

Community perspectives on leprosy and related stigma in northern Nigeria: a qualitative study

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Summary

Aim This study explored community perceptions about leprosy and the extent, root causes, and drivers of stigma in Kano State, northern Nigeria.

Methodology The study used a cross-sectional design with a qualitative approach. Semi-structured in-depth interviews were conducted with community members unaffected by leprosy. Participants were selected using stratified purposive sampling. Thematic analysis was performed based on the “Framework Approach”.

Results A total of 21 community members were included in this study. We found that the majority of the participants perceived persons affected by leprosy negatively, they were considered dirty, incurable, and inferior. Participants indicated that they avoid touching, social interactions, and sharing meals with persons affected by leprosy. In addition, leprosy was said to negatively impact employment opportunities and the marriage prospects of persons affected and their family members. Marriage prospects were considered worse for women affected by leprosy. We identified four main drivers of stigmatization: (1) local beliefs and misconceptions about leprosy (e.g. the belief that leprosy is hereditary, incurable, or highly infectious), (2) fear of disability and deformity, (3) fear of infection, and (4) perceived poor personal hygiene of persons affected.

Conclusion This study revealed negative perceptions regarding leprosy, including misconceptions about etiology, fear and desire to keep social distance towards persons

affected. Our findings underscore the importance of community education and behavior change as key to transforming perceptions and behavior towards persons affected.

Keywords: Leprosy, stigma, community members, Nigeria

Introduction

Since antiquity leprosy has been variously misconstrued as a divine curse, retribution for sins, or an inherited disease.¹ Despite the discovery of *Mycobacterium leprae*, the bacterium that causes leprosy, over a century ago,² these perceptions have persisted in communities around the world.³ Leprosy is an infectious disease that is characterised by hypopigmented, anaesthetic skin patches. The disease is caused by *Mycobacterium leprae* and transmitted by close and long-term exposure to droplets from an infectious person.⁴ However, leprosy is often associated with severe disabilities and disfigurements with attendant heavy stigma which may result in abandonment, social isolation, and condemnation to the margins of society.⁵ Leprosy-related disabilities, however, can be prevented with early detection and treatment.⁶ Leprosy is curable with multidrug therapy (MDT). Treatment lasts six to 12 months, and patients are no longer infectious within days after their first dose.⁴

Stigma has been referred to as a “spoiled identity”, and has been defined as “an attribute that is deeply discrediting that reduces the bearer from a whole and usual person to a tainted discounted one”.⁷ Stigma is also a social process that exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them to occur.⁸ From the perspective of those who stigmatize, a distinction can be made between enacted (actively engaging in), endorsed (justifying and supporting) and accepted (accepting without endorsing) stigma. From the perspective of persons affected, stigma can be enacted, internalized and anticipated.⁹ Studies have found that stigma can affect many aspects of life.¹⁰ Leprosy may affect social status, employment opportunities, relationships, marriage (prospects), and family life.⁹ These effects manifest at the individual, family, and community levels.^{11,12} At the individual level, persons affected may experience emotional stress and anxiety, which may lead to psychological and psychiatric morbidity.^{13,14} At the community level, social participation can be restricted with difficulties related to community interaction, social relationships such as friendship and marriage (prospects), and employment. This may be extended to their family members, limiting educational opportunities, leading to further inequities. These negative effects originate from negative public perceptions about leprosy, including poor community knowledge and misconceptions about the disease.¹⁵

The stigma of leprosy has religious, sociocultural, and psychological roots.^{8,16} It is fueled by a lack of understanding of the disease, including misconceptions of the cause, mode of transmission and treatment of leprosy, and fear of the severe deformities and disfigurements that can result if leprosy remains untreated.¹⁷ Negative perceptions of leprosy are not limited to the uneducated; the highly educated and even medical professionals could display a lack of knowledge, such as low knowledge about the reservoirs, the mode of transmission, and the incubation period.¹⁸ Addressing leprosy-related stigma, therefore, requires a multifaceted approach to dispel myths and misconceptions through awareness creation. In addition, interventions are necessary to address the psychological and social effects on persons affected, the family, and the community.⁹ When community perspectives about leprosy are not addressed, this could lead to concealment, delayed presentation, and persistence of stigma even after

treatment.^{19,20} Context-specific strategies require a thorough understanding of the community perspectives on leprosy and the extent, root causes, and drivers of stigma.

Previous reports indicate varying levels of stigmatization toward persons affected by leprosy in Nigeria.^{21,22} However, the community perspectives about leprosy and stigma have not been recently investigated in northern Nigeria. Limited leprosy research has been conducted in Nigeria generally and less so in northern Nigeria due to the perception that leprosy is old fashioned, a “neglected disease” and the failure of stakeholders to make leprosy research attractive to local researchers.²³ This study sought to explore community perspectives on leprosy and the extent, root causes, and drivers of stigma in Kano State, northern Nigeria. The findings could inform stigma-reduction measures in leprosy control programs in northern Nigeria and similar settings.

Material and methods

STUDY DESIGN

The study used a cross-sectional design with a qualitative approach. Semi-structured in-depth interviews were conducted with community members unaffected by leprosy living in the catchment communities of multidrug therapy (MDT) clinics in Kano State, Nigeria.

STUDY SITE

The study was conducted in Kano State, northern Nigeria. In 2020, the prevalence of leprosy was 1,837 in Northern Nigeria, compared to 587 in Southern Nigeria. The Northwest zone of the country, that includes Kano State, had a registered prevalence of 986 cases, followed by Northcentral zone with 506 and the Northeast with 345 cases. Kano State had 214 leprosy cases out of Nigeria’s 2,424 in 2020.^{23,24} Data were collected in both urban and rural catchment communities of MDT clinics in Kano State. The state has 46 MDT clinics out of a total of 774 MDT clinics in Nigeria serving an estimated population of 13 million inhabitants of Kano and the surrounding northern states of Nigeria.²⁵ Kano State also has one of the oldest leprosy hospitals in northern Nigeria, the Yadakunya specialist hospital. This 153-bed capacity hospital takes care of leprosy complications, orthopedic services, general outpatient services, antenatal care, and other maternal health services, in addition to having a MDT clinic.

STUDY POPULATION AND SAMPLING METHODS

The study population consisted of community members unaffected by leprosy, 18 years or older, and residents within the catchment communities of MDT clinics for at least one year. Persons without the capacity to provide informed consent were excluded. Stratified purposive sampling was used to select participants. The aim was to include participants until theoretical data saturation, whereby no novel findings emerged from subsequent interviews. Potential participants were stratified by residence (rural and urban), sex (male and female), and education (no formal education and some formal education) to ensure representation and maximum variation in experiences.

DATA COLLECTION

An interview guide was used to conduct semi-structured interviews. The questions in the interview guide were formulated to gain insights into community perspectives about perceived and enacted stigma towards persons affected by leprosy and the drivers of leprosy-related stigma in their communities. We used elements of the explanatory model interview catalogue

(EMIC) to develop the interview guide, allowing for emergent themes. The domains explored include (1) perceptions about cause and mode of transmission, (2) community perceptions of and behavior towards persons affected by leprosy, (3) participants' response to community attitudes, (4) perceptions about marriage prospects, (5) perceptions about employment opportunities, and (6) reasons for stigmatization.²⁶ The in-depth interviews were conducted by an experienced social scientist using the interview guide. The interviews were conducted face-to-face in the catchment communities ensuring confidentiality and observing COVID-19 precautions. Data were collected in January and February 2021.

DATA ANALYSIS

The interviews were audiotaped, transcribed, and translated from the local Hausa to English language. Subsequently, the transcripts were coded and analyzed manually. Thematic analysis was performed based on the "Framework Approach",²⁷ and included familiarization through repeated reading, coding, theme generation (*a priori* from the interview guide and emergent from the data), applying the codes to the transcripts, matrix formation, deductive content analysis, and interpretation.

ETHICAL APPROVAL

The study was approved by the Kano State Research ethics committee of the Ministry of Health vide a letter number MOH/OFF/797/T.1/2068 dated 31st August 2020. All participants were fully informed about the objectives of the study, voluntary participation, and the confidentiality of the data. Written informed consent was obtained from all participants prior to data collection.

Results

PARTICIPANT CHARACTERISTICS

A total of 21 community members were interviewed in-depth. The average age of the participants was 41 years, ranging from 24 to 65 years. Eleven participants were women. Ten participants were from rural areas. Half of the participants had no formal education ($n = 10$). The participants who had received education, had completed primary ($n = 4$), secondary ($n = 2$) or tertiary/post-secondary education ($n = 5$). The majority of the participants ($n = 19$) were married, while two were widowed. Participants were civil servants ($n = 7$), petty traders ($n = 6$), farmers ($n = 5$), commercial motorcyclist ($n = 1$), manual laborer ($n = 1$) and unemployed ($n=1$).

Most participants were acquainted with someone affected by leprosy in their community, but generally, they were of the view that the number of people affected by leprosy in their communities has decreased over the years. The persons affected were relatives, friends, neighbors, acquaintances, and other community members.

"Yes, I know someone with leprosy in our community. We are not related but I used to see him begging and whenever we met, I greet him from afar." 37-year-old, female, civil servant.

"In the past, I knew men and women that had leprosy in our community, but now they are fewer and I cannot say the last time I saw one of them." 35-year-old, female, petty trader.

PERCEPTIONS ABOUT CAUSE AND MODE OF TRANSMISSION

No participant knew the cause of leprosy (*Mycobacterium leprae* or bacteria), however, some mentioned the mode of transmission of leprosy (airborne transmission, close bodily

contact with affected persons or their secretions/discharges) without stating that a bacterium is transmitted. Other participants mentioned that they think that leprosy is hereditary or a divine retribution for unfulfilled oaths. There were also suggestions that drinking water contaminated by a poisonous spider or gecko, sharing food and drinks with affected persons, eating incompatible food items, such as milk and fish, or uncooked groundnut and fish causes leprosy. Further, participants indicated that wearing shoes of a leprosy patient, waking up before a guest who is affected by leprosy, cutting down a paw-paw tree, cultivating on a termite hill, and making disparaging statements against persons affected could cause leprosy. The possibility of the transformation of “eczematous” lesions to leprosy was also entertained. These perceived causes were all mentioned more or less equally.

“Yes, people are saying if you have a leprosy affected guest who slept overnight in your house, you should not wake up before him, because if you do you can get infected. That is why one is advised to exercise patience for him to wake up and go with his infection.” 47-year-old, female, petty trader.

“There was somebody who cut down a paw-paw tree that was how he got leprosy. There is also another person who cultivated on a termite hill [gidan tururuwa], that was how he also contracted leprosy. Also, someone laughed and ridiculed a person affected by leprosy, he was angered and he cursed him, and that was how he became affected. Further, in some people “eczema” lesions transform into leprosy. I don’t believe in these explanations, but that is what people are saying.” 57-year-old, female, teacher.

Some participants strongly associated leprosy with disability/deformity which instilled fear and the need to keep away from persons affected, thereby fueling stigma.

“If you are infected with leprosy all your body structures will change. Your voice will change and likewise, your lips will also drop downwards. If you speak your nose and your eyes will be watery before it comes to your hands. Others have discharging wounds in their hands and their leg structure changes. It is therefore not possible to hide it.” 33-year-old, female, petty trader.

PERCEPTIONS ABOUT CONCEALMENT AND DIAGNOSIS

Participants indicated that persons affected tend to go to great lengths to conceal the symptoms of leprosy to avoid stigmatization. They indicated that this is only partly successful in the early stages of the disease. According to the participants, concealment is often unsuccessful in the long run as the lesions become more severe and obvious.

“I swear to God, they use to keep others from knowing their condition because they don’t want people to discriminate against them. There was one of our teachers who used to hide this infection from public glare, and it was after his condition became worse, after series of investigations he was diagnosed with leprosy. He covered his legs inside nylon and soaks with a plastic cover shoe because he was afraid of stigma from the community.” 34-year-old, female, petty trader.

Participants said they were unwilling to disclose leprosy in a family member, except for medical reasons as it was viewed as a breach of confidentiality. Non-disclosure was to avoid stigmatization, exposing the family to ridicule, and limiting marriage prospects, and not to portray the family as being happy with the diagnosis. A minority indicated that they would disclose it as it is from God so that people can pray for the person affected.

“To be honest I cannot disclose it to anybody, unless for a medical reason. If I disclose it to the public he will be stigmatized and people will avoid him. But if we did not disclose, we will put him on medication until he is cured.” 37-year-old, female, civil servant.

Some participants indicated that they would be worried if a family member has leprosy. Their concerns are mostly related to fear of the extension of stigmatization to other family members, including a sense of pity, transfer of economic burden and family responsibilities of persons affected to the extended family, the negative image begging brings to the family, limited marriage prospects, and desertion by friends.

“Of course, I will be worried that my child is affected by leprosy, all the family members will be emotionally touched and it will affect them in one way or the other. First of all, being a ‘Kuturu’ [Hausa swear word for person affected by leprosy], if you don’t have grown-up children that are capable of assisting you it is a problem because you will not have any means of getting income unless you go out and beg so that people will help you. At times if you go out you may not get anything and the fact that you have a family to feed and take care of them.” 40-year-old, male, civil servant.

However, one participant held a contrary view where he indicated that he won’t be worried because the disease is from God and no one can avoid his fate.

“I will not be worried or disturbed if a member of my family is infected with leprosy. Because I know it is from God. Like I told you, people are different, one will see something on the affected person but would not be worried and he can even sit and eat in that place but another person would not sit or interact with such affected persons. It can also happen to me, then what is the need of running away from him.” 35-year-old, male, farmer.

COMMUNITY PERCEPTIONS AND BEHAVIOR

The predominantly Hausa community refers to persons affected as [*Kuturu*] (swear word for person affected by leprosy), a new identity that overrides the pre-morbid social status. The leader of persons affected is referred to as [*Sarkin Kutare*] (Emir of persons affected by leprosy). Participants indicated that persons affected are perceived by community members as infectious, deformed, dirty, and incurable. Participants indicated that this stigma persists even after treatment:

“Persons affected by leprosy are avoided by community members. The community’s reaction is because some of them are untidy and dirty. They do not wash their clothes and they smell. They consider them dirty people and that they can infect somebody.” 55-year-old male, civil servant.

“They are afraid of interacting with people even after treatment out of fear that the stigma experienced at the beginning of their illness, which mostly persists even after being certified cured. People are now even doubting those certificates because there are fake ones all over the place.” 65-year-old, male, retired civil servant.

Participants reported that community members treat people with leprosy differently. They are considered second-class citizens and inferior. According to participants, they avoid touching, social interactions, and sharing meals with them. Underlying these is the fear of contracting leprosy as participants feel persons affected by leprosy are still infectious even after treatment. Stigmatization was said to be more towards those with visible impairment and poor hygiene habits. Stigma is extended to the children and close family members of persons affected, as they are all considered potentially infectious.

“They don’t take [persons affected by leprosy] as human beings, talk less of interacting with them because of leprosy. They consider them as nobody and the way they interact with other people is not the same as the way they interact with persons with leprosy.” 35-year-old female, a petty trader.

“People regard them as second-class citizens and they only beg to survive even if they attempt to trade household essential items, nobody will buy from them. Because of leprosy, they are seen as different and that even God does not like them.” 33-year-old, female, petty trader.

Most participants indicated that people kept their distance to avoid getting infected. Derogatory gestures and subjugation of affected persons are commonplace. Non-touch methods are used by dropping alms for them. Close interactions are avoided as the disease is considered incurable. Debasing proverbs and metaphors are used to describe those affected.

“They stigmatize them, avoid close contact with them to prevent acquiring leprosy. People point at them and make gestures with their mouth and fingers indicating to others that, those people you see there are persons affected by leprosy. They also view them as sub-humans and people believe that the disease is inherited.” 40-year-old, male, civil servant.

“There is the belief that if you marry a person affected by leprosy you will also be infected, so also your children.” 33-year-old, female, petty trader.

This was not universal, as three participants indicated that persons affected are cared for by relatives and some community members interacted with them. The solidarity is reported to be stronger among family members and relatives.

“We don’t show them differences in our area. Even my grandfather was affected by leprosy but he is late. So we could not show him any difference as a senior member of the family.” 27-year-old, female, farmer.

Though a common practice previously, now it is discouraged to prevent disease transmission. Most participants indicated that they would not share cups with persons affected to reduce stigma, while a few would.

“In as much as we can eat together, I can also drink water with the same cup as a person affected by leprosy. I told you my reason is because of my profession. I will try and drink to be an example for the community as a way to reduce stigma. But 90% will not drink with the same cup used by a person affected by leprosy.” 35-year-old, female, petty trader.

Participants indicated that they would hesitate to buy cooked ready-to-eat food from leprosy-affected persons. This hesitation was out of fear of transmitting leprosy through food handling, particularly cooked food. Some indicated readiness to buy raw or uncooked food, which they will cook and “destroy” the causative germs from contamination by leprosy-affected persons.

“Yes, I can buy from him, if it is something I can cook. I can only buy the fresh one or uncooked one so that I can cook it myself. [Dafaffe?] (What about cooked food?) [Laughter...], I cannot buy it but I will buy the fresh one to go and cook at home. The reason being that even if they touched it when I go home, I will boil it before I eat. It may be possible there are germs contaminating the cooked food.” 47-year-old, female, petty trader.

PARTICIPANTS’ RESPONSE TO COMMUNITY ATTITUDES

Some participants expressed sadness at how the community treats people affected by leprosy. They empathized with persons affected as human beings and that anyone could contract leprosy.

