

Magnitude and determinants of leprosy-related stigma among persons affected by leprosy and community contacts in southern Benin: a mixed-methods study

Fifamin Noël Christelle GBAGUIDI

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Sètondji Diane ZANVO

dianezanvo@yahoo.fr

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Sonagnon Inès Elvire AGBO

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Sèdjro Gimatal Esai ANAGONOU

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Karine Lucrèce Marie CODJO-SEGNON

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Armelle Sabine Yélignan HOUNKPATIN

Université Nationale des Sciences, Technologies, Ingénierie et Mathématiques

Ricardo AHISSIN

Ecole Doctorale des Sciences de la Santé de Cotonou, Université d'Abomey-Calavi

Jean Gabin HOUZO

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d' Abomey-Calavi

Vignon BEDIE

Institut Régional de Santé Publique de Ouidah, Université d'Abomey-Calavi

Sékou SAMADOULOUGOU

Université libre de Bruxelles

Cristina JUAN JIMENEZ

Fondation Anesvad

Pierre VELUT

Fondation Raoul Follereau

Anil FASTENAU

German Leprosy and Tuberculosis Relief Association (DAHWA)

Anna GINE-MARCH

Fondation Anesvad

Roch Christian JOHNSON

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi

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Abstract

Background

leprosy remains a highly stigmatized disease, despite being curable, with stigma contributing to delayed diagnosis, social exclusion, and reduced quality of life among affected individuals. This study aimed to assess the magnitude and factors associated with leprosy-related stigma, distinguishing between self-stigma among people affected and perceived stigma among their contacts in the Zou department of Benin.

Methods

we conducted a cross-sectional analytical study using a convergent mixed-methods approach. The study included former multibacillary leprosy patients registered between 2013 and 2023, their close contacts living within a 100-meter radius, and community members. Quantitative data were collected using ODK Collect between October 2024 and February 2025. Self-stigma and perceived stigma were assessed using the standardized Explanatory Model Interview Catalogue (EMIC) scale. Given the skewed distribution of stigma scores, median (50th percentile) quantile regression was used to identify associated factors.

Results

a total of 92 people affected by leprosy and 343 close contacts were included. Median stigma scores were 13.5 (IQR: 17.5) among affected individuals and 18 (IQR: 10.5) among close contacts, indicating a substantial burden of stigma, particularly at the community level. Among affected individuals, active screening ($\beta = 14$, $p < 0.001$) and late diagnosis ($\beta = 10$, $p < 0.001$) were associated with higher self-stigma scores. Additionally, participants residing in rural areas had significantly higher perceived stigma levels compared to those in urban settings ($p = 0.03$).

Conclusions

these findings suggest that stigma is shaped not only by individual disease experiences but also by social and structural factors, including screening practices and community context. Targeted interventions in rural areas that incorporate appropriate sociocultural approaches and involve also former leprosy patients are essential for limiting the psychosocial consequences of leprosy and promoting more humane and inclusive care.

Background

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, an intracellular bacillus with neurocutaneous tropism [1,2]. Its clinical presentation depends largely on the host's immune response. While skin lesions generally allow early detection, nerve damage, which is more insidious, progressively leads to loss of function, deformities, and sometimes permanent disability. Historically, leprosy has been considered an incurable, disfiguring, and highly contagious disease that has, since ancient times, generated fear, exclusion, and marginalization of those affected [3,4].

Stigma is a universal social phenomenon affecting many vulnerable groups worldwide [5,6]. It manifests as negative attitudes, prejudices, and discriminatory or exclusionary behaviours towards individuals perceived as different, particularly because of their health status [7]. Neglected tropical diseases (NTDs) are part of a cycle of poverty that leads to delayed diagnosis and limited access to treatment, resulting in severe complications, impairments, and disabilities. These often visible consequences expose those affected to stigma and discrimination [8]. Some fear, for example, that they will be unable to marry or secure a social future for their children because of the negative perception of their illness. Among the most stigmatized NTDs is leprosy, which causes irreversible deformities and severe social exclusion and remains highly stigmatizing despite being curable through multidrug therapy [9–11]. The physical sequelae it can cause, the cultural and religious history associated with the disease, and beliefs related to contagion or impurity continue to fuel the rejection and discrimination of those affected [12,13]. These stigmatizing attitudes often persist even after a clinical cure, reflecting the weight of social perceptions [14].

Beyond the social stigma imposed by the community, family, friends, or healthcare providers, self-stigma represents a major dimension that is often underestimated. This psychological process occurs when individuals internalize the negative prejudices and stereotypes perpetuated by society, leading to reduced self-esteem, feelings of shame, and a tendency to withdraw from social interactions [15]. Self-stigma can thus reinforce isolation, delay seeking care, exacerbate psychological distress, and limit social reintegration. The available data illustrate the persistence of leprosy-related stigma at the global, regional, and national levels. Internationally, approximately 35% of people affected by leprosy are estimated to experience moderate to severe perceived stigma, while 20–44% exhibit significant self-stigma [16,17]. In sub-Saharan Africa, studies report particularly high levels, with perceived stigma affecting 40–70% of people living with leprosy and rates of self-stigma ranging from 30% to 55%, depending on sociocultural context [18–20]. Nationwide in Nigeria, approximately 52% of people with leprosy report experiencing perceived stigma, while 42% exhibit clinically significant self-stigma. Thus, despite therapeutic advances and the control strategies implemented, the stigma associated with leprosy, whether social or internalized, remains a major public health issue. It not only hinders prevention, screening, and treatment adherence but also profoundly affects the mental health, quality of life, and social integration of those affected, underscoring the urgency of comprehensive interventions that integrate psychosocial dimensions [4,6,19].

In Benin, despite the persistence of leprosy in certain regions, there is a lack of empirical evidence quantifying stigma using validated instruments [22]. Previous studies have primarily addressed stigma

indirectly, without standardized measurement tools, limiting comparability and depth of analysis [23]. To address this gap, this study aimed to assess the magnitude of leprosy-related stigma, distinguishing between self-stigma among people with leprosy and perceived stigma among their contacts in the Zou Department, and to identify associated factors using a mixed-methods approach. By combining quantitative assessment with qualitative insights, this study seeks to provide a more comprehensive understanding of how stigma is experienced and reproduced in this context.

Study framework and methods

1.1. Study framework

The study was conducted in southern Benin in Zou Department. The department has a population of approximately 983,126 [24]. All municipalities in the department where a person affected by multibacillary leprosy (PAL) resides were included. The context is predominantly rural. Leprosy care is centralized around a specialized referral centre, identified by participants as the primary site for diagnosis and treatment, which gives care pathways high social visibility. In this context, the study aimed to assess the magnitude of leprosy-related stigma by examining self-stigma among people with leprosy and perceived stigma among their contacts in the Zou Department, and to identify associated factors using a mixed-methods approach.

1.2. Study design

This was a cross-sectional analytical study using a convergent mixed-methods design, in which quantitative and qualitative data were collected concurrently and integrated during analysis to provide complementary insights into stigma. A preparatory phase preceded data collection, during which the study protocol was submitted to the ethics committee, data collection tools were developed and validated, and interviewers were recruited and trained. Data collection began on October 29th, 2024, and ended on February 28th, 2025.

1.3. Target populations

The target population included the following:

- PAL in Zou Department,
- Their close contacts living within a 100-metre radius,
- Community members were recruited through focus group (FG) discussions. These are people living in the same village as the PAL but beyond the 100-metre radius.

1.4. Source population

On the one hand, the source population consisted of PALs registered from 2013 to 2023 in the records of Programme National de Lutte contre la Lèpre et l'Ulcère de Buruli (PNLLUB). These cases were geolocated using GPX Viewer software. It also included close contacts living within a 100-metre radius

of these PALs, as well as community members living within the same village as the PAL. The census of close contacts within the 100-metre radius was conducted using the trackbook tool from GPX Viewer software.

1.5. Inclusion criteria

For close contacts, the inclusion criterion was 14 years of age or older. This age threshold was not applied to the PAL, given their direct experience with the disease.

1.6. Sampling

1.6.1. Sample size

1.6.1.1. People with leprosy

PALs registered between 2013 and 2023 were identified. A total of 110 PALs were identified, of whom 11 had died, 6 were displaced, and 1 was deaf and mute. The questionnaire was therefore ultimately administered to 92 PALs.

1.6.1.2. Close contacts

For the quantitative component, the sample size for close contacts was determined using the sample size formula for mean estimation. The following parameters were considered:

σ : Standard deviation of the mean stigma score = 7.73 [25]

α : Confidence level = 95%

E: Margin of error = 1

N = 230 participants. The minimum number of close contacts to include is therefore 230.

For the qualitative component, purposive sampling was used to capture the diversity of experiences. Interviews were conducted until thematic saturation was reached, defined as the absence of new relevant information emerging in successive interviews. In total, 81 and 119 individual interviews were conducted with the PAL and close contacts, respectively, followed by 12 focus groups with community members. This sample size allowed clear thematic saturation to be achieved.

