

Emotions, Relationships and Behaviour: a Qualitative Study on Experiences of Stigma among Persons Affected by Leprosy in Northern Nigeria

Tahir Dahiru^{1,2*}, Zubairu Illiyasu³, Aliyu T Mande⁴, Anna T van't Noordende^{5,6}, Muktar H Aliyu⁷

1. Leprosy and TB Relief Initiative, Jos, Nigeria

2. Texila American University, Georgetown, Guyana

3. Department of Community Medicine, Bayero University, Kano, Nigeria

4. Department of Community Medicine, Ahmadu Bello University, Zaria, Nigeria

5. Programmes, Research & Partnerships Department, NLR, Amsterdam, the Netherlands

6. Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands

7. Department of Health Policy and Vanderbilt Institute for Global Health, Vanderbilt University Medical Centre,

ABSTRACT

Purpose: *Leprosy is a highly stigmatised disease with far-reaching psychosocial and economic consequences. This study explored the social consequences of leprosy and the factors that drive stigma among persons affected by leprosy in northern Nigeria.*

Method: *The study used a cross-sectional design with a qualitative approach. Semi-structured in-depth interviews were conducted with 20 persons affected by leprosy. Data were collected from September to November 2020. ILEP's four stigma domains (emotions, thoughts, behaviour and relationships) were used to develop the interview guide and to analyse the data. The framework approach to thematic analysis was performed.*

Results: *The study identified: (1) negative societal attitudes and behaviour towards persons affected by leprosy, (2) restrictions in social participation among affected persons, such as in communal eating, job opportunities and education, (3) negative impact of leprosy on marital life and marriage prospects, also experienced by family members, and (4) negative emotions such as sadness and despair. Some of the problems seemed to be caused by negative perceptions and a lack of knowledge of leprosy. The main coping strategies included adjustments in behaviour (e.g., marrying other persons affected by leprosy and communal*

* **Corresponding Author:** Tahir Dahiru, Leprosy and TB Relief Initiative Nigeria and Texila American University Nigeria. Email: drtahirdahiru@gmail.com

eating amongst persons affected), and religion (by seeking consolation through faith in God/Allah).

Conclusion: *High levels of stigma were experienced by the participants. This underscores the importance of sustained information, education and communication interventions via traditional and modern media, to fill knowledge gaps and address misconceptions and myths about leprosy.*

Key words: *stigma, leprosy, participation, Nigeria*

INTRODUCTION

Leprosy, one of the oldest recorded diseases, is caused by *Mycobacterium leprae*. The disease affects the largest and the most visible organ of the body, namely the skin (Attama et al., 2015). It is an infectious disease that can have far-reaching psychosocial and economic consequences (Rao, 2015). Leprosy can cause physical impairments and is a highly stigmatised disease.

Stigma is “a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group” (Weiss et al., 2006). It enables varieties of discrimination that ultimately deny an individual or group full social acceptance, reducing opportunities (Goffman, 1963) and fuelling social inequalities (Parker & Aggleton, 2003). Stigma also influences population health outcomes by worsening, undermining, or impeding several processes, including social relationships, resource availability, stress, and psychological and behavioural responses (Hatzenbuehler et al., 2013). Despite enormous cultural diversity, the areas of life affected by stigma are remarkably similar across different stigmatised conditions. They include mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious gatherings (van Brakel, 2006; Rao, 2010; van Brakel et al., 2019).

Leprosy-related stigma can persist even after release from treatment and remains an enduring challenge to leprosy control programmes (Weiss et al., 2006; Udo et al., 2013). It can impact the emotions, thoughts, behaviour, and relationships of persons affected (The International Federation of Anti-Leprosy Associations - ILEP, 2011). For example, persons affected by leprosy experience restrictions in education, employment, and participation in social events (van Brakel, 2006). In a study in India, persons affected were found to have left their families, including

their spouses and children, fearing the repercussions of their condition (Kaur & van Brakel, 2002). A diagnostic label of leprosy may alter the social identity of the individual and the family. When a person is diagnosed with leprosy, sometimes the social status of the entire family is reduced, and all the family members may be considered inferior by their community.

Leprosy-related impairments have often been associated with stigma. For example, a study in Nepal showed that persons affected by leprosy still experience negative behaviour and that 95% of the persons that experienced social stigma had visible wounds, swellings, and deformity of the feet and hands (de Stigter et al., 2000). Another study, in India, found that the proportion of families of persons affected with deformities that faced problems was nearly ten times higher (57%) than those without deformities (6%) (Kopparty et al., 1995). In addition to external manifestations of the disease, leprosy-related stigma has also been attributed to cultural and religious beliefs, fear of transmission, and the association of the disease with people who are considered inferior (van Brakel, 2003; Sermrittirong & van Brakel, 2014).

Despite leprosy being declared eliminated as a public health problem globally, over two decades ago, it remains a problem in Nigeria. Northern Nigeria reports more new cases of leprosy compared to the South (Mustapha et al., 2012). Studies have also reported a high level of stigma across Nigeria (Ebenso et al., 2019; Ogban et al., 2020). Addressing stigma in northern Nigeria requires an understanding of the degree of stigmatisation and the underlying mechanisms that fuel leprosy-related stigma. This could inform the development of culturally sensitive stigma-reduction interventions.

Objective

This study explored the social consequences of leprosy and the factors that drive stigma among persons treated for leprosy in the context of northern Nigeria, from the perspectives of the persons affected.

