

Treatment experiences of adults with cutaneous leishmaniasis in Ethiopia: A hospital-based phenomenological study

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Abstract

Background

Early treatment for cutaneous leishmaniasis (CL) is effective but remains restricted to specialised hospitals in Ethiopia. We explored the experiences of CL-affected people receiving treatment at Boru Meda and ALERT hospitals to understand their perspectives on issues that may require specific interventions.

Methods

We interviewed 22 adults receiving care for complicated CL and observed the culture of service delivery in both settings.

Results

Care-seeking was driven by failure of traditional remedies, recommendations from former patients, or referrals from other health facilities. However, treatment initiation was delayed by drug stockouts, insufficient bed capacity and the financial costs of treatment monitoring tests. CL-affected people's lack of prior knowledge about the requirement for prolonged hospital admission and unclear communication about treatment by hospital staff contributed to initial confusion and anxiety. The daily intramuscular injections of sodium stibogluconate were experienced as extremely painful. Despite this, participants expressed optimism in hospital-based CL treatment. Healthcare staff compassion and support from other CL in-patients were positive experiences associated with hospital-based treatment. 13/18 people rated their lesions as 'better' after treatment. Individuals with poor outcomes attributed lack of healing to taboo behaviors said to exacerbate CL (sexual intercourse, agricultural work and social mixing) and delayed care-seeking.

Conclusion

Strengthening community engagement may reduce treatment delays and suffering by improving access to culturally appropriate information through trusted channels, enhance provider–patient communication by incorporating community feedback into services, and reduce out-of-pocket expenses by increasing awareness of free or subsidized care. However, better tolerated, non-hospital-based CL treatments remain essential.

Introduction

In Ethiopia most individuals with cutaneous leishmaniasis (CL) rely on traditional medicine and home remedies to manage their lesions [1–5]. The individuals most at risk of contracting CL live in highland

areas far from hospitals, but where sandflies, which transmit this parasitic disease, are more commonly found amongst dry rocky outcrops [6–8]. Ethiopia's estimated incidence of CL is between 20,000 and 30,000 case per year [9]. CL causes painless skin lesions, often on the face, that can lead to permanent scarring and anatomical changes [10,11], so the disease is often associated with significant psychological distress including anger, sadness, shame, fear, hopelessness and even suicidal ideation [1,4,11,12].

Early allopathic treatment is effective but only a minority of people with CL access formal healthcare. Historically, there has been little investment in CL public health programmes in Ethiopia and a lack of therapies suitable for use in less specialised facilities. Most primary healthcare facilities are not equipped to manage CL because of a lack of proper training or equipment [12]. People who attend hospitals for CL treatment typically have larger or complex lesions [16,17]. In some areas, there is low community awareness of the mode of transmission, the availability of treatment at health facilities and what practices promote or hinder healing [1,12,18].

Understanding CL-affected people's experiences of treatment at health facilities is essential to improve timely diagnosis and management, care quality, enhance treatment adherence and address unmet needs. CL can manifest as several different clinical phenotypes including localized CL (LCL), mucocutaneous leishmaniasis (MCL) and diffuse CL (DCL) each of which require different treatment approaches [19]. While many people with LCL can be treated on an outpatient-basis with lesion-directed therapies, those with large or multiple lesions, or lesions affecting the mucosa may need to be admitted for several weeks of daily systemic treatment and monitoring. In addition, available CL treatments are not very effective against *Leishmania aethiopica*, the major cause of CL in the Horn of Africa [20]. One seven-country study of patient preferences about the measurement of CL treatment outcomes suggests their understandings and fears of allopathic CL treatment can be quite context-specific [21], but there is very little documentation of these issues in Ethiopia.

Alongside a cohort study reporting clinical outcomes of the current standard CL treatment modalities [22], we used a phenomenological research design to explore patients' lived experiences of seeking and receiving treatment for CL in hospitals in Ethiopia, with a focus on treatment pathways, provider interactions, and barriers to care.

Methods

We used a phenomenological research design which is defined as “the study of human experience and of the ways things present themselves to us in and through such experience” [23].

Study setting

We conducted this study at two leishmaniasis treatment centres. ALERT Comprehensive Specialized Hospital (ALERT) in Addis Ababa, is Ethiopia's national referral and teaching centre for dermatology

where routine and complex cases from across the country are managed. The dermatology department is staffed by nine dermatologists, supported by trainees. There are 44 inpatient dermatology beds. Approximately 360 inpatients and 130,000 outpatients were treated between 1 September 2024 and 31 August 2025. Adult and adolescent males affected with CL are treated in a large, dedicated leishmania ward. Women, adolescent girls and younger children are cared for in a different building with smaller rooms for females with a range of skin conditions.

Boru Meda General Hospital (BMGH) is located in the rural South Wollo zone of Amhara region and is the regional dermatology hub for Northeast Ethiopia. The dermatology department is staffed by three dermatology specialists, has 44 inpatient beds and cared for 261 inpatients and 28,758 outpatients between 1 September 2024 and 31 August 2025. Patients admitted for CL treatment stay in large communal single sex dermatology wards.

At the time of the study (2022-2023), political instability and armed conflict affected healthcare provision and care seeking across many parts of Ethiopia served by the two study hospitals [24–26].

Clinical suspicion of CL at any health system level is confirmed by the visualization of *Leishmania* amastigotes on microscopy of slit-skin smear samples in hospital laboratories. The Ethiopian national guideline recommends a 28-day inpatient course of intramuscular (IM) injections of sodium stibogluconate (SSG) for the treatment of complicated forms of CL, in designated treatment centers enabling necessary monitoring of adverse effects [27]. Some patients might receive adjuvant therapies such as cryotherapy (localized application of liquid nitrogen, available at ALERT only), oral allopurinol (used only at BMGH) or paromomycin (both hospitals) [22] (see also Supplementary file S1). Uncomplicated LCL is typically managed on an outpatient basis by lesion-directed therapies including cryotherapy and/or intralesional (IL) injections of SSG. Individuals enrolled in the cohort study were asked to attend follow-up appointments at Days 14, 28, 42, 90, 180 and 360 to assess outcomes [22,28].

Participant selection

Twenty-two adults (aged 18 years or older) with confirmed CL were purposively recruited from those receiving inpatient or outpatient treatment for CL in the study hospitals during the study period (August 2022 to February 2023) aiming for a balance across characteristics that may shape experiences including gender, area of residence (urban/rural), clinical manifestation, and severity of CL lesion. Of these, 19/22 were enrolled in the prospective cohort study conducted between April 2022 and October 2024 [22,28]. We recruited three patients at ALERT who were not participants in the cohort study to achieve maximum variation of the sample characteristics. Only one person in this study was managed on an outpatient basis during the study period, at BMGH.

Data collection

A team of researchers (AYA, TC, DBD, DEW, DD & SC) conducted in-depth interviews (IDIs) in Amharic or Afan Oromo using a guide developed by research team members in Ethiopia and the United Kingdom (Supplementary file S2). Each participant was interviewed once. Interviews took place at varying stages of the treatment journey, depending on patient and researcher availability. Participants were asked to narrate their journey from the onset of CL to the time of the interview allowing them to describe their experiences related to care-seeking, treatment, and relationships with others during times of care. Interviews lasted 30-80 minutes, were audio-recorded and were conducted in private rooms at the hospitals. Interview data were supplemented with demographic and clinical data recorded in the larger CL cohort study, where available, including participant- and physician-reported outcomes [22]. To explore the culture of service delivery in each hospital setting, ethnographic observations were also recorded using unstructured field notes, capturing routine interactions and daily activities among CL-affected individuals interviewed and others within the hospital's waiting areas, dermatology outpatient unit, CL and dermatology wards, and places used for eating and socializing. The interview team had weekly debriefing sessions with other team members to help guide data collection and analysis.

Data management and analysis

Audio-recorded interviews were transcribed in Amharic or Afan Oromo and then translated into English for analysis. Transcripts were stored in REