



# Medical mistrust, discrimination and healthcare experiences in a rural Namibian community

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#### **ABSTRACT**

Substantial evidence indicates that medical mistrust, resulting from experiences with discrimination and marginalisation, is a determinant of health disparities in minority populations. However, this research is largely limited to the US and other industrialised countries. To broaden our understanding of the role of medical mistrust on health-care decision making, we conducted a study on healthcare experiences and perceptions in a rural, underserved indigenous community in northwest Namibia (n = 86). Mixing semi-structured interview questions with the medical mistrust index (MMI), we aim to determine the relevance of the MMI in a non-industrialised population and compare index scores with reports of healthcare experiences. We find that medical mistrust is a salient concept in this community, mapping onto negative healthcare experiences and perceptions of discrimination. Reported healthcare experiences indicate that perceived incompetence, maltreatment and discrimination drive mistrust of medical personnel. However, reporting of recent healthcare experiences are generally positive. Our results indicate that the concept of medical mistrust can be usefully applied to communities in the Global South. These populations, like minority communities in the US, translate experiences of discrimination and marginalisation into medical mistrust. Understanding these processes can help address health disparities and aid in effective public health outreach in underserved populations.

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#### Introduction

Medical mistrust has been repeatedly implicated in the perpetuation of health inequalities in the United States (Benkert et al., 2019; LaVeist et al., 2009). Often, this work references infamous research like the Tuskegee Syphilis Study, the sterilisation of minority women, and the misappropriation of biological specimens, as catalysts of mistrust, linking the specific history of discriminatory research on minority communities with a legacy of mistrust (Gamble, 1997; Ho et al., 2022). However, there is a growing recognition that broader patterns of discrimination, as well as negative first- or second-hand experiences with the medical system are more likely to foster mistrust (Brandon et al., 2005; Jaiswal & Halkitis, 2019; Scharff et al., 2010). Importantly, this recognition expands conceptions of medical mistrust

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beyond the experience of a particular group, toward a more general focus on intergroup power dynamics. As Benkert et al. (2019, p. 87) write, 'Mistrust is rooted in histories and hierarchies that influence the nature of one's relationship to institutions, communities, and other individuals, and shape enduring beliefs about one's position and vulnerability within those relationships.'

In line with this broader conception of medical mistrust, more research is needed with populations outside the US who also have histories of discrimination and marginalisation. Patterns of inequality in health care access and utilisation have been well documented around the world (Ruger & Kim, 2006), with health inequality often greater within countries than between them (Pradhan et al., 2003). There are myriad sources of this inequality, but medical mistrust has been posited to be a protective response against inequality and discrimination in the United States (Benkert et al., 2019; Jaiswal & Halkitis, 2019) and may be operating similarly in other countries. Despite this, there is relatively little work looking at the relationship between medical mistrust and people's individual experiences with health-care systems outside of the United States (Williamson & Bigman, 2018).

The impacts of medical mistrust on healthcare decisions and treatment compliance are not trivial. Medical mistrust has been linked to numerous negative health outcomes. Those with greater mistrust tend to underutilise healthcare services (Adams et al., 2017; Hammond et al., 2010; LaVeist et al., 2009), and they have greater dissatisfaction with care received (Guadagnolo et al., 2008; LaVeist et al., 2000). Individuals high in medical mistrust are less likely to receive cancer screenings or participate in organ donation or clinical trials (Morgan, 2006; Thompson et al., 2004). Further, the link between medical mistrust and negative health outcomes has also been shown to be exacerbated by lower levels of literacy and education (Idan et al., 2020; White et al., 2016), as well as cultural barriers between providers and patients (Canales et al., 2011; Lightfoot et al., 2019). In the context of COVID-19, medical mistrust has been associated with a reduction in the likelihood of receiving COVID-19 vaccinations and greater COVID-19 vaccine hesitancy (Allen et al., 2022; Bogart et al., 2021), and mediates differences in vaccination beliefs and decisions in marginalised communities (Charura et al., 2023; Thompson et al., 2021). These findings point to the need for more studies outside of the United States, where differences between patient and provider education levels may be larger and where colonial histories and ethnic tensions may impact treatment in medical settings.

While formal studies of medical mistrust are relatively rare outside the US, there is some strong evidence that mistrust has led to underutilisation of health care services within the Global South. For example, studies of Ebola outbreaks point to mistrust of the medical system as a major factor in people's hesitancy to seek care and remain in treatment centres (Carrión Martín et al., 2016; Woskie & Fallah, 2019). Other studies link inhospitable treatment at health facilities with underutilisation of services (Essendi et al., 2011; Helova et al., 2016). Poor communication with and treatment of patients is also widely reported (Kwame & Petrucka, 2021; Østergaard, 2015), which may also lead to mistrust and affect future use of medical facilities, but these links are still understudied.

To better understand the role of medical mistrust outside of the US, we conducted a study of healthcare experiences and perceptions of the healthcare system in a rural, underserved community in northwest Namibia. Our team has been working with this community for more than ten years, enabling us to blend rich, ethnographic data with standardised measures of medical mistrust. This mixed-method approach is used to determine the relevance of a widely used measure of mistrust, the 7-item medical mistrust index (MMI), in a novel setting, compare intra- and inter-group variability across items in the MMI, and map healthcare experiences within this community with levels of medical mistrust.

# **Methods**

# Study population

The focal study community of Omuhonga is located in the Kunene region of northwest Namibia, about 150 km from the regional capital of Opuwo. Most residents of Omuhonga belong to the

Ovahimba (Himba) tribe and continue to practice semi-nomadic pastoralism. A 2017 census of the community recorded 40 households and more than 600 residents. Most families who have compounds in Omuhonga also maintain cattle posts elsewhere, where family members reside at different times of the year. Access to markets in this area is still limited, although there is a large primary and secondary school in the community, and a small market that opened recently where maize meal and a few other staples can be purchased. Virtually all adults in the community lack formal education and most have only completed one to three years of primary education. The closest medical facility is a clinic in the town of Okongwati, ~15 km from Omuhonga. The regional hospital (located in Opuwo) is a two-hour drive. As few people in the community have vehicles, getting to the hospital usually requires finding and paying for a ride, raising both logistical and financial hurdles.

Omuhonga is one of many rural communities in Namibia, one of the least densely populated countries in the world. Despite being an upper-middle-income country, Namibia is one of the least equitable nations in the world, second only to South Africa in its Gini coefficient for wealth inequality (The World Bank Group, 2023). In a multidimensional measure of poverty, Chamboko et al. (2017) found that rural regions showed the greatest levels of deprivation, with the Kunene region reporting 51% of those surveyed having the maximum level of deprivation. Namibian residents may take advantage of public health care, with exiguous fees for low-income patients. However, a high proportion of the poorest households still cannot afford to seek care for illness or injury as payments for medicine, medical supplies and travel costs to visit a clinic or hospital are prohibitively expensive (World Bank, 2019). These inequalities are reflected in people's utilisation of the healthcare system, with rural regions faring worse (Eide et al., 2015; Rashid & Antai, 2014). Kunene residents also tend to live much farther from clinics and hospitals than do Namibians on average, and have fewer hospital beds per capita (Levine et al., 2008; World Bank, 2019). Travel from these rural areas to hospitals and clinics is a major obstacle to seeking healthcare, and can influence the propensity to seek formal medical treatment, in favour of increased reliance on traditional medicines (Kamati et al., 2019; Matengu et al., 2005; Van Rooy et al., 2015). Members of minority ethnic groups (like Himba) tend to have poorer health outcomes, including lower rates of immunisation and higher infant mortality (Brockerhoff & Hewett, 2000). Moreover, Himba's experiences with the outside world have been shaped by decades of social and economic marginalisation, described by Bollig (1998) as 'colonial encapsulation.' This included restrictions on movement, livestock sales and land tenure by past colonial powers, limiting market sales and the potential for economic mobility, unlike more market integrated Otjiherero speaking tribes who reside in the same area.

## Recruitment and data collection

Participants were opportunistically recruited during visits to households in the focal community during the summer of 2022. The majority of adults in this community have been involved in anthropological research with the co-authors since 2010, and have experience with semi-structured interviews, Likert scale questions and experimental tasks. As such, researchers and the local translators have all developed good rapport with the community. All adults who were present were given the opportunity to participate, and no adult declined to participate on the basis of the content of the study (although some declined due to time constraints or prior obligations). Participants were interviewed individually with the assistance of a translator and were compensated with small gifts of maize meal, washing powder, or cell phone credits for their participation in this study. Data and open-ended responses were collected on tablet computers using RedCap software.

#### **Variables**

# **Demographics**

The majority of participants were known to researchers from previous studies and their demographic data was already present in the longitudinal database. These data were checked for accuracy and updated where necessary. For the 21% of participants not represented in the demographic database, data on gender, tribal affiliation and age were collected. Ages were calculated using the local year name system (Scelza, 2011).

# Medical mistrust

A slightly amended version of the 7-item Medical Mistrust Index (MMI) (LaVeist et al., 2009) was used. The MMI is a validated survey which has been used in a variety of settings to assess individuals' propensity to distrust medical personnel and institutions, and has been associated with underutilisation of healthcare in multiple contexts (Buscemi et al., 2023; Hammond et al., 2010; Hamoda et al., 2020; LaVeist et al., 2009; Morgan et al., 2023; Williamson & Bigman, 2018). The MMI is particularly recommended for research settings where participants are predicted to be distrustful of healthcare systems, rather than just individual medical personnel (Williamson & Bigman, 2018). Given the history of detrimental colonial policies, inter-ethnic conflict in Namibia and the minority status of Himba, this scale was deemed the most appropriate. Small changes were made to make the language more amenable to translation into Otjihimba. Original survey items and the modified questions for translation can be found in Table S1. Four-point Likert responses were recorded, with participants first asked for a binary positive/negative response, followed by a prompt about degree (e.g. 'Do you agree or disagree with this statement?' [If agree] 'Do you agree a lot or a little?'). Final responses were coded as 'strongly agree,' 'agree,' 'disagree,' and 'strongly disagree.' Following LaVeist et al. (2009) and others, an MMI score was calculated by creating an average of item responses, creating a scale from 1 (low medical mistrust) to 4 (high medical mistrust).

# Healthcare experiences

A mix of binary and open-ended questions were asked of participants to elicit their experiences with the local clinic and hospital. These included questions about first and secondhand mistreatment ('Have you ever been mistreated or harmed by a doctor/nurse?'), and perceptions of bias by practitioners ('Do you think that Himba are treated the same as patients from other tribes?'). Binary response questions were followed by open-ended ones to gather qualitative information and contextualise participants' experiences. All question prompts are detailed in the supplementary materials.

# **Analysis**

Data was exported from the RedCap database into CSV format for analysis in R (R Core Team, 2020). Reliability of MMI items was assessed via Cronbach's  $\alpha$  and was calculated using the ltm package (Rizopoulos, 2006). MMI score was compared to healthcare experiences using simple distributional models in a Bayesian framework using the brms package (Bürkner, 2017). Below we report posterior medians and 95% credible intervals and the probability of distributions falling above or below zero (Pr[ $\beta$  </>/>> 0]). Open ended responses were evaluated by study authors and manually coded for thematic analysis.

# Ethical approval

Ethical approval was granted by the University of California, Los Angeles (IRB #10-000238). This work was conducted in collaboration with the Hizetjitwa Indigenous People's Organization (HIPO), based in Opuwo, Namibia. Within the community, permission was granted by the local chiefs, and oral consent was obtained from all individuals participating in the study.

#### Results

# Sample

Survey data was collected from 86 adult participants, 61 (71%) of which were women. Most participants identified as Himba (83 or 96.5%), while two identified themselves as Hakaona, and one as Themba. The average age of participants was 34.9 years (sd = 16). Men tended to be older, with an average age of 41.3 (sd = 19.9), while women had an average age of 32.2 (sd = 14).

# Reliability

To examine reliability of this translated medical mistrust survey in a non-industrialised setting, a reliability coefficient was computed for the seven-item scale. Standardised Cronbach's  $\alpha$  was estimated at 0.73 (95% CI = 0.64–0.79), indicating an acceptable level of reliability similar to that published in the original validation of the 7-item survey ( $\alpha$  = 0.76 in LaVeist et al., 2009), as well as other published papers which report validation statistics (Morgan et al., 2023).

#### **Medical** mistrust

Average medical mistrust scores are similar in our sample of Himba (mean = 2.66, sd = 0.82), to the original validation study of residents of Baltimore, MD (LaVeist et al., 2009), as well as to other inperson and online studies of minority populations in the US that use the same scale and report sample averages. Item 1, regarding caution when dealing with healthcare organisations, had the strongest agreement, while item 5, regarding information privacy had the lowest agreement (Figure 1). These averages are representative of a trend in these survey results; items dealing with intentional deception by healthcare personnel tend to have lower agreement, while items dealing with incompetence by healthcare personnel tend to have higher agreement. Linear models indicate that standardised age predicts an increase in medical mistrust ( $\beta$  = 0.16, CI = -0.02-0.34), while there is no difference in gender, although men's medical mistrust trends higher ( $\beta$  = 0.14, CI = -0.26-0.54, Figure S1).

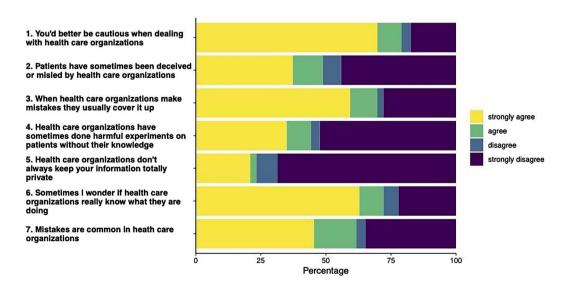


Figure 1. Medical mistrust survey responses by question.

# Healthcare experiences

In addition to medical mistrust, participants were asked a series of binary response questions about their healthcare experiences, followed by open ended questions. We contextualise these binary responses with qualitative information in the discussion. Personal mistreatment by a doctor or nurse was common, with 40.7% of respondents reporting that they had experienced mistreatment or harm or reporting that they had friends and family who had been harmed or mistreated. When asked about their most recent experience with the healthcare system, for either themselves or a family member, 80.2% of participants recounted stories that were neutral or positive. When asked whether there was ever a time that they personally needed to go to the hospital or clinic but didn't, 47.7% of respondents responded in the affirmative. Finally, participants were asked if they thought Himba were treated equally compared to other tribes. While the majority reported that they were, 41.9% of participants reported a perception of unequal treatment.

To examine how healthcare experiences map on to medical mistrust, we compared these healthcare experiences with medical mistrust scores (Figure 2). Medical experience questions all meaningfully predict medical mistrust, such that reporting personal or familial mistreatment, and avoiding healthcare when it was needed are all associated with greater medical mistrust (Pr[\beta] > 0] > 99.5%). Similarly, participants who reported perceived differences in treatment between Himba and other tribes also have higher medical mistrust ( $Pr[\beta < 0] = 99.8\%$ ). Model coefficients are plotted in Figure S2.

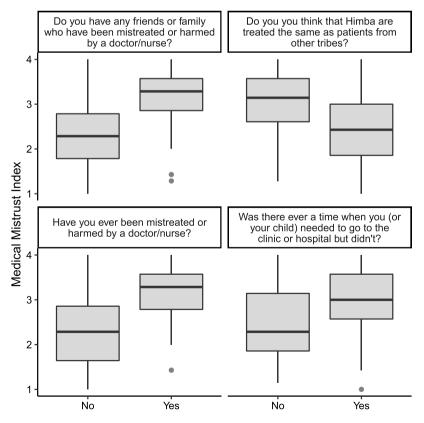


Figure 2. Medical mistrust scores by healthcare experience.



#### Discussion

Scholars have sought to interpret medical mistrust as a variable through which discrimination, racism and marginalisation impact health. For example, Benkert et al. (2019), drawing from a framework created by Williams and Mohammed (2013), place medical mistrust as an important linkage between socio-economic status, race, and gender, and behavioural and psychological responses mediating health outcomes. In accordance with this pathway approach, we focus our interpretation of the qualitative and quantitative data collected from this project to understand specific pathways linking tribal identity, local cultural histories and legacies of colonialism to medical mistrust. We highlight three such pathways here: incompetence, maltreatment and discrimination.

We find that Himba experiences differ somewhat from studies of medical mistrust in the US, which have focused mainly on the role of intentional, unethical medical testing and practice as the historical basis fomenting mistrust in marginalised communities (Bates & Harris, 2004; Gamble, 1997). Our results indicate that Himba largely minimise intentional deception by healthcare personnel and systems, in contrast to work in the US indicating that perceptions of deception and poor or inadequate communication are associated with distrust (Scharff et al., 2010; White et al., 2016). However, our findings are similar to studies in the US that point to current and ongoing experiences of poor quality care, disrespect and mistreatment leading to mistrust (Hammond, 2010; Scharff et al., 2010). Additionally, as in the US where perceived discrimination based on race/ethnicity, education and language was associated with mistrust (Bazargan et al., 2021; Hammond, 2010; Smirnoff et al., 2018; Williamson et al., 2019), we find medical mistrust indices higher in participants who view Himba as being treated differently in healthcare settings. Here we use qualitative data to reflect on how these experiences can shape healthcare decision making, ultimately leading to health disparities.