METHOD

Study Design

The study used a cross-sectional design with a qualitative approach. It was the qualitative component of a mixed methods study that focused on the prevalence

and determinants of social participation restriction among persons affected by leprosy, who were released from MDT at least two years previously. Semi-structured in-depth interviews were conducted with persons affected by leprosy.

Study Site

The study was conducted in Kano State, Nigeria. The state recorded 118 new cases out of Nigeria's 2,424 new cases in 2020 (The Nation News Paper, 20th June, 2021). In-depth interviews were carried out in both urban and rural catchment communities of Yadakunya Leprosy hospital, which is a major leprosy rehabilitation centre located in northern Nigeria. This 153-bed hospital houses a leprosy clinic administering multidrug therapy (MDT) to people diagnosed with leprosy. The hospital also takes care of leprosy complications, and offers orthopaedic services, general outpatient services, antenatal care, and other maternal health services.

Study Sample

The participants were selected by stratified purposive sub-sampling from the quantitative strand sample until data saturation was reached. Potential participants were stratified by sex (male and female), marital status (married, divorced, widowed), residence (rural and urban), and educational level (at least primary education versus no formal education) to ensure representation and maximum variation in experiences.

Inclusion criteria:

Persons affected by leprosy, 18 years of age or older, who used to receive MDT at the clinic and were discharged from treatment at least two years prior to the study.

Twenty persons were found eligible for inclusion in the study.

Theoretical Framework of Stigma and its Impact

The elements of the International Federation of Anti-Leprosy Associations (ILEP) Stigma Framework were used, which identified emotions, thoughts, behaviour, and relationships as the four stigma domains that have impacts on persons affected by leprosy. The domains are said to be interconnected and are manifested in different degrees, moments, and contexts (ILEP, 2011). The feelings of "fear, grief, depression, guilt, shame, anxiety, low self-esteem, anger, inability to express such

feeling and hopelessness” constitute the first domain. Negative and pessimistic thoughts about self, the world, and the future are part of the second domain. Emotions and thoughts that are in the first and second domains determine the way affected persons react to the health condition, and subsequently influence their behaviour. This is manifested through loss of confidence, avoidance, isolation, and withdrawal from social life. This (behaviour) is the third domain. The fourth and final domain is relationships, and is described as “rejection, forced isolation, and restricted social participation” (ILEP, 2011).

Data Collection

Data were collected from September to November 2020. The in-depth interviews were conducted by an experienced social scientist, using the interview guide. The questions in the interview guide were formulated to gain insights into anticipated and experienced stigma and the associated drivers. The interview guide was based on the results of a quantitative survey that was conducted prior to this study. The face-to-face interviews were conducted in the catchment communities, while ensuring privacy and observing COVID-19 precautions. Themes in the interview guide included: response to diagnosis, disclosure, attitudes of others (thoughts on leprosy, general attitude of the community of persons not affected, experiences with education, work, marriage, participation in social events, differential experience of persons who have visible impairments), and preferred occupation.

Data Analysis

The interviews were audiotaped, transcribed verbatim, and translated from the local Hausa to the English language. Subsequently, the anonymised transcripts were coded and analysed manually. The framework approach to thematic analysis was performed (Pope et al., 2000) and included familiarisation 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 the participants were informed about the objectives of the

study, voluntary participation, the risks and benefits of participating, their right to withdraw at any point in time, and the confidentiality of the data. Written informed consent was obtained from all the participants prior to data collection.

RESULTS

A total of 20 persons affected by leprosy were interviewed in depth. The average age of the participants was 52 years, with ages ranging from 38 to 72 years. Ten participants were male, and 10 were from rural areas. While 4 participants had completed at least primary education, the rest had no formal education. The majority of the participants ($n=14$) were married, and six of them ($n=6$) had no current partner. Six male participants had multiple spouses. Eleven participants were petty traders, four were beggars, three were farmers, one was a road transport union worker and one was a civil servant (see Table 1). All the participants were Muslims (see Table 1 below).

Table 1: Demographic Attributes of Persons affected by Leprosy who participated in the in-depth Interview in Kano, Nigeria (n=20)

Characteristics	Category	Frequency
Age (years)	30-39	2
	40-49	4
	50-59	10
	= or >60	4
Total participants		20
Male	Rural	5
	Urban	5
Female	Rural	5
	Urban	5
Total participants		20
Marital status	Married	14
	No current partner (single, widow, divorced)	6
Total participants		20
Level of education	No formal education	16
	Formal education of at least primary school level	4
Total participants		20
Occupation	Beggars	4
	Manual workers including farming	4
	Petty trading,	11
	Civil servant	1

Religion	Islam	20
	Other faiths	0
Total participants		20

The in-depth interviews yielded six major thematic areas. These included: response to leprosy diagnosis, disclosure of diagnosis, community attitudes and behaviour, intermarriages, preferred occupation, and participation in social events.

Response to Leprosy Diagnosis

In their reaction to leprosy diagnosis, participants revealed social prejudice against leprosy, myths about the disease, and lack of knowledge about transmission. In addition, the diagnosis of leprosy uniformly evoked negative emotions such as sadness, anger, and despair. Participants indicated that their family members and significant others also experienced negative emotions.

“I was not happy at all. My mother also cried a lot when she discovered I had leprosy. But there was a time I got burned in an open fire unknowingly. When I showed my uncle, he shook his head, felt bad, and said “this is leprosy” (61-year-old male).

Negative reactions were caused by society’s perception of leprosy as invariably leading to deformities, stigma, and social exclusion. These apprehensions fuelled fear and negative emotions among newly-diagnosed persons and their families.