“To be honest I feel bad, about how they treat them. Because they did not buy the infection from the market, it is from God. So, I don’t support the way people are treating them.” 35-year-old, female, petty trader.

PERCEPTIONS ABOUT MARRIAGE PROSPECTS

Some participants indicated that they would marry those declared cured of leprosy if they have no deformities and are in love. However, marrying someone with active leprosy was considered against religious teachings.

“Yes, I can marry such a person if there is love. Because he is a human being like me and if I were like him somebody will look at me in that way and if we continue to be avoiding them; they will not be happy in their life and is not proper to be avoiding or running away from them.” 35-year-old, female, petty trader.

“I cannot marry a girl with physical impairment due to leprosy. I cannot marry her because of her condition and also Islamically it is not permitted to marry an unhealthy person.” 55-year-old, male, civil servant.

A few participants believed if there is love, marriage could occur. A female participant believed that an unaffected woman can marry an affected man because women are submissive and tolerant. However, she felt the opposite is not likely as most men would divorce their wives even if they acquire leprosy within marriage, talk less of marrying one who is affected before the marriage. Some participants would not marry an affected person, man, or woman under any circumstance out of fear of transmission to children and societal rejection.

“To be honest intermarriages are rare. It happened once in our community where an affected man married a beautiful healthy woman, but they have both died. Their children are alive and only one of them has a minor infection.” 57-year-old, female, petty trader.

“A woman can marry a person affected by leprosy but a man cannot marry a woman affected by leprosy. Because women are simple and honest. A man cannot do that, because a man can marry a healthy woman but if she is diagnosed with a health problem in his house, he will divorce her. I have seen many of them.” 27-year-old, female, farmer.

On the effect of leprosy on marital prospects, there was consensus among participants on the negative impact of leprosy on marital prospects. The reasons for reduced marriage prospects were said to include deformity and stigma. Participants indicated that there were gender differences: a woman's beauty will be eroded by leprosy and she will find it more difficult to get a suitor compared to men who can use their financial influence to marry unaffected women. Further, culturally, men are expected to approach a woman and not the other way round. Participants indicated that the situation persists after cure and community members ridicule unaffected persons who show interest in affected persons.

“Yes, it can be a problem when getting married. Because her body structures have changed and not every person wants to marry a deformed person because the infection has changed her body structures and also this stigma can also contribute to not getting married because she is affected by leprosy. Even a man affected with leprosy, it is not possible to get or marry an unaffected person, but as a man, if he has money and spends money on the family, she can marry him compared to a woman because somebody will marry her but she cannot marry him, based on our culture.” 37-year-old, female, civil servant.

Regarding the effects of leprosy on family members' social participation and marriage prospects, participants indicated that stigma extends to immediate and extended families as leprosy is considered hereditary. Participants explained that marriage proposals of persons affected by leprosy are rejected, and that weddings will be aborted at any stage following disclosure of links with leprosy. (Unwanted) delayed marriages are the norm among daughters and sometimes sons in affected families.

“[Having a family member with leprosy] can constitute a barrier [to marriage] because of gossips that their family is affected with leprosy and the disease is hereditary. Even if one goes

out and marries somewhere still, he might expect some challenges before he gets the person to marry. He will be jumping from one place to another because he will face a lot of criticisms that he belongs to a family that is affected by leprosy. Women also face similar problems. We have friends, their mother is affected by leprosy and one of them [children] after all marriage plans, the groom family later discovered that her mother is affected by leprosy and they changed their mind because they don't want to have such infection in their family or to bear children with leprosy. Even now, one of the children is over 30 years and nobody is willing to marry her because her mother is affected by leprosy." 37-year-old, female, civil servant.

In contrast, one participant had an opposite view, he stated that based on experience family members of affected persons do not contract the disease and hence it has no effect on their social participation and marriage prospects.

PERCEPTIONS ABOUT EMPLOYMENT OPPORTUNITIES

Concerning the effects of leprosy on employment opportunities, participants were of the view that it is difficult for persons affected by leprosy to find work, and that it is proportionate to the degree of impairment. For instance, loss of fingers impedes dexterity thereby reducing the chances of office employment, as they cannot write without fingers. However, they can engage in non-formal occupations such as trading, farming, and cattle rearing with some notable exceptions.

"Yes, it can be a challenge for a person affected by leprosy to be employed. If a person does not have fingers he cannot write if it is office work and even if he is a messenger or laborer, he cannot do it because it has destroyed his parts. Unless if there is any other job apart from this." 37-year-old, female, civil servant.

In addition, participants believed that employment opportunities were related to fear of infection and a lack of hygiene that is associated with being affected by leprosy. For example, the restaurant business was considered a no-go area for affected persons as there will be little patronage due to the stigma of leprosy. This has to do with hygiene and fear of acquiring leprosy as the food is ready-to-eat with no chance of re-heating to kill leprosy causing germs.

"It can be a challenge because [a person affected by leprosy is] somebody who people avoid and stigmatize (...) Because he is going to use his hands to do the job and this is one of the challenges and any person that comes close to him and sees that he is a person affected by leprosy, he will not interact with him because he is afraid of being infected. The challenge is whatever he touches people will not touch for fear of being infected." 43-year-old, male, civil servant.

Some participants held a more positive view and indicated that with the increased awareness about treatment and the possibility of a cure for leprosy, persons affected, especially, those with no deformities can be gainfully employed in the formal and informal sectors.

"There is awareness and things are easier now. Because [people] understand well about this infection and [that leprosy] can be cured and where they [people affected by leprosy] are going to work are not illiterate people and they are not going to be stigmatized. If they follow the right way, they will not face any difficulty getting a job. If [the community] know that this infection is not communicable and can be cured and also if you believe in fate you can assist him in the right way." 33-year-old, female, petty trader.

"On the part of the government, I don't know but in private they are given work and we interact together and nobody is infected and also, they can be employed and work together. I don't know that about government work but private work is not a problem we work together with them." 47-year-old, male, farmer.

With the high rate of unemployment among able-bodied unaffected persons, participants felt it is more difficult to employ a person affected by leprosy. Even in circumstances where organizations are sympathetic towards persons affected, it is only lowly jobs such as a cleaner, messenger, and security guard that are offered to such persons.

“Presently those persons that are unaffected are finding it difficult to secure a job talk less of a person affected by leprosy, it is more difficult to them to get any kind of job.” 34-year-old, female, petty trader.

REASONS FOR STIGMATIZATION

Describing the possible reasons for stigmatization, participants identified poor knowledge about the cause (including misconceptions about leprosy being hereditary), mode of transmission, treatment, and (lack of a) cure as reasons for stigma. Other factors mentioned by participants are deformity, perceived high infectiousness and fear of infection, and poor personal hygiene of persons affected. Further, participants indicated that as a result of the initial stigmatization, even after cure persons affected are afraid of being harassed, and for that reason, they will isolate themselves. The reasons for stigmatization were related. For example, the belief that there is no cure for leprosy is the reason why no matter how persons affected are certified and declared cured, people still stigmatize and avoid them, so that they do not get infected.

“Yes, there is ignorance and illiteracy because this infection has a remedy and if people know that this infection has a cure, they would not reject them and their families.” 37-year-old, female, civil servant.

“No matter how much treatment is given, and declaration of cure, people will avoid him because they think they will still transmit to another person. But, some do interact with them, but in our area, no person interacts with a person affected by leprosy who is declared cured, especially if they have disability.” 47-year-old, female, petty trader.

On ways to reduce stigma, participants suggested the involvement of traditional and religious leaders in awareness creation about treatment and cure. Further, persons affected should be encouraged to maintain personal hygiene and participate in social events.

“One of the ways to reduce stigma is to mobilize the literate, philanthropists, ward heads, village heads, and government to create awareness through media and other channels that leprosy can be cured and once cured, one cannot infect other people and also advise the community to interact with those that are cured as they don’t like participating in public affairs out of fear of stigmatization and the fact that people are running away from them.” 37-year-old, female, married, civil servant.

Discussion

This study explored community perceptions and behavior towards persons affected by leprosy and the extent, root causes, and drivers of stigma in northern Nigeria. We found that persons affected by leprosy were perceived negatively, they were considered dirty, incurable, and inferior. Participants avoid touching, social interactions, and sharing meals with persons affected by leprosy. In addition, leprosy was said to negatively impact employment opportunities and the marriage prospects of persons affected. Marriage prospects were considered worse for women affected by leprosy. Participants said they were unwilling to disclose leprosy in a family member and that leprosy-related stigma extends to immediate and extended families. Some participants expressed sadness at how the community treats persons affected by leprosy. We

identified four main reasons for stigmatization: (1) local beliefs and misconceptions about leprosy (e.g. the belief that leprosy is hereditary, incurable, or highly infectious), (2) fear of disability and deformity, (3) fear of infection, and (4) perceived poor personal hygiene of persons affected.

Negative community perceptions of persons affected by leprosy have been reported in parts of Nigeria,^{16,28-30} other parts of sub-Saharan Africa,³¹⁻³³ Asia,^{20,34,35} and South America.^{19,36,37} This stigmatization, social degradation, and isolation of persons affected by leprosy have been reported since antiquity and appears deeply rooted. Other studies have reported that disturbed social relationships with family members, friends, and neighbors may further isolate persons affected by leprosy and result in feelings of loneliness.³⁸⁻⁴⁰ Historically, these negative perceptions have led to the formation of leprosy colonies where persons affected lived as outcasts and in isolation.⁵ Poor knowledge and fear of contracting leprosy have been linked to these negative perceptions, as community members considered persons affected by leprosy highly infectious.^{41,42} Indeed, other studies have found that it is possible to positively influence the perception of leprosy and increase knowledge of leprosy.^{43,44}

The limited understanding of and local beliefs surrounding the cause of leprosy, the perception of leprosy as a disfiguring disease, and the associated strong stigma have also been reported in other parts of Nigeria,¹⁶ Africa,^{40,45} and Asia.^{35,42} Leprosy may manifest as a mild skin lesion in the early stage. It is when left untreated that these lesions could progress becoming much more noticeable. A study in India also revealed poor knowledge regarding leprosy, high levels of stigma, fear, and desire to keep social distance from persons affected.⁴² Since ancient times, various misconceptions have existed about leprosy. As mentioned by our participants, there were a range of perceived causes and misconceptions rooted in cultural beliefs. Though, findings such as leprosy being hereditary, a divine curse, due to witchcraft, food taboos, evil spirits, sin or evil deeds in this or previous life and contracted from prostitutes have been reported,⁴⁶ the perceived acquisition of leprosy from poisonous spider or gecko, and waking up before a guest affected by leprosy is far-fetched. However, geckoes are considered unclean and spiritually cursed in Islam, the dominant religion in the study area.⁴⁷ These could shape community attitudes towards persons affected by leprosy.

As in our study, reports indicate that persons affected by leprosy encounter difficulties in finding work or maintaining employment.^{17,48} There are instances of persons affected by leprosy being fired from their jobs as a result of stigma. Community members consider restaurants and other ready-to-eat food vending businesses a no-go area for persons affected as customers feel food items touched by them become contaminated and impure.^{49,50} In addition, persons affected could face challenges from colleagues in the workplace who may refuse to work with them, and from customers who may refuse to be served. These discriminatory practices were said to be amplified by the appearance of visible deformities.⁵¹

The negative effects of leprosy on marriage prospects, often extending to family members was reported in other studies, especially in cultures and societies in which arranged marriages were common.^{52,53} These were in the form of difficulties in finding a spouse and rejection of marriage proposals.⁴⁰ The perceived gender differences in marital prospects have also been described by others.⁵⁴ In addition, like in other studies, in the present study leprosy in a partner was considered grounds for divorce among couples.^{40,54}