# Pathways to medical mistrust

# Incompetence

According to MMI survey responses, more than 70% of participants agreed or strongly agreed that medical personnel 'sometimes don't know what they are doing,' and more than half of participants agreed or strongly agreed that 'medical mistakes are common.' This perception of incompetence as a common feature of healthcare was also borne out in open ended responses to questions about people's own healthcare experiences. Several participants described receiving the wrong medication or being injured as the result of poor or incompetent medical treatment. A number of participants recounted stories of having broken bones that healed improperly as the result of inadequate treatment. For example, one man responded with the following: 'I had a broken arm and when I went to the hospital, they couldn't help me at first, and took long to treat me. I went back home and then went again and by the time they fixed it, it was too late, and it didn't heal straight.' Another participant recounted that he had a broken arm improperly set, which had to be surgically broken and reset. Following surgery, the participant was too fearful to return to the hospital to have the cast removed, so he removed it himself and threw it in the river.

# Maltreatment

A number of participants recounted stories of mistreatment by doctors and nurses. Many of these narratives were centred around very long wait times, due in part to perceived ambivalence by medical personnel. For example, one participant in describing their experience said, 'I went there, and they weren't even looking at me. I even slept there into the night. For three days I slept there, slept again. They saw I was there, but they were doing their own things.' Another man noted that he, 'needed an x-ray and the nurses were saying it's lunchtime and didn't care I was suffering, and we had to wait a really long time into the night.' Several participants reported getting into verbal

or physical altercations with medical personnel because of lack of treatment or perceived ambivalence over their medical needs. One woman reported going to give birth, but being forced to wait in line for so long that she gave birth outside the hospital. Notably, long wait times were interpreted as a lack of concern, rather than other potential causes, such as understaffing or from high demand for medical services.

#### Discrimination

Perceived discrimination of Himba patients by non-Himba medical personnel was another consistent refrain by participants. When asked if they thought Himba were treated the same as people from other tribes, 41.9% of participants believed that Himba were treated worse. When asked why, responses centred on perceptions of cleanliness and dress. For example: 'When you are dirty, they treat you differently. When you are clean, they treat you the same. Himba are seen as unclean.' Many participants believed that discrimination was due to wearing traditional clothes and adornments. Himba women still frequently dress in leather garb, and wear ochre mixed with milk fat on their skin, while men tend to wear mainly cloth clothing, and use some charcoal and milkfat on their skin. Himba women also continue to use smoke-baths in place of soap and water. These traits may result in greater stigmatisation in healthcare settings. Multiple participants reported being called 'dirty' and being told they needed to bathe prior to coming to the hospital. Several women we spoke with will go so far as to remove all traditional adornments, and change into western clothes before going to the hospital in hopes of receiving better care. Participants report that they believe their traditional garb results in them being disregarded by healthcare staff. As one participant noted: 'If they see Himba and they see those that are wearing clothes, first they take the ones wearing clothes.' Other participants emphasised the differential level of education, not Himba tribal identity, as being the primary driver of mistreatment and discrimination in healthcare settings. As one woman noted: 'They don't treat us the same because we are uneducated. The attention they are giving to me is not the same as the attention they give to others.'

Others reported that discrimination results from healthcare personnel's general preferences for other tribes. For example, participants reported that even if Himba arrive at the hospital first, patients of a different tribe who arrive later will receive treatment first. Several participants suggested that they would receive better treatment if there were Himba doctors and nurses working at healthcare institutions, but a lack of Himba medical personnel means worse care for Himba patients. For example, as one man argued, 'There are no Himba working in the hospital. If you don't have your own people working there, you won't be treated well.'

These anecdotes suggest that experiences of incompetence, maltreatment and discrimination from medical personnel are frequent, and shape Himba attitudes towards healthcare institutions However, when participants were asked about their most recent experience at the clinic, or hospital, the majority reported neutral or positive experiences. When coded, only 19.8% of participants reported an overtly negative experience during their last healthcare visit. This contradiction suggests that isolated negative experiences may be extremely influential in shaping general beliefs about healthcare personnel and likely influence future medical treatment. We find that almost half of the participants noted that they didn't seek medical care when they felt they needed it, partially due to distrust and dissatisfaction with the healthcare system. As others have pointed out, these responses should not be viewed as conspiracy beliefs, lack of education, or as cultural barriers to healthcare, but instead protective responses to discrimination and maltreatment by the healthcare system (Benkert et al., 2019; Terrell & Terrell, 1981; Whaley, 2001).

# Limitations and future directions

This study has several limitations that constrain our ability to generalise from these findings. We recruited from only a single rural Himba community, but it is possible that perceptions of medical mistrust and experiences with medical personnel vary between communities and between Himba and other tribes living in the area. Relative wealth and status, access to cash, level of market integration, and ease of transport may similarly influence access to and frequency of interaction with medical personnel, shaping mistrust. We find little gender difference in medical mistrust scores, but given the demands placed on women, including obstetric and gynecological care, the need to transport and accompany children, female kin, and other family members to clinics and hospitals, women's experiences with the healthcare system are fundamentally different than men's. Future work should seek to better understand how these experiences differ, and how these experiences shape women's propensity to seek healthcare, Previous work in this area indicates that interactions with aid and medical workers and perceptions of the frequency of various practices can fundamentally shift perinatal care norms (Hagen & Scelza, 2020). As women are primarily responsible for having children vaccinated, we expect that medical mistrust and perceptions of medical personnel may also be influential in childhood vaccination uptake and treatment of childhood illnesses.

Lastly, while we focus here on the perceptions and experiences of an indigenous group, systemic issues likely also play a major role in these outcomes. Qualitative data collected suggest that Himba don't attribute issues of maltreatment like inappropriately long wait times to structural issues, but instead to lack of appropriate consideration and concern by medical personnel. However, evidence suggests that long wait times for care are a major issue for Namibia, and can influence propensity to seek care more broadly (El Sherif, 2010; Kamati et al., 2019; Meguid et al., 1999). Low retention of medical personnel resulting from high workloads and poor working conditions may exacerbate wait-times and access to healthcare services (Washeya, 2018). Namibia continues to have a lower per capita number of physicians and nurses compared to similar countries, and many of the doctors and nurses they do have work in private sector hospitals, which are out of reach to the majority of the population financially and geographically (World Bank, 2019). These structural forces may directly shape patients' experiences with healthcare. Future work should directly link structural issues like clinic and hospital funding, staffing, and patient-load to patient experiences, to better understand how these issues impact patient care in rural and indigenous communities.

# Conclusion

Results from this project indicate that medical mistrust is a salient factor mediating perceptions of healthcare in rural Namibia. Medical mistrust scores map onto negative healthcare experiences and perceptions of discrimination. Qualitative reports suggest that three domains in particular drive mistrust of healthcare personnel: perceived incompetence, perceived maltreatment and perceived discrimination. Discrimination may be particularly important for Himba, whose experiences suggest that traditional dress, use of ochre and lack of education place them at risk of discrimination in healthcare settings. With the exception of perceived deception by medical personnel, results found here are similar to those in studies of minority populations in the US. In both settings, perceptions of discrimination can influence mistrust of the medical establishment. Similarly, perceived maltreatment is a feature of both populations, although there are substantial differences in the ways in which maltreatment may manifest.

Health disparities are influenced by historical, cultural and economic forces that result in discrimination and marginalisation of populations, racial groups and individuals. At a more proximate level, this can include individual experiences and interactions with the healthcare system, stemming from these broader historical and economic forces. The concept of medical mistrust is largely only applied to minority populations in the US, but these findings suggest that applying medical mistrust in the context of marginalisation, colonialism and inequality in the Global South may shed light on healthcare decisions more broadly. Our data also suggest that medical mistrust stems largely from individual interactions and experiences with hospital staff, which may include perceptions of discrimination resulting from tribal differences, education and wealth. Where maltreatment is linked with tribal identity, mistrust can be a product of economic inequality between groups or the result of inter-group division. Ultimately, this impedes people's ability to access or acquire healthcare.



Future work should seek to better understand relevant drivers of medical mistrust in rural Africa, in order to better address healthcare experiences and health inequalities.

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# Disclosure statement

No potential conflict of interest was reported by the author(s).

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# Ethics approval and consent to participate

The study received ethics approval from the Institutional Review Board (IRB) of the University of California, Los Angeles (IRB #10-000238). Within the community, permission was granted by the local chiefs and in collaboration with the Hizetjitwa Indigenous People's Organization (HIPO). The authors confirm that verbal informed consent was obtained from all individuals participating in the study, as approved by the UCLA IRB, as the study population is non-literate. All methods were carried out in accordance with relevant guidelines and regulations.

# Availability of data and materials

Data and R code used as part of this study are available at the Open Science Framework at https:// osf.io/ctrxy/.

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