“Those that were infected have lost their fingers and other parts of their body. People run away from them, pointing fingers saying that they are infected with leprosy; also, I considered how people with this disease are treated in the society” (60-year-old male).

Other concerns were the eventual loss of friends and marital dissolution. Some married women affected by leprosy requested divorce as they could no longer cope with the demands of marital life and the embarrassment of co-wives. While none of the men reported that they feared being unable to live up to the demands of marital life, some men said they were abandoned by their wives because the wives believed that men afflicted with leprosy could no longer provide for the family.

“My two wives abandoned me because of this condition. They said I could not take care of them. So, someone whose wives deserted him, and ran away from him, is there any more obstacle to face than that?” (65-year-old male).

One participant said that she was forced to abandon her hometown and migrate in order to escape the shame and ridicule associated with leprosy.

“I felt bad, that was the reason I left my hometown [migrated] to this place where I remarried and had my children as people were calling me names in my hometown and I felt really bad” (52-year-old female).

Others said they were mentally disturbed by community members; this affected their mental well-being, but they held on to their marriages and sought treatment outside their communities.

Post-diagnosis, participants with visible impairments described experiencing a negative life transformation due to the stigma and social isolation.

“Because I witnessed a change in my life, I could no longer do things I took for granted. For instance, my hands were bleeding in public, and even my close friends no longer extended their hands to shake mine or eat with me. It is a whole new life” (58-year-old male).

Disclosure of Diagnosis

Participants indicated that parents were informed about their disease first, in most cases, especially mothers, then fathers, grandparents, and other family members. This was followed by friends and other close confidants. A few participants consulted healthcare professionals in search of a diagnosis and treatment. In general, disclosure was met with negative emotions ranging from sadness to anger.

‘My mother was the first to know. She was very angry and at that time I didn’t know exactly what her anger was about, nor did I know the danger of this infection [leprosy]’ (53-year-old female).

Family members were worried about where to get effective treatment. Parents, especially the mothers, became preoccupied with the search for a cure. The actions taken by participants were largely dependent on the health-seeking behaviour of the family. Traditional medicine was often the first option, based on firm traditional and cultural beliefs.

“My mother continued searching for medication to get me healed. There was no rest of mind as the focus was on how to get a cure. Wherever she thought or heard of a place that treated such cases, she ran to that place for help. She continued like this into my

adulthood, and I also started looking for medicine myself. Because of this experience, if I meet a person newly infected with leprosy I can heal him completely using traditional medicine” (60-year-old male).

Some participants indicated that in general the attitude of family members did not change towards them, and they also felt it was their destiny. Indeed, the majority of participants and the people they spoke to had strong belief in fate and destiny. Friends consoled the affected persons saying it was their fate as destined by God/Allah. This sense of spirituality provided succour and hope, leading to acceptance of the situation.

“I first told my elder sister and she counselled me and asked me to be patient and that God is with us and it is my fate, and I should consider it a trial from God in good faith. She was not happy and every time we met, her words were remain patient and live with people well, whatever stigma you encounter, and do not worry because this is from God” (52-year-old female).

Some participants faced strong opposition from their parents regarding hospital treatment, out of fear that doctors would amputate body parts. Some had to wait till the opposing parent’s demise before they could access hospital treatment, or they sneaked into the hospitals secretly, without approval from their parents.

In addition, a participant described experiences of enacted stigma in the form of discriminatory experiences at a close relative’s home. Narrating her ordeal, a woman described as unforgettable the denial of permission to stay and receive treatment at her uncle’s place.

“Some people sympathised with me. It was when I came here [uncle’s house] that the infection worsened. I left my husband and came here to live with my uncle. However, I discovered some changes in attitude from his family members. I told him that I will live here [in his house] and be going to collect my medicine. He then told me that I could not stay with him because the disease is transmissible. I was shocked. If my maternal uncle disowns me, where else can I go? This, I cannot forget” (47-year-old female).

Community Attitudes and Behaviour

While some participants reported no untoward social responses from the community members who continued to invite them to social functions, others described various forms of stigma and social exclusion, such as avoidance, social distancing, and refusal to engage in communal eating.

“Yes, it is basic you will see changes from some individuals in the community. Like some people when you go to the mosque, market, and other places, you will notice they would not like to come close to you. Similarly, when you attend marriage ceremonies and food is served, some people will not eat with you. But some other people will eat with you” (61-year-old male).

There was evidence of anticipated stigma before and after diagnosis, and enacted stigma after diagnosis of leprosy. Negative perceptions about leprosy informed anticipated stigma, while lack of understanding of the infectiousness and mode of transmission heightened the fear of acquiring infection, thereby fuelling stigma and social exclusion of persons affected. Some participants also blamed poor hygiene practices of some affected persons as being partly responsible for the persistence of stigma from community members.

A participant reported migrating from her hometown because of the shame of having leprosy. The use of traditional medications was popular. Treatment completion which renders affected persons non-infectious did not eliminate stigma. The persistence of stigma was worse among those with visible impairment.

“There is much difference in the way community members treat those with visible impairments. They fare worse. I remember someone that refused to shake hands with a leprosy-affected person with visible impairments. He instead used a stick that he held at one end and gave the leprosy-affected person the other end to replace a direct handshake” (51-year-old male).

Beyond the family, a participant reported that his neighbour ordered the cutting down of a tree to prevent affected persons from gathering under it. Similarly, items (such as a wooden bench) borrowed by persons affected were washed thoroughly by the owner before use. Stigma also manifested in educational institutions, both formal and non-formal (Qur’anic) schools. Other (unaffected) students avoid students affected by leprosy and sometimes leave the class to avoid sharing seats. A participant who was a student, shared his experience in a non-formal school where, despite being the major contributor to food, his friends barred him from eating with them.

