient, no previous TB, not asked to wear a mask 'You can't just push the bed to that [High Risk Coughing] cubicle [to isolate a TB patient]. They [the patient] might be a little bit jittery about moving. You have to counsel them and explain thoroughly. You introduce these patients[using their clan names] to the ones that are already there in that cubicle. I would start the conversation just to break the ice. Monitoring the situation even in the upcoming days. When she's laughing [with the other patients in the new room] that makes me happy.' – participant 22, Mamele hospital, male nurse	This patient participant gave a sample script of what level of detail health workers should include when discussing improving ventilation as TB IPC, whereas in our broader dataset others provided similar recommendations for discussions on masks. This focuses on the knowledge asymmetry between health workers and patients that may mitigate experiences where health workers exert their *power* based on expertise, without providing context and detailed explanations. It also highlights the importance of respectful interactions The nurse describes how placing someone in an isolation ward should be done 'in a dignified manner' and how he looks to facilitate conversation and relationships between patients who are in the isolation cubicle together [in this facility, patients with potentially infectious TB are admitted into the same room that has multiple patient beds]. By emphasising that a patient's clan names ('isiduko') should be used when introducing them to others in the room, it aims to counter the *loss of status* associated with having TB and being a patient, instead of evoking the status that the person has in the community
2. **Respectful communication** Pay attention to tone of voice, gestures and eye contact when discussing TB IPC, especially when masks may obscure parts of facial expression	'I would advise them … [what you say] does not really matter it is how you say it. You should … give them the reasons.**'** – participant 10, male TB patient, previously asked to wear mask 'I would like [my health worker] to be polite and humble, and say, "Sorry my brother, here is a mask for [you], when you are coughing you are going to infect other people. So, it's for protection." They must speak in a human way. There are some people who are rough. When you are looking at them you wonder, [is] this person disrespecting me and undermining me, maybe I'm disgusting? You don't feel well. When they are speaking politely, and have a good expression on their face, you also feel comfortable.' – participant 20, male TB patient, previously asked to wear a mask 'It's not easy [when wearing a mask]because the [patients] can't see the real expression of your face. But at least your voice might tell a different story. It's very important that you are smiling [while] wearing that mask. [He demonstrates by covering mouth with hand.] "Molo gogo! [hallo granny, in a warm, friendly voice]" [The patient] will say this nurse is friendly, although she cannot see his mouth. If you say "Gogo. Here's your medication." [Deep, rough voice] Then certainly she'll understand, "Hey! This is a lion!" So, she will be very scared of you. The nurse who listens will be like a Father Christmas. "Will you please pull that curtain …." "Please bring me a bedpan." "I'm hungry."' – participant 22, Mamele hospital, male nurse	The two patient participants described what tone of voice and body language they would like health workers to use. This recommendation focuses on health workers being aware of their relational *power* through acknowledging the emotive components of being ill and responding in an empathetic way. The nurse explained how he tries to compensate for the components of interpersonal communication that are lost through wearing a mask by intentionally emphasising having a friendly tone of voice, finding ways to express care and empathy despite physical barriers and infectious risk It is also touches on *loss of status* as stigma subcomponent — and that through being addressed in a respectful way acknowledges that a person's status has not changed because they developed TB.

Table 2 (continued)

Recommendation	Illustrative quote	Stigma subcomponent that is targeted
3. **Reframe IPC to emphasise communal safety** Describe TB IPC as a way of creating a safer healthcare environment for patients and health workers	'I am protecting [the health workers] and other people so that [the TB] remains with me and not go to other people. I would not get upset over something that is in my health—it will end. It will get cured and I will be that person again.' – participant 8, female patient, no previous TB, not previously asked to wear a mask [When I received a mask] I felt good … because it protects. It protects—for you to be safe on your side.—participant 20, male patient, current TB, asked to wear mask 'They—my doctors or nurses—should always remain protected from my disease.' – participant 9, male patient, no previous TB, asked to wear mask	These three patient participants emphasised the communal benefit of mask wearing for health workers and other patients. Through different framing, this attempts to introduce a new connotation to the *label* of wearing a mask — instead of responding to a mask with the fear of being infected by that person, it could be viewed as a protective, prosocial act. It also introduces interdependence between these groups: how communal safety depends on people with infectious TB to wear masks, which in turn places a responsibility on people who are being protected to avoid behaviour that may be stigmatising.
4. **Promote universal airborne TB IPC precautions** Consider universal airborne precautions such as improved ventilation in all clinical areas, routine use of outdoor waiting rooms and mask use by everyone in the health facility instead of precautions targeted at infectious patients	'I think when we are standing in the queue, we should try to protect everyone—including the nurses and doctors—everyone should wear a mask. We should all protect each other inside the premises, so that their sickness doesn't get to me and mine doesn't get to them. We don't know who between us is sick.'—participant 9, Male patient, no previous TB, previously asked to wear a mask '[Describing an ideal TB isolation unit that does not stigmatise patients.] Let's not think of it as a TB ward, not an isolation ward either. It's a separation ward. A place where we can manage people in single or double rooms, not just if they've got TB. There are a whole lot of other diseases that we need to separate out from the general patient population as well. And I hope that TB will become a bit like that. That it will be something that we take seriously, but that we actually have good facilities for managing so that they aren't left in a storeroom [where the current MDR TB ward is based] and that they aren't the pariah at the end of the passage. … I hope that with new facilities and a broader mindset into what we're doing, we can do infection control in a more human way. That you feel like you're getting the same great care, whether it's TB or heart failure, and it doesn't matter too much.' – participant 12, Mamele hospital, male doctor, manager	This patient participant suggested broadening the group of people who are asked to wear a mask. This recommendation focuses on changing the *label* of infectiousness that characterised previous use of masks for TB IPC, by adding the use of masks as protection. This approach could create a different symbolic meaning of airborne IPC measures that has a broader application than for TB. It could also mitigate the experience of feeling *discriminated* against, because instead of targeted measures, universal measures are used. The recommendation from the health worker tries to mitigate the *separation* that contributes to TB IPC stigma by blurring the groups of 'us' (the people who are sick with TB who are isolated) and 'them' (the people who need to be protected against TB) by introducing separation (described as single or double rooms) as universal measures for a range of different illnesses.

This health worker voluntarily disclosed that she had TB to patients to challenge the stereotype that only poor people are affected by TB. This recommendation uses her position of power relating to the status that a health worker has in this context, based on their employment and education, to reframe conceptions of who gets TB.

Several participants pointed out that encouraging people with TB to voluntarily disclose their illness (instead of involuntary disclosure through cues like masks) could be uncomfortable and could lead to isolation or psychological harm. However, they felt that on a community level, it could contribute towards decreasing the stigma for other people affected by TB.

> *I've thought about it in terms of normalising. I sometimes feel very uncomfortable [disclosing sensitive information about myself and risk stigma], but I do it anyway. Because I think that's what has to be done. So that's why I say with TB [if I developed it], I would be open about it. With HIV I hope I would, for that exact same reason. – participant 29, hospital doctor.*

There is an implied responsibility for the 'receiver' to respond tactfully and supportively, to meet the vulnerability of the person disclosing their illness. The benefit may not necessarily be directly for the individual disclosing their illness, although it might enable more support from family and friends:

> *What kills us sick people is that a person overthinks it, they think, "O God – maybe this person is disgusted by what I am."– participant 18, female previous TB patient, not previously asked to wear mask.*

The largest benefit would be for people from the same community affected by TB who may then face less stigma, as the conceptualisation of who falls ill is broadened and challenged. What is relevant to an infectious disease like TB is that disclosure may also make colleagues or family members aware of the potential risk of developing TB after exposure. 'Ubuntu' brings an interconnected, community-focused perspective (in contrast with an individual perspective) that could contribute to addressing some of the underlying causes of TB stigma.

Discussion

We had three main findings: TB IPC measures can both generate stigma experiences of patients but also reflect the stigma associated with the disease. Patient and health workers had contrasting perspectives on the implications of TB IPC-related stigma, with patients focussing on communal benefit, while health workers focussed on the negative impact on the health worker-patient relationship. Finally, recommendations to mitigate TB IPC-related stigma included comprehensive information, respectful communication, shifting the focus to communal safety and universal IPC precautions.

