

Measuring Leprosy Case Detection Delay and Associated Factors in Southeast Nigeria: A Community-Based Study

Chinwe Eze

chinwendu5000@gmail.com

PRIME Data Nexus

Ngozi Murphy-Okpala

Vertex Health Limited

Charles Nwafor

RedAid Nigeria

Joseph Chukwu

Deutsche Lepra- und Tuberkulosehilfe

Daniel Egbule

RedAid Nigeria

Martin Njoku

RedAid Nigeria

Okechukwu Ezeakile

RedAid Nigeria

Anthony Meka

RedAid Nigeria

Francis S. Iyama

RedAid Nigeria

Nkechi Anne Enechkwu

Nnamdi Azikiwe University Teaching Hospital

Onyeka Ugwu

RedAid Nigeria

Chigozie Monica Onuzulike

Catholic Caritas Foundation

Chidimma Okoye

Catholic Caritas Foundation

Angela Uche Eze

Nottingham University Hospitals NHS Trust

Clement Adesigbin

National Tuberculosis, Leprosy and Buruli Ulcer Control Program

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Abstract

Background

Delayed diagnosis of leprosy remains a major challenge to leprosy control because it increases the risk of irreversible disability and sustains community transmission. Nigeria consistently reports a high proportion of newly diagnosed leprosy cases with Grade 2 Disability (G2D), yet contemporary evidence on the magnitude and determinants of case detection delay is limited. This study measured leprosy case detection delay (CDD), patient delay (PD), and health system delay (HSD), and identified factors associated with delayed diagnosis in Southeast Nigeria.

Methods

A convergent mixed-methods study was conducted in Ebonyi State, Nigeria. Quantitative data were collected from 100 persons affected by leprosy using a validated case detection delay questionnaire and analysed in R version 4.5.2. CDD, PD, and HSD were assessed in months. Due to right-skewed distributions, delay outcomes were log-transformed before analysis. Univariate associations were assessed using independent t-tests, one-way ANOVA, and Pearson's correlation, while multivariable linear regression with backward elimination was used to identify independent predictors. Qualitative data were collected through four focus group discussions involving 31 participants and analysed using inductive thematic content analysis.

Results

The median CDD was 74.0 months (IQR: 46.0–114.0), comprising a median PD of 58.0 months (IQR: 36.0–95.2) and a median HSD of 0 months (IQR: 0–12.5). All participants experienced delays exceeding six months, and 55% presented with G2D at diagnosis. In multivariable analysis, the number of healthcare consultations was positively associated with CDD, while higher stigma scores were negatively associated with CDD. Distance to the nearest health facility was the only factor independently associated with PD. Qualitative findings identified poor knowledge and awareness of leprosy, normalization of early symptoms, reliance on informal care providers, financial constraints, geographic barriers, and limited diagnostic capacity among healthcare workers as key contributors to delayed diagnosis.

Conclusions

Leprosy case detection delay in Southeast Nigeria is substantially longer than reported in many endemic settings and is driven predominantly by prolonged patient delay. Although delays appear patient-related, they are strongly influenced by health system accessibility and diagnostic capacity. Strengthening community awareness, decentralizing leprosy services, and engaging informal care providers in referral networks may reduce diagnostic delay, disability, and ongoing transmission.

Clinical Trial Registration

Not applicable.

Introduction

Leprosy (Hansen's disease), a neglected tropical disease (NTD) caused by *Mycobacterium leprae*, remains a leading infectious cause of permanent disability globally(1). Leprosy impairs the quality of life and mental health status of persons affected by it(2). The advent of multidrug treatment (MDT) marked a major milestone in disease control, contributing to a sustained decline in global case detection from over 500,000 annually in the late 1980s to fewer than 200,000 in recent years (3, 4). Similarly, the trend in annual new leprosy cases notified in Nigeria has declined steadily from 3623 cases in 2011 to 1770 in 2024, with pockets of high endemicity in some states (5).

Despite this progress, the persistence of grade 2 disability (G2D) among newly diagnosed cases remains a critical concern. G2D, defined by visible deformities, is widely recognized as a proxy indicator of delayed diagnosis and programmatic performance(6). Globally, 5.3% of newly detected cases presented with G2D in 2024, whereas Nigeria has consistently reported higher rates. In 2024, 12% of new cases had G2D, with the Southeast region which has ongoing active case finding activities, reporting particularly high proportions of up to 38%(7). These figures underscore gaps in early detection and timely treatment.

G2D is strongly associated with delayed diagnosis and is linked to stigma, discrimination, functional impairment, and reduced social participation(8–10). Reducing its occurrence is a central target of the Global Leprosy Strategy 2021–2030, which aims for a 90% reduction in new cases with G2D(6). Achieving this goal requires a clear understanding of the magnitude and drivers of diagnostic delay, including both patient- and health system–related factors(11).

Evidence from endemic settings has identified multiple determinants of delay, including reliance on passive case detection, self-treatment, use of informal care providers, low awareness of early symptoms, stigma-related care avoidance, and misdiagnosis within health systems(8, 10, 12–15). However, the relative importance of these factors varies across contexts, highlighting the need for local evidence to inform targeted interventions.

In Nigeria, leprosy control is implemented through the National Tuberculosis, Buruli Ulcer, and Leprosy Control Program (NTBLCP), coordinated via state and local government structures. At the local level, Local Government Tuberculosis, Buruli Ulcer, and Leprosy Supervisors (LGTBLSSs) play a central role in case detection, diagnosis, treatment initiation, and follow-up. However, limited funding, poor capacity of general health workers for leprosy detection and management(16) and heavy reliance on these supervisors constrain decentralization and may contribute to diagnostic delays.

Despite Nigeria's high burden of G2D, contemporary evidence on case detection delay is scarce. Existing studies are few, outdated, limited in sample size, and geographically restricted to northern Nigeria(17–19),

with little exploration of determinants(17). This evidence gap limits effective programme planning and targeted interventions.

This study addresses this gap by estimating the duration of leprosy case detection delay and identifying associated factors in Southeast Nigeria using a culturally adapted and validated leprosy case detection delay (CDD) questionnaire developed under the PEP4LEP project in Mozambique, Ethiopia, and Tanzania(20). Prior to deployment, the tool was culturally validated for use in the Nigerian context (reported elsewhere), ensuring its validity and reliability for this study population.

Methods

Study design

The study employed a cross-sectional mixed-methods design to measure case detection delay and its associated factors.

Study area

The study was conducted in Ebonyi State, one of the five states in southeastern Nigeria (Fig. 1), with a projected 2024 population of 3.6 million. Agriculture is the predominant occupation, and Igbo is the main language spoken. Ebonyi consistently reports the highest burden of leprosy and G2D in the region. In 2024, 92 new leprosy cases were notified, of which 31 (34%) presented with G2D. Leprosy services are primarily delivered through St. Patrick's Hospital, Mile 4, the state's only referral facility for leprosy and Buruli ulcer (BU), which manages more than half of all leprosy cases in the state. The hospital also operates outreach services in three local government areas (LGAs), supporting active case-finding and community-level leprosy control activities, coordinated by the LGTBLS.

Population and sample

The study included persons affected by leprosy who were either receiving treatment or had completed treatment and were willing to participate. Participants were recruited from St. Patrick's Hospital, Mile 4, and an outreach site in Ohaukwu LGA. Using the leprosy central register, consecutively registered patients were approached for enrolment. For children, parents or guardians were interviewed. To minimize recall bias, priority was given to individuals diagnosed between 2020 and 2025, with only a few beyond this period. Patients unable to provide informed consent or who were severely ill or distressed were excluded.

A total of 297 persons affected by leprosy were registered in the two study LGAs between 2019 and 2024. The minimum sample size for the quantitative survey was calculated using the formula for estimating a finite population mean, at a 95% confidence level ($Z = 1.96$), precision of ± 1.5 months, and an assumed standard deviation of 6.5 months (derived from a 50% coefficient of variation applied to the mean CDD of 13 months and median of 5 months from a similar study(21)). A total of 58 participants was estimated after finite population correction. Allowing for 10% non-response, the final target sample size was 64

participants. For the qualitative component, participants were purposively selected for focus group discussions to ensure variation in age, sex, and disability status.

Measurement tools

Quantitative data were collected using a semi-structured questionnaire covering case detection delay (CDD) (22), knowledge of leprosy, health-seeking behaviour, and anticipated stigma (See Additional Files 3 & 4). CDD was assessed using a questionnaire previously validated in Nigeria(23). Total CDD was defined as the interval between the first symptom noticed by the respondent and confirmed diagnosis. Patient delay (PD) was defined as the time from symptom onset to first healthcare consultation, while health system delay (HSD) referred to the period between first healthcare contact and diagnosis(21).

Knowledge of leprosy was measured using eight questions adapted from the Knowledge, Attitude, and Practice (KAP) component of the Perception Study Toolkit (PST)(24). Scores ranged from 0 to 8 and were categorized as poor (0–2), moderate (3–5), and adequate (6–8).

Anticipated stigma was assessed using three questions adapted from a similar study in Indonesia and derived from the SARI Stigma Scale(21, 25). Scores ranged from 0 to 8 and were classified as low (0–3), moderate (4–5), and high (6–8).

Questions assessing health-seeking behavior were adapted from the same Indonesian study and contextualized for the Nigerian setting.

Data Collection

Data were collected between July and October 2025. Quantitative data were obtained using an electronic questionnaire administered via KoBoCollect by two trained LGTBLSs, and clinical information was extracted from patient records.

Qualitative data were collected through four sex-segregated focus group discussions using a semi-structured guide (See Additional File 4). Discussions were facilitated by the Principal Investigator and a research assistant, audio-recorded, and supplemented with field notes.

Data Analysis

Quantitative data analysis

Data were analyzed in R version 4.5.2. Descriptive statistics were used to summarize participant characteristics, knowledge, stigma, and health-seeking behaviour. The distributions of CDD, PD, and HSD were assessed using the Shapiro–Wilk test and Q-Q plots. A 6-month cut-off for CDD was applied because initiating corticosteroids within this window reduces peripheral nerve inflammation, preventing irreversible nerve damage and disability (21, 26). Due to right-skewed distributions, these outcomes were log-transformed prior to inferential analyses. Normally distributed variables were summarized using means and

95% confidence intervals (CIs), while skewed variables were summarized using medians and bootstrapped 95% CIs.

Univariate associations with CDD and PD were assessed using independent t-tests, one-way ANOVA, or Pearson's correlation, as appropriate. Variables with $p < 0.25$ were entered into multivariable linear regression models using stepwise backward elimination to identify independent predictors. Regression coefficients, 95% CIs, and adjusted R^2 values were reported. Model assumptions and multicollinearity were assessed using standard diagnostic procedures: Homoscedasticity using the Scale–Location plot; linearity using residuals vs. fitted values; normality using the Normal Q–Q plot and multicollinearity using the Variance Inflation Factor (VIF), with values < 5 considered acceptable. Association analyses were not performed for HSD due to substantial zero inflation, resulting in a median HSD of 0.

Qualitative data analysis

Audio recordings were transcribed using intelligent verbatim transcription and checked for accuracy against the recordings and field notes by the Principal Investigator. Data were analysed using inductive thematic content analysis. Initial codes were generated directly from participants' accounts and iteratively refined into broader themes capturing key experiences and perceptions related to delayed leprosy detection

Results

Quantitative results

Sociodemographic characteristics

Table 1 presents respondents' sociodemographic characteristics. A total of 100 respondents were included in the survey, of whom 55% had grade 2 disability. The mean age was 46.1 years (95% CI: 43.1–49.1) and median age 45 years (IQR: 35–57), with ages ranging from 14 to 78 years. Most respondents were female (54%), married (76%), employed (92%) and rural residents (93%). Nearly half had no formal education (45%), and a similar proportion lived 3–5 km from the nearest health facility.

Table 1
Sociodemographic characteristics of study participants

Variables	Frequency N (%)	Median CDD* (95% CI)
Age		
14–29	17 (17%)	68 (51–96)
30–44	29 (29%)	65 (22–80)
45–59	31 (31%)	77 (54–93)
60+	23 (23%)	76 (50–99)
Sex		
Female	54 (54%)	80.5 (63.5-101.5)
Male	46 (46%)	72.5 (49.1–95)
Education		
No formal education	45 (45%)	73 (52–87)
Primary school completed	33 (33%)	55 (17–64)
Secondary and above	22 (22%)	97.5 (69.1-126.5)
Employment status		
Employed (including self-employed)	92 (92%)	75.5 (57.5–88.5)
Unemployed	8 (8%)	51 (6.0–66.0)
Marital status		
Married	76 (76%)	73 (56–87)
Single	14 (14%)	76 (45.5–105)
Others	10 (10%)	102 (72–151)
Area of residence		
Rural	93 (93%)	73 (53–87)
Urban	7 (7%)	75 (38–103)
Distance to health facility		
<=2km	35 (35%)	68 (50–92)
3km-5km	45 (45%)	77 (50–93)
> 5km	20 (20%)	74.5 (41–103)

*CDD = Case Detection Delay (measured in months).

Clinical and psychosocial characteristics of respondents

Table 2 shows the clinical and psychosocial characteristics of participants.

Table 2
Clinical and psychosocial characteristics of participants

Variables	Frequency N (%)	Median CDD* (95% CI)
Type of leprosy		
Multibacillary Leprosy	99 (99%)	75 (57–90)
Paucibacillary Leprosy	1 (1%)	23 (NA-NA)
Mode of detection		
Active case search	27 (27%)	86 (32–111)
Passive (self-report)	73 (73%)	68 (51–81)
KAP score		
Poor knowledge	33 (33%)	61 (24–79)
Moderate knowledge	52 (52%)	84 (69-109.5)
Adequate Knowledge	15 (15%)	80 (44-104.9)
WHO Grading		
0	24 (24%)	63 (49–86)
1	21 (21%)	59 (22–65)
2	55 (55%)	86 (68–104)
Type of HCW visited		
CHEW/CHO	83 (83%)	63 (49–73)
Dermatologist	1 (1%)	126 (NA-NA)
Medical doctor	10 (10%)	97.5 (35.5–123)
Nurse	6 (6%)	126 (51–157)
Number of consultation visits		
1 consult visit	68 (68%)	59.5 (43.5–69)
2–3 consult visits	13 (13%)	77 (35–100)
4 or more	19 (19%)	126 (118–153)
Anticipated Stigma score		
Low stigma	11 (11%)	100 (60–145)
Moderate stigma	71 (71%)	73 (61–93)
High stigma	18 (18%)	72 (32–97)

Variables	Frequency N (%)	Median CDD* (95% CI)
Health-seeking behaviour		
Initially ignored symptoms	17 (17%)	76 (12–105)
Patent medicine vendor	24 (24%)	62.5 (44–83)
Self-medication	34 (34%)	74.5 (40–93)
Sought help in a conventional health facility	1 (1%)	55 (NA-NA)
Sought help in unorthodox settings (faith/traditional healers etc)	24 (24%)	89 (74–125)
Initial suspicion of leprosy		
No, not at all	91 (91%)	72 (58–87)
Yes, but I was not sure	9 (9%)	128 (39–217)
Disclosure after diagnosis		
No	42 (42%)	66.5 (48–82)
Yes, only with family or close friends	57 (57%)	86 (66–104)
Yes, with anybody who showed interest	1 (1%)	148 (NA)

Most respondents (99%) had multibacillary leprosy, and 55% presented with grade 2 disability at diagnosis. Knowledge scores ranged from 1 to 8, with a mean of 3.48 (95% CI: 3.16–3.79). Only 15% of the respondents had adequate knowledge of leprosy. Many respondents had moderate knowledge (52%), while the rest (33%) had poor knowledge.

Most participants (91%) did not recognize early symptoms as leprosy. Only 1% first sought care at a health facility; others used self-medication (34%), patent medicine vendors (24%), or traditional/faith healers (24%). Among those attending health facilities, community health extension workers (CHEWs) were the first point of care for 83%. 68% had only one consultation at the health facility before diagnosis.

Anticipated stigma scores ranged from 1 to 7 out of 8, with a mean of 4.52 (95% CI: 4.30–4.73). Most respondents had moderate (71%) or high (18%) stigma scores. Only 1% reported openly disclosing their diagnosis with persons other than immediate family or close friends.

Table 2: *Clinical and psychosocial characteristics of participants*

Case detection delay

Overall median CDD (Table 1) for patients with multibacillary leprosy was 75 months (95% CI: 57–90). When stratifying by the mode of detection, median CDD was notably higher among cases identified through active search at 86 months (95% CI: 32–111) compared to 68 months (95% CI: 51–81) for those who passively

self-reported. Across KAP categories, the longest diagnostic delays were observed in the moderate knowledge group (median 84; 95% CI: 69–109.5). Participants with baseline WHO Grade 2 disability presented with the longest median CDD of 86 (95% CI: 68–104).

The distribution of treatment delays (Fig. 2) shows significant right-skewness across all categories, with total CDD primarily driven by PD. The total CDD ranged from 13 to 289 months, with a median of 74.0 months (IQR: 46–114; 95% CI: 62.5–88.0) and a mean of 88.0 months. PD ranged from 2 to 289 months, with a median of 58.0 months (IQR: 36–95.2; 95% CI: 42.5–67.0) and a mean of 72.4 months. Notably, HSD exhibits a distinct clustering at zero, resulting in a median delay of 0 months (IQR: 0–12.5; 95% CI: 0–0) and ranging from 0 to 130 months.

All respondents (100%) experienced a delay of more than six months.

Longer delays were observed among females, older age groups, previously married individuals, those with higher education, urban residents, those living 3–5 km from facilities, respondents with G2D, multiple consultations, faith/traditional first care-seeking, low stigma and moderate knowledge levels (Table 1, Table 2).

Factors associated with case detection delay

In the univariate analysis (Table 4), several variables met the inclusion criterion ($p < 0.25$) for the multivariable regression model. However, after multivariable analysis, only the number of consultation visits and stigma score remained significantly associated with total CDD, while distance to the nearest health facility was the only variable significantly associated with PD (Table 5). Notably, stigma score was an independent negative predictor of CDD.

Table 4
Univariate association between respondent characteristics and CDD (months)

Variables	Case detection delay		Patient delay	
	Test statistics	p-value	Test statistics	p-value
Age*	1.33	0.18**	1.64	0.1**
Sex				
Female				
Male	0.3	0.76	1.08	0.27
Education				
No formal education				
Primary school completed				
Secondary and above	1.15	0.32	1.92	0.15**
Employment status				
Employed				
Unemployed	1.13	0.29	1.29	0.23**
Marital status				
Married				
Single				
Others	0.79	0.45	0.02	0.97
Area of residence				
Rural				
Urban	-0.22	0.84	-0.12	0.9
Distance to the nearest health facility				
<=2km				
3km-5km				
> 5km	1.08	0.34	6.89	0.001**
Leprosy Detection mode				
Active case search				
Passive (self-report)	1.24	0.22**	-0.17	0.86
WHO Grading				

Variables	Case detection delay		Patient delay	
	Test statistics	p-value	Test statistics	p-value
0				
1				
2	4.21	0.017**	0.32	0.72
Number of consultation visits				
1 consult visit				
2–3 consult visits				
4 or more	7.88	0.0006**	1.85	0.16**
Stigma Score*	1.8	0.07**	1.44	0.15**
Knowledge Score*	-1.42	0.15**	-1.91	0.05**
Health-seeking behaviour				
Initially ignored symptoms				
Patent medicine vendor				
Self-medication				
Sought help in a conventional health facility				
Sought help in unorthodox settings (faith/traditional healers etc)	0.83	0.5	1.16	0.33
Initial suspicion of leprosy				
No, not at all				
Yes, but I was not sure	-1.42	0.18**	-1.42	0.18**

***Pearson test; **Included in the regression model**

Table 5
Linear regression model for the factors related to total case detection and patient delays (log10)

Factors related to case detection delay				
Predictor Variable	Estimate (β)	Std. Error	t-value	p-value
(Intercept)	5.187	0.264	19.647	< 0.001
Multiple consultation visits	0.532	0.109	4.87	< 0.001
Stigma Score	-0.166	0.055	-3.036	0.003
$R^2 = 0.1906$; $F(3, 96) = 8.773$, $p < 0.001$				
Factors related to patient delay				
(Intercept)	4.0329	0.0811	49.727	< 0.001
Distance to the nearest health facility	0.4105	0.1519	2.703	0.008
$R^2 = 0.1064$; $F(2, 97) = 6.897$, $p = 0.0015$				

Model diagnostics confirmed that all linear regression assumptions were met, with no evidence of multicollinearity (GVIF = 1.12) (Table 6) or influential outliers affecting model stability (Figs S1 & S2).

Table 6
Multicollinearity check for final CDD significant factors

Predictor	GVIF	Df	Adjusted GVIF	Multicollinearity conclusion
Number of consultations	1.1224	2	1.0293	Very Low
Stigma score	1.1224	1	1.0595	Very Low

Qualitative results

A total of 31 participants (6–11 per FGD) took part in four FGDs. Findings were organized into three broad categories: individual, health system access and psychosocial factors (Fig. 3).

Individual factors

Poor knowledge and awareness

Limited knowledge of leprosy emerged as a major driver of delayed care-seeking. Participants reported diverse misconceptions regarding causes, including hereditary factors, insect bites, contaminated water, and spiritual explanations such as witchcraft or divine punishment.

“My mother took me to a native doctor who said it was from my husband’s family.” –Female

“Leprosy starts when a cockroach bites a person.” –Male

Participants also had poor understanding of early symptoms, often identifying only advanced manifestations.

“Skin rashes... nodules that exude water.” –Male

“Painless ulcer.” –Female

Misconceptions about transmission, such as spread through shared items or spiritual causes, were common and reinforced by community beliefs and poor knowledge of the disease. These gaps in knowledge contributed to misinterpretation of symptoms and delayed presentation to health facilities. Information from peers and social networks often reinforced incorrect interpretations and delayed appropriate care-seeking, with participants often turning to traditional healers, diviners, or home remedies before presenting at a health facility:

“My relatives were aware, although none of us knew it was leprosy.... ”- Male

“I didn’t consider the hospital because of the wrong directions from people.” - Male

A few participants reported that exposure to information, education, and communication (IEC) materials or media advertisements prompted them to seek care. One participant reported that an almanac displayed at a PMV’s shop featured images similar to his symptoms, which informed his decision to seek care there. Another participant noted that seeing a television advertisement depicting similar lesions helped him identify where to seek proper treatment.

“Why I went to the PMV first is because he has an almanac in his shop that showed people with similar lesions...” - Male

“I didn’t know it was leprosy. It was when I saw similar lesions on an advert on the TV, that I went to Mile 4 for treatment”. – Male

Normalization of early symptoms and under-estimation of severity

Most participants initially perceived early lesions or numbness as minor and self-limiting. Because symptoms were painless and did not interfere with daily activities, they were often ignored until progression to disability.

“I didn’t consider it serious. It was when it got worse that I started looking for a solution.”-Female

“I thought it would stop. But when walking became difficult, I had to go to the hospital.” -Male

Poor health-seeking behaviour

Initial care was commonly sought outside formal health facilities, including self-medication, PMVs, traditional healers, and prayer houses. This was driven by low disease awareness, symptom

underestimation, and sociocultural preference for informal care. Participants often viewed hospitals as a last resort.

"I did not go to the hospital because I was told it is mmanu anu (a local name for a particular skin condition)"- Male

"We don't use to go to the hospital, even to give birth. We use local herbs normally. So, we didn't consider the hospital as the first option"- Female

Financial constraint

Some participants reported delaying hospital visits due to lack of money for transport or perceived treatment costs. However, financial barriers were generally secondary to beliefs about illness severity and cause.

.....I did not have much money on me at the time for hospital expenses. People made contributions to support me in going to the hospital after the PMV failed.

.....I don't have much money for hospital expenses. PMV was not expensive for me because he is my relative and didn't charge me much.

Distance to the health facility

Several participants reported that long distances and poor access to health facilities influenced their decision to seek care first from nearby PMVs or traditional providers. Proximity and convenience were key reasons for bypassing formal services, particularly when symptoms were not considered severe.

"I went to PMV first because it is closer to me...."- Male

"The hospital was far from us, and the lesion wasn't that painful...."- Male

Health System Factors

Limited capacity for leprosy diagnosis

Several participants reported multiple visits to different facilities without diagnosis before being referred to the leprosy centre. Misdiagnosis and low clinical suspicion at peripheral facilities contributed to prolonged delays. In contrast, diagnosis was often prompt once patients reached the Mile 4 referral center or its outreach sites.

"I went to xxx and xxx (tertiary health facilities) and another hospital before I met a white man who directed me to Mile 4" – Male

"I was experiencing loss of sensation in my feet, but I attributed it to the bleeding I had during childbirth. Went to the hospital several times without remedy, until I was referred to Mile 4." - Female.

Psychosocial factor

Anticipation of Stigma

Anticipated stigma did not influence initial care-seeking, as most participants were unaware of their condition at symptom onset. However, after diagnosis, some participants became more cautious in disclosure due to fear of discrimination.

"Fear of stigma did not stop me initially because I did not know it was leprosy". – Male

"No..., but after I was diagnosed, I was not so open about it because of (the fear of) stigmatization". -Female

Discussion

To the best of our knowledge, this is the first study to quantitatively estimate leprosy CDD, PD, and HSD and to examine their associated factors in southern Nigeria. The median CDD was 74 months (PD: 58 months; HSD: 0 months). Key determinants of longer CDD were multiple healthcare consultations and longer distance to health facilities, while higher stigma scores were unexpectedly associated with shorter CDD. Qualitative findings reinforced these results, highlighting geographic barriers, limited diagnostic capacity, poor knowledge of leprosy, symptom normalization, and reliance on informal care providers. IEC materials occasionally facilitated earlier care-seeking.

The mean and median PD in this study exceed reports from northern Nigeria and other endemic countries, including Nepal, Mozambique, Tanzania, Bangladesh, India, Ethiopia, and Brazil, where substantially shorter delays have been documented. In these studies, total median CDD ranged from 12 to 36 months(11, 27–29), and the median PD ranged from 1.5 to 36 months(17–19, 21, 30). The highly right-skewed distribution of CDD, with no diagnosis within the first year of symptom onset, is concerning and aligns with the high proportion of grade 2 disability (55%) observed. These delays likely contribute to ongoing transmission and irreversible disability, underscoring the need for strengthened early detection strategies.

The median health system delay (HSD) of 0 months observed in our study, consistent with findings from Indonesia(21), suggests that most patients experienced little or no delay after entering the formal healthcare system. However, the long right tail of the distribution indicates that a subset of patients experienced substantial delays within the health system, highlighting an important area for targeted intervention. This is supported by the strong association between multiple consultations and CDD, as well as qualitative evidence of multiple facility visits before diagnosis, corroborating the findings of studies conducted in other endemic settings (8, 27). The most timely diagnoses occurred at the Mile 4 leprosy referral facility, highlighting gaps in diagnostic capacity at different levels of care, including the apex hospitals in Nigeria. This reinforces the need to strengthen training and the integration of leprosy into pre-service and in-service health worker education.

Although patient delay accounted for most of the overall case detection delay, our findings suggest that many apparently patient-related behaviours were shaped by underlying health system constraints. Long distance to health facilities was significantly associated with patient delay and emerged in the FGDs. Participants frequently described PMVs, traditional healers, and prayer houses as more accessible,

affordable, familiar, and trusted than formal health services, particularly in rural communities. Consequently, reliance on informal providers should not be viewed solely as a patient choice but also as a reflection of how leprosy services are organized and accessed. Similar observations have been reported in other settings where geographic barriers and limited service availability influence care-seeking pathways(31–33).

Poor knowledge and awareness further reinforced these patterns. Misinterpretation of early symptoms, reliance on traditional explanatory models, and low risk perception led to normalization of symptoms and delayed formal care-seeking, consistent with prior studies (8, 10, 17, 27, 34, 35). Cultural norms favouring PMVs and traditional healers strengthened these pathways, while experiences from participants exposed to IEC materials demonstrated the potential of community awareness interventions to promote earlier care-seeking. Together, these findings suggest that reducing delay requires not only improving community knowledge but also making leprosy information, screening, referral, and diagnostic services more accessible through community-level and informal provider networks.

Financial constraints, a known barrier to good health seeking behaviour(36, 37), further reinforced reliance on informal providers. Although leprosy treatment is free, transport costs and other indirect expenses remain important barriers, particularly in rural settings. These costs interact with geographic access barriers and may encourage care-seeking from nearby informal providers before presentation to formal health facilities.

The inverse association between anticipated stigma and case detection delay, which is contrary to findings from other studies (8, 10, 11, 27, 28) should be interpreted cautiously. Qualitative findings suggest that stigma was not a primary driver of initial delay because most participants were unaware of their diagnosis at symptom onset. The stigma scale likely captured post-diagnosis concerns, reflected in near-universal reluctance to disclose status. This highlights the importance of distinguishing between stigma as a determinant of delay and stigma as a consequence of diagnosis.

Comparison with earlier Nigerian studies shows consistency in the role of informal care-seeking and lack of awareness as major contributors to delay. Overall, these findings emphasize the need for integrated community-level health provider structures and education, strengthened primary care diagnostic capacity, and systematic engagement of informal providers to reduce diagnostic delay and disability in Nigeria.

Strengths and Limitations

Strengths

This study's mixed-methods design allowed triangulation of quantitative estimates of case detection delay with qualitative insights into behavioural and health system drivers. The qualitative component provided contextual explanations for observed delays, particularly regarding health-seeking pathways and community norms. Use of a validated and culturally adapted CDD questionnaire enhanced the reliability and comparability of findings. In addition, the relatively large sample size for a leprosy delay study improves the robustness and transferability of results to similar high-burden rural settings.

Limitations

Although measures were taken to minimize recall bias, such as prioritizing recently diagnosed patients, using probing questions to clarify responses, and anchoring dates to locally meaningful landmark events, the estimation of delays may not be entirely free of recall error. However, any recall inaccuracies are more likely to have resulted in underestimation rather than overestimation of the delay, given respondents' tendency to shorten timelines when uncertain.

The absence of healthcare workers' perspectives limits a comprehensive understanding of health system constraints, including diagnostic capacity, referral practices, and service readiness. Inclusion of frontline providers, referral clinicians, and informal providers such as patent medicine vendors would have strengthened interpretation of system-level barriers.

In addition, as most participants were recruited from rural high-burden LGAs, findings may not be fully generalisable to urban or low-endemic settings.

Conclusion

Although delays in diagnosis initially appear to be primarily patient-driven, our findings suggest these poor health-seeking behaviors are shaped by underlying health system constraints. Informal providers are often preferred first point of contact because they are more accessible, affordable, and trusted than formal health services, particularly in rural settings. Thus, apparent patient delay should be interpreted within the broader context of health system accessibility and responsiveness. Efforts to reduce diagnostic delay should therefore go beyond patient education to include strengthening community-based case detection and engaging informal providers through training and referral linkages. Such integrated strategies are essential to reduce disability, interrupt transmission, and accelerate progress toward leprosy elimination.

Abbreviations

CDD

Case Detection Delay

CHEW

Community Health Extension Workers

G2D

Grade 2 Disability

HSD

Health System Delay

HCW

Health Care Workers

LGTBLS

Local Government Tuberculosis, Leprosy and Buruli ulcer Supervisor

LGA

Local Government Area

MDT

Multi-drug treatment
PEP4LEP
Post-exposure prophylaxis for leprosy
PD
Patient delay
NTBLCP
National Tuberculosis, Leprosy and Buruli ulcer Control Program
VIF
Variance Inflation Factor

Declarations

Ethics Approval

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Ethical approval was obtained from the Health Research and Ethics Committee of the University of Nigeria Teaching Hospital, Enugu, Nigeria (NHREC 0501-2008B).

Clinical Trial Registration

Not applicable.

Consent to Participate

Informed consent was obtained from all individual participants included in the study. All participants were provided with study information, including details about leprosy, the study's purpose, the right to withdraw, and the confidentiality of respondents' disease status prior to obtaining their consent. Thereafter, written informed consent was obtained from literate participants prior to data collection. For participants who were unable to read or write, the informed consent form was read aloud in their local language in the presence of a witness, and consent was documented via a witnessed thumbprint. This alternative procedure was included in the study protocol to ensure inclusivity, as the catchment areas include rural populations with varying literacy levels; this approach received prior approval from the ethics review board (The Health Research and Ethics Committee of the University of Nigeria Teaching Hospital, Enugu, Nigeria-NHREC 0501-2008B). For participants under the age of 18, written informed consent was obtained from parents or legal guardians, along with child assent. Confidentiality was maintained by anonymizing all data sheets.

Consent for publication

Not applicable. The image included in the Case Detection Delay (CDD) Questionnaire is not an original photograph obtained during this study and does not depict a participant enrolled in the present research. Rather, it is reproduced from the Case Detection Delay (CDD) Questionnaire, a validated instrument developed under the PEP4LEP project and made publicly available through InfoNTD for use by researchers and program implementers in the leprosy field. Accordingly, no additional consent for publication was required for this study.

Availability of data and materials

The datasets generated and/or analysed during the current study are available in figshare at the following link <https://figshare.com/s/ff6e941def64cdf55ea4>

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

CE and NMO conceptualized the study, developed the research questions, and the data collection tools. CE, CMO, and NE contributed to the data collection. CE performed the data analysis, interpreted the results, and drafted the initial manuscript. NMO, CN, DE, AM, MN, FSI, OE, CA, CMO, CO, OU, NAE, AUE, JC, and NE reviewed the initial draft, edited it, and approved the final version for publication.

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References

1. World Health Organization (WHO). Integrating neglected tropical diseases into global health and development: fourth WHO report on neglected tropical diseases. [Internet]. World Health Organization. 2017. 270 p. Available from: https://unitingtocombatntds.org/wp-content/uploads/2017/11/4th_who_ntd_report.pdf
2. Tsutsumi A, Izutsu T, Md Islam A, Maksuda AN, Kato H, Wakai S. The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. *Soc Sci Med* [Internet]. 2007 Jun [cited 2022 Apr 13];64(12):2443–53. Available from: <https://pubmed.ncbi.nlm.nih.gov/17382441/>
3. Harrell GT. Epidemiology of leprosy. *J Am Med Assoc*. 1947;135(11):732.
4. World Health Organization (WHO). Global leprosy (Hansen disease) update, 2024: Beyond zero cases – what elimination of leprosy really means. *Wkly Epidemiol Rec*. 2025;37:365–84.

5. Nigeria, Federal Ministry of Health., (2015). Nigeria Multi - Year Master Plan for Neglected Tropical Diseases - Google Search [Internet]. [cited 2022 Apr 13]. Available from: https://espen.afro.who.int/system/files/content/resources/NIGERIA_NTD_Master_Plan_2015_2020.pdf
6. WHO. Towards zero leprosy Global Leprosy (Hansen's disease) Strategy 2021–2030. Word Heal Organ. 2021;1–30.
7. Federal Ministry of Health Nigeria. Q1 2025 Zonal Review Meeting National Update. 2025.
8. Henry M, GalAn N, Teasdale K, Prado R, Amar H, Rays MS, et al. Factors Contributing to the Delay in Diagnosis and Continued Transmission of Leprosy in Brazil – An Explorative, Quantitative, Questionnaire Based Study. PLoS Negl Trop Dis. 2016;10(3):1–12.
9. World Health Organization (WHO). Global leprosy update, 2014 : need for early case detection Situation de la lèpre dans le monde, 2014 : nécessité d ' un dépistage précoce des cas. Wkly Epidemiol Rec. 2015;90(36):461–74.
10. Urgesa K, de Bruijne ND, Bobosha K, Seyoum B, Mihret A, Geda B et al. Prolonged delays in leprosy case detection in a leprosy hot spot setting in Eastern Ethiopia. PLoS Negl Trop Dis [Internet]. 2022;16(9):1–14. Available from: <http://dx.doi.org/10.1371/journal.pntd.0010695>
11. Dharmawan Y, Fuady A, Korfage I, Richardus JH. Individual and community factors determining delayed leprosy case detection: A systematic review. PLoS Negl Trop Dis [Internet]. 2021;15(8):1–17. Available from: <http://dx.doi.org/10.1371/journal.pntd.0009651>
12. Lockwood DNJ, Reid AJC. The diagnosis of leprosy is delayed in the United Kingdom. QJM Int J Med. 2001;94(4):207–12.
13. Nicholls PG, Chhina N, Bro AK, Barkataki P, Kumar R, Withington SG, et al. Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives in northern Bangladesh and in West Bengal, India. Lepr Rev. 2005;76(1):35–47.
14. Giri VC, Bhagat VM, Baviskar SR, Showkath M. Achieving Integration through Leprosy Case Detection Campaign (LCDC). Int J Biomed Res. 2017;8(01):38–41.
15. Dharmawan Y, Fuady A, Korfage IJ, Richardus JH. Delayed detection of leprosy cases: A systematic review of healthcare-related factors. PLoS Negl Trop Dis [Internet]. 2022;16(9):1–14. Available from: <http://dx.doi.org/10.1371/journal.pntd.0010756>
16. Dahiru T, Hudu S, Knippenberg K, Van. Leprosy capacity in health facilities and among health workers : A baseline survey in Nigeria. 2023;317–31.
17. Van De Weg N, Post EB, Lucassen R, De Jong JTV, Van Den Broek J. Explanatory models and help-seeking behaviour of leprosy patients in Adamawa State, Nigeria. Lepr Rev. 1998;69(4):382–9.
18. Post E. Patient and health services delay in the diagnosis of leprosy in Kaduna State, Nigeria. Lepr Rev. 2003;74(1):79–82.
19. Varkevisser CM, Lever P, Alubo O, Burathoki K, Idawani C, Moreira TMA, et al. Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. Lepr Rev. 2009;80(1):65–76.
20. de Bruijne ND, Urgesa K, Aseffa A, Bobosha K, Schoenmakers A, van Wijk R et al. Development of a questionnaire to determine the case detection delay of leprosy: A mixed methods cultural validation

- study. *PLoS Negl Trop Dis* [Internet]. 2022;16(1):1–16. Available from: <http://dx.doi.org/10.1371/journal.pntd.0010038>
21. Dharmawan Y, Korfage IJ, Abqari U, Widjanarko B, Richardus JH. Measuring leprosy case detection delay and associated factors in Indonesia: a community-based study. *BMC Infect Dis*. 2023;23(1):1–10.
 22. infoNTD. Case Detection Delay Questionnaire. 2021;(October). Available from: <https://www.infondt.org/resource/case-detection-delay-questionnaire>
 23. Eze C, Murphy-okpala N, Ekeke N, Nwafor C, Njoku M, Ezeakile O et al. Translation and Cross-cultural Validation of Leprosy Case Detection Delay Questionnaire Among Persons Affected by Leprosy in Southeast Nigeria Short Title : Cross-cultural validation of leprosy case detection. *medRxiv*. 2026.
 24. infoNTD. Perception Study Toolkit [Internet]. 2025 [cited 2025 Dec 8]. Available from: <https://www.infondt.org/toolkits/perception-study-toolkit-pst>
 25. infoNTD. SARI Stigma Scale [Internet]. [cited 2026 Jun 4]. Available from: <https://www.infondt.org/toolkits/ntd-morbidity-and-disability-toolkit/sari-stigma-scale>
 26. Nicholls PG, Croft RP, Richardus JH, Withington SG, Smith WCS. Delay in presentation, an indicator for nerve function status at registration and for treatment outcome - The experience of the Bangladesh Acute Nerve Damage Study cohort. *Lepr Rev*. 2003;74(4):349–56.
 27. Gnimavo RS, Sopoh GE, Djossou P, Anagonou EG, Ayélo GA, Wadagni ACA, et al. Associated factors study into the belated screening for leprosy in Benin. *PLoS Negl Trop Dis*. 2022;16(6):1–21.
 28. Marega A, Hambridge T, Stakteas YP, Schoenmakers A, van Wijk R, Mieras L, et al. Leprosy indicators and diagnosis delay in Mogovolas, Meconta and Murrupula district of Nampula Province, Mozambique: A baseline survey. *Lepr Rev*. 2022;93(3):197–208.
 29. Mwageni N, Kamara D, Kisonga R, Njako B, Nyakato P, Pegwa A, et al. Leprosy epidemiological trends and diagnosis delay in three districts of Tanzania: A baseline study. *Lepr Rev*. 2022;93(3):209–23.
 30. Chu T, Liu D, Huai P, Chen X, Han S, Chen S et al. Comprehensive measures succeeded in improving early detection of leprosy cases in post-elimination era: Experience from Shandong Province, China. *PLoS Negl Trop Dis* [Internet]. 2020;14(2):1–12. Available from: <http://dx.doi.org/10.1371/journal.pntd.0007891>
 31. Noordam AC, Carvajal-Velez L, Sharkey AB, Young M, Cals JWL. Care seeking behaviour for children with suspected pneumonia in countries in sub-Saharan Africa with high pneumonia mortality. *PLoS ONE*. 2015;10(2):1–14.
 32. Muthuvel T, Govindarajulu S, Isaakidis P, Shewade HD, Rokade V, Singh R, et al. I Wasted 3 Years, Thinking It's Not a Problem: Patient and Health System Delays in Diagnosis of Leprosy in India: A Mixed-Methods Study. *PLoS Negl Trop Dis*. 2017;11(1):1–15.
 33. Atre SR, Rangan SG, Shetty VP, Gaikwad N, Mistry NF. Perceptions, health seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India. *Lepr Rev*. 2011;82(3):222–34.
 34. Engelbrektsson UB, Subedi M, Nicholls P. The challenge of health-seeking: Recollections of leprosy inpatients in post-elimination Nepal. *Lepr Rev*. 2019;90(4):433–43.

35. Murtaza A, Iqbal M, Salam A, Hambridge T, Vettel C, Schwermann F et al. Challenges of delay in diagnosis and high disability rate among newly diagnosed leprosy patients in Karachi, Pakistan. *Lepr Rev.* 2024;95(4).
36. Onwujekwe O, Onoka C, Uzochukwu B, Hanson K. Constraints to universal coverage: Inequities in health service use and expenditures for different health conditions and providers. *Int J Equity Health* [Internet]. 2011;10(1):50. Available from: <http://www.equityhealthj.com/content/10/1/50>
37. Amaghionyeodiwe LA. Determinants of the choice of health care provider in Nigeria. *Health Care Manag Sci.* 2008;11(3):215–27.

Figures

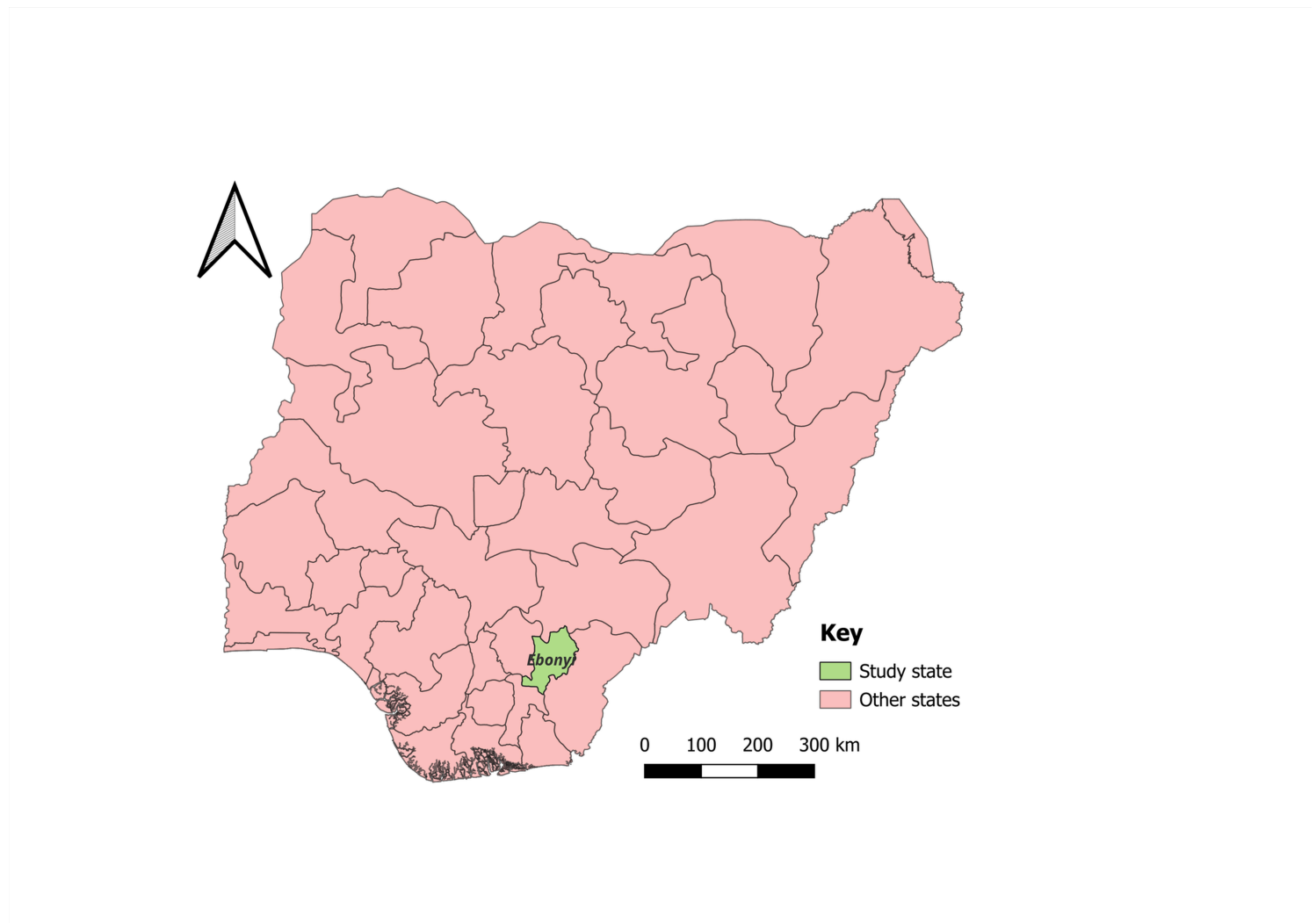


Figure 1

Map showing the study state

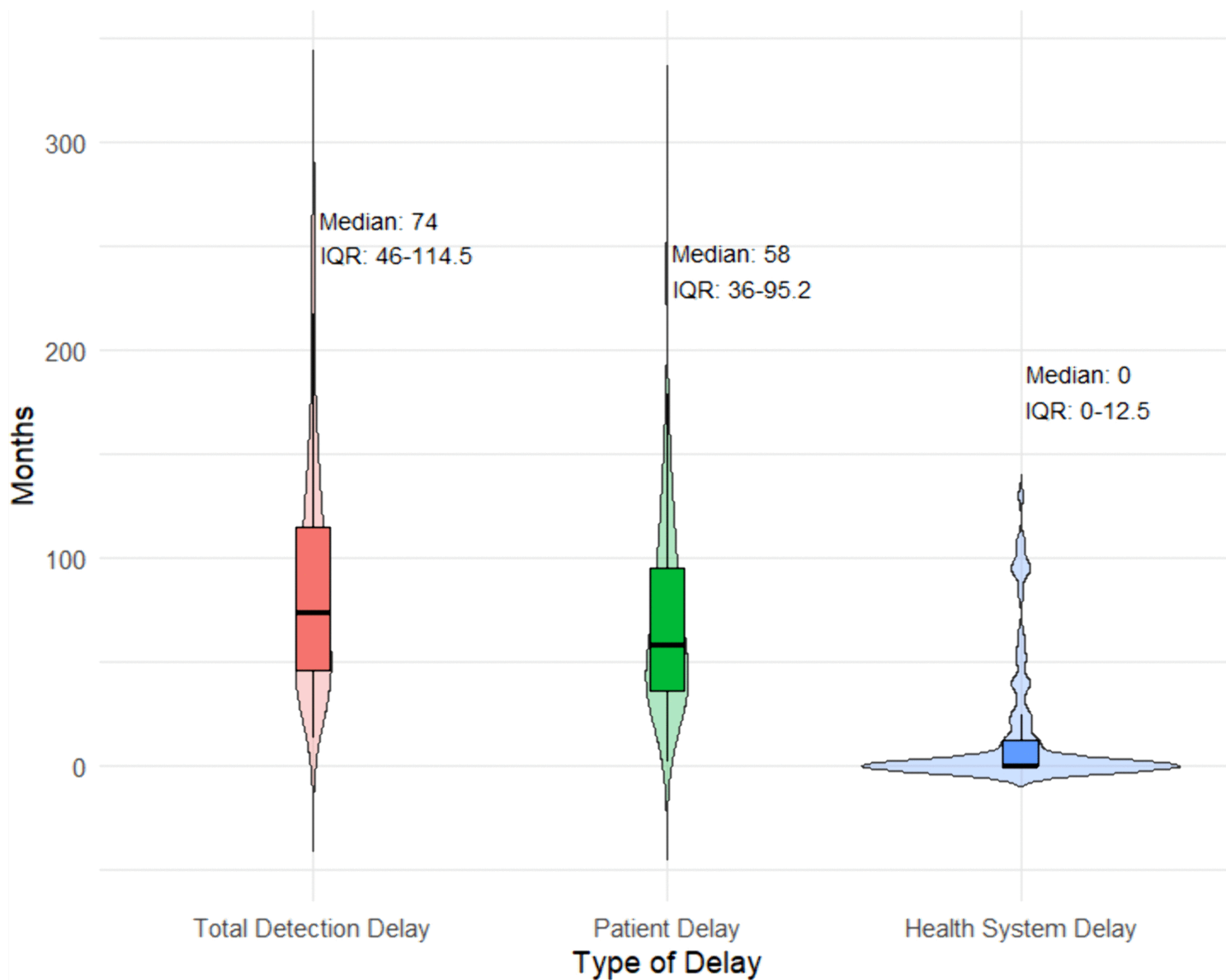


Figure 2

A violin map showing the distribution of case detection delay categories

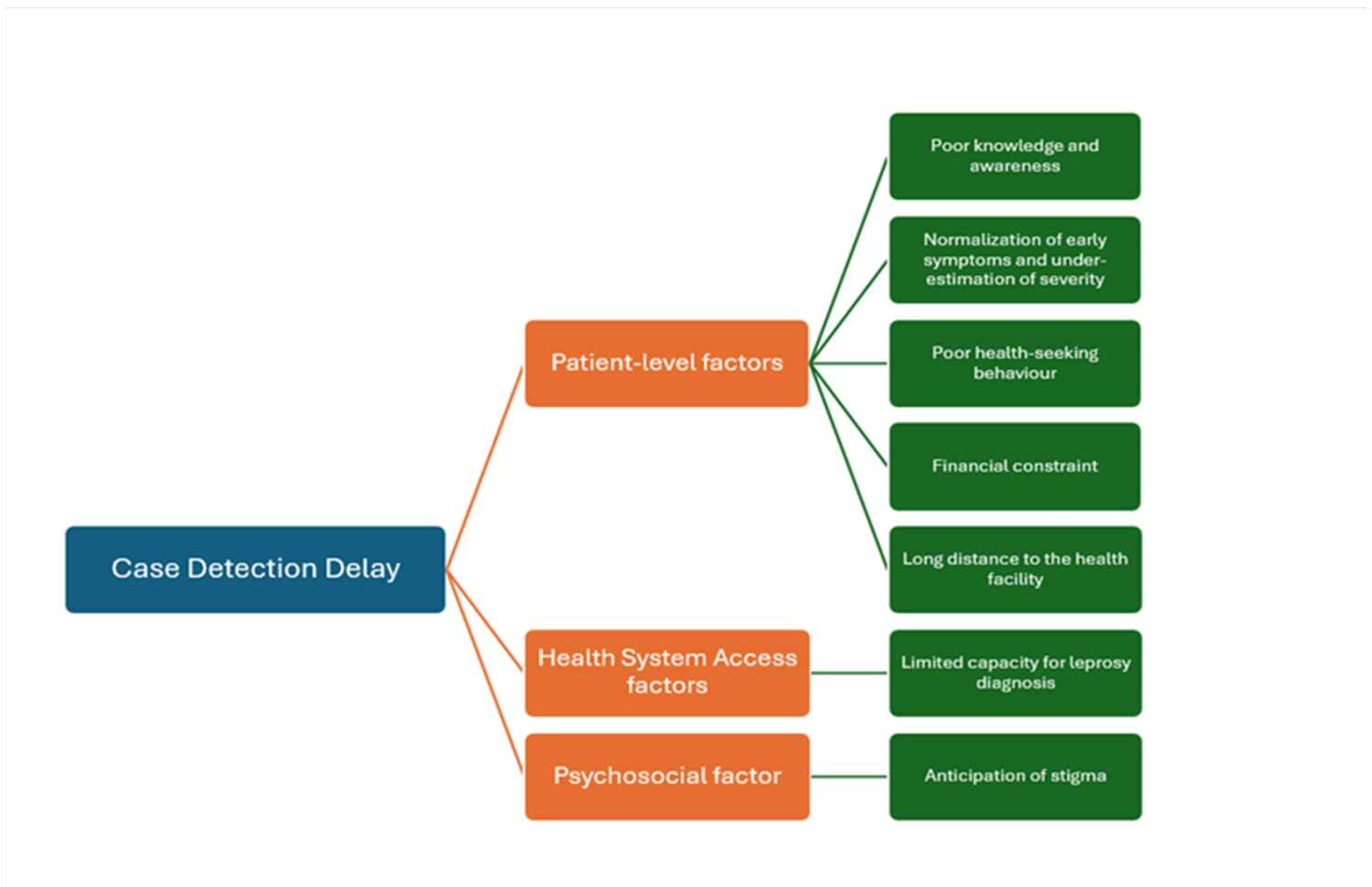


Figure 3

Qualitative result_Thematic Map

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