“An event happened when I was in Arabic school in [location] that I won’t forget. ... [my friends] decided to stop eating with me because of my condition. This was revealed when one day we warmed leftover food and when I attempted putting my hand in the bowl to start eating, one of my friends confronted me and said ‘honestly [name] you are cheating us’. At that time, I felt bad, and from then on I had to eat alone. That was despite me being the largest contributor of [food] that we ate” (61-year-old male).

In addition, commercial vehicles avoid carrying persons affected with visible impairment, even if there are vacant seats.

“The second unforgettable incident happened at [location] within old Kano city when I waved down a commercial bus and when the driver and conductor realised that I had an impairment, they zoomed off and refused to take me” (61-year-old male).

Participants indicated that they were eager to go to school and study, but that stigma towards them constituted a barrier. Some participants believed that affected persons had limited opportunities compared to their unaffected counterparts. However, enacted stigma towards affected persons by non-affected classmates results in minimal interaction between affected and unaffected persons. Some participants said that persons with disabilities not caused by leprosy have better educational opportunities as compared to persons affected by leprosy, because of negative perceptions and a lack of knowledge of leprosy. Persons affected by leprosy and also their children face stigma mainly from other students in educational institutions.

“Educational opportunities were limited for leprosy clients. There is stigmatisation which is very usual. We want to learn but interaction with unaffected people is difficult, and it is not easy to sit together at the same time in the same place to learn. If you look at this situation, there is room for crippled or deformed people to study; likewise the blind men are all recognised in the community, and they can interact with people well without showing any differences, but for people suffering from leprosy, their case is different and it is only God that loves us” (40-year-old female).

Participants also lamented the difficulty in getting accommodation whenever they travelled. They are denied hotel accommodation when the hoteliers discover that they are affected by leprosy, even if they can afford their stay. In addition, apart from maintaining a social distance, some relatives and community members stigmatise them by rejecting their food and drinks. This is not the case within the community of affected persons.

“Affected persons face stigmatisation from unaffected persons. They will not sit near you; they will not drink from you or eat your food and when you visit them, they treat you differently. When you want to drink, they will not provide you with a clean container because you are a sick person. Even your relatives stigmatise you and behave towards you differently. However, within our community of affected people, we don’t have a problem and we do everything together. But members of a neighbouring village stigmatise us and call our children all sorts of names. Our children have to attend separate schools because

of stigmatisation against their parents”

(52-year-old female).

Intermarriages

Another challenge relates to marriage proposals. These are promptly turned down, especially by parents and relatives of the girls, as soon as they discover that the man has leprosy.

While intermarriages did occur, they were often mainly between a man affected by leprosy and an unaffected woman. Even then, these marriages were carried out before the man was diagnosed with leprosy. These intermarriages faced societal opposition.

A participant described a boycott of a wedding ceremony by neighbours in protest against marriage between affected and unaffected persons. To avoid such challenges, persons affected, as a group, resolved to marry among themselves:

“There was an episode where one of us married an unaffected woman with her consent and that of her parents. But the neighbours boycotted the wedding wondering how she could accept marrying a leprosy-affected man. Therefore, to avoid problems, we have resolved to marry among ourselves (58-year-old male).

According to the participants, community opposition and the opposition of parents of the prospective bride and groom, if one of them is leprosy-affected, are common. This opposition is strongest if the girl is not leprosy-affected but the man is. This often ends in the dissolution of the agreement to go ahead with the marriage. The participants explained that intermarriages between affected and unaffected persons were reported to be more common in other parts of Nigeria, but were rare in the north.

“I married my husband in my village. He was also affected with leprosy. Some people do marry unaffected people. For instance, when I went to Lagos, I discovered that most of their wives are unaffected women. But here [in the North], it is a rare phenomenon for a person affected by leprosy to marry an unaffected person” (40-year-old female).

As mentioned previously, apart from restricting potential partners to affected persons, divorce seemed common following leprosy diagnosis, mostly at the request of women.

Disappointments regarding marriage proposals were not limited to periods of

treatment; it persisted after being declared cured, as the public still considered them active leprosy clients.

“Yes, we encounter rejection regarding intermarriages with unaffected persons. I proposed to marry several unaffected women after I was declared cured, but they all refused because they still considered me a leprosy client even after cure” (51-year-old male).

Challenges with family formation were experienced by both men and women. Divorce as a result of leprosy was common. Often, the stigma was extended to children of persons affected by leprosy, who also faced challenges in their marriage.

“Yes, what I experienced was when I got married to my first husband, people started complaining to him and asking why he married a person affected by leprosy. I had to leave my matrimonial home to my family house after which I was brought here to Bela to receive medical attention. My parents later requested him to divorce me. After my divorce, I then remarried a person affected by leprosy. Secondly, one of my daughters got married to an unaffected person but because we [her parents] have leprosy, the marriage ended. Her husband’s family members sent her away. We now prefer giving out our daughters to our people [persons affected] because of these experiences” (52-year-old female).

In sum, leprosy affects marriage prospects and can be a reason for divorce, resulting in persons affected marrying other persons affected.

Preferred Occupation

In compliance with healthcare workers’ counsel, persons affected by leprosy selected their jobs carefully. They engaged in petty trading and selling inedible essentials such as firewood and kerosene, either directly or through their children. They avoided physically demanding jobs and selling cooked or ready-to-eat food items because the public perceived that for any item touched by an affected person to be safe for consumption, it needs to be cooked after purchase.