An important question when considering IPC-related stigma is as follows: where is the boundary between IPC in the interest of public health and an example of direct discrimination against someone who is ill? From a consequentialist philosophical perspective applied to TB, it would be when TB IPC stops serving a purpose, when it is futile and unnecessary. There were examples in our data where TB IPC measures caused harm when it evolved into broader social norms of engaging with TB patients in all settings, irrespective of whether they pose a risk of infection. TB IPC can in certain contexts be used to rationalise not only direct discrimination (through individual interactions) but also structural discrimination (which may be through social structures of institutional policies). An example of structural discrimination from our data was some of the health facilities having norms that expected MDR TB patients to wear masks irrespective of how long they have been on treatment and whether they are still infectious to other people. Guidelines that provide specific advice on the likely duration of infectiousness for people who have started TB treatment and whether and how TB IPC should be implemented in different settings (household, community and health facility) would make an important contribution and should include considerations for harm caused by prolonged isolation. See for example the National Tuberculosis Coalition of America's recent guidelines on isolation in community settings that makes significant progress on this [26].

The differences in health worker and patient perspectives on TB IPC-related stigma suggest that stigma mitigation interventions will need to account for these power dynamics to ensure that both perspectives are engaged with. It would also be interesting to present the emphasis that patients place on communal safety to health workers and see whether this may be a different way to train health workers on IPC, instead of emphasising individual benefit through improving the safety of the health worker. Using participatory research methods for TB IPC stigma interventions may be supporting co-creating interventions that engage with power dynamics between health workers and patients [30].

Future work could focus on piloting stigma interventions based on the recommendations in Table 2 and should ideally focus on different levels of the Health, Stigma and Discrimination Framework as we outlined in Fig. 1. Two recommendations for mitigation (namely requests for detailed information and respectful communication) align with the work of Gammon and colleagues who advised that health workers should compensate for potentially stigmatising isolation practices with increased social contact with patients [13]. One recommendation focussing on policy (universal instead of targeted use of IPC measures) was made by our participants pre-pandemic and implemented as part of the broader COVID-19 pandemic response. This widespread use of masks has been viewed as having a positive impact on the stigma associated with mask wearing for TB [31]. Drawing on evidence from previous epidemics, the broader conceptualisation of the utility of mask wearing (for COVID-19, TB and other respiratory illnesses) may support ongoing use of masks and could also be applicable to other airborne IPC measures [16]. However, this needs to be researched further, as the connotations with COVID-19 may bring new symbolic meanings to mask wearing.

Existing research in South Africa has highlighted the need for TB stigma interventions to be adapted to local contexts — as there can be differences between cultural groups [32]. In this rural Eastern Cape context, 'ubuntu' as a conceptual framework place emphasis on shared humanity and collective wellbeing. The participant recommendation to focus the framing of TB IPC messages on community-level benefits and the use of principles of 'Ubuntu' warrants further exploration. There is a rich history both in the academic literature and in community contexts that could be drawn on.

'Ubuntu' could refer to a moral quality in a person but also an intellectual tradition that falls within African humanism [33, 34]. It can be defined as follows: '*You are what you are because of other people. We don't live in isolation; we live in a community. That sense of community is what makes you who you are, and if that community becomes broken, then you yourselves also become broken. And the restoration of that community, the healing of that community, cannot happen unless you contribute to the healing of it in a broader sense. I am because of others, in relationships with others. I am not an island of myself, I am part of the community, I am part of the greater group*' [33].

'Ubuntu' is a way to foreground African constructions of the world and has been used as a conceptual framework to inform diverse fields such as social work practice and African philosophy [35, 36]. It could engage with some of the deep-rooted contributors to TB stigma — such as feeling less than human. This shift towards collectivism is also supported by research during the COVID-19 pandemic that suggested public communication framing mask use as important for communal safety was more effective than messages describing it to be important for individual safety [37, 38].

Voluntary disclosure of TB, particularly of people who are seen to have higher status in a certain context, aligns with this community-focussed approach and could reduce stigma more broadly. There may also be insights from other illnesses that used this approach, for example the use of HIV-positive T-shirts (with former President Nelson Mandela wearing this) as part of advocacy for the Treatment Action Campaign [39]. As Stangl and colleagues point out, in the example of HIV, stigma experiences fuelled patient advocacy efforts, resilience and improved access to healthcare [5]. Further research should evaluate our recommendations for a stigma intervention and translating it to other contexts.

Our research had key strengths, in that the team collecting data combined insider perspectives (having lived and worked in the setting) with outsider perspectives (approaching the topic through a research lens) and a multidisciplinary team. Limitations were that we relied on self-reporting of TB IPC and stigma practices, since planned observational fieldwork was disrupted by the COVID-19 pandemic. We also acknowledge that interventions that only focus on TB IPC-related stigma in health facilities may not be sufficient to address the broader stigma associated with the disease in different contexts and recommend that IPC stigma interventions should be sensitive to this. Due to our recruitment strategy that was based at health facilities, our study did not include participants for whom TB IPC-related stigma may have entirely prevented health care engagement. The sense of community responsibility reported by our participants may therefore not represent the perspectives of people with TB who did not engage in care.

Conclusions

In the rural health facilities in South Africa we studied, TB IPC measures both reflected and contributed to the suffering caused by TB through stigma. Health facilities can play an important role in mitigating or perpetuating this stigma, and context-sensitive interventions should explore this further. We recommend focussing on providing comprehensive TB IPC information to patients, respectful communication that also pays attention to non-verbal cues, shifting the focus from individual benefit of IPC implementation to communal safety and using universal airborne IPC precautions instead of measures targeting potentially infectious patients. Evoking 'ubuntu' as an African humanist conceptual framework could provide a novel perspective to guide these stigma mitigation interventions.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s44263-024-00097-8.

Additional file 1. Interview guide.

Additional file 2. Coding tree.

Additional file 3. COREQ checklist.

Acknowledgements
The authors would like to thank the following people who supported the research: Dr Karl Le Roux, Dr Nadisha Meyer and Catherine Young. We deeply appreciate the contributions of the health workers and TB affected community members who participated in this study.

Authors' contributions
HvdW, CB, RE, STC contributed to the design of the study, HvdW, NS contributed to the data collection, all authors contributed to the interpretation of data, HvdW produced the first draft of the paper and all authors provided input on the paper and approved the submitted version. All authors have agreed both to be personally accountable for their own contributions and the integrity of any part of the work.

Funding
This publication is part of HvdW's doctoral research which was funded by a Rhodes Scholarship. She received support for fieldwork from the Africa Oxford Initiative, Murrey-Speight Fund from the Rhodes Trust, Newton Exchange Fund and Green Templeton College's Fieldwork Funding. TG's research is funded from the following sources: National Institute for Health Research (BRC-1215–20008), ESRC (ES/V010069/1), Wellcome Trust (WT104830MA) and Health Data Research UK (HDRUK2020.139). STC is funded by the National Institute for Health Research (NIHR) Health Protection Research Unit in Healthcare Associated Infections and Antimicrobial Resistance (NIHR200915), a partnership between the UK Health Security Agency (UKHSA) and the University of Oxford. The views expressed are those of the author(s) and not necessarily those of the NIHR, UKHSA or the Department of Health and Social Care. CCB acknowledges part support as Senior Investigator of the NIHR, the NIHR Community Healthcare MedTech and In-Vitro Diagnostics Co-operative (MIC) and the NIHR Health Protection Research Unit on Health Care Associated Infections and Antimicrobial Resistance and was a part-time salaried general practitioner for the Cwm Taf Morgannwg University Health Board. The funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

Data availability
The datasets generated and/or analysed during the current study are not publicly available due to ethics approvals requiring us to protect the confidentiality of our participants. Through full transcriptions, participants may be identifiable. To discuss access to anonymised segments and any further requests for the data further please contact the corresponding author at helene.vdw@phc.ox.ac.uk

Declarations

Ethics approval and consent to participate
The study was approved by the research ethics committees at the University of Cape Town Health Sciences Faculty (HREC REF: 259/2019) and the University of Oxford (Oxtrec number: 541–19). It received institutional permission from the Eastern Cape Department of Health (EC_201907_010) and local permissions from each health facility. Written informed consent was obtained from all participants. The research conformed to the principles of the Helsinki Declaration.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Nuffield Department of Primary Care Health Sciences, Oxford University, Oxford, UK. [2]Division of Occupational Medicine, School of Public Health, University of Cape Town, Cape Town, South Africa. [3]Zithulele Research Unit, Mqanduli, South Africa.

Received: 2 July 2024 Accepted: 14 September 2024

References

1. World Health Organization (WHO). Global tuberculosis report 2021. 2021. Available from: https://www.who.int/publications/i/item/9789240037021. Cited 2022 Aug 28.
2. Daftary A, Frick M, Venkatesan N, Pai M. Fighting TB stigma: we need to apply lessons learnt from HIV activism. BMJ Glob Health. 2017;2(4):e000515.
3. World Health Organization (WHO). WHO guidelines on tuberculosis infection prevention and control. 2019. Available from: https://www.who.int/tb/publications/2019/guidelines-tuberculosis-infection-prevention-2019/en/.
4. World Health Organisation (WHO). Guidelines for the prevention of tuberculosis in health care facilities in resource-limited settings. 1999. Available from: https://apps.who.int/iris/handle/10665/66400. Cited 2022 Aug 28.
5. Stangl AL, Earnshaw VA, Logie CH, Van Brakel W, Simbayi LC, Barré I, et al. The health stigma and discrimination framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Med. 2019;17(1):1–3.
6. Dodor EA, Kelly SJ. Manifestations of tuberculosis stigma within the healthcare system: the case of Sekondi-Takoradi Metropolitan district in Ghana. Health Policy. 2010;98(2–3):195–202.
7. Nyblade L, Stockton MA, Giger K, Bond V, Ekstrand ML, Lean RM, et al. Stigma in health facilities: why it matters and how we can change it. BMC Med. 2019;17(1):1–15.
8. Goffman E. Stigma: notes on the management of spoiled identity. A Touchstone Book, editor. Harmondsworth: Penguin. New York: Simon & Schuster Inc.; 1963.
9. Scambler G. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. Soc Theory Health. 2004;2(1):29–46.
10. Buregyeya E, Mitchell EMH, Rutebemberwa E, Colebunders R, Criel B, Kiguli J, et al. Acceptability of masking and patient separation to control nosocomial tuberculosis in Uganda: a qualitative study. J Public Health (Bangkok). 2012;20(6):599–606.
11. Abney K. "Containing" tuberculosis, perpetuating stigma: the materiality of N95 respirator masks. Anthropology Southern Africa. 2018;41(4):270–83.
12. van der Westhuizen HM, Dorward J, Roberts N, Greenhalgh T, Ehrlich R, Butler CC, et al. Health worker experiences of implementing TB infection prevention and control: a qualitative evidence synthesis to inform implementation recommendations. PLOS Global Public Health. 2022;2(7):e0000292.
13. Gammon J, Hunt J, Musselwhite C. The stigmatisation of source isolation: a literature review. J Res Nurs. 2019;24(8):677–93.
14. Sin MSY. Masking fears: SARS and the politics of public health in China. Crit Public Health. 2016;26(1):88–98. https://doi.org/10.1080/09581596.2014.923815.
15. Lou NM, Noels KA, Kurl S, Zhang YSD, Young-Leslie H. Chinese Canadians' experiences of the dual pandemics of COVID-19 and racism: implications for identity, negative emotion, and anti-racism incident reporting. Can Psychol. 2021;63(3):279–97.
16. Tsang PM, Prost A. Boundaries of solidarity: a meta-ethnography of mask use during past epidemics to inform SARS-CoV-2 suppression. BMJ Glob Health. 2021;6(1):e004068. Available from: http://gh.bmj.com/content/6/1/e004068.abstract.
17. Burgess A, Horii M. Risk, ritual and health responsibilisation: Japan's "safety blanket" of surgical face mask-wearing. Sociol Health Illn. 2012;34(8):1184–98.
18. Hansstein FV, Echegaray F. Exploring motivations behind pollution-mask use in a sample of young adults in urban China. Global Health. 2018;14(1):1–10.
19. McCreesh N, Karat AS, Govender I, Baisley K, Diaconu K, Yates TA, et al. Estimating the contribution of transmission in primary healthcare clinics to community-wide TB disease incidence, and the impact of infection prevention and control interventions, in KwaZulu-Natal, South Africa. BMJ Glob Health. 2022;7(4):e007136.
20. Packard RM. White plague, black labor: tuberculosis and the political economy of health and disease in South Africa. Berkeley: University of California Press; 1989.

21. Kanabus A. GHE. Information about tuberculosis. 2021. Available from: https://tbfacts.org/tb-statistics-south-africa/. Cited 2021 Apr 6.
22. Day C, Gray A, Ndlovu N. Health and related indicators 2018. S Afr Health Rev. 2018;139–250. Available from: http://www.hst.org.za/publications/SouthAfricanHealthReviews/Chap15IndicatorsSAHR2018.pdf.
23. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893–907.
24. Braun Virginia, Clarke Victoria. Using thematic analysis in psychology. Qual Res Psychol. 2006;2006(3):77–101. Available from: . http://search.proquest.com.ezp1.villanova.edu/docview/223135521?pq-origsite=summonandaccountid=14853.
25. Link BG, Phelan JC. Conceptualizing stigma. Annu Rev Sociol. 2001;27:363–85.
26. Shah M, Dansky Z, Nathavitharana R, Behm H, Brown S, Dov L, et al. National Tuberculosis Coalition of America (NTCA) guidelines for respiratory isolation and restrictions to reduce transmission of pulmonary tuberculosis in community settings. Clin Infect Dis. 2024;ciae199. https://doi.org/10.1093/cid/ciae199.
27. Craig GM, Daftary A, Engel N, O'Driscoll S, Ioannaki A. Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. Int J of Infect Dis. 2017;56:90–100. https://doi.org/10.1016/j.ijid.2016.10.011.
28. Schei E. Doctoring as leadership: the power to heal. Perspect Biol Med. 2006;49(3):393–406.
29. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042.
30. Egid BR, Roura M, Aktar B, Amegee Quach J, Chumo I, Dias S, et al. You want to deal with power while riding on power': global perspectives on power in participatory health research and co-production approaches. BMJ Glob Health. 2021;6(11):e006978.
31. Driessche KV, Mahlobo PZ, Venter R, Caldwell J, Jennings K, Diacon AH, et al. Face masks in the post-COVID-19 era: a silver lining for the damaged tuberculosis public health response? Lancet Respir Med. 2021;9(4):340–2.
32. Bresenham D, Kipp AM, Medina-Marino A. Quantification and correlates of tuberculosis stigma along the tuberculosis testing and treatment cascades in South Africa: a cross-sectional study. Infect Dis Poverty. 2020;9(1):145. https://doi.org/10.1186/s40249-020-00762-8.
33. Gade CBN. What is Ubuntu? Different interpretations among South Africans of African descent. S Afr J Philos. 2012;31(3):484–503. https://doi.org/10.1080/02580136.2012.10751789.
34. Ndlovu-Gatsheni SJ. Epistemic freedom in Africa: deprovincialization and decolonization. 1st ed. Abingdon: Routledge; 2018.
35. Metz T. Ubuntu as a moral theory and human rights in South Africa. Afr Hum Rights Law J. 2011;11(2):532–59.
36. van Breda AD. Developing the notion of Ubuntu as African theory for social work practice. Soc Work. 2019;55(4):439–50.
37. Bokemper SE, Cucciniello M, Rotesi T, Pin P, Malik AA, Willebrand K, et al. Experimental evidence that changing beliefs about mask efficacy and social norms increase mask wearing for COVID-19 risk reduction: results from the United States and Italy. PLoS ONE. 2021;16(10):e0258282.
38. Bir C, Widmar NO. Social pressure, altruism, free-riding, and non-compliance in mask wearing by US residents in response to COVID-19 pandemic. Soc Sci Human Open. 2021;4(1):100229.
39. González LL. How many of these iconic protest posters can you recognise? Bhekisisa Centre for Health Journalism; 2018. Available from: https://bhekisisa.org/article/2018-12-12-00-treatment-action-campaign-south-africa-hiv-movement-celebrates-20-years/. Cited 2024 Jul 2.

Publisher's Note