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Beyond the Skin: Stigma, School Refusal, and Psychosocial Distress in a Child with Multibacillary Leprosy from a Primary Care Perspective

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Abstract
Childhood leprosy can cause substantial psychosocial distress, particularly when visible skin lesions expose affected children to stigma, discrimination, and peer rejection. However, emotional difficulties and disruptions in school participation may remain unrecognized during routine clinical management. This case report aimed to describe the psychosocial and functional burden associated with facial lesions in a child with multibacillary leprosy from a primary care perspective. A descriptive assessment was conducted in a 10-year-old girl using clinical histories obtained from the patient and her mother, available medical records, the Strengths and Difficulties Questionnaire (SDQ), and the KUKUH quality-of-life questionnaire. The findings were interpreted descriptively without establishing a formal psychiatric diagnosis. The patient had experienced a visible cheek lesion for approximately 18 months, accompanied by feelings of shame, peer teasing, school refusal lasting two weeks, social withdrawal, and decreased appetite. SDQ responses indicated emotional symptoms and peer relationship difficulties, while prosocial behavior remained relatively preserved. The quality-of-life assessment revealed worry, embarrassment, perceived social rejection, and interference with daily activities, school participation, and interpersonal relationships. These findings suggested that psychosocial distress and functional impairment accompanied the visible skin lesion and negative peer experiences. Although clinical photographs documented changes in the lesion after five months of multidrug therapy (MDT), psychosocial outcomes were not reassessed during follow-up. This case highlights the importance of integrating psychosocial screening, family-centered support, school-based coordination, and stigma-reduction interventions into pediatric leprosy management alongside appropriate medical treatment to address the emotional, social, and functional needs of affected children.

INTRODUCTION

Leprosy, also known as Hansen's disease, remains a clinically significant neglected tropical disease despite the availability of effective multidrug therapy (MDT) (Fonseca et al., 2025; Franco-Paredes et al., 2022; Higuita et al., 2026). The disease is caused primarily by Mycobacterium leprae and predominantly affects the skin, peripheral nerves, mucosa of the upper respiratory tract, and eyes. With early detection and appropriate treatment, leprosy is curable, and leprosy-related disabilities can often be prevented. However, delayed diagnosis and treatment may result in persistent skin lesions, sensory impairment, deformities, and long-term functional limitations (Chen et al., 2022; Gilmore et al., 2023; Samosir et al., 2023; World

Health Organization [WHO], 2025). In many communities, the visible manifestations of leprosy carry social implications that extend beyond the infection itself. Facial lesions, changes in skin pigmentation, deformities, and nerve-related disabilities may become recognizable indicators of the disease, increasing affected individuals' vulnerability to stigma, discrimination, and social exclusion (Gilmore et al., 2023; Marpaung et al., 2022).

The psychosocial burden of leprosy is particularly important because stigma may persist despite the availability of effective treatment. Leprosy-related stigma is among the oldest and most widely recognized forms of disease-associated stigma and is often reinforced by fear of transmission, misconceptions, cultural beliefs, and negative social labeling (Goh et al., 2024; Hofstraat & van Brakel, 2016; Marpaung et al., 2022). Studies conducted in leprosy-endemic settings have demonstrated that stigma affects multiple aspects of life, including family relationships, education, employment, social participation, marriage prospects, healthcare-seeking behavior, and emotional well-being (Abdul Rahman et al., 2022; van Brakel et al., 2012). In Indonesia, leprosy-related stigma has also been documented across various domains of daily life, highlighting how the disease may influence not only physical health but also social identity, interpersonal relationships, and overall functioning (Marpaung et al., 2022).

Mental health consequences are increasingly recognized as an insufficiently addressed component of comprehensive leprosy care. Individuals affected by leprosy may experience psychological distress, depressive symptoms, anxiety, social isolation, diminished self-esteem, and internalized shame (Sharma et al., 2022; Somar et al., 2020; van Dorst et al., 2020). A systematic review examining the mental well-being of individuals affected by leprosy and their family members highlighted associations between psychological difficulties, physical impairment, stigma, social exclusion, and restricted participation in everyday activities (Somar et al., 2020). These findings emphasize that leprosy should not be managed solely as a dermatoneurological infectious disease but should also be recognized as a condition with potentially substantial psychosocial consequences (van Dorst et al., 2020).

Children may be particularly vulnerable to these consequences because their emotional and social development is closely associated with peer acceptance, school participation, body image, and a sense of belonging. During school age, visible differences in skin appearance may expose children to teasing, bullying, avoidance, and unfavorable social comparisons. Research in pediatric dermatology has demonstrated that children and adolescents with visible chronic skin conditions frequently experience stigmatization, bullying, impaired peer relationships, anxiety, depressive symptoms, and reduced health-related quality of life (Paller et al., 2024; Parga & Liska, 2025). Although these findings are not specific to leprosy, they provide a relevant conceptual framework for understanding how visible facial lesions may contribute to psychosocial difficulties that extend beyond the physical manifestations of the disease.

In pediatric leprosy, psychological well-being and quality-of-life concerns may receive insufficient attention because clinical management primarily emphasizes diagnosis, MDT, assessment of peripheral nerve involvement, and prevention of disability. However, the most disruptive consequences for affected children may emerge in everyday environments, particularly schools, playgrounds, and peer interactions. Disease-related stigma may contribute to school avoidance or refusal, social withdrawal, reduced self-confidence, embarrassment, fear, sadness, and diminished participation in age-appropriate activities. Although these

manifestations may not meet the diagnostic criteria for a psychiatric disorder, they can represent clinically significant emotional distress and functional impairment requiring attention in primary care and mental health services (Adriono et al., 2026; Ahmad, 2023; Vieira et al., 2022). Therefore, understanding the psychosocial experiences of children with leprosy is essential for developing comprehensive care strategies that integrate medical treatment, psychosocial assessment, family support, school-based interventions, and stigma reduction.

Evidence concerning mental well-being further reinforces the importance of understanding these social experiences. Somar et al. (2020), in a systematic review of 65 studies, documented psychological consequences associated with leprosy, including depressive symptoms, anxiety, and reduced self-esteem, with stigma and discrimination identified as relevant contributing factors. Complementing these findings, van Dorst et al. (2020) reported poorer mental well-being and a greater burden of depressive symptoms among individuals affected by leprosy who participated in self-help groups in southern Nepal compared with a reference population. Although these studies did not establish the prevalence of psychiatric disorders specifically among children with leprosy, their findings support the importance of assessing emotional well-being alongside physical manifestations and interpreting psychological distress within patients' social and environmental circumstances.

More specifically, pediatric dermatology research has demonstrated that visible skin conditions can adversely affect children's psychological and social functioning. Paller et al. (2024), in a multicenter cross-sectional study published in JAMA Dermatology, investigated 1,671 children and adolescents with chronic skin disorders. The study reported that 43.8% of participants experienced at least moderate levels of stigma and identified significant associations between stigma, reduced quality of life, and impaired psychosocial functioning. These findings provide a relevant framework for understanding the experiences of children with visible leprosy lesions. Nevertheless, because the study involved various chronic dermatological conditions rather than pediatric leprosy specifically, its findings should inform contextual interpretation rather than be considered direct estimates of stigma prevalence or psychological morbidity among children with leprosy.

In addition to documenting psychosocial difficulties, previous research has explored interventions aimed at reducing leprosy-related stigma. Lusli et al. (2016) investigated a rights-based counseling intervention in Cirebon, Indonesia, incorporating cognitive behavioral principles and the participation of lay and peer counselors. Their subsequent work (Lusli et al., 2017) described the development of counseling practices and supporting educational materials, emphasizing the involvement of individuals affected by leprosy. These findings provide a locally relevant foundation for considering supportive interventions that extend beyond pharmacological treatment (Willis et al., 2024). In pediatric practice, similar counseling principles may be adapted to children's developmental needs and integrated with family-centered care and school-based support. However, the feasibility and effectiveness of such adaptations require further evaluation in pediatric populations.

Collectively, these studies demonstrate the importance of stigma, psychological well-being, and social support in leprosy care. Nevertheless, a more specific clinical question remains insufficiently addressed: how these dimensions intersect in the everyday experiences of a child with visible multibacillary leprosy receiving primary healthcare services. Existing

evidence does not fully characterize the combination of visible facial lesions, peer teasing, school refusal, emotional distress, and relatively preserved prosocial functioning observed in the present case. Accordingly, the research gap concerns the detailed clinical characterization of overlapping psychosocial difficulties rather than the absence of previous research on leprosy-related psychological consequences. A carefully documented case report may therefore complement population-based studies by illustrating how these interconnected challenges become apparent during routine clinical encounters.

Addressing this gap is important because school refusal and withdrawal from peer interactions represent meaningful disruptions to children's daily functioning, even when available assessments do not establish a formal psychiatric diagnosis. In the present case, a 10-year-old girl with a visible cheek lesion experienced embarrassment, peer teasing, two weeks of school refusal, reduced participation in peer activities, and decreased appetite. These manifestations highlight the importance of extending clinical assessment beyond physical examination and medication management to include emotional well-being, social participation, and educational functioning. Furthermore, when caregivers collect medications without the child attending follow-up appointments, opportunities to identify bullying, assess psychological symptoms, and discuss school participation may be limited. Direct, developmentally appropriate communication with affected children is therefore essential for recognizing psychosocial concerns that might otherwise remain undetected.

The distinctive contribution of this case report lies in integrating clinical history, the Strengths and Difficulties Questionnaire (SDQ), and the KUKUH quality-of-life questionnaire to characterize psychosocial difficulties associated with a visible facial lesion in a child with multibacillary leprosy. Particular attention is given to the coexistence of emotional symptoms and peer relationship difficulties with relatively preserved prosocial functioning. This combination provides a more nuanced understanding of social withdrawal without interpreting avoidance behaviors as an absence of social competence or interpersonal capacity. The novelty of this report is primarily contextual and clinical, illustrating how a biopsychosocial approach can be applied within primary healthcare services while maintaining a clear distinction between screening findings, functional impairment, and formally diagnosed psychiatric disorders.

Accordingly, this case report aimed to describe the psychosocial and functional consequences associated with visible facial lesions in a child with multibacillary leprosy from a primary care perspective. Specifically, it sought to characterize emotional concerns, document disruptions in school attendance and peer relationships, and interpret psychosocial screening and quality-of-life findings alongside the patient's clinical history. The report was intended to strengthen recognition of psychosocial needs in routine pediatric leprosy management and inform consideration of family counseling, school coordination, stigma-reduction strategies, and appropriate referral pathways. Its anticipated practical contribution was to support more comprehensive, child-centered care, while its research contribution was to identify priorities for future longitudinal investigations examining psychosocial recovery, school reintegration, and the effectiveness of supportive interventions among children affected by leprosy.

METHOD

This descriptive clinical case report involved a 10-year-old girl with multibacillary leprosy who presented with a visible facial lesion and associated psychosocial difficulties in a primary care setting. Clinical information was obtained through interviews with the patient and her mother, supplemented by available medical records and follow-up documentation. Data were collected on the progression of the skin lesion, treatment history, school attendance, peer relationships, daily activities, social interactions, appetite, and emotional responses associated with the condition.

Psychosocial and functional assessments were conducted using clinical history, the age-appropriate Strengths and Difficulties Questionnaire (SDQ; version for children aged 4–11 years), and the KUKUH Quality of Life Questionnaire. The SDQ was administered to assess emotional symptoms, peer relationship difficulties, behavioral characteristics, and prosocial behavior. The KUKUH questionnaire was used to evaluate disease-related concerns, embarrassment, emotional distress, physical symptoms, limitations in daily activities, school participation, interpersonal relationships, perceived social rejection, perceived treatment-related improvement, and knowledge of skin self-care. Findings from the clinical interviews and questionnaire assessments were analyzed descriptively to characterize the patient's psychosocial distress and functional impairment.

No structured psychiatric diagnostic interview was conducted; therefore, the assessment focused on identifying psychosocial difficulties and functional limitations rather than establishing a formal psychiatric diagnosis. Clinical follow-up was performed five months after the initiation of multidrug therapy (MDT) to document changes in the facial lesion. Clinical photographs obtained at the initial presentation and five-month follow-up were used to support the assessment of physical changes. Psychosocial outcomes were not reassessed at follow-up.

RESULT AND DISCUSSION

Clinical Presentation and Psychosocial Findings

A 10-year-old girl presented to primary care with a visible skin lesion on the right cheek that had been present for approximately 1.5 years. The lesion initially appeared as a small patch and gradually widened over time. Before the diagnosis was established, she had received topical treatment, but the lesion did not improve and continued to worsen. She was subsequently diagnosed with multibacillary leprosy and was started on multidrug therapy consisting of rifampicin, clofazimine, and dapsone. Her treatment follow-up was not always attended directly by the patient, as her parents often collected the medication from the primary health care facility on her behalf. Clinical follow-up at five months demonstrated a change in the appearance of the facial lesion compared with the initial presentation (Figure 1).



Figure 1. Clinical appearance of the facial lesion in a child with multibacillary leprosy. (A) Facial lesion involving the right cheek at initial presentation. (B) Clinical appearance of the lesion after five months of multidrug therapy.

Although the patient's initial presentation was dermatological, the most prominent burden of the illness was psychosocial. The lesion was located on the face, making it constantly visible to others and difficult for the patient to conceal during daily social interactions. Over time, the patient became increasingly ashamed of the appearance of her cheek. Her mother reported that the patient repeatedly asked to stop going to school because she felt embarrassed by the visible facial lesion. The patient also described being teased by her peers, who called her face "wajah topeng" ("mask-like face"). In the two weeks before presentation, she refused to attend school. This school refusal was accompanied by a clear change in daily functioning, as she spent more time at home watching television and no longer wanted to play with children of her own age. Her appetite was also reported to have decreased.

The psychiatric relevance of this case lies in the way a chronic visible skin disease affected the patient's emotional state, self-perception, peer relationships, and school functioning. The patient's shame was not an isolated emotional symptom but appeared to be closely connected with avoidance behavior. Her refusal to attend school followed repeated experiences of being mocked by peers, suggesting that the school environment had become a source of distress rather than social support. The patient's withdrawal from peer play also indicated impairment in age-appropriate social participation.

The Strengths and Difficulties Questionnaire (SDQ) responses provided additional support for this psychosocial pattern. The responses suggested emotional and peer-related difficulties, including worry, sadness or unhappiness, reduced confidence in new situations, a tendency to prefer being alone, and experiences of teasing or disturbance from other children. However, prosocial functioning appeared relatively preserved, as responses related to helping others, being kind to younger children, and considering the consequences of actions remained favorable. This pattern suggests that the patient's social withdrawal was not due to a lack of prosocial capacity but was more likely related to shame, peer rejection, and stigma surrounding her visible skin condition.

Assessment using the Quality of Life Questionnaire (KUKUH) further emphasized the severity of the subjective burden. The patient reported marked worry about her skin condition, including concerns that the lesion could spread, worsen, become wounded, numb, or disabling. She also reported feeling very ashamed because of her skin condition. Negative emotional effects were present, including sadness, anxiety, insecurity, and depressive feelings related to

the lesion. The condition interfered with daily activities, school or study, and interactions with other people. She also reported feeling shunned by friends and neighbors because of the skin condition. These findings were consistent with the narrative history of embarrassment, bullying, school refusal, and social withdrawal.

Overall, the clinical history, SDQ findings, and KUKUH assessment indicate clinically meaningful psychosocial distress and functional impairment associated with the visible facial lesion. Preserved prosocial functioning suggests that the patient retained positive social capacity, while her withdrawal appeared to be shaped primarily by stigma, peer rejection, and repeated negative social experiences.

Leprosy-related stigma has long been recognized as one of the most persistent social consequences of the disease. Although leprosy is curable with multidrug therapy, public understanding often remains shaped by fear, misconception, and social labeling. Stigma may manifest as rejection, avoidance, teasing, discrimination, internalized shame, and reduced participation in daily life (Chen et al., 2022; Gilmore et al., 2023; Marpaung et al., 2022). In Indonesia, leprosy-related has been reported across private and public domains, including family life, social interaction, work, marriage, and community participation (Marpaung et al., 2022). The present case reflects a pediatric manifestation of the same phenomenon. The patient's visible facial lesion became a socially recognizable marker that exposed her to peer ridicule, subsequently affecting her self-perception, school participation, and willingness to interact with children of her age.

The psychiatric relevance of this case extends beyond the presence of sadness or shame. More importantly, the patient demonstrated functional impairment across several developmentally important domains. School refusal, avoidance of peer play, withdrawal into home-based passive activity, and decreased appetite indicate that the psychological distress had already interfered with her daily functioning. In children, school attendance and peer interaction are central to emotional development, identity formation, self-esteem, and social learning. Therefore, school refusal occurring in the context of shame and bullying should not be interpreted as a minor emotional reaction, but rather as a clinically meaningful disruption of age-appropriate functioning.

The Strengths and Difficulties Questionnaire (SDQ) findings further support this interpretation. Emotional and peer-related difficulties were accompanied by relatively preserved prosocial functioning, indicating that the patient retained the capacity for positive social engagement. This distinction is important because her withdrawal was less consistent with diminished social interest or antisocial behavior and more consistent with avoidance arising from shame, peer rejection, and repeated negative social experiences. Thus, the presentation is better understood as stigma-associated psychosocial distress with impaired school and peer functioning rather than as evidence of a formal psychiatric disorder.

The dermatology-related quality-of-life findings also supported the severity of the burden. Based on the KUKUH responses, the patient reported marked worry about her skin condition, shame, negative emotional responses, interference with daily activities and school participation, impaired interactions with other people, and feelings of being shunned by friends and neighbors. The overall pattern suggests marked impairment in dermatology-related quality

of life, particularly in emotional and social domains (Paller et al., 2024; Somar et al., 2020; van Dorst et al., 2020).

This present case also aligns with findings from pediatric dermatology literature. Children with chronic visible skin diseases may experience stigma, bullying, poor self-image, anxiety, depressive symptoms, and impaired peer relationships (Ahmad, 2023; Paller et al., 2024; Parga & Liska, 2025). Although these studies are not specific to leprosy, the underlying mechanism is highly relevant: visible skin differences may expose children to unwanted attention, teasing, avoidance, and social comparison. Facial lesions may be particularly impactful because the face is central to identity and interpersonal communication. In this patient, the lesion was located on the cheek, making it difficult to conceal in school or peer settings. Its visibility may therefore have contributed to persistent shame and negative peer experiences.

School refusal represents an important psychiatric signal in this case. The patient's refusal to attend school occurred after repeated embarrassment and peer teasing. However, the available data do not establish a formal diagnosis such as depressive disorder, anxiety disorder, or adjustment disorder, because no structured psychiatric diagnostic interview was performed. This distinction is important: the findings support clinically meaningful psychosocial distress, avoidance behavior, impaired school functioning, and reduced quality of life, but should not be interpreted as evidence of a definitive psychiatric diagnosis.

The relatively preserved prosocial domain provides a more nuanced interpretation of the patient's social functioning. The patient continued to demonstrate kindness, helping behavior, and concern for others, suggesting that her social withdrawal may be potentially reversible if the stigma and bullying environment are addressed. Rather than representing fixed social impairment, her reduced social participation appeared to be shaped by shame and fear of negative peer evaluation. This has practical implications because interventions should address not only the patient individually, but also on the family, school, peers, and wider community environment.

From a primary care perspective, this case demonstrates why leprosy management should not end with the provision of multidrug therapy. The patient's parents frequently collected medication from the primary health care facility on her behalf, while the patient herself was not consistently present during follow-up. Consequently, emotional distress, school refusal, social withdrawal, and changes in appetite may be overlooked when clinical encounters focus primarily on medication continuation. Primary care providers are often the first and most continuous point of contact for patients with leprosy and are therefore well positioned to screen for stigma, school avoidance, bullying, treatment adherence, family concerns, and quality-of-life impairment.

A biopsychosocial approach is particularly important in pediatric leprosy. Biologically, the child requires appropriate multidrug therapy and monitoring for disease progression, reactions, and disability. Psychologically, clinical should recognize shame, worry, sadness, reduced confidence, and avoidance behavior. Socially, support is needed to facilitate safe school reintegration, reduce bullying, and restore peer interaction. Anti-stigma education for family members, teachers, and classmates may also be important, because misconceptions regarding leprosy can contribute to fear and social exclusion. Evidence from leprosy stigma

literature emphasizes that stigma reduction requires more than biomedical treatment; it also requires education, social support, participation, and community-level change (Lusli et al., 2017; Rafferty, 2005).

This case also highlights the importance of integrating mental health screening into dermatology and infectious disease care. Brief screening instruments such as the Strengths and Difficulties Questionnaire (SDQ), complemented by a condition-specific quality-of-life assessment such as KUKUH, can help identify psychosocial difficulties that may otherwise remain unrecognized. In this patient, the questionnaires provided structure to concerns already suggested by the clinical history, including emotional distress, social withdrawal, impaired school functioning, and perceived rejection. These instruments do not replace comprehensive psychiatric assessment but may assist primary care clinicians in identifying children who require further psychosocial support, counseling, family intervention, or referral (Lusli et al., 2017).

The main limitation of this case is that the psychiatric assessment was based on clinical history and screening questionnaires rather than a full diagnostic interview. Although clinical follow-up of the facial lesion was available at five months, longitudinal reassessment of psychosocial symptoms, school reintegration, and dermatology-related quality-of-life scores was not available. Therefore, this case cannot determine whether the patient's emotional and social difficulties improved following treatment and supportive measures. Nevertheless, the case is valuable because it captures an early and clinically meaningful psychosocial burden that may otherwise be overlooked in routine leprosy care.

Overall, this case illustrates that visible pediatric leprosy can become a source of stigma-associated psychiatric distress and quality-of-life impairment. The patient's shame, bullying experience, school refusal, social withdrawal, reduced peer interaction, and decreased appetite show that the impact of leprosy extends beyond the skin and nerves. For children, especially those with facial lesions, leprosy care should include early psychosocial screening, family counseling, school-based support, and stigma reduction. Recognizing these hidden burdens is essential to ensure that successful treatment means not only microbiological cure, but also restoration of confidence, school participation, and social well-being.

CONCLUSION

This case report highlighted the psychosocial and functional burden associated with a visible facial lesion in a 10-year-old girl with multibacillary leprosy. Feelings of shame, peer teasing, school refusal, social withdrawal, and decreased appetite were accompanied by emotional symptoms and peer relationship difficulties identified through clinical history, the Strengths and Difficulties Questionnaire (SDQ), and the KUKUH quality-of-life assessment. Relatively preserved prosocial functioning suggested that social withdrawal coexisted with positive interpersonal capacities. Although these findings did not establish a formal psychiatric diagnosis or a causal relationship between the skin lesion and psychosocial distress, they underscored the importance of integrating psychosocial assessment into routine pediatric leprosy management. Comprehensive care should address emotional well-being, school attendance, peer relationships, and perceived stigma alongside appropriate multidrug therapy (MDT). This case emphasized the value of a biopsychosocial, child-centered approach in

primary healthcare settings to identify psychosocial difficulties early and support the overall well-being and daily functioning of children affected by leprosy.

Future research should employ longitudinal, multicenter study designs to investigate psychosocial outcomes among children with leprosy, particularly those presenting with visible facial lesions. Repeated assessments using validated, age-appropriate psychosocial instruments, supplemented by structured psychiatric diagnostic interviews when clinically indicated, could help distinguish psychological distress from diagnosable psychiatric disorders and monitor changes throughout treatment and recovery. Further studies should evaluate the effectiveness of family-centered counseling, school-based stigma-reduction programs, bullying prevention strategies, and coordinated school reintegration interventions. Incorporating the perspectives of affected children, caregivers, teachers, and healthcare professionals would provide a more comprehensive understanding of psychosocial needs and barriers to participation. Such investigations could identify effective interventions for promoting sustained improvements in emotional well-being, social inclusion, educational participation, and health-related quality of life among children affected by leprosy.

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