“No one will buy cooked food or ready-to-eat food from you because they feel you have contaminated it. They prefer that anything you touch should be cooked to kill any germs from you before use” (58-year-old female).

According to the study participants, despite the careful selection of occupation, the chances of making good sales and profit, given a particular capital and market location, was lower for persons affected compared to their unaffected peers.

“You know, because of peoples’ stigma and negative perceptions, with this kind of infection you cannot cook and sell, so preferably you can sell firewood, kerosene, vegetables like tomatoes, pepper and palm oil. Even for the inedible items, if the public knows that you are a leprosy-affected person, they will not buy from you. But what we do is if you have a small boy, he can sell it for you. But for me, I can do everything but the impaired ones they cannot do that” (55-year-old female).

Participants confirmed that begging was common among persons affected by leprosy. They identified lack of education, unemployment, and lack of capital as reasons for begging. Some participants attributed it to the belief in ancient times that persons affected by leprosy could seek divine healing by humbling themselves through begging. Others reported that persons affected had turned begging into a business by engaging their children as fronts, while others beg because they lack formal education and cannot be employed in the formal sector.

Participation in Social Events

Some participants told us that they attend social gatherings of relatives, friends, and neighbours affected and unaffected by leprosy, with little or no experience of stigma.

“Yes, I participate in every activity. I have not experienced any stigmatisation from the unaffected people. We do everything together. I get invited to ceremonies like every other person. If there is ‘Ashobi’ [uniform cloth made specifically for a ceremony], they send the sample to me and I make mine” (40-year-old female).

However, some participants indicated that they gradually withdrew from social engagements. Others mentioned that some persons affected by leprosy limited themselves to social events organised by their relatives and close family members. Participants again emphasised that persons with visible impairments fare worse than their counterparts without impairments. They avoided other invitations based on previous unpleasant experiences, including various forms of stigma from other invitees.

“Sometimes if you intend to go to such public events and you remember your condition and previous encounters, you change your mind. Others do not even try to go to public places because they know what they will face, so they prefer to stay back. Whatever you do to your body, they will still avoid you. Those that were declared cured also do not fully participate in public events” (53-year-old female).

Participants' experiences of communal eating at such social events were varied. Those with visible impairments especially, experienced more restrictions during communal eating. Some participants restricted group eating to their relatives and other persons affected, out of fear of discrimination. While some affected persons engaged in communal eating during ceremonies, just as they used to before being diagnosed, albeit using a spoon (eating with hands is normal in this part of Nigeria), others avoided eating with unaffected people due to anticipated stigma. However, eating with other affected persons was acceptable.

"No, to be honest, I don't eat with other people because of this infection. It is better to eat alone or among yourselves. They will not eat food with you; it is only those among you with the same condition that will eat from and with you. We don't eat together; even when you attempt to eat, some will refuse to eat with you. So it is better not to attempt it" (50-year-old female).

During ceremonies, while some persons affected by leprosy ate communally, using a spoon as instructed by health professionals, most of them avoided eating in public. They preferred to eat with their members or opt for 'take away' packs to avoid embarrassment.

"No, I don't eat with other people. I would rather ask them to bring my own, with a spoon to eat separately, because nobody will eat our leftovers except dogs" (65-year-old male).

When asked if there were changes in leprosy-associated stigma over the years, one participant was of the view that there has been some reduction, attributing it to increased public awareness and healthcare workers treating persons affected by leprosy with respect.

DISCUSSION

The study explored the experiences of stigma among persons affected by leprosy in northern Nigeria. The findings transcend the four domains of the impact of stigma in the ILEP Stigma Framework (ILEP, 2011). These include: (1) negative attitudes and societal behaviour which seem to be caused by negative perceptions and lack of knowledge of leprosy, (2) restrictions in social participation such as in communal eating, job opportunities and education, (3) the negative impact on marital life and marriage prospects also experienced by family members, and (4) the negative emotions this causes.

Attitudes and Behaviour of the Community

Themes indicated pervading myths and incorrect fears about leprosy due to its perceived infectiousness and the resultant disabilities. These could be fuelled by unfounded and unscientific views about the infectiousness of the disease and the fear of dealing with affected persons. The findings are similar to reports in India and Nepal where persons affected by leprosy have been subjected to all sorts of isolation and forced migration (Try, 2006; Poestges, 2011).

Participation Restrictions

The extension of stigma to family members has also been reported in other studies in Nigeria (Ebenso et al., 2019), Cameroon (Nsagha et al., 2011), Ethiopia (van't Noordende et al., 2020), Nepal (Marahatta et al., 2018) and India (Frist, 2000). If a family member is affected by leprosy, it seems that it alters both the individual and family's social identity, with damaging consequences. This could include social isolation, avoidance, rejection, and diminished marital prospects. Apart from lack of knowledge regarding leprosy, this is probably accentuated by considering leprosy as divine punishment for past sins (Lewis, 1987) and some religious scriptures cautioning against matrimonial alliances with families of persons affected by leprosy (Brody, 1974; Fordham University, 1998). This highlights the need to engage religious and community leaders, and healthcare workers, to dispel myths and clarify the mode of transmission, availability of treatment, and rehabilitation of persons affected as a means to minimise stigma and discourage the use of traditional medications. It is also necessary to empower organisations of persons affected by leprosy to be actively involved in stigma-reduction interventions.