1.6.2. Sampling technique

This involved exhaustive sampling of all PALs meeting the inclusion criteria. For close contacts, simple random sampling was used following the procedure described here: A census of close contacts was conducted around each PAL. Following this census, a rate P was determined by dividing the calculated sample size (N) by the total number of identified contacts (T); that is, $P = N/T$. This rate determines the number of people to be surveyed per PAL on the basis of the number of contacts identified around each PAL. The calculated rate was 1/50; thus, for a PAL with 50 contacts, the minimum number of contacts to

be surveyed is 1. Next, a list of all eligible contacts (age ≥ 14) was constructed. From this list, a random selection of participants was made using R software and the Random command. For the qualitative component, purposive sampling was used. The contact interviewed was a close relative of the PAL who had experienced the illness with them.

1.7. Variables

The dependent variables were self-stigma (among PALs) and perceived stigma (among contacts), measured using the standardized Explanatory Model Interview Catalogue (EMIC), which consists of 15 items for perceived stigma and 15 items for self-stigma. This tool was developed by the International Federation of Anti-Leprosy Associations (ILEP). For each question, a score is assigned based on the participant's response. The total score was obtained by adding the scores for the different items. The mean of this total score is then calculated; the higher the mean is, the higher the level of stigma. Indeed, Self-stigma refers to the process through which a person affected by leprosy internalizes the negative attitudes, prejudices, or stereotypes associated with the disease, leading to reduced self-esteem, feelings of shame, and withdrawal from social participation. In contrast, perceived stigma reflects the attitudes, beliefs, and discriminatory behaviours expressed by the community toward individuals affected by leprosy. It captures the way the population views the disease and the extent to which it endorses social rejection or exclusion.

The explanatory variables included sociodemographic variables (age, sex, education level, marital status, occupation and place of residence), socioeconomic variables, and knowledge of the disease. With respect to self-stigma among PALs, variables such as family history of leprosy, screening mode (active or passive) and screening delay (early or late) were also examined. The analyses of marital status focused exclusively on subjects aged 18 or older.

Economic status was assessed using wealth scores calculated via principal component analysis (PCA), considering household assets and property ownership. The scores were classified into three equal groups (terciles): "poor," "middle," and "rich."

Knowledge of leprosy was assessed using a score derived from responses concerning knowledge of the causes of the disease, early signs, treatment, and complications. The maximum score was 12. The participants were classified into two categories:

- Insufficient knowledge: score < 6
- Good knowledge: score ≥ 6

Furthermore, close contacts who had never heard of leprosy were not included in the analyses of knowledge regarding its causes, early signs, treatment, mode of transmission, complications of leprosy, and perceived stigma.

Late detection was defined as the presence of a Grade 2 disability according to the WHO classification scale. Grade 2 disability is an acquired, permanent, and visible impairment affecting the eyes, hands,

and/or feet of a person with leprosy. It represents the manifestation of irreversible complications of leprosy.

Active leprosy screening is a strategy in which health teams visit communities to identify cases early. Conversely, passive screening refers to the situation in which a patient voluntarily presents at a health facility for screening.

Finally, the qualitative data allowed us to explore the influence of cultural factors and beliefs on the stigma surrounding leprosy.

1.8. Data collection techniques and tools

A questionnaire was developed, pretested, and validated to collect quantitative data. Additionally, interview and focus group guides were developed for in-depth interviews with the PALs, their contacts, and other community members. All the data collection tools are provided in the supplementary files section.

1.9. Data processing and analysis

Quantitative data were collected using the digital tool ODK Collect and exported to Excel. Data analysis was performed using R software within the RStudio environment. Given the non-normal distribution of the data (self-stigma score and perceived stigma score), quantitative variables were described using the median and interquartile range. Univariate analysis was conducted to explore the associations between the explanatory variables and the stigma score using nonparametric tests (Mann–Whitney and Kruskal–Wallis). Variables with a p value < 0.20 were selected for the multivariate analysis to avoid excluding potentially relevant variables. A quantile regression was then used to identify the factors associated with stigma. The measure of association used to quantify the relationship between the stigma score (EMIC-CSS) and the identified factors was the β coefficient followed by its confidence interval. Differences were considered statistically significant when the p value was less than 0.05.

In addition, a qualitative analysis was conducted to supplement and contextualize the quantitative results. It was performed using Nvivo software. The interviews with the various groups were recorded using a voice recorder. The content of the recordings was transcribed in full into French and coded. This allowed for a comprehensive, interpretive description of the interviewees' discourse flow, ensuring that the data were preserved "in readable terms." This data entry procedure enabled the categorization and cross-referencing of data, as well as the synthesis of findings by theme, based on the previously defined hypotheses and indicators. On the basis of the triangulation of the various perspectives emerging from the interviews, the data analysis was structured around the main themes identified following the analysis of the verbatim transcripts, the results, and the key questions the study sought to address.

Qualitative findings were used to interpret and contextualize quantitative results, particularly in relation to mechanisms underlying stigma and the social implications of screening practices.

Results

2.1. Description of the sample according to socioeconomic characteristics

A total of 435 participants, 92 PALs, and 343 close contacts were included in the quantitative component.

Tables I and II present the distribution of participants based on sociodemographic characteristics.

Table I

Distribution of PALs and close contacts by sociodemographic characteristics, Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
Age group	n = 92	n = 343
< 15	02 (02.17)	07 (02.04)
≥ 15	90 (97.83)	336 (97.96)
Sex	n = 92	n = 343
Male	44 (47.80)	130 (37.90)
Female	48 (52.20)	213 (62.10)
Marital status	n = 90	n = 307
Single	10 (11.11)	31 (10,10)
Married	55 (61.11)	236 (76.87)
Divorced/widowed	25 (27.78)	40 (13.03)
Education level	n = 92	n = 343
No education	59 (64.13)	156 (45.48)
Primary	26 (28.26)	115 (33.53)
Secondary/university	07 (07.61)	72 (20.99)

Table II

Distribution of PALs and close contacts by sociodemographic characteristics, Benin (Zou), 2024.
(Continued).

	PAL	Close contacts
	n (%)	n (%)
Main occupation	n = 92	n = 343
Casual worker	5 (0.543)	8 (2.33)
Student	01 (01.09)	17 (4.96)
Merchant	10 (10.87)	60 (17.49)
Artisan	14 (15.22)	78 (22.74)
Farmer	53 (57.61)	170 (49.56)
Other*	09 (09.78)	10 (2.92)
Place of residence	n = 92	n = 343
Rural	88 (95.70)	323 (94.17)
Urban	04 (04.30)	20 (5.83)
Economic status	n = 92	n = 343
Poor	39 (42.39)	122 (35.57)
Moderate	31 (33.70)	120 (34.98)
High	22 (23.91)	101 (29.45)

* Religious, official

Tables I and II show that the majority of participants were 15 years of age or older (97.83% among PALs and 97.96% among contacts). With respect to sex, 52.20% of the PALs were women, and 62.10% of the close contacts were women. In terms of marital status, married individuals predominated in both groups: 76.87% among contacts and 61.11% among PALs. With respect to educational level, the majority of participants were uneducated: 64.13% among those with a PAL and 45.48% among those with a contact. With respect to economic status, the percentage of poor individuals was 42.39% among the PAL group and 35.57% among the contact group. Professionally, farmers were the most represented group, accounting for 57.61% of the PAL group and 49.56% of the contact group. This distribution is consistent with the predominantly rural living environment in both groups (95.70% among the PAL group and 94.17% among the contact group).

With respect to socioeconomic aspects, the results of the semistructured interviews reveal, among other things, that illness appears to exacerbate preexisting precariousness: *"When you're already poor, illness complicates everything."* (PAL, man). This increased vulnerability extends beyond the economic sphere and affects intimate relationships as well as social trajectories, particularly those related to marriage and social recognition. a woman notes, *"With this disease, even marriage becomes fragile."* (PAL, woman).

The highly rural context in which those affected live is characterized by a close-knit and highly interconnected social sphere, which exacerbates an experience of leprosy that is already difficult to endure, as expressed by a close contact: *“Here, everyone knows each other; you can’t hide anything.”* (Close contact, woman).

2.2. Distribution of PALs and close contacts according to their level of knowledge about leprosy.

2.2.1 Distribution of PALs and close contacts according to their level of knowledge of the causes, early signs, and treatment of leprosy.

Tables III, IV, and V summarize information concerning the level of knowledge of the causes, early signs, and treatment of leprosy among PALs and close contacts.

Table III

Distribution of PALs and close contacts by awareness of the causes of leprosy, Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
Witchcraft/Spells		
Yes	21 (23.33)	18 (07.38)
No	69 (76.67)	226 (92.62)
Divine punishment/curse		
Yes	06 (6.67)	06 (02.46)
No	84 (93.33)	238 (97.54)
Poor Hygiene and Sanitation		
Yes	15 (16.67)	27 (11.07)
No	75 (83.33)	217 (88.93)
Total	90 (100)	244 (100)

Table IV

Distribution of PALs and close contacts according to knowledge of early signs of leprosy, Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
Insensitive skin patch		
Yes	72 (80)	110 (45.08)
No	18 (20)	134 (54.92)
Sensory disorders		
Yes	28 (31.11)	21 (08.61)
No	62 (68.89)	223 (91.39)
Skin and neurological signs		
Yes	15 (16.67)	11 (04.51)
No	75 (83.33)	233 (95.49)
Thick skin		
Yes	06 (06.67)	24 (09.84)
No	84 (93.33)	220 (90.16)
Total	90 (100)	244 (100)

Table V

Distribution of PALs and close contacts according to knowledge of leprosy treatment, Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
Traditional		
Yes	07 (07.78)	22 (09.02)
No	83 (92.22)	222 (90.98)
Medical		
Yes	85 (94.44)	205 (84.02)
No	05 (05.56)	39 (15.98)
Spiritual		
Yes	02 (02.22)	00 (00)
No	88 (97.78)	244 (100)
Self-medication		
Yes	05 (06.56)	02 (0.82)
No	85 (94.44)	242 (99.18)
Total	90 (100)	244 (100)

These results revealed that a significant proportion of PALs attributed leprosy to supernatural factors, particularly witchcraft or sorcery (23.3%). Among contacts, this proportion was 7.4%. Beliefs related to divine punishment were also cited by 6.7% of the PALs. Furthermore, poor hygiene was cited by 16.7% of the PAL and 11.1% of the contacts. Knowledge of early signs remains insufficient, particularly among contacts. While 80% of the PALs recognize insensitive skin patches, only 45.1% of the contacts are aware of them. Other signs, such as sensory disturbances (31.1% among PALs and 8.6% among contacts) and early neurological signs, were also noted. With respect to treatment, the majority of the PALs (94.4%) knew that leprosy was treated medically; 84.1% of the contacts had this information. However, reliance on or beliefs associated with traditional treatments persists among 7.8% of PALs and 9.1% of contacts.

2.2.2 Distribution of PALs and close contacts according to knowledge of leprosy complications and modes of transmission.

Tables VI and VII summarize information concerning the complications and modes of transmission of leprosy among PALs and close contacts.

Table VI

Distribution of PALs and close contacts by knowledge of leprosy complications, Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
Handicap	72 (80)	
Yes	18 (20)	136 (55.74)
No		108 (44.26)
Death	56 (62.22)	
Yes	34 (37.78)	00 (00)
No		244 (100)
Disability		
Yes	35 (38.89)	136 (55.74)
No	55 (61.11)	108 (44.26)
Total	90 (100)	244 (100)

Table VII

Distribution of close contacts by mode of leprosy transmission (n = 244), Benin (Zou), 2024.

	PAL	Close contacts
	n (%)	n (%)
By direct contact with an infected person		
Yes	27 (30.0)	118 (48.36)
No	63 (70.0)	126 (51.64)
Airborne transmission		
Yes	06 (06.67)	04 (01.64)
No	84 (93.33)	240 (98.36)
By microbes		
Yes	08 (08.89)	10 (04.10)
No	82 (91.11)	234 (95.90)
By contact with contaminated objects		
Yes	19 (21.11)	68 (27.87)
No	71 (78.89)	176 (72.13)
By occult route		
Yes	09 (10.0)	05 (02.05)
No	81 (90.0)	239 (97.95)
Total	90 (100)	244 (100)

With respect to knowledge of complications, the majority of PALs identified disability because of the disease (80%); among close contacts, 55.7% reported this type of disease. PALs were more likely to report the risk of death (62.2%), whereas no contacts mentioned this possibility. Similarly, disability was perceived by 38.9% of the PALs and 55.7% of the contacts. Finally, knowledge of transmission modes was limited; 30% of the PALs identified prolonged direct contact as a mode of transmission, and 48.4% of contacts identified it. Airborne transmission was poorly understood, with 6.7% of the PALs and 1.6% of the contacts citing it. Beliefs related to transmission via microbes or contaminated objects were also uncommon, and occult explanations were cited by 10% of the PALs.

Ethnographic interviews demonstrate how these explanatory frameworks take shape in daily interactions and guide social behaviour. Participants draw on hybrid beliefs combining heredity (in the blood), impurity/cleanliness (water, hygiene), mystical/ritual causality, and biomedical factors; this pluralism reinforces precautionary rules but perpetuates confusion about transmission. In the FGs, “heredity” and

“uncleanliness” are dominant, in addition to spiritual explanations; the FG matrix shows a strong prominence of the “Beliefs & Explanations” axis.

The following comment comes from a PAL: *“I often wonder how someone can catch it... it seems to me that the disease must be hereditary...”* (PAL, man). *“People often say it can be caused by drinking dirty water.” “I believe it’s a hereditary disease... it’s through their father’s blood”* (FG). Another explained, *“They say it’s a punishment, so we’re careful.”* (Close contact, woman).

2.3. Distribution of PALs and close contacts according to overall knowledge of leprosy.

Figure 1

Distribution of PALs and close contacts by overall level of knowledge about leprosy.

These results reveal a low overall level of knowledge about leprosy among both PALs and their close contacts. Indeed, 79.30% of PALs and 80.17% of close contacts have an insufficient level of knowledge. The difference in knowledge levels between PALs and close contacts was not significant ($p = 0.86$).

2.4. Distribution of PALs by screening method

The distribution of the PAL by the screening method is shown in Fig. 2.

This figure shows that 32.61% of the PALs were detected late, whereas 67.39% were detected early.

2.5. Distribution of PALs by family history of leprosy

The distribution of PALs by family history of leprosy is shown in Fig. 3.

This figure shows that 52.22% of the PALs had a family history of leprosy, whereas 47.78% did not.

2.6. Median score of EMIC-CSS items among PALs

Table VIII: Median score by EMIC-CSS item among the PAL (range: 0–3), Benin (Zou), and 2024.

EMIC-CSS items	Median (IQR*)
I1- If possible, would you prefer to keep people from knowing about leprosy?	0 (3)
I2- Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?	0 (2)
I3- Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?	1 (3)
I4- Have you ever been made to feel ashamed or embarrassed because of this problem?	2 (3)
I5- Do your neighbours, colleagues or others in your community have less respect for you because of this problem?	0 (3)
I6- Do you think that contact with you might have any bad effects on others around you even after you have been treated?	0 (1)
I7- Do you feel others have avoided you because of this problem?	0 (3)
I8- Would some people refuse to visit your home because of this condition even after you have been treated?	0 (2.25)
I9- If they knew about it would your neighbours, colleagues or others in your community think less of your family because of this problem?	0 (2)
I10- Do you feel that your problem might cause social problems for your children in the community?	0 (1)
I11- Do you feel that this disease has caused problems in getting married? /in your marriage?	0 (3)
I12- Do you feel that this disease makes it difficult for someone else in your family to marry?	0 (3)
I13- Have you been asked to stay away from work or social groups?	0 (1)
I14- Have you decided on your own to stay away from work or social group?	0 (3)
I15- Because of leprosy people think you also have other health problems?	0 (3)
*Interquartile range	

2.7. Median score of EMIC-CSS items among close contacts

Table IX presents the median scores for the EMIC-CSS item among close contacts.

Table IX: Median score by EMIC-CSS item for participants (range: 0–2), Benin (Zou), 2024.

EMIC-CSS items	Median (IQR*)
I1 - Would a person with leprosy keep others from knowing, if possible?	1 (2)
I2 - If a member of your family had leprosy, would you think less of yourself, because of this person's problem?	1 (2)
I3 - In your community, does leprosy cause shame or embarrassment?	2 (0)
I4 - Would others think less of a person with leprosy?	2 (2)
I5 - Would knowing that someone has leprosy have an adverse effect on others?	0 (2)
I6 - Would other people in your community avoid a person affected by leprosy?	2 (2)
I7 - Would others refuse to visit the home of a person affected by leprosy?	0 (2)
I8 - Would people in your community think less of the family of a person with leprosy?	1.5 (2)
I9 - Would leprosy cause problems for the family?	2 (1)
I10 - Would a family have concern about disclosure if one of their members had leprosy?	1 (2)
I11 - Would leprosy be a problem for a person to get married?	2 (0)
I12 - Would leprosy cause problems in an on-going marriage?	2 (1)
I13 - Would having leprosy cause a problem for a relative of that person to get married?	1 (2)
I14 - Would having leprosy cause difficulty for a person to find work?	1 (2)
I15 - Would people dislike buying food from a person affected by leprosy?	2 (0)
*Interquartile range	

2.8. Median of stigma

The total median EMIC-CSS among PALs was 13.5 (IQR: 17.5). Among the contacts, 18 (IQR: 10.5) were included. These scores reflect the overall level of stigma measured in each group. Furthermore, among PALs, the highest scores were observed for items related to negative social perception, particularly item I4. Among contacts, the highest scores were found across several items, particularly those related to social avoidance, marriage, and economic interactions (I3, I4, I6, I6, I11, I12, I15, respectively).

The qualitative data provide a concrete social context for these scores. With respect to whether they are PALs or contacts, participants agree: *"Before anyone even rejects me, I'd rather withdraw."* (PAL, man); *"Hmm (...) when I look at myself today, with the changes in my body, my appearance! it's a thousand times better not to mix with others, to live apart, than to endure their stares, their pity, and force them to live with you against their will..."* (PAL, woman); *"We avoid them without being rude; it's better that way"* (Close

contact, woman) or “You never know how this disease acts.” (Close contact, man). Furthermore, the fear of contagion justifies separating utensils and social distancing. A community member states the following during the focus groups: “We’ll avoid them... safety distance measures are needed.” (FG); “At home, I always eat alone from my own plate...” (PAL, woman). The notion of a safety distance present in the FGs is based on a cultural perception of contagion, where simple contact, sharing objects, or physical proximity is perceived as dangerous. The idea of “separating plates” is part of a cultural symbolism of the pure/impure, which is very present in societies in southern Benin.

2.9. Classification of perceived stigma and self-stigma levels

The classification of the level of perceived stigma and self-stigma among PALs and close contacts is shown in Fig. 4.

As shown in Fig. 4, 25% of the PALs had a high level of self-stigma, and 38.53% of the close contacts had a high level of perceived stigma.

2.10. Factors associated with stigma

2.10.1. PAL

2.10.1.1. Univariate analysis

Tables X, XI, and XII present the relationships between self-stigma and the study variables in a univariate analysis.

Table X

Relationships between self-stigma and sociodemographic factors (Benin) Zou 2024.

Age group	Median (IQR*)	p value
		0.98
< 15	12.5 (3.5)	
≥ 15	13.5 (18.5)	
Gender		0.39
Male	16.5 (22.50)	
Women	11 (15.25)	
Marital status		0.53
Single	13 (24.75)	
Married	15 (21)	
Divorced/widowed	9 (15)	
Education level		0.74
Uneducated	13 (18)	
Primary	16.5 (17.75)	
Secondary/university	15 (16)	
*Interquartile range		

Table XI

Relationships between self-stigma and sociodemographic factors (Benin) Zou 2024 (continued).

Main occupation	Median (IQR)	p value
		0.74
Casual worker	23 (18)	
Student	9 (0)	
Merchant	17 (8.75)	
Artisan	8.5 (2.50)	
Farmer	13 (18)	
Others	15 (20)	
Place of residence		0.99
Rural	13 (18.5)	
Urban	18 (9.0)	
Economic status		0.60
Poor	15 (22)	
Middle	12 (19.50)	
Rich	15 (18.75)	
Knowledge of leprosy		0.63
Good	14 (17)	
Insufficient	13 (18)	
* Religious, official		

Table XII

Relation between self-stigma and clinical factors (Benin) Zou 2024.

Screening mode	Median (IQR)	p value
		0.01
Passive	11 (17.5)	
Active	23 (16.5)	
Family history of leprosy		0.57
Yes	14 (19.5)	
No	13 (18.5)	
Screening delay		0.02
Early	09 (16.75)	
Late	20.5 (24.00)	

The results of the univariate analysis revealed that screening mode ($p = 0.01$) and screening delay ($p = 0.02$) were significantly associated with self-stigma.

2.10.1.2. Multivariate analysis

Table XIII presents the results of the multivariate analysis among PALs.

Table XIII

Factors associated with self-stigma (Benin) Zou 2024.

Screening mode	β	95% CI	p value
Passive	1		
Active	14	6.08–21.92	$p < 0.001$
Screening delay			
Early	1		
Late	10	3.48–16.52	$p < 0.001$

- Screening mode as a factor associated with self-stigma

Quantile regression indicated that screening method and delay significantly influence self-stigma. Compared with passively screened patients, those who were screened actively had a significantly higher median level of self-stigma ($\beta = 14$; 95% CI: 6.08–21.92; $p < 0.001$).

Ethnographic interviews shed light on these significant differences. Active screening, particularly when it takes the form of home visits, is frequently described as a moment of social exposure, during which the presence of health workers makes the disease visible within the community.

One participant said, *"When the health workers came to my house, the whole neighbourhood knew."* (PAL, woman). This visibility is perceived as ambivalent: although recognized as necessary for care, it is also associated with the spread of gossip and suspicion, as one contact points out: *"Even if it's for treatment, it gets people talking."* For some people, this institutional exposure leads to adjustments in daily practices and social interactions. One participant explained, *"After they visited, I went out less."* (PAL, woman).

For other categories of patients, referral to or regular attendance at leprosy referral and treatment centres leads to rejection, which is often accompanied by a refusal to engage in any social contact. D. B. explained that *"people are referred to the leprosy treatment centre, and no one wants to associate with them anymore"* (PAL, woman), revealing a disconnect between accepting medical care and enduring social exclusion. A social situation that often leads patients of a certain social status to take their treatment in complete discretion, far from discriminatory stares and social isolation. A PAL states, *"Since I am a member of the teaching profession, I avoided revealing my status as a leprosy patient because it is a disease of shame and impurity. To do so, I negotiated with the treating nurse, and I follow my treatment in complete discretion."* The health centre thus becomes a space of symbolic confinement, a place of exclusion, separating sick people from the remaining community.

- Delay in screening as a factor associated with self-stigma

Furthermore, screening delay was significantly associated with self-stigma. Patients who were screened late exhibited a greater level of self-stigma than those who were screened early did ($\beta = 10$, 95% CI: 3.48–16.52; $p < 0.001$).

Moreover, qualitative analyses revealed that the physical visibility of leprosy constitutes another central mechanism of stigma. Skin lesions, deformities, and limb loss are perceived as alarming signs, triggering fear, rejection, and immediate isolation. H. A. describes leprosy as *"a dangerous and contagious disease because it destroys limbs,"* adding that *"no one agrees to spend time with him, or sit on the same chair as him, or eat, drink, or even talk in close proximity"* (PAL woman). These remarks show that physical visibility suspends ordinary social interactions, as the diseased body is perceived as a carrier of impurity and constant risk.

The body thus becomes an object of public scrutiny and judgement. H. C. reports that *"people criticize someone with such a disease because they themselves don't have it, so they ask themselves: what's wrong with her body? Where did he get that?"* (Close contact, woman), illustrating how physical difference is immediately interpreted as an anomaly requiring a moral explanation. Even after recovery, the stigma persists. A. V. notes that *"if you see him, you automatically know he had leprosy"* (close contact, man),

indicating that physical appearance continues to define the person’s social identity, regardless of their medical status.

2.10.2. Close contacts

2.10.2.1. Univariate analysis

Tables XIV and XV present the relationships between perceived stigma and the study variables in a univariate analysis.

Table XIV

Relationships between perceived stigma and sociodemographic factors among close contacts (Benin) Zou 2024.

Age	Median (IQR)	p value
		0.21
< 15	26 (0)	
≥ 15	18 (10.5)	
Gender		0.52
Male	18 (11)	
Female	18 (9.5)	
Marital status		0.67
Single	19 (7.75)	
Married	18 (8)	
Divorced/widowed	17 (10.75)	
Level of education		0.54
No education	18 (9)	
Primary	19 (10)	
Secondary/university	17 (11)	

Table XV

Relationships between perceived stigma and sociodemographic factors (Benin) Zou 2024 (continued).

Main occupation	Median (IQR)	p value
		0.21
Farmer	18 (10)	
Artisan	18.5 (10)	
Merchant	20 (10.5)	
Student	17 (12)	
Casual worker	19.5 (8)	
Others	16 (6.75)	
Place of residence		0.03
Rural	18 (11)	
Urban	16 (14)	
Economic situation		0.22
Low	18 (10)	
Medium	18.5 (12)	
Rich	17 (8)	
Knowledge of leprosy		0.71
Good	18 ± 8	
Insufficient	18 ± 12	

The results revealed that the median level of perceived stigma was greater among participants under 15 years old, among merchants, and among those with a primary education; however, the difference was not significant. Similarly, there was no significant difference in perceived stigma levels across variables such as, sex, marital status, economic status, and level of knowledge about leprosy. However, a significant difference was identified between perceived stigma and place of residence ($p = 0.034$). Indeed, subjects residing in rural areas had higher median perceived stigma scores.

The qualitative data show that leprosy-related stigma is not limited to the affected individual but is embedded in a lasting family and community dynamic. The disease tends to mark not only bodies but also lineages and affiliations, transforming family names into carriers of the social memory of the stigma. Even after clinical recovery, this memory continues to shape social interactions, neighbourhood relations, and, more specifically, marital trajectories. A village elder highlights the persistence of this collective memory: *“Even after treatment, people remember the family.”* (close contact, man). A. R. reports that *“some people say it’s in the blood...”* (Close contact, man), which shows that partial biological

explanations of leprosy fuel the idea of hereditary transmission. This belief thus condemns not only the affected individual but also their family to lasting exclusion, particularly in social relationships that could lead to having children. This extension of stigma to relatives is experienced as an injustice, especially for children who find themselves associated with a disease that they have not contracted. As one contact states, *“The children have nothing, but people look at them differently.”* (close contact, man). For those who have lived with the illness, this persistence is described as a social mark that is difficult to erase: *“The illness leaves a social mark.”* (PAL, woman)

Discussion

This study demonstrates a substantial burden of stigma related to leprosy in the Zou Department, affecting both individuals with lived experience of the disease and their close contacts. Notably, stigma levels were higher among contacts than among affected individuals, highlighting the importance of community-level perceptions in sustaining stigma.

Several methodological elements reinforce the validity of these results. The exhaustive recruitment of PALs ensured coverage of all municipalities in the department, contributing to a more representative sample. Furthermore, the selection of contacts via simple random sampling helped limit selection bias. The sample size ($n = 343$) provides satisfactory statistical power. Furthermore, the use of the standardized EMIC-CSS tool allows for good comparability with the literature. Finally, data collection, carried out by trained interviewers proficient in local languages, helped limit information bias. The use of the GPX Viewer software also ensured high precision in measuring the 100-metre radius.

3.1. Comparison of the results with those of other authors

3.1.1. Family history

The results revealed that the prevalence of a family history of leprosy was high among PAL. This can be explained by the very nature of the disease’s transmission, which occurs primarily within a household where prolonged, close, and repeated contact facilitates exposure to *Mycobacterium leprae*. Thus, members of the same family who share the same living space, socioeconomic conditions, and sometimes the same environmental factors are more likely to be exposed to the risk of infection. Furthermore, the presence of an infected person within a household greatly increases the likelihood of new cases emerging, which supports the idea that family history is a major risk factor. Numerous studies have reported that family contacts of PAL face a significantly greater risk [26]. These findings highlight the urgent need to strengthen community-based interventions aimed at breaking the chain of transmission.

3.1.2. Economic situation

PAL and their contacts had a low socioeconomic status. This vulnerability appears to be more pronounced among PALs, who face more limited economic opportunities. Several factors may explain

this situation: On the one hand, leprosy disproportionately affects people living in poverty, characterized by insufficient access to formal employment and basic services. On the other hand, the disease itself can contribute to the deterioration of individuals economic status because of physical disabilities, social withdrawal, and stigma, which can lead to a loss of income or exclusion from income-generating activities. These findings align with data published in various endemic settings, where leprosy is often associated with precarious living conditions, low levels of education, and dependence on informal activities [26,27]. These findings reinforce the idea that leprosy is part of a vicious cycle between poverty and disease; the most disadvantaged people are at higher risk of infection, and once they become ill, they may sink further into precarious circumstances.

3.1.3. Level of knowledge about leprosy

The results also revealed a low overall level of knowledge about leprosy among both PALs and their contacts. These findings are consistent with those of several previous studies that have also documented limited knowledge of leprosy among exposed populations. In a survey of rural communities in Nigeria, Ebenso *et al.* reported that more than 75% of participants were unaware of the true causes of leprosy and that misconceptions about its contagiousness were widespread, even among high-risk groups [28]. A study in India conducted by Chauhan *et al.* revealed that despite health education programs, a large portion of the population was still unaware of basic facts about leprosy, with fewer than 30% of respondents able to correctly identify the modes of transmission [29]. This trend is also reflected in a study in Brazil, where Goulart *et al.* reported that accurate knowledge of the disease remained low even in endemic areas, suggesting that raising awareness remains a major challenge despite public health efforts [30].

Notably, regarding treatment, both groups appeared to know that leprosy is curable. However, some mention inappropriate treatments. This persistence of misconceptions suggests that, despite some awareness of the disease's curability, understanding of proper treatment remains incomplete for a portion of the population. This finding has also been reported by other studies, which show that traditional beliefs, misinformation, or mistrust of healthcare facilities can lead patients to first turn to nonmedical alternatives, often resulting in delayed diagnosis and treatment [31,32]. This underscores the need to strengthen awareness strategies focused on appropriate treatment and the importance of early access to care.

Furthermore, although the overall level of knowledge about leprosy remains limited, compared with contacts, PALs appear to have a better understanding of certain symptoms, particularly early symptoms. This could be explained by their direct experience with the disease, their diagnosis, and their contact with the healthcare system. This finding has also been reported in other studies, such as the one conducted by Mankar *et al.* [33].

Qualitative data show that heredity, cleanliness/impurity, and mystical references constitute deeply ingrained explanatory frameworks. In several communities in Zou, the link between disease and lineage ("in the blood") functions as a cultural logic that structures the fear of "transmitting" the disease across

generations. This conception, combined with ideas of contamination through water or the environment, fuels a cultural imagination of defilement: Leprosy is perceived as a disease resulting from a moral, social, or spiritual imbalance. The invocation of witchcraft, in particular, appears to be a powerful driver of social distancing and relational rupture, as one informant highlights. These moral interpretations give rise to forms of vigilance and social control, particularly towards women. For the PAL themselves, the coexistence of these explanations with biomedical discourse creates lasting areas of uncertainty. These findings show that moral and supernatural representations of leprosy legitimize practices of social avoidance and contribute to the persistence of stigma, despite the availability of effective treatment.

The extent of the knowledge gap identified in our population highlights persistent shortcomings in health education among both patients and their close contacts. This is concerning, as limited knowledge of the disease can lead to delays in seeking care, an inability to recognize early clinical signs, and stigmatizing attitudes towards those affected. These findings therefore underscore the importance of strengthening education and awareness programs targeting not only patients but also their contacts and surrounding communities. Greater knowledge of leprosy is key for improving attitudes, reducing stigma, and encouraging early screening and treatment, as highlighted in the WHO's recommended strategies for neglected tropical diseases.

3.1.4. magnitude of Stigma

The total median EMIC-CSS score among PALs was 13.5 ± 17.5 , indicating a significant level of self-stigma. Van Brakel *et al.* (2006) reported a mean EMIC-CSS score of 12.3 in the Philippines, reflecting internalized stigma [34]. Similarly, Lusli *et al.* (2015), in Indonesia, reported self-stigma scores ranging from 9 to 14. These results indicate that PALs continue to face high levels of self-stigma fuelled by their own internalized perception of the disease[35].

Among close contacts, the median score was 18 ± 10.5 , which is well above the threshold of 8 proposed by Sermrittirong *et al.* [36]. This particularly high score among close contacts highlights persistent fear related to transmission, a lack of information about recovery, or cultural beliefs associated with leprosy. Similar observations were made in Nigeria in 2024, where Murphy-Okpala N *et al.* reported high levels of stigma among community members, with a mean score of 18.96 ± 7.73 [25]. Furthermore, Singh *et al.* (2019) in India reported that family contacts frequently have higher EMIC-CSS scores than patients do, reflecting strong community stigma linked to fear, contagion, and perceptions of impurity [37]. These high levels of stigma, particularly among contacts, suggest that stigma is not limited to the sick individual but circulates within the social environment. This leads us to examine how stigma develops over time, from initial suspicions to social withdrawal.

3.1.5. Factors associated with perceived stigma

With respect to associated factors, the findings of this study align with those of Rao *et al.* in India, who demonstrated that stigma was more pronounced in rural settings [38]. These findings suggest that rural settings are likely associated with sociocultural or structural factors that amplify stigma, such as limited access to health information and persistent traditional beliefs surrounding leprosy. Silatham

Sermrittirong *et al.* also highlighted the role of cultural and religious beliefs and the external manifestations of the disease in the genesis of stigma [39].

The qualitative findings show that popular explanations of leprosy are based on a set of hybrid beliefs that combine heredity, impurity, mystical or spiritual causes, and biomedical factors. These beliefs frequently recur in the discourse of the PAL, close contacts, and community groups (*“the disease is hereditary... it’s in the blood”*). This interpretive framework confers an inevitable or fatal dimension on the disease, reinforcing stigma and the fear of contracting the disease even without actual exposure. The data also show that stigma is not merely an individual emotional reaction but a socially legitimized practice embedded in norms of caution and community preservation. The use of separate utensils, social distancing, avoidance of the sick or those who have recovered, and suspicion towards shared objects (“sponges,” clothing) illustrate this normativity. This dynamic can be explained by the persistence of a cultural representation of defilement and impurity, in which illness is associated with a threat to moral and social order. In this sense, stigma functions as a mechanism for community risk management, even when biological risk is low or nonexistent.

However, accounts of support from family and friends show that these norms are not absolute. Some people draw on values of solidarity, faith, or social belonging to counter the logic of exclusion, reminding us that cultural norms are constraining but negotiable.

3.1.6. Factors associated with self-stigma

Multivariate analysis revealed that individuals who were diagnosed through active screening exhibited a significantly greater level of self-stigma than those who were diagnosed through passive screening did. These results suggest that certain public health practices, although designed with prevention and access to care in mind, can produce unintended social effects. In this specific case, the visibility resulting from active screening interacts with local perceptions of leprosy and helps shape experiences of self-stigma. Indeed, when health teams conduct active screening, those affected may perceive this process as a public exposure of their health status, which can create the impression of being labelled or singled out. This exposure can thus reinforce feelings of self-stigma. It is therefore important to rethink the implementation of active screening campaigns to ensure that those screened do not feel exposed or vulnerable as a result of the process.

Furthermore, the results revealed that participants who were diagnosed late exhibited a greater level of self-stigma than those who were diagnosed early did; these findings are consistent with the literature on the impact of diagnostic delays on patients psychosocial experience. Studies have shown that individuals who are diagnosed late, often after the onset of visible complications or disabilities, are more likely to experience social rejection and increased stigma [34,38,39]. Visibility thus functions not only as a clinical sign but also as a lasting social label that fixes the individual in a stigmatized identity, subject to social isolation and discrimination. Van’t Noordende *et al.* reported that late diagnoses were associated not only with more severe physical sequelae but also with more pronounced social stigma, which was sometimes exacerbated by fear and ignorance within communities [40]. These observations

fit into a conceptual framework in which the characteristics of access to screening interact with social perceptions of the disease. Several authors have emphasized that early screening, integrated with educational interventions, can reduce not only clinical complications but also self-stigma by promoting a better understanding of the disease, thereby reducing fear and misconceptions [34,40].

The integration of quantitative and qualitative findings highlights how leprosy-related stigma in the Zou department is shaped not only by individual disease trajectories but also by deeply rooted cultural beliefs. Qualitative data reinforced these results by showing that fears of contagion, spiritual interpretations of leprosy, and moral judgments embedded in local belief systems contribute to strong community rejection. Together, these convergent findings demonstrate that stigma is sustained by both structural factors and culturally embedded representations of leprosy, underscoring the need for interventions that address medical misconceptions as well as local belief systems.

3.2. Limitations of the study

This study has certain limitations that should be noted. Indeed, the cross-sectional design does not allow for causal inference. The observed associations reflect correlations at a given point in time, without the possibility of determining the timing of events or examining the evolution of stigma over time. It is important to highlight the possibility of social desirability bias, particularly in the context of a stigmatized disease such as leprosy. Participants, especially contacts, may have downplayed their perceptions or behaviours related to stigma to present a more favourable image of themselves or to avoid judgement. This bias may lead to an actual underestimation of stigma.

Furthermore, the study may have been subject to memory bias. Certain information, such as family history, diagnostic delays, or specific aspects of experienced stigma, relies on participants' ability to recall events that may be distant in the past or emotionally charged, which can affect the accuracy of self-reported data. The relatively small size of the PAL could reduce the statistical power to detect certain associations and may limit the generalizability of the results. Finally, the limited geographic representativeness of a single department constitutes another limitation. Sociocultural contexts vary from one department to another, meaning that the levels and determinants of stigma could differ across other departments in the country.

Conclusion

This study highlights the significant stigma associated with leprosy, both among those affected and within the community. Stigma appears to be shaped not only by individual knowledge but also by social norms, cultural beliefs, and structural factors such as screening practices and diagnostic delay. Addressing stigma therefore requires comprehensive, context-specific interventions that go beyond information provision to engage with underlying social dynamics.

Multivariate analysis reveals that stigma is largely influenced by structural and contextual factors, notably the screening method, the time to detection, and the residential setting. Overall, these results

underscore the need to strengthen communication, education, and awareness strategies and to improve early detection to reduce stigma within the community. Targeted interventions in rural areas that incorporate appropriate sociocultural approaches and involve also former leprosy patients are essential for limiting the psychosocial consequences of leprosy and promoting more humane and inclusive care.

Abbreviations

EMIC

Explanatory Model Interview Catalogue

FG

Focus Group

ILEP

International Federation of Anti-Leprosy Associations

IQR

Interquartile Range

NTD

Neglected Tropical Diseases

ODK

Open Data Kit

PAL

Person Affected by multibacillary Leprosy

PCA

Principal Component Analysis

PNLLUB

Programme National de Lutte contre la Lèpre et l'Ulcère de Buruli

WHO

World Health Organization

Declarations

Ethics approval and consent to participate

In accordance with the principles of the Declaration of Helsinki, the study protocol was submitted for approval to the National Ethics Committee for Health Research (Comité National d’Ethique pour la Recherche en Santé) which operates under the authority of the Ministry of Health of Benin prior to the start of activities (Ref. No.: CNERS 011/2024, session of August 27th, 2024). Participation in the study was entirely voluntary. Each adult participant, or the parent/guardian for minors, signed a written informed consent form after receiving full information about the study’s objectives, methods, expected benefits, and potential risks. For illiterate individuals, a fingerprint was used in the presence of an independent witness. Minors provided their own assent in addition to parental consent. Confidentiality and anonymity were also respected.

Consent for publication

Not applicable

Availability of data and materials

The datasets collected and analysed during the current study are not publicly available due to confidentiality and privacy considerations involving study participants but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Conception, design and data acquisition: RCJ, SDZ, AH, JGH, CJJ, AGM, PV.

Writing original draft: SDZ, RH, KS, FNCG.

Data curation: SDZ, FNCG, JGH.

Analysis and interpretation: SDZ, FNCG, RCJ, SS, KS, VB, SIEA, RA, CJJ, AGM, PV, AF.

review & editing: RCJ, KS, SS, CJJ, AGM, AF, AH.

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All authors read and approved the final manuscript.

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References

1. White C, Franco-Paredes C. Leprosy in the 21st century. *Clin Microbiol Rev.* 2015;28(1):80-94.
2. Scollard DM, Adams LB, Gillis TP, Krahenbuhl JL, Truman RW, Williams DL. The continuing challenges of leprosy. *Clin Microbiol Rev.* 2006;19(2):338-381.
3. Grijzen ML, Nguyen TH, Pinheiro RO, et al. Leprosy. *Nat Rev Dis Primers.* 2024;10(1):90.
4. Leprosy review. ResearchGate. Published online January 12, 2026.
5. Stigma: Notes on the Management of Spoiled Identity. *Postgrad Med J.* 1969;45(527):642.
6. Tossou YB, Biaka PH, Gbaguidi FNC, et al. Barriers to social participation for people with disabilities in NTD-endemic areas of Benin and Côte d'Ivoire: Assessing scope and associated factors. *PLOS Global Public Health.* 2024;4(12).
7. Guides on Stigma and Mental Wellbeing | InfoNTD. Accessed April 5, 2026.
8. ILEP/NNN Guides on Stigma and Mental Wellbeing | ILEP Federation. Accessed April 4, 2026.
9. Guidelines for the diagnosis, treatment and prevention of leprosy. Accessed April 4, 2026.
10. Brakel, Wim H. van, Ruth M. H. Peters and Zoica Bakirtzief da Silva Pereira. "Stigma Related to Leprosy - A Scientific View." (2019).
11. Alio AP, Sani IMM, Abdou Y, Gado M, Harouna I, Celiktemur B. Leprosy stigma in the healthcare setting: Lived experiences of persons affected by leprosy in Niger. *PLOS Neglected Tropical Diseases.* 2025;19(10).
12. (PDF) Reducing Stigmatisation of Leprosy: What is Being Done? *ResearchGate.* Accessed April 5, 2026.
13. Gargiulo M. Handicap, figure de stigmatisation. *Cliniques méditerranéennes.* 2016;94(2):125-138.
14. Willis M, Fastenau A, Penna S, Klabbers G. Interventions to reduce leprosy related stigma: A systematic review. *PLOS Glob Public Health.* 2024;4(8):e0003440.
15. Esmail-Onyima A, Ekeke N, Ezenwosu I, et al. Quality of life and stigma among persons affected by leprosy or buruli ulcer in Nigeria: a community-based cross-sectional study. *BMC Public Health.* 2025;25(1):2315.
16. 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.
17. Tahir Dahiru, Zubairu Iliyasu, Aliyu T. Mande, Anna T. van 't Noordende, Muktar H. Aliyu; Community perspectives on leprosy and related stigma in northern Nigeria: a qualitative study; *Leprosy Review;* 2022; 93; 1; 48-62.
18. Alio AP, Malam Mamane Sani I, Abdou Y, Gado M, Harouna I, Celiktemur B. Leprosy stigma in the healthcare setting: Lived experiences of persons affected by leprosy in Niger. *PLoS Negl.*
19. Tsutsumi A, Izutsu T, Akramul Islam MD, et al. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. *Lepr Rev.* 2004;75(1):57-66.
20. Imbert G. Semi-structured interview: at the boundary of public health and anthropology. *Nursing Care Research.* 2010;102(3):23-34.

21. National Program for Leprosy and Buruli Ulcer Control in Benin. Annual Leprosy Monitoring Report. 2015.
22. Gnimavo RS, Sopoh GE, Djossou P, et al. Associated factors study into the belated screening for leprosy in Benin. *PLoS Negl Trop Dis*. 2022;16(6).
23. RGPH5 | 5e Recensement Général de la Population et de l'Habitat – Je compte pour l'avenir. July 18, 2024.
24. Murphy-Okpala N, Dahiru T, Eze C, et al. Investigation of community knowledge, attitudes and stigma towards leprosy in Nigeria: a mixed-methods study. *Trans R Soc Trop Med Hyg*. 2024;118(10):697-709.
25. Juan C, Lledó L, Torralba M, Gómez JR, Giménez C. Leprosy in Spain: A Descriptive Study of Admissions at Fontilles Sanatorium between 1909 and 2020. *Trop Med Infect Dis*. 2024;9(6):130.
26. Nery JS, Ramond A, Pescarini JM, et al. Socioeconomic determinants of leprosy new case detection in the 100 Million Brazilian Cohort: a population-based linkage study. *The Lancet Global Health*. 2019;7(9).
27. (PDF) Impact of Socio-Economic Rehabilitation on Leprosy Stigma in Northern Nigeria: Findings of a Retrospective Study. ResearchGate. Accessed April 5, 2026.
28. Chauhan R, Kumar R, Thakur S. A study to assess the knowledge, attitude, and practices about blood donation among medical students of a medical college in North India. *J Family Med Prim Care*. 2018;7(4):693-697.
29. Goulart IMB, Bernardes Souza DO, Marques CR, Pimenta VL, Gonçalves MA, Goulart LR. Risk and protective factors for leprosy development determined by epidemiological surveillance of household contacts. *Clin Vaccine Immunol*. 2008;15(1):101-105.
30. 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).
31. Adhikari B, Kaehler N, Chapman RS, Raut S, Roche P. Factors Affecting Perceived Stigma in Leprosy Affected Persons in Western Nepal. *PLOS Neglected Tropical Diseases*. 2014;8(6).
32. Mankar MJ, Joshi SM, Velankar DH, Mhatre RK, Nalgundwar AN. A Comparative Study of the Quality of Life, Knowledge, Attitude and Belief About Leprosy Disease Among Leprosy Patients and Community Members in Shantivan Leprosy Rehabilitation centre, Nere, Maharashtra, India. *J Glob Infect Dis*. 2011;3(4):378-382.
33. van Brakel WH, Anderson AM, Mutatkar RK, et al. The Participation Scale: measuring a key concept in public health. *Disabil Rehabil*. 2006;28(4):193-203.
34. Peters R, Lusli M, Zweekhorst M, et al. Learning from a leprosy project in Indonesia: making mindsets explicit for stigma reduction. *Development in Practice*. 2015;25(8):1105-1119.
35. Sermrittirong S, Van Brakel WH, Kraipui N, Traithip S, Bunders-Aelen JFG. Comparing the perception of community members towards leprosy and tuberculosis stigma. *Lepr Rev*. 2015;86(1):54-61.

36. Noordende AT van 't, Lisam S, Singh V, et al. Changing perception and improving knowledge of leprosy: An intervention study in Uttar Pradesh, India.*PLOS Neglected Tropical Diseases*. 2021;15(8).

37. Rao PSS, Raju MS, Barkataki A, Nanda NK, Kumar S. Extent and correlates of leprosy stigma in rural India.*Indian J Lepr*. 2008;80(2):167-174.

38. Sermittirong S, Van Brakel WH. Stigma in leprosy: concepts, causes and determinants. *Lepr Rev*. 2014;85(1):36-47.

39. Noordende AT van 't, Korfage IJ, Lisam S, Arif MA, Kumar A, Brakel WH van. The role of perceptions and knowledge of leprosy in the elimination of leprosy: A baseline study in Fatehpur district, northern India. *PLOS Neglected Tropical Diseases*. 2019;13(4).

Figures

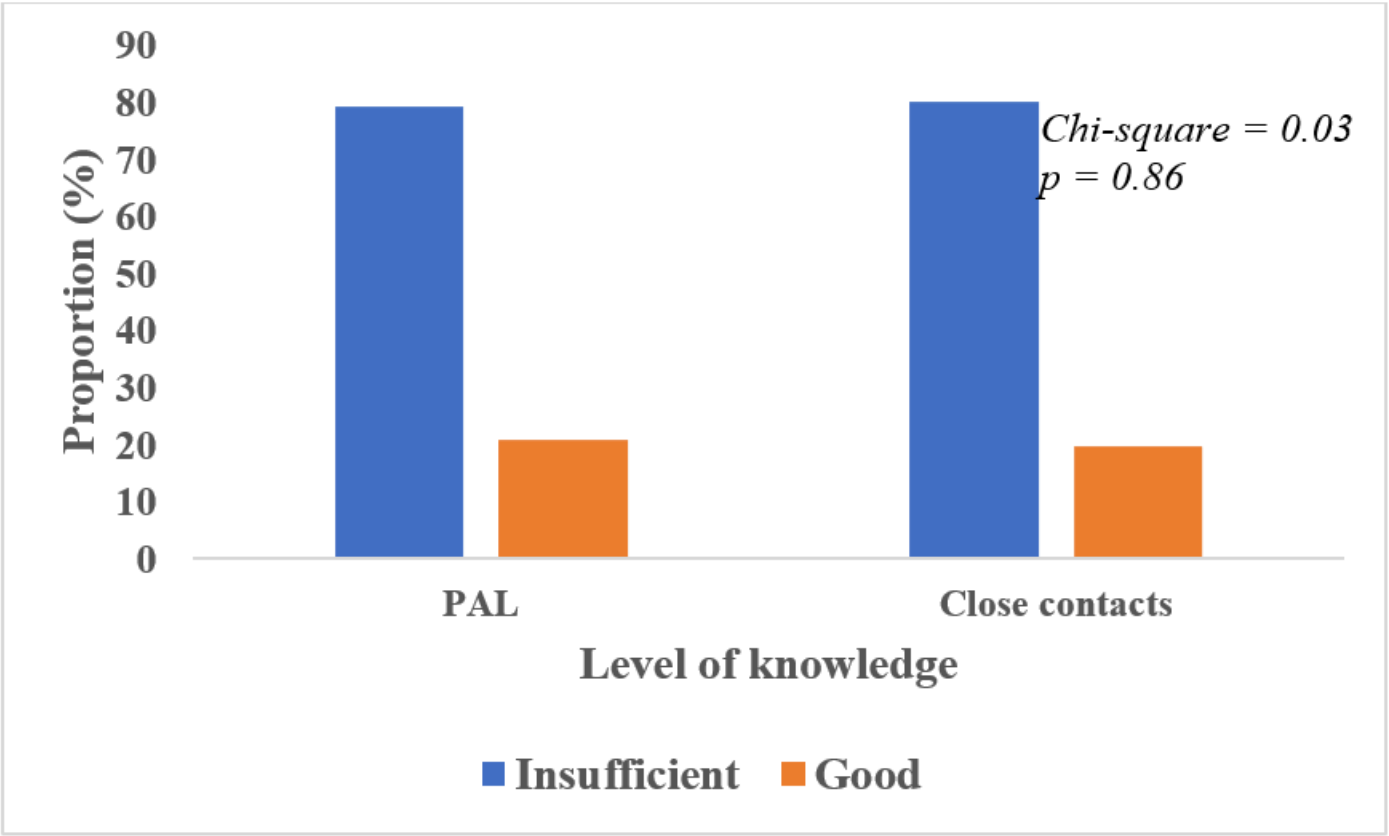


Figure 1

Distribution of PALs and close contacts by overall level of knowledge about leprosy.

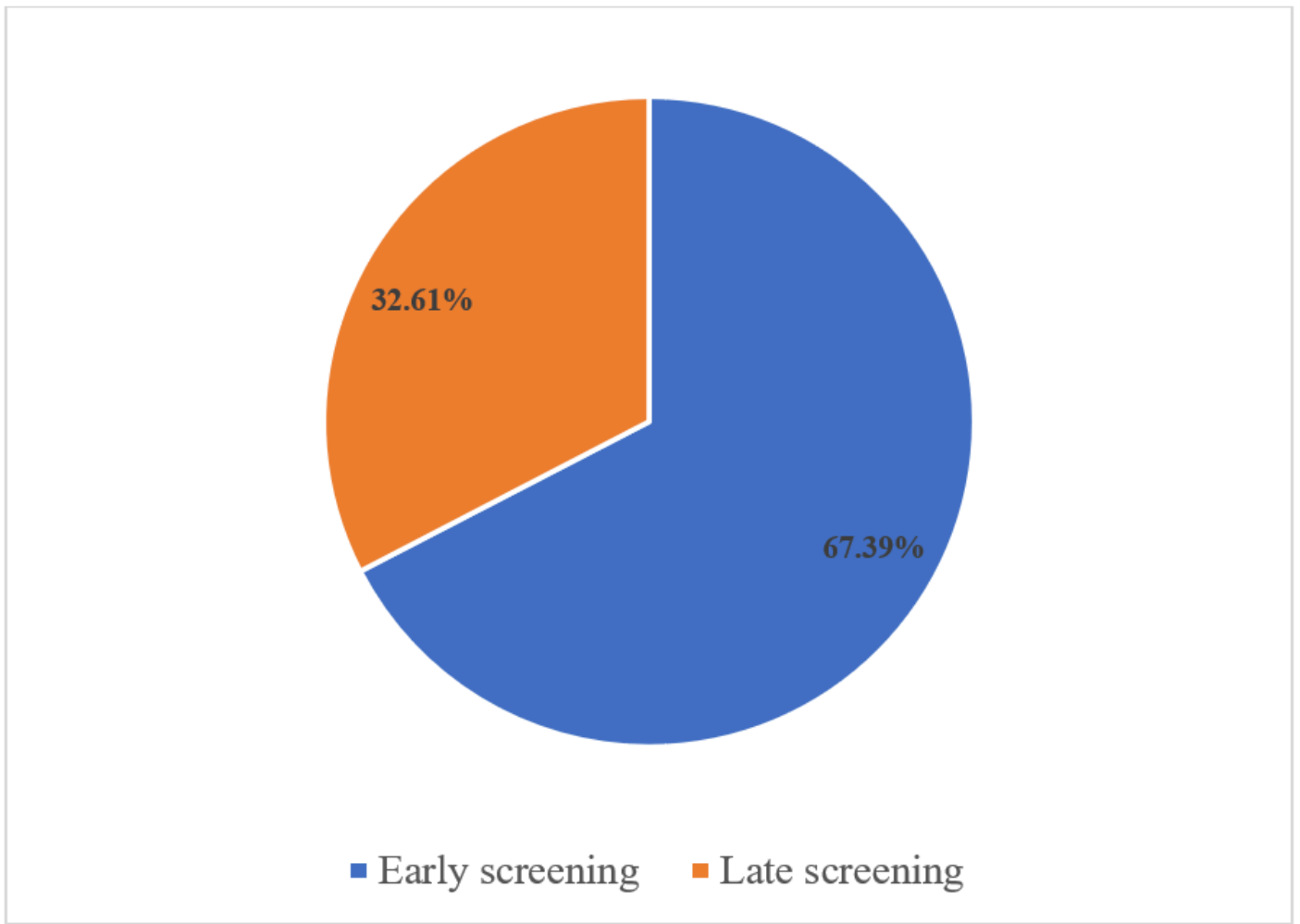


Figure 2

Distribution of PALs by screening method (Benin) Zou 2024; n = 92.

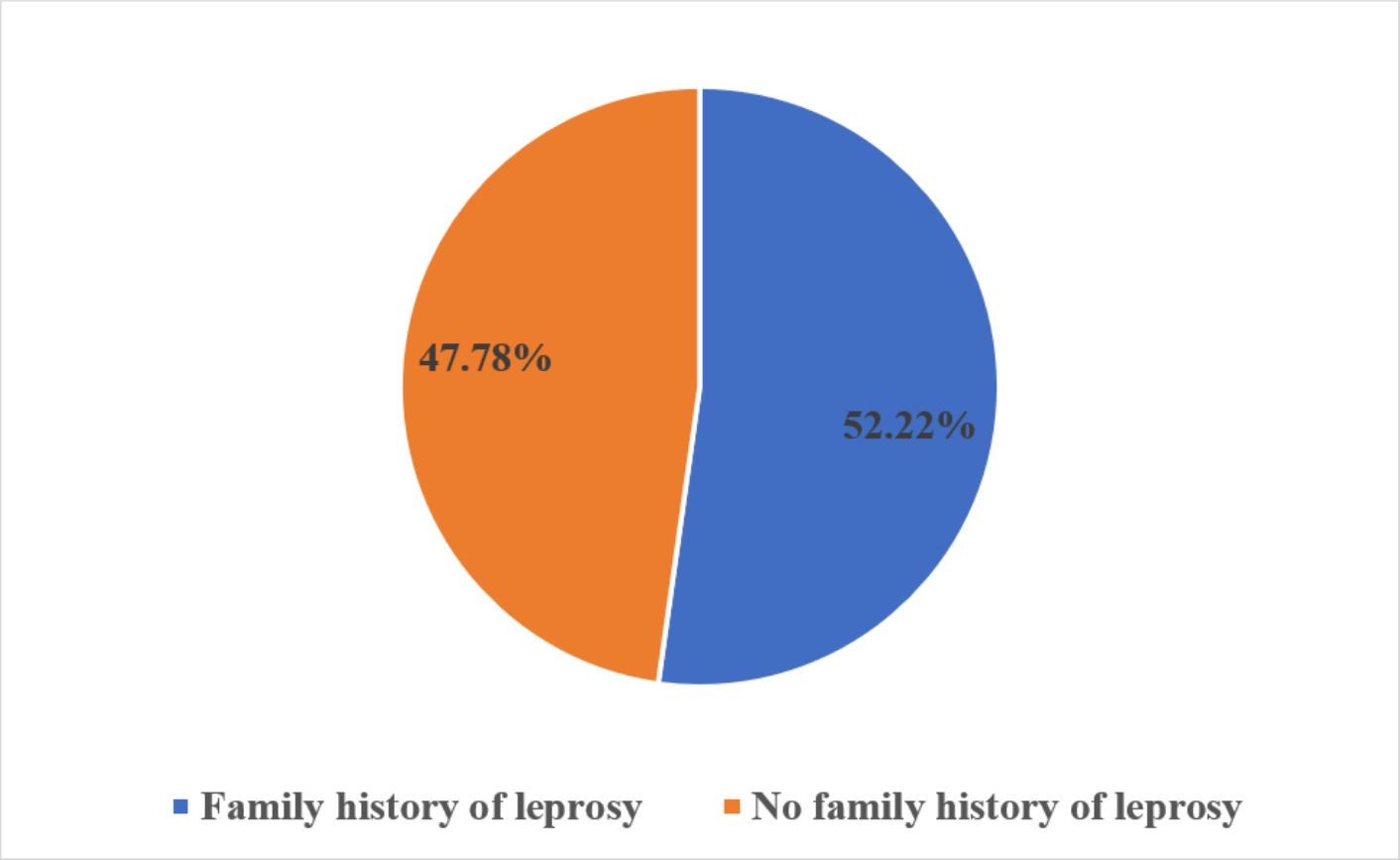


Figure 3

Distribution of PALs according to family history of leprosy (Benin) Zou 2024; n = 92.

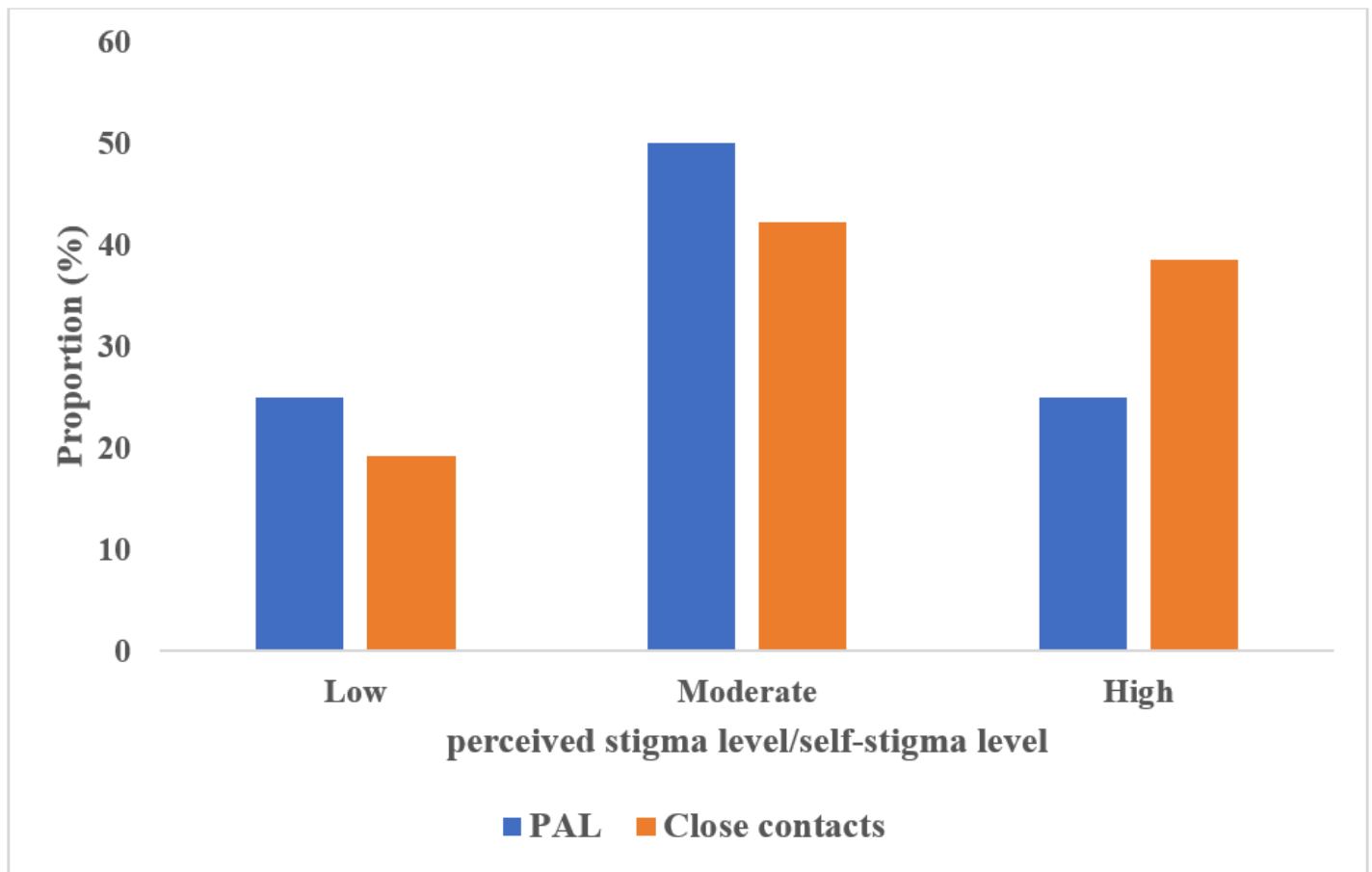


Figure 4

Distribution of PALs and close contacts by level of stigma, Benin (Zou), 2024.

Supplementary Files

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