Efforts at concealment by persons affected and non-disclosure by families as a measure against the negative social consequences are only temporary, as this is no longer possible following the development of ulcers and deformities as reported by others.⁵⁵ The reasons and drivers of stigma have also been reported by others. Stigma follows the presence of an attribute

that distinguishes the person from “normal” people,^{7,56} with far-reaching effects on the social status and reputation of the individual and members of his family.⁷ The manifestations and psychosocial consequences of stigma and discrimination have been reported to be remarkably similar across conditions and cultures,^{17,57,58} as the likely reason is that at the core of stigma is a common human response to difference. Despite being curable with MDT, the strong stigma of leprosy persists after release from treatment especially with visible deformities.^{59,60} Other studies also report that leprosy-associated stigma is influenced by the social, economic, and cultural beliefs of the community.⁴¹

Our findings have implications for leprosy control programs. First, the influence of poor knowledge, misconceptions and fear of contracting leprosy on community perceptions underscores the importance of community education as the key to transforming perceptions and behavior towards persons affected. Therefore, it is imperative to educate community members about leprosy, its causes, transmission, and treatment to enhance attitudinal and behavior change. This could facilitate the social reintegration of persons affected. The interventions should take into account the current knowledge gaps, cultural beliefs, and perceptions of community members.^{61–63} Studies in other countries have also shown that addressing knowledge gaps and local beliefs can positively change the perception of and behavior towards persons affected by leprosy.⁴³ Secondly, on ways to reduce stigma, local beliefs, misconceptions, fears of disability and deformity, fear of infection and perceived poor personal hygiene should be addressed through contextualized interventions. Interventions such as socio-economic empowerment have the potential to change the perceptions community members have of persons affected by leprosy, and can improve financial means, dignity and social participation of persons affected.⁶⁴ A socio-economic empowerment intervention has been conducted successfully in northern Nigeria in the past.⁶⁵ In addition, as suggested by some participants, there is need for influential people including traditional and religious leaders to play a key role in reducing stigma through awareness creation about treatment and cure.

Conclusions

Findings from the present study show that persons affected by leprosy were perceived negatively among community members in Kano State, Nigeria. We found that perceptions about leprosy impacted employment opportunities and marriage. The drivers of stigma were local beliefs, misconceptions, fear of disability and infection, and perceived poor personal hygiene of persons affected. Considering the close connection between perceptions (including knowledge and beliefs) and behavior, stigma-reduction interventions should take account of current cultural beliefs, knowledge gaps, and fears. Compassionate community members could be trained to champion attitudinal and behavior change together with confidence-building measures to overcome leprosy-related stigma in endemic areas.

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Review board approval if obtained, including the reference number of the approval letter

This research was approved by the Kano State Research Ethics Committee reference number MOH/OFF/797/T.1/2068. Data collection only started after its approval by this committee.

Conflict of interest (COI) statement

All authors declare that the answer to the question on competing interest forms are “No”, and therefore have nothing to declare.

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TD, ZI, ATM conceived and designed the study, TD and ATM collected the data while ZI, ATvN and MHA analyzed the data and prepared the draft manuscript. All authors reviewed and approved of the final manuscript. ZI accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Patient consent statement

All participants were fully informed about the objectives of the study, voluntary participation, and the confidentiality of the data. Written informed consent was obtained from all participants prior to data collection.

Data sharing statement

The authors confirm that the data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

References

- 1 Staples J. Interrogating leprosy ‘stigma’: why qualitative insights are vital. *Lepr Rev*, 2011; **82**: 91–97.
- 2 Hansen GA, Looft C. *Leprosy in Its Clinical and Pathological Aspects*. London: John Wright, 1895.
- 3 White C, Franco-Paredes C. Leprosy in the 21st century. *Clin Microbiol Rev*, 2015; **28**(1): 80–94. doi:10.1128/CMR.00079-13.
- 4 Suzuki K, Akama T, Kawashima A, Yoshihara A, Yotsu RR, Ishii N. Current status of leprosy: epidemiology, basic science and clinical perspectives. *J Dermatol*, 2012; **39**: 121–129.
- 5 Editorial. Abandoning the stigma of leprosy. *Lancet*, 2019; **393**: 378.
- 6 Ganapati R, Pai VV, Kingsley S. Disability prevention and management in leprosy: a field experience. *Indian J Dermatol Venereol Leprol*, 2003; **69**(6): 369–374.
- 7 Goffman E. *Stigma: Notes on the Management of a Spoiled Identity*. New York: Simon & Schuster, 1963.
- 8 Frist TF. Stigma and the societal response to leprosy: experience of the last half-century. *Indian J Lepr*, 2000; **72**: 1–3.
- 9 Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Negl Trop Dis*, 2008; **2**(5): e237.
- 10 Sundar Rao PS. Worldwide elimination of leprosy. *Expert Rev Dermatol*, 2012; **7**: 513–520.
- 11 van’t Noordende AT, Bakirtzief da Silva Pereira Z, Biswas P, Ilyas M, Krishnan V, Parasa J *et al*. Strengthening individual and family resilience against leprosy-related discrimination: a pilot intervention study. *PLoS Negl Trop Dis*, 2021; **15**(4): e0009329. doi:10.1371/journal.pntd.0009329.
- 12 Van Brakel WH. Measuring health-related stigma—a literature review. *Psychol Health Med*, 2006; **11**(3): 307–334. doi:10.1080/13548500600595160.
- 13 Govindasamy K, Jacob I, Solomon RM, Darlong J. Burden of depression and anxiety among leprosy affected and associated factors—a cross sectional study from India. *PLoS Negl Trop Dis*, 2021; **15**(1): e0009030. doi:10.1371/journal.pntd.0009030.
- 14 Tsutsumi A, Izutsu T, Islam AM, Maksuda AN, Kato H, Wakai S. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. *Soc Sci Med*, 2007; **64**(12): 2443–2453. doi:10.1016/j.socscimed.2007.02.014.