Social participation restrictions related to communal eating, experienced by persons affected, has been reported in parts of Nigeria (Ogbewe, 1999; Ebenso, 2007) and Brazil (Lesshafft, 2010). Underlying this could be the fear of acquiring leprosy, resulting from poor knowledge about transmission. Most community members view persons affected as infectious even after release from treatment. This could result in public avoidance and non-invitation of affected persons to social events. This underscores the importance of sustained information, education and communication interventions via traditional and modern media to fill knowledge gaps, and address misconceptions and myths about leprosy.

The negative experiences of affected persons and their children in educational institutions limits educational opportunities as earlier reported in other studies in

Nigeria (Ebenso & Ayuba, 2010), South Sudan (Luka, 2010) and Indonesia (Lusli et al., 2015). The low educational attainment and stigma limit job opportunities to occupations deemed by society as 'appropriate' for persons affected. This restricts the economic participation of persons affected to subsistence agriculture, animal husbandry, petty trading, or begging, thereby perpetuating the cycle of poverty in affected families (Kaur & van Brakel, 2002). These are important considerations for holistic educational, occupational and socioeconomic rehabilitation of persons affected and their families.

Thoughts and Emotions

Participants in this study felt bad, sad and expressed a sense of despair in response to the diagnosis of leprosy, consistent with the first domain of the ILEP Stigma Framework (ILEP, 2011). Previous studies in Nigeria (Ubah, 1992) and Indonesia (Peters et al., 2013; Lusli et al., 2015) reported that such a diagnostic label evoked strong negative emotions, probably fuelled by society's image of leprosy as invariably leading to deformities, stigma, and restricted social participation. These negative emotions were not restricted to persons affected by the disease, but also involved family members. It was, however, tempered by a strong sense of spirituality facilitating acceptance of the disease as their fate and an inescapable destiny. This concurs with findings from Brazil, where spirituality/faith was also a source of strength for persons affected (van't Noordende et al., 2021). This is important as it could minimise denial by serving as a coping strategy for religious people.

Impact on Marital Life

In the present study, the thought of living with disabilities and its consequences made participants worry about their future. They contemplated life with leprosy and the consequences on their relationships and marriage. For instance, some married women were particularly concerned about how to cope with co-wives. Some of them requested a divorce at the thought of living with co-wives. Others deserted their matrimonial homes and settled elsewhere to avoid being stigmatised in their original communities or by co-wives. These pessimistic thoughts about self, the world, and the future are part of the second domain of the ILEP Stigma Framework (ILEP, 2011) and are similar to reports from India and Nepal (Try, 2006; Poestges, 2011). Apart from marital instability, separation, or divorce, leprosy also diminished future marital prospects for persons affected

and their families. Contrary to the general belief that women are more affected in terms of marriage prospects than men (Rao et al.,1996; Le Grand, 1997; Try, 2006), in the present study participants indicated that marriage proposals were promptly turned down, especially by parents and relatives of the women, as soon as they discovered that the man has leprosy. This treatment was also meted out to family members to a certain degree. Underlying this is the desire to protect the family identity and protect the lineage from an 'inheritable' disease (Stangl et al., 2019). Community enlightenment programmes are required to address the misconceptions that drive this form of stigma.

Behaviour

In line with the impact of the first and second ILEP stigma domains on the behaviour of persons affected (ILEP, 2011), participants reported self-exile and isolation among persons who could not cope with the diagnosis. Some experienced a difficult time, and the majority established new friends among persons affected by leprosy instead of the community they originally hailed from. Some questioned why society treated them that way, because even after being released from treatment that made them non-infectious, society still treated them as being different. Their children faced similar challenges in schools and other public places. Intermarriages between persons affected and non-affected were problematic when they occurred. Even the daughters and sons of persons affected by leprosy are stigmatised and face similar challenges in marriage. These forced persons affected by leprosy to intermarry among themselves or to prefer that their daughters who are not affected marry persons affected by leprosy, to promote peaceful and stigma-free married life. These findings are similar to what was reported in India (Poestges, 2011).The adjustments in behaviour concerning marriage – marrying other persons affected by leprosy instead of 'intermarriage', and communal eating that is done 'amongst themselves' - are coping strategies that are temporary. However, more lasting and sustainable stigma-reduction activities based on socioeconomic rehabilitation programmes are needed in communities in the studied region.

Relationships

The study findings revealed forced migration, rejection, self-isolation, and social participation restrictions. Participants demonstrated perceived or felt stigma, experienced or had enacted stigma, and demonstrated internalised stigma. These

findings are similar to a report from Brazil where it was stated that leprosy-related stigma was more 'persistent than the disease' (Silva et al., 2014).

Perceived stigma was demonstrated by affected persons and their immediate families following the news of being affected by leprosy. Some endured, while some had to leave their communities on self-exile to other communities, usually of persons affected by leprosy, located close to where leprosy treatment could be accessed. The act of migrating from one's original community to another, either on self-exile or by force, has been reported in Nepal where leprosy-diagnosed persons are forced to leave their families to live in isolation around the riverbanks (Poestges, 2011). The respondents in the current study experienced stigmatisation by neighbours, and rejection and isolation from family and community members in several ways. In Brazil, changes were also reported in the family, the receptiveness of neighbours and co-workers, and the social lives of persons affected, after the diagnosis of leprosy (Silva et al., 2014).

Strengths and Limitations of the Study

The strength of this study lies in the fact that it is one of its kind being reported from the study area. Being a qualitative component of a mixed methods study, it provided a more in-depth understanding to the quantitative findings (reported elsewhere). However, its cross-sectional nature limited causal attribution. It however provided information for further research on the subject to be conducted in the study area.

CONCLUSION

The study found profound stigma manifesting as negative attitudes and societal behaviour, restrictions in social participation impacting on marital life and prospects, and limiting jobs to those deemed "appropriate" for persons affected. These resulted in adjustments in behaviour, such as marrying other persons affected by leprosy instead of 'intermarriage', and communal eating 'amongst themselves'. These coping strategies are temporary and need to be replaced with more sustainable stigma-reduction activities in communities, based on socioeconomic rehabilitation programmes in the studied region.

ACKNOWLEDGEMENT

The authors acknowledge with gratitude the cooperation and support of the

leadership of persons affected by leprosy, and the individuals who participated in this study.

The data underlying this article will be shared on request to the corresponding author.

The authors declare no conflict of interest.

REFERENCES

- Attama CM, Uwakwe R, Onyeama GM, Igwe MN (2015). Psychiatric Morbidity among Subjects with Leprosy and Albinism in southeast Nigeria: A Comparative Study. *Ann Med Health Sci Res.* 5(3):197-204. <https://doi.org/10.4103/2141-9248.157503>. PMID:26097762 PMCID:PMC4455010
- Brody SN (1974). The disease of the soul: leprosy in medieval literature. *Cornell University Press.*
- De Stigter DH, de Geus L, Heynders ML (2000). Leprosy: between acceptance and segregation: Community behaviour towards persons affected by leprosy in eastern Nepal. *Lepr Rev.* 71(4):492-8. <https://doi.org/10.5935/0305-7518.20000051> PMID:11201904
- Ebenso B (2007). Impact of socioeconomic rehabilitation in leprosy in northern Nigeria. *Asia Pacific Disabil. Rehabilitation J.* 18: 98-120.
- Ebenso B, Ayuba M (2010). 'Money is the vehicle of interaction': insight into social integration of people affected by leprosy in northern Nigeria. *Lepr Rev.* 81(2):99-110. <https://doi.org/10.47276/lr.81.2.99> PMID:20825114
- Ebenso B, Newell J, Emmel N, Adeyemi G, Ola B (2019). Changing stigmatisation of leprosy: an exploratory, qualitative life course study in Western Nigeria. *BMJ Glob Health.* 4(2):e001250. <https://doi.org/10.1136/bmjgh-2018-001250>. PMID:30997168 PMCID:PMC6441294
- Fordham University (1998). Indian history sourcebook: *The Laws of Manu*, c. 1500 BCE, translated by G. Buhler. Available Accessed June 3, 2021. from: <http://www.fordham.edu/halsall/india/manu-full.html>.
- Frist TF (2000). Stigma and the societal response to leprosy: experience of the last half-century. *Indian J Lepr.* 72:1-3.
- Goffman E (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York, NY, USA: Prentice Hall.
- Hatzenbuehler ML, Phelan JC, Link BG (2013). Stigma as a fundamental cause of population health inequalities. *Am J Public Health.* 103(5):813-21. <https://doi.org/10.2105/AJPH.2012.301069> PMID:23488505 PMCID:PMC3682466
- IILEP- International Federation of Anti-Leprosy Associations (2011). *Guidelines to Reduce Stigma: Counselling to Reduce Stigma*. London, UK: IILEP.
- Kaur H, Van Brakel W (2002). Is beggary a chosen profession among people living in a 'leprosy colony'? *Lepr Rev.* 73: 334-345. <https://doi.org/10.47276/lr.73.4.334> PMID:12549841

- Kaur H, Van Brakel W (2002). Dehabilitation of leprosy-affected people — a study on leprosy-affected beggars. *Lepr Rev.* 73(4):346-55. <https://doi.org/10.47276/lr.73.4.346> PMID:12549842
- Kopparty SN, Kurup AM, Sivaram M (1995). Problems and coping strategies of families having patients with and without deformities. *Indian J Lepr.* 67(2):133-52.
- Le Grand A (1997). Women and leprosy: a review. *Lepr Rev.* 68(3): 203-11. <https://doi.org/10.5935/0305-7518.19970028> PMID:9364820
- Lesshafft H, Heukelbach J, Barbosa JC, Rieckmann N, Liesenfeld O, Feldmeier H(2010). Perceived social restriction in leprosy-affected inhabitants of a former leprosy colony in northeast Brazil. *Lepr Rev.* 81(1):69-78. <https://doi.org/10.47276/lr.81.1.69> PMID:20496571
- Lewis G (1987). A Lesson from Leviticus: Leprosy. *Man* 22 (4):593-612. <https://doi.org/10.2307/2803354>.
- Luka EE (2010). Understanding the stigma of leprosy. *South Sudan Medical Journal*, 3(3):1-4.]c
- Lusli M, Zweekhorst MBM, Galarza BM, Peters RMH, Cummings S, Seda FSSE, Bunders JFG, Irwanto (2015). Dealing with stigma: experiences of persons affected by disabilities and leprosy. *Biomed Res. Int.*2015:261329. <https://doi.org/10.1155/2015/261329>. PMID:25961008 PMCid:PMC4413953
- Marahatta SB, Amatya R, Adhikari S, Giri D, Lama S, Kaehler N, Rijal KR, Marahatta S, Adhikari B (2018). Perceived stigma of leprosy among community members and health care providers in Lalitpur district of Nepal: A qualitative study. *PloS One.* 13(12):e0209676. <https://doi.org/10.1371/journal.pone.0209676> PMID:30589875 PMCid:PMC6307718
- Mustapha G, Olusegu OJ, Mustapha S, Clement A, Dahiru T, Gajere J, Olusola AA (2012). Leprosy Elimination: Progress and Challenges in Nigeria; Kaduna State TB and Leprosy Control Programme as a Case Study. *Afr J Infect Dis.* 6(1):5-9. <https://doi.org/10.4314/ajid.v6i1.77734>. PMID:23878709 PMCid:PMC3555439
- Nsagha DS, Bissek AZ, Nsagha SM, Njunda AL, Assob JC, Tabah EN, Bamgboye EA, Oyediran AB, Nde PF, Njamnshi AK (2011). Social stigma as an epidemiological determinant for leprosy elimination in Cameroon. *J Public Health Afr.* 2(1):e10. <https://doi.org/10.4081/jphia.2011.e10>. PMID:28299051 PMCid:PMC5345469
- Ogban GI, Iwuafor AA, Emanghe UE, Ushie SN, Ndueso EM, Nwadiaro RIE-, Osuchukwu NC(2020). Unfavorable Attitude and Perceived Stigma towards Leprosy: A Concern for Status Perpetuation in a Community in Cross River State, Nigeria. *Asian J Med Health.* 18(8):1-13. <https://doi.org/10.9734 / AJMAH / 2020 / v18i830225>
- Ogbeiwi O, Nash J (1999). What would make your life better? A needs analysis of leprosy settlements in the middle belt region of Nigeria. *Lepr Rev.* 70: 295-304
- Parker R, Aggleton P (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med.* 57(1):13-24. [https://doi.org/10.1016/s0277-9536\(02\)00304-0](https://doi.org/10.1016/s0277-9536(02)00304-0). PMID:12753813
- Peters RM, Dadun, Lusli M, Miranda-Galarza B, van Brakel WH, Zweekhorst MB, Damayanti R, Seda FSSE, Bunders JF, Irwanto (2013). The meaning of leprosy and everyday

experiences: an exploration in Cirebon, Indonesia. *J Trop Med.* 2013;507034.<https://doi.org/10.1155/2013/507034>. PMID:23577037 PMCID:PMC3615632

Poestges H (2011). Leprosy, the key to another kingdom. *Lepr Rev.* 82(2):155-67 PMID:21888140

Pope C, Ziebland S, Mays N (2000). Qualitative research in health care. Analysing qualitative data. *BMJ.* 320(7227):114-116. <https://doi.org/10.1136/bmj.320.7227.113> PMID:10625273 PMCID:PMC1117368

Rao S, Garole V, Walawalkar S, Khot S, Karandikar N (1996). Gender differentials in the social impact of leprosy. *Lepr Rev.* 67(3):190-9.<https://doi.org/10.5935/0305-7518.19960019>.

Rao PS(2010). Study on differences and similarities in the concept and origin of leprosy stigma in relation to other health-related stigma. *Indian J Lepr.* 82(3):117-21.

Rao PSS (2015). Perspectives on the impact of stigma in leprosy: strategies to improve access to health care. *Res Rep Trop Med.* 6:49-57. <https://doi.org/10.2147/RRTM.S55903>

Sermrittirong S, van Brakel WH (2014). Stigma in leprosy: concepts, causes and determinants. *Lepr Rev.* 285(1):36-47.

Silva CA, Albuquerque VL, Antunes MF (2014). Leprosy as a neglected disease and its stigma in the northeast of Brazil. *Indian J Lepr.* 86(2):53-9.

Stangl AL, Earnshaw VA, Logie CH, van Brakel WC, Simbayi L, Barré I, Dovidio JF (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med.* 17(1):31. <https://doi.org/10.1186/s12916-019-1271-3>. PMID:30764826 PMCID:PMC6376797

The Nation News Paper (2021, June 20th). The Nigerian Leprosy situation. Last accessed 20th June 2021 from <http://www.thenationonlineng.net>

Try L (2006). Gendered experiences: Marriage and the stigma of leprosy. *Asia Pacific Disabil. Rehabilitation J.* 17:55-72.

Ubah C (1992). Hope for the despondent: A colonial health care scheme at Uzuakoli, Eastern Nigeria. *Transafr J Hist;* 21: 51-68.

Udo S, Chukwu J, Obasanya J (2013). Leprosy Situation in Nigeria. *Lepr Rev.* 84: 229-237. PMID:24428117

Van Brakel WH (2003). Measuring leprosy stigma - a preliminary review of the leprosy literature. *Int J Lepr Other Mycobact Dis.* 71(3):190-7. PMID:14608814

Van Brakel WH (2006). Measuring health-related stigma—a literature review. *Psychol Health Med.* 11:307–34. PMID:17130068

Van Brakel WH, Calaido J, Grover S, Kohrt BA, Nyblade L, Stockton M, Wouters E, Yang LH(2019). Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention. *BMC Med.* 17:13. PMID:30764817 PMCID:PMC6376667

Van't Noordende AT, Aycheh MW, Schippers A (2020). The impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life: a qualitative study in northwest Ethiopia. *PLoS neglected tropical diseases*, 14(3), e0008173. PMID:32155158 PMCID:PMC7083326

Van't Noordende AT, Bakirtzief da Silva Pereira Z, Kuipers P (2021). Key sources of strength and resilience for persons receiving services for Hansen's disease (leprosy) in Porto Velho, Brazil: What can we learn for service development? *Int Health*. ihab001.<https://doi.org/10.1093/inthealth/ihab001>. PMID:33547894 PMCID:PMC8643449

Weiss MG, Ramakrishna J, Somma D (2006). Health-related stigma: rethinking concepts and interventions. *Psychol Health Med*. 11:277–87