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Challenges of delay in diagnosis and high disability rate among newly diagnosed leprosy patients in Karachi, Pakistan

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Summary
Objectives Early case detection and thus prevention of disability among new leprosy cases remain a global challenge. This study aims to identify factors contributing to the delayed case detection and persistently high disability rates found among newly diagnosed leprosy patients in Karachi, Pakistan.
Methods A mixed-methods approach was utilised, combining quantitative data analysis of case detection delays and grade 2 disability (G2D), as well as qualitative data collection from patients and healthcare providers. A total of 150 new leprosy cases diagnosed from 2019 to 2021 were included in the quantitative analysis.
Results There was a high proportion of disability reported, with 51 (34.0%) cases presenting with G2D. The mean case detection delay reported by leprosy patients was 42.3 months (95% CI: 34.5–50.0 months) with a median of 24.0 months (IQR: 7.0–60.0 months). Case detection delay was notably longer in males, older individuals, those with multibacillary leprosy (MB) and higher grades of disability. Contact tracing emerged as a significantly more effective method of early detection, with cases identified throughthis approach showing a substantially lower

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incidence of G2D compared to those detected passively (OR: 0.22, 95% CI: 0.10–0.49, $p < 0.001$). Females and younger patients presented with less G2D than males and older patients. The qualitative analysis highlighted patient neglect of symptoms, poverty and lack of knowledge as primary factors leading to delayed leprosy diagnosis.

Conclusions Our study found that males, older individuals and those with MB experienced more prolonged diagnostic delays and severe disability in Karachi. Early detection through active case finding, particularly contact screening, substantially reduces disability rates and accelerates diagnosis. Training healthcare providers, engaging in community awareness and active case finding efforts will reduce case detection delay and disability, further supporting the goal of achieving zero leprosy in Pakistan.

Keywords: Leprosy, case detection delay, disability, epidemiology

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and one of the most common causes of preventable disabilities globally.[1] The World Health Organization (WHO) introduced multidrug therapy (MDT) in the 1980s, which resulted in a substantial decline in the number of registered cases. However, new cases continue to occur in many areas of the world.[2,3] Timely detection of new cases is essential for preventing disabilities at the individual level, as well as interrupting transmission within the community.[4] Delay in diagnosis for leprosy-affected persons is defined as the period from the onset of first signs and symptoms to the initiation of treatment with MDT. It includes both the patient delay, from onset of symptoms to the first interaction with health services and the health system delay, from the first visit to health services to initiation of treatment.[5,6] Prolonged delay in diagnosis commonly results in damage to peripheral nerves, which ultimately culminates in visible deformities, or grade 2 disability (G2D), as per the WHO classification system. G2D is often used as a proxy indicator for delayed diagnosis and the presence of a high number of cases with visible deformity could be indicative of significant diagnostic delay in a population, which has been reported in several countries.[7–10] Depending on the context, several factors ranging from sociodemographic characteristics and health-seeking behaviour to health system performance have been reported to contribute to leprosy case detection delay.[11]

Pakistan achieved the WHO target of elimination of leprosy as a public health problem in 1996 (prevalence of less than 1 per 10,000 population). While the country is now classified as low endemic, 259 new cases were reported in 2022.[2] Karachi, the largest city in Pakistan with a population of over 20 million, still has a significant number of new leprosy cases each year. In 2022, there were 50 new leprosy cases reported in Karachi, with 19 (38.0%) presenting with G2D.[12] With fewer cases being detected over the past decade, timely diagnosis remains a challenge, as evidenced by the high proportion of disability among persons affected by leprosy. This study aims to identify potential factors associated with and understand potential reasons for long case detection delays and the high disability rate observed among newly diagnosed leprosy patients in Karachi in recent years. A better understanding of these contributing factors will help in developing a strategy to enhance early diagnosis and treatment, and in turn prevent disability and continued transmission.

Materials and methods

STUDY DESIGN

This was a cross-sectional descriptive study, applying both quantitative and qualitative tools. Quantitative data was collected through a structured questionnaire, locally adapted from a case detection delay questionnaire described in the literature,[13] while qualitative information was gathered through focus group discussions (FGD) and in-depth interviews. The FGD and interview guides were developed after going through the available literature, as well as prior interaction with patients, field workers and other care providers. The data was collected between August and December 2022.

STUDY POPULATION

The study was conducted in Karachi, Pakistan, the country's largest city. For the quantitative analysis, the study population comprised all 150 leprosy patients who were registered from 2019 to 2021. Eight of these individuals who presented with G2D were interviewed as part of the qualitative analysis (4 male and 4 female) and another five with G2D (all male) took part in the FGD. A further 50 leprosy health workers were participated in the study, including a leprosy knowledge self-assessment, while six leprosy field workers participated in the FGD.

GRADING IMPAIRMENT IN LEPROSY

According to the WHO classification, leprosy-related disabilities are an impairment of body function (loss of sensation) and structure (visible deformity or damage) as a consequence of leprosy.[14] It comprises three grades: grade 0 (G0D) - no deformity; grade 1 (G1D) - loss of sensation; and grade 2 (G2D) - visible impairment and/or loss of visual acuity.

Eye, Hand, Feet (EHF) score is a way to assess the extent or severity of disabilities in leprosy, ranging from zero to two for eye, hand and foot. Therefore, a person with a G2D can have a minimum score of 2 and a maximum of 12, showing a wide range. Usually, a score of four and above is considered significant as it indicates the presence of deformity or disability on either side or different parts of the body.

DATA COLLECTION

Individual patient records and annual summary data sheets were collected and reviewed from the Marie Adelaide Leprosy Centre (MALC) in Karachi. MALC is a national NGO working for the control/elimination of the disease in the country. The organisation operates a 60-bed secondary level facility for patients affected by leprosy, as well as ten clinics across the city, to provide timely management and continued surveillance of patients. All persons affected by leprosy with G2D were approached for an interview at a leprosy clinic closest to their residence. Participants were assured of assistance to commute from their homes to the clinic and those who were either not available in the daytime due to work commitments or showed reluctance were offered the option to interview over the phone. Leprosy health workers from various clinics in Karachi, including field workers, postgraduate dermatology students and general practitioners (GPs), were asked to complete a self-assessment on their experience, knowledge about leprosy, prior expertise and place to refer, and to participate in a FGD to understand their perspective on the problem, challenges faced, and a possible way forward. Data from interviews and FGDs were collected face-to-face and notes taken on their responses. The purpose of the study was explained to all the participants when informed consent was taken.

STATISTICAL ANALYSIS

Both quantitative and qualitative data were entered in Excel for analysis. Quantitative data were analysed in SPSS, with graphs and figures generated in Python.[15,16] The data was cross tabulated and analysed using Chi-squared test for association. All p-values for this test were two-tailed with $p < 0.05$ considered significant. Unadjusted ORs were also calculated from contingency tables to quantify the strength of associations. Qualitative data were transcribed and a thematic analysis was performed to identify common themes with a selection of quotes for demonstration. Focus group discussions and in-depth interviews revealed reasons for long case detection delays.

ETHICAL CONSIDERATION

This study was reviewed and approved by the Ethical Review Committee of Marie Adelaide Leprosy Centre, Pakistan on March 3rd, 2022 (MAC/ERC/2022/01). Informed verbal/written consent was taken from all participants. They were informed about the voluntary nature of their participation with a right to decline at any time. Children below the age of 14 years were interviewed in the presence of their parents or guardians, after due understanding and agreement.

CONFIDENTIALITY

Personal information of all participants remained confidential, and the identity of the patient was protected with their registration number. All collected data were kept confidential and used for the study purposes only.

Results

QUANTITATIVE FINDINGS

Data from 150 patients registered in Karachi between 2019 and 2021 are presented below in Table 1, including the period of case detection delay reported in months. Patient age ranged from 4 to 70 years, with a median of 38.0 years. The longest detection delay was reported by those aged 46–60 years, with a mean of 52.3 months (95% CI: 33.3–71.4 months). Of the 150 patients, 97 (64.7%) were males and 53 (35.3%) females, with a majority presenting with MB leprosy (94.0%). There was a high proportion of disability reported, with 51 (34.0%) cases presenting with G2D and 45 (30.0%) with G1D. The 51 with G2D experienced the longest delay on average, with a mean of 61.4 months (95% CI: 45.2–77.6 months). The main sources of detection were from contact screening (62, 41.3%) or by a dermatologist (61, 40.7%), with the remaining 27 (18.0%) cases diagnosed through other means, such as in the hospital or by leprosy staff. From these different sources, the shortest case detection delay was reported by those identified through contact tracing, with a mean of 33.5 months (95% CI: 22.1–44.9 months).

The mean case detection delay for all 150 patients was 42.3 months (95% CI: 34.5–50.0 months) with a median of 24.0 months (IQR: 7.0–60.0 months). The longest delay reported was 240 months (20 years), a 49-year-old male who presented with G2D. The distribution of leprosy case detection delay was right skewed and followed a normal distribution when plotted on the log scale, suggesting a log-normal distribution (Figure 1).

Additional patient information is shown below in Table 2, along with the WHO disability grade at diagnosis. A majority were married (62.7%) or single (31.3%), with a higher disability proportion observed in the married group (40.4% vs. 21.3% in the single group). In terms of

Table 1. Descriptive statistics and case detection delays reported for leprosy patients

Characteristics	*N*	Mean case detection delay (months)	95% CI for mean		Median case detection delay (months)	IQR		Range	
			Lower bound	Upper bound		Lower quartile	Upper quartile	Min	Max
Age									
0–14 years	16	20.7	6.2	35.3	9.0	4.0	30.0	2	96
15–30 years	37	36.7	24.1	49.3	24.0	7.0	60.0	1	160
31–45 years	44	48.1	33.5	62.7	24.0	9.0	96.0	1	196
46–60 years	41	52.3	33.3	71.4	24.0	12.0	60.0	2	240
61 and above	12	31.5	4.5	58.6	12.0	6.0	60.0	3	124
Sex									
Female	53	41.0	27.6	54.4	12.0	7.0	72.0	1	196
Male	97	43.0	33.3	52.6	24.0	8.0	60.0	1	240
Clinical subtype									
PB	9	18.3	4.7	32.0	8.0	6.0	24.0	6	48
MB	141	43.8	35.6	52.0	24.0	8.0	72.0	1	240
Disability grade									
G0D	54	26.9	18.1	35.7	12.0	5.0	48.0	1	120
G1D	45	39.4	25.6	53.2	24.0	11.0	48.0	1	196
G2D	51	61.4	45.2	77.6	42.0	12.0	108.0	3	240
Source of detection									
Contact	62	33.5	22.1	44.9	12.0	6.0	48.0	1	240
Dermatologist	61	42.6	31.2	53.9	24.0	9.5	60.0	1	196
Other	27	61.7	38.9	84.6	36.0	12.0	120.0	1	224
Total	**150**	**42.3**	**34.5**	**50.0**	**24.0**	**7.0**	**60.0**	**1**	**240**

Abbreviations: PB: paucibacillary; MB: multibacillary; G0D: grade 0 disability; G1D: grade 1 disability; G2D: grade-2 disability; CI: confidence intervals; *N*: number; IQR: interquartile range.

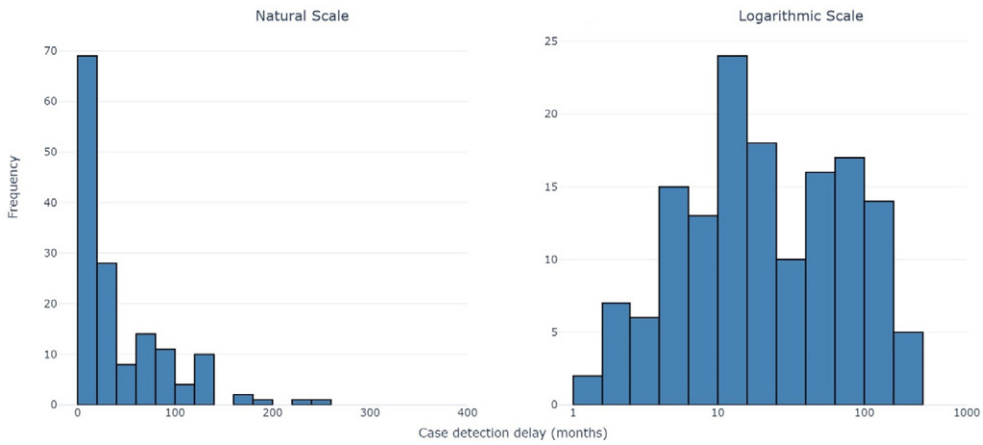

Figure 1. Distributions of case detection delay (months) for 150 leprosy cases in Karachi, Pakistan. The data are presented on the natural scale (left) and the logarithmic scale (right).

educational status, 65 (43.3%) were illiterate, while the major sources of working income were salary and daily wages/labourer. The most common first symptom reported was skin

Table 2. Disability grade reported for different groups of leprosy patients (N=150)

	Disability grade			Total
	G0D	G1D	G2D	
Marital Status				
Unmarried (single)	24 (51.1%)	13 (27.7%)	10 (21.3%)	**47**
Married	27 (28.7%)	29 (30.9%)	38 (40.4%)	**94**
Divorced	1 (33.3%)	1 (33.3%)	1 (33.3%)	**3**
Widow	2 (33.3%)	2 (33.3%)	2 (33.3%)	**6**
Education				
Illiterate	27 (41.5%)	24 (36.9%)	14 (21.5%)	**65**
Primary level (1–5)	4 (36.4%)	3 (27.3%)	4 (36.4%)	**11**
Madrassah/middle level (6–8)	10 (33.3%)	11 (36.7%)	9 (30.0%)	**30**
Secondary and above	11 (47.8%)	6 (26.1%)	6 (26.1%)	**23**
Not reported	2 (9.5%)	1 (4.8%)	18 (85.7%)	**21**
Source of income				
Salary	8 (22.2%)	11 (30.6%)	17 (47.2%)	**36**
Daily wages/labourer	9 (29.0%)	8 (25.8%)	14 (45.2%)	**31**
Own business	3 (33.3%)	3 (33.3%)	3 (33.3%)	**9**
Unemployed	6 (33.3%)	5 (27.8%)	7 (38.9%)	**18**
Housewife/girls	19 (44.2%)	16 (37.2%)	8 (18.6%)	**43**
Student	9 (69.2%)	2 (15.4%)	2 (15.4%)	**13**
First reported symptom				
Skin patch with loss of sensation	40 (58.0%)	20 (29.0%)	9 (13.0%)	**69**
Nodules/papule/raised lesion/thickened skin	7 (28.0%)	13 (52.0%)	5 (20.0%)	**25**
Numbness - hand or feet/tingling	6 (22.2%)	10 (37.0%)	11 (40.7%)	**27**
Muscle weakness	0 (0.0%)	0 (0.0%)	4 (100.0%)	**4**
Ulcers/cuts/wounds/blisters	0 (0.0%)	0 (0.0%)	17 (100.0%)	**17**
Not reported	1 (12.5%)	2 (25.0%)	5 (62.5%)	**8**

patch with loss of sensation (46.0%). All those who experienced muscle weakness and ulcers/cuts/wounds/blisters as the first symptom (21 in total) were classified as G2D, in line with the WHO grading definition.

A list of potential factors associated with G2D are shown below in Table 3. When distinguishing between younger and older age groups, those 31 and above had significantly higher G2D compared to 0–30 years (OR: 3.15, 95% CI: 1.42–6.99, $p = 0.004$). Similarly, males had a significantly higher G2D rate compared to females (OR: 3.15, 95% CI: 1.42–6.99, $p = 0.004$). There were more G2D in MB cases compared to PB, although the total number of PB cases was too low to perform a robust analysis (OR: 4.40, 95% CI: 0.53–36.16, $p = 0.135$). Leprosy cases who were detected through contact screening had significantly lower G2D (OR: 0.22, 95% CI: 0.10–0.49, $p < 0.001$) compared to those who were detected through other means.

Categories of case detection delay estimates reported by leprosy patients (in months), along with their corresponding EHF scores showing the extent of disability are presented below in Figure 2. Notably, 60 patients (40.0%) had a score of 4 and above, while 18 of the 51 patients (35.3%) diagnosed with G2D had an EHF score of 7 or above, reflecting extensive nerve damage and/or visible deformities. The data suggest that the total EHF score rose as the delay in diagnosis reported became longer.

Table 3. Contingency tables and Chi-squared test of factors related to grade 2 disability (N=150)

		G2D		ORs (95% CIs)	*p*-value
		No	Yes		
Age	**0–30 years**	43	10	3.15 (1.42, 6.99)	0.004
	31 and above	56	41		
Sex	**Female**	43	10	3.15 (1.42, 6.99)	0.004
	Male	56	41		
Clinical subtype	**PB**	8	1	4.40 (0.53, 36.16)	0.135
	MB	91	50		
Contact screening	**No**	47	41	0.22 (0.10, 0.49)	<0.001
	Yes	52	10		

Abbreviations: PB: paucibacillary; MB: multibacillary; G0D: grade 0 disability; G1D: grade 1 disability; G2D: grade-2 disability.

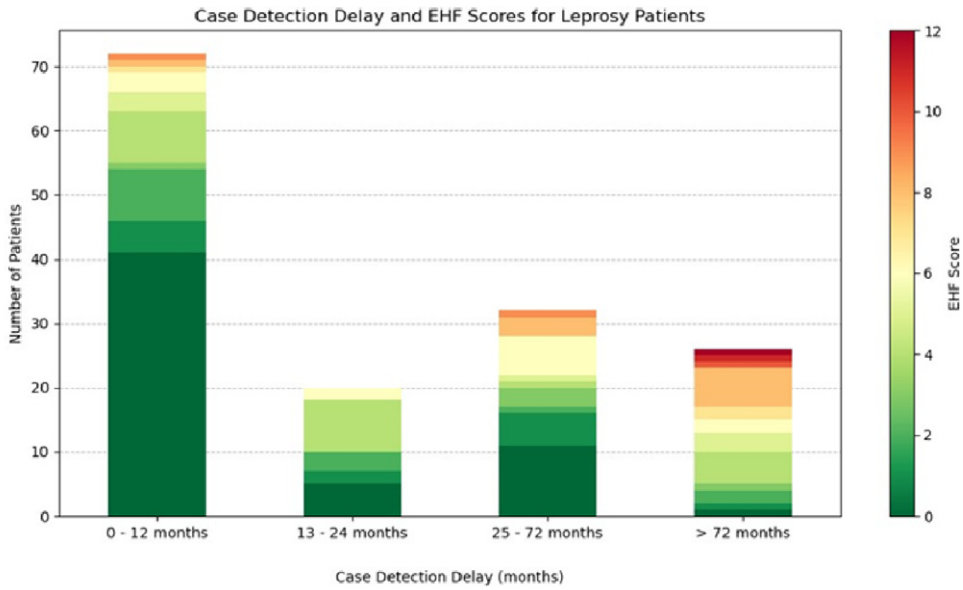

Figure 2. Case detection delay and corresponding EHF scores for leprosy patients.

Qualitative findings

PERSONS AFFECTED BY LEPROSY

Focus group discussions and in-depth interviews revealed reasons for delay. Among the most common issues reported were, poverty, daily struggle to earn a livelihood and neglect of the initial symptoms, considered as trivial or self-limiting:

Neglect - Lack of attention to initial symptoms, especially skin patches, was found to be a common issue, as participating patients reported usually not to pay attention to them. Even when such patches are on visible parts of the body, most patients tend to seek home remedies or consult a local general health care practitioner. As one male participant said during the FGD,

"I developed a small patch on my forearm, I did not pay any attention in the beginning, and it was on my wife's insistence, I went to see the local GP, who prescribed a skin ointment, which I applied for a month and then stopped using it as the lesion remained unchanged. After that for a year and a half, I did not do anything, but when the lesion started growing with occasional numbness and tingling in my arm, then I started following it again for the treatment."

Poverty and livelihood - The majority of people affected by leprosy were either daily wage earners/jobless, or those with a job having strict working conditions and limited salaries. Thus, as another participant shared, "I cannot afford to take time off from my work, as it will result in salary deduction. I already have to arrange for food and clothing for my children, I cannot afford a deduction in pay. Therefore, I waited for some time and then sought advice from a local herbalist." A common observation was that patients sought medical help only after they were no longer able to earn a living or perform daily tasks. They preferred to visit private health practitioners, whether qualified or unqualified, who were closer to their homes and more affordable and accessible.

Lack of knowledge - Patients in general lack knowledge about leprosy and its symptoms. Most of the time skin patches were taken lightly, assumed to have a self-limiting course or to respond to skin ointments or creams. A male in his 40s shared, "Nobody in my neighbourhood or immediate family was aware of initial symptoms of leprosy. I thought that the patch was because of an insect bite or poor hygiene in hot and humid working conditions." They are compelled to seek medical help only after they begin losing power in their hands or feet or develop recurrent wounds that disrupt their daily routine.

Leprosy knowledge

POSTGRADUATE DERMATOLOGY STUDENTS AND GPS

A total of 47 participants (41 female, 6 male) completed the self-assessment questionnaire before a leprosy awareness seminar. 57.4% of the attendees acknowledge that this is the first time that they are participating in a session on leprosy. A majority (78.7%) described leprosy as a curable disease and 40.4% of the doctors knew about various parts of the body that leprosy usually affects. However, when asked what the common symptoms of leprosy were, only 19.1% mentioned the neurological symptoms like tingling sensation or recurrent burns and wounds on hands and feet. 63.8% of the respondents mentioned seeing a presumptive or confirmed case of leprosy during the last three years.

Discussion

The aim of this study was to identify potential factors associated with and understand potential reasons for the persistently long case detection delays and high disability rate among newly diagnosed leprosy patients in Karachi in recent years. As with many other leprosy endemic areas in the world, Karachi has areas where the disease is being detected with regularity. Timely diagnosis of leprosy continues to be a challenge, and its inclusion in the list of neglected tropical diseases by the WHO highlights the need for due attention by the public health system and communities alike. Notably, there was a high proportion of disability reported in our study, with 51 (34.0%) cases presenting with G2D. There are several factors previously shown to be associated with diagnosis delay and G2D, including age, sex and subtype, as well as low perception of disease symptoms and lack of knowledge, which were further established in this study.[17]

Case detection delay occurs at either the patient level or the health system level, or a combination of both. At the health system level, it has been reported that significant delays can occur on the part of the primary health care provider as most individuals prefer to visit a GP who usually does not have the requisite knowledge and skills to diagnose leprosy.[6] On the other hand, it could also be an issue of a patient's access to appropriate health services and having the opportunity to see a dermatology specialist. Here, we found that the average delay reported by recently diagnosed cases was around 3.5 years, with a median of 2 years, indicating that delayed detection and treatment of cases is indeed an ongoing issue in Karachi. Case detection delays in this cohort were non-normally distributed with a right-skew driven by very long delays, which has been demonstrated in other populations and is characteristic of the long incubation period and diagnostic delays often reported in leprosy.[18,19] We found that leprosy cases detected through contact screening reported a much lower period of delay compared to those identified through other means, such as in the hospital, by a dermatologist or leprosy staff. As the number of cases decreases, leprosy control typically becomes less emphasised from a public health perspective, leading to a decline in knowledge of recognising the signs and symptoms of leprosy by health workers.[20,21] There were also clear differences between subgroups, namely longer delays reported by older age groups, MB cases and those presenting with G2D.

In our patient cohort, factors associated with G2D were older age (31 and above), being male and presenting with MB leprosy, with similar findings reported in previous studies.[1,5,22,23] However, these findings should be carefully considered. For instance, older individuals may appear to have longer diagnostic delays and higher rates of disability simply because they have had a longer lifetime for these delays to occur and disabilities to develop, which could mean that age is more of an associated factor rather than a direct risk factor. It is also possible that MB leprosy could be seen as an outcome of delayed diagnosis to a more severe subtype rather than an initial risk factor for longer delays. Moreover, while we observed that men experienced more disability, this could very much be context specific and warrants further exploration. An examination of potential socio-cultural, economic, or healthcare access factors contributing to this disparity would provide valuable insights. Importantly, contact screening was found to be the most effective method of identifying new cases at an early stage, highlighted by a significantly lower proportion of G2D compared to those identified by other means. However, we also noted certain patients with G2D gave a history of family contacts who had received leprosy treatment more than 5–10 years prior. Such cases demand continued surveillance of people affected by leprosy and their families beyond the routine follow up period of five years after treatment. The recent initiative of single-dose rifampicin post-exposure prophylaxis (SDR-PEP) is likely to complement not only in preventing the spread of new infection, but also provide an opportunity to visit present and past patients to check their family contacts and look for hidden cases.[24] The exact period that constitutes a delayed diagnosis is not very clear, although various studies have used six months as a timeframe in which leprosy cases should be identified.[25–27] Neurological symptoms are rarely seen in cases diagnosed within a year, but their frequency increases with further delay in diagnosis.[25] In addition to progression of physical symptoms, delay in diagnosis and treatment can lead to a greater psychological burden for the patient, resulting in reduced quality of life in individuals affected by leprosy.[28] Here, we found that patients without disabilities were diagnosed within a year of the appearance of symptoms, while those with G2D had a long delay ranging from 2 to 15 years. Additionally, we found that EHF scores, which show the extent of disability in leprosy patients, rose as the case detection delay reported by the patients became longer.

Most persons affected by leprosy in this study without disabilities were manual labourers, who had to work daily to support their families. There has been an element of self-neglect shown by individuals as they prefer to attend to their survival needs. A common observation was that patients approached for medical help once they were unable to earn a living or carry out daily tasks. They preferred to visit a private health practitioner (qualified or unqualified) closer to their home, based on their affordability and accessibility, who often lack proper capacity for diagnosing leprosy. A common observation was that patients do not pay attention to skin lesions, which are considered milder problems and supposedly treated by cream or otherwise resolve on their own. It is once they start losing power in their hands or feet or they develop recurrent wounds hampering their daily routine, that they are forced to seek medical help. Another common reason for delay is patients ignoring the early signs and symptoms, considered as minor or self-limiting. Only once the symptoms aggravate or associate with neurological issues that patients are compelled to seek medical care.[29] A lack of expertise and awareness of many doctors to think about leprosy symptoms like numbness, tingling, recurrent wounds, or muscle weakness was also revealed. In fact, we found that all patients in this cohort reporting these clinical manifestations as the first symptoms of leprosy presented with G2D.

The mixed methods approach used in this study allowed us to identify factors associated with detection delay and G2D through quantitative analysis, while our use of FGDs and surveys for persons affected by leprosy and healthcare workers revealed some of the reasons for these delays in the context of Karachi. In terms of limitations, tracing patients for physical meetings was resource and time-intensive, leading to interviews carried out over the phone in certain cases. Moreover, incessant rains in the province during the study period resulted in disruption of fieldwork. While the sample of 150 recently diagnosed leprosy patients provided insights into case characteristics, it was too small to allow for more robust analyses such as multivariate modelling. Another issue was that patients often have difficulty remembering their initial symptoms, the period of time that has elapsed, as well as treatment taken prior to receiving their final diagnosis, potentially leading to inaccuracies in the data for the entire study population.

Conclusion

Leprosy control in Pakistan has led to a sustained decline in cases, yet the slow onset of the disease and frequent delays in diagnosis continue to pose significant challenges. This study underscores the significant impact of delayed diagnosis on the high disability rates among newly diagnosed leprosy patients in Karachi. Our findings revealed that males, older individuals and those with multibacillary leprosy experienced more prolonged diagnostic delays and severe disability in this context. Importantly, active case finding through contact screening has proven to be a highly effective strategy in reducing the disability. These measures are essential to advance towards the goal of zero leprosy in Pakistan.

Conflicts of interest

The authors declared no conflict of interest.

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Contributorship

AM and AS oversaw collection of the field data. AM, MI and TH drafted the manuscript and analysed the data. All co-authors reviewed the draft and provided comments.

Patient consent

Consent was collected from all study participants interviewed.

Data sharing

The data from this study are not available for open access but can be requested directly from the first or corresponding author.

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