- ¹⁵ Tabah EN, Nsagha DS, Bissek AZ, Njamnshi TN, Njih IN, Pluschke G, Njamnshi AK. Community knowledge, perceptions and attitudes regarding leprosy in rural Cameroon: the case of Ekondotiti and Mbonge health districts in the south-west region. *PLoS Negl Trop Dis*, 2018; **12**(2): e0006233. doi:10.1371/journal.pntd.0006233.
- ¹⁶ Ebenso B, Newell J, Emmel N, Adeyemi G, Ola B. Changing stigmatisation of leprosy: an exploratory, qualitative life course study in western Nigeria. *BMJ Glob Health*, 2019; **4**(2): e001250. doi:10.1136/bmjgh-2018-001250.
- ¹⁷ van Brakel WH. Measuring leprosy stigma—a preliminary review of the leprosy literature. *Int J Lepr Other Mycobact Dis*, 2003; **71**(3): 190–197. doi:10.1489/1544-581X(2003)71<190:MLSPRO>2.0.CO;2.
- ¹⁸ Navon L. Beggars, metaphors and stigma. *Soc Hist Med*, 1998; **11**: 89–105.
- ¹⁹ Kaehler N, Adhikar B, Raut S, Marahatta SB, Chapman RS. Perceived stigma towards leprosy among community members living close to Nonsomboon leprosy colony in Thailand. *PLoS One*, 2015; **10**(6): e0129086. doi:10.1371/journal.pone.0129086.
- ²⁰ Marahatta SB, Amatya R, Adhikari S, Giri D, Lama S, Kaehler N *et al*. Perceived stigma of leprosy among community members and health care providers in Lalitpur district of Nepal: A qualitative study. *PLoS One*, 2018; **13**(12): e0209676. doi:10.1371/journal.pone.0209676.
- ²¹ Udo S, Chukwu J, Obasanya J. Leprosy situation in Nigeria. *Lepr Rev*, 2013; **84**(3): 229–237.
- ²² Ebenso B, Ayuba M. ‘Money is the vehicle of interaction’: insight into social integration of people affected by leprosy in northern Nigeria. *Lepr Rev*, 2010; **81**: 99–110.
- ²³ Udo S, Chukwu J, Obasanya J. Leprosy situation in Nigeria. *Lepr Rev*, 2013; **84**: 229–237.
- ²⁴ <https://www.thenationonline.ng.net>. Last accessed 20th June 2021.
- ²⁵ Nigeria Population Commission. Report of Nigeria’s national population commission on the 2006 census. *Popul Dev Rev*, 2007; **33**(1): 206–210. <https://www.jstor.org/stable/25434601>. Last accessed 4 July 2021.
- ²⁶ Weiss M. Explanatory model interview catalogue (EMIC): framework for comparative study of illness. *Transcult Psych*, 1997; **34**(2): 235–263. doi:10.1177/136346159703400204.
- ²⁷ Pope C, Ziebland S, Mays N. Qualitative research in health care. Analyzing qualitative data. *BMJ*, 2000; **320**(7227): 114–116.
- ²⁸ Ogban GI, Iwuafor AA, Emanghe UE, Ushie SN, Ndueso EM, Nwadiaro RIE *et al*. Unfavorable attitude and perceived stigma towards leprosy: a concern for status perpetuation in a community in Cross River State, Nigeria. *Asian J Med Health*, 2020; **18**(8): 1–13. doi:10.9734/ajmah/2020/v18i830225.
- ²⁹ Manton J. Leprosy in eastern Nigeria and the social history of colonial skin. *Lepr Rev*, 2011; **82**(2): 124–134.
- ³⁰ Ibikunle PO, Nwokeji SC. Assessment of stigma among people living with Hansen’s disease in south-east Nigeria. *Lepr Rev*, 2017; **88**(1): 43–57.
- ³¹ Nsagha DS, Bissek AZ, Nsagha SM, Njunda AL, Assob JC, Tabah EN *et al*. Social stigma as an epidemiological determinant for leprosy elimination in Cameroon. *J Public Health Afr*, 2011; **2**(1): e10. doi:10.4081/jphia.2011.e10.
- ³² Sottie CA, Darkey J. Living with stigma: voices from the cured Lepers’ village in Ghana. *Soc Work Health Care*, 2019; **58**(2): 151–165. doi:10.1080/00981389.2018.1526842.
- ³³ Asampong E, Dako-Gyeke M, Oduro R. Caregivers’ views on stigmatization and discrimination of people affected by leprosy in Ghana. *PLoS Negl Trop Dis*, 2018; **12**(1): e0006219. doi:10.1371/journal.pntd.0006219.
- ³⁴ Patil S, Mohanty KK, Joshi B, Bisht D, Rajkamal KA *et al*. Towards elimination of stigma & untouchability: a case for leprosy. *Indian J Med Res*, 2019; **149**(Suppl): S81–S87. doi:10.4103/0971-5916.251663.
- ³⁵ Van’t Noordende AT, Lisam S, Ruthindartri P, Sadiq A, Singh V, Arifin M, van Brakel WH, Korfage IJ. Leprosy perceptions and knowledge in endemic districts in India and Indonesia: differences and commonalities. *PLoS Negl Trop Dis*, 2021; **15**(1): e0009031. doi:10.1371/journal.pntd.0009031.
- ³⁶ Silva CA, Albuquerque VL, Antunes MF. Leprosy as a neglected disease and its stigma in the northeast of Brazil. *Indian J Lepr*, 2014; **86**(2): 53–59.
- ³⁷ Tosepu R, Gunawan J, Effendy DS, Fadmi FR. Stigma and increase of leprosy cases in southeast Sulawesi Province, Indonesia. *Afr Health Sci*, 2018; **18**(1): 29–31. doi:10.4314/ahs.v18i1.5.
- ³⁸ Peters RMH, Dadun D, Lusli M, Miranda-Galarza B, van Brakel WH, Zweekhorst MB, Damayanti R, Seda FS, Bunders JF, Irwanto. The meaning of leprosy and everyday experiences: an exploration in Cirebon, Indonesia. *J Trop Med*, 2013; **2013**: 507034. doi:10.1155/2013/507034.
- ³⁹ Lusli M, Zweekhorst MBM, Miranda-Galarza B, Peters RMH, Cummings S, Seda FSSE *et al*. Dealing with stigma: experiences of persons affected by disabilities and leprosy. *Biomed Res Int*, 2015; 261329.
- ⁴⁰ van’t Noordende AT, Aycheh MW, Schippers A. The impact of leprosy, podocniosis and lymphatic filariasis on family quality of life: a qualitative study in northwest Ethiopia. *PLoS Negl Trop Dis*, 2020; **14**(3): e0008173. doi:10.1371/journal.pntd.0008173.

- ⁴¹ Singh R, Singh B, Mahato S. Community knowledge, attitude, and perceived stigma of leprosy amongst community members living in Dhanusha and Parsa districts of southern central Nepal. *PLoS Negl Trop Dis*, 2019; **13**(1): e0007075. doi:10.1371/journal.pntd.0007075.
- ⁴² van 't Noordende AT, Korfage IJ, Lisam S, Arif MA, Kumar A, van Brakel WH. The role of perceptions and knowledge of leprosy in the elimination of leprosy: a baseline study in Fatehpur district, northern India. *PLoS Negl Trop Dis*, 2019; **13**(4): e0007302. doi:10.1371/journal.pntd.0007302.
- ⁴³ van 't Noordende AT, Lisam S, Singh V, Sadiq A, Agarwal A, Hinders DC *et al*. Changing perception and improving knowledge of leprosy: an intervention study in Uttar Pradesh, India. *PLoS Negl Trop Dis*, 2021; **15**(8): e0009654.
- ⁴⁴ Ukpe IS. Educational posters and leaflets on leprosy: raising awareness of leprosy for health-care workers in rural South Africa. *Public Health Rep*, 2008; **123**(2): 217–221.
- ⁴⁵ Nyamogoba HDN, Mbuthia G, Mulambalah C. Endemicity and increasing incidence of leprosy in Kenya and other world epidemiologic regions: a review. *Afr J Health Sci*, 2019; **32**(3): 38–62.
- ⁴⁶ Harrison M. *Disease and the Modern World: 1500 to the Present Day*. Cambridge, UK: Polity Press Ltd., 2004; p. 20.
- ⁴⁷ Sahih al-Bukhari. In: Esposito JL (ed.), *The Oxford Dictionary of Islam*. Oxford Islamic Studies Online. Dec. 16, 2021. <http://www.oxfordislamicstudies.com/article/opr/t125/e2056>.
- ⁴⁸ van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R *et al*. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Glob Health Action*, 2012; **5**: 1–11.
- ⁴⁹ Seshadri D, Khaitan B, Khanna N, Sagar R. Dehabilitation in the era of elimination and rehabilitation: a study of 100 leprosy patients from a tertiary care hospital in India. *Lepr Rev*, 2015; **86**: 62–74.
- ⁵⁰ Rao PS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and correlates of leprosy stigma in rural India. *Indian J Lepr*, 2008; **80**: 167–174.
- ⁵¹ Dadun D, Peters RMH, Lusli M, Miranda-Galarza B, van Brakel WH, Zweekhorst MBM, Damayanti R, Irwanto BJFG. Exploring the complexities of leprosy-related stigma and the potential of a socio-economic intervention in a public health context in Indonesia. *Disabil CBR Incl Dev*, 2016; **27**: 5–23.
- ⁵² Schuller I, van Brakel WH, van der Vliet I, Beise K, Wardhani L, Silwana S *et al*. The way women experience disabilities and especially disabilities related to leprosy in rural areas in south Sulawesi, Indonesia. *Asia Pac Disabil Rehabil J*, 2010; **21**: 60–70.
- ⁵³ Kathé VJ, Naik SS. Leprosy patients and their spouses. *Indian J Lepr*, 2000; **72**: 248–249.
- ⁵⁴ Try L. Gendered experiences: marriage and the stigma of leprosy. *Asia Pac Disabil Rehabil J*, 2006; **17**: 55–72.
- ⁵⁵ Heijnders ML. The dynamics of stigma in leprosy. *Int J Lepr Other Mycobact Dis*, 2004; **72**: 437–447.
- ⁵⁶ Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol*, 2001; **27**(1): 363–385.
- ⁵⁷ Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Negl Trop Dis*, 2008; **2**: e237.
- ⁵⁸ Pescosolido BA, Medina TR, Martin JK, Long JS. The “backbone” of stigma: identifying the global core of public prejudice associated with mental illness. *Am J Public Health*, 2013; **103**: 853–860.
- ⁵⁹ Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. *Psychol Health Med*, 2006; **11**: 277–287.
- ⁶⁰ Sermritirong S, Van Brakel WH. Stigma in leprosy: concepts, causes and determinants. *Lepr Rev*, 2014; **85**: 36–47.
- ⁶¹ Singh S, Sinha AK, Banerjee BG, Jaswal N. Participation level of the leprosy patients in society. *Indian J Lepr*, 2009; **81**(4): 181–187. doi:10.5463/dcid.v23i4.179.
- ⁶² van Brakel WH. Measuring health-related stigma—a literature review. *Psychol Health Med*, 2006; **11**: 307–334.
- ⁶³ Eram U, Akhouri D, Parveen S. Review article on beliefs and myths on leprosy. *Saudi J Med*, 2017; **2**(2): 44–46.
- ⁶⁴ Dadun D, Van Brakel WH, Peters RMH, Lusli M, Zweekhorst M, Bunders JGF *et al*. Impact of socio-economic development, contact and peer counselling on stigma against persons affected by leprosy in Cirebon, Indonesia—a randomised controlled trial. *Lepr Rev*, 2017; **88**: 2–22.
- ⁶⁵ Ebenso B, Fashona A, Ayuba M, Idah M, Adeyemi G, Fada S. Impact of socio-economic rehabilitation on leprosy stigma in northern Nigeria: findings of a retrospective study. *Asia Pac Disabil Rehabil J*, 2007; **18**: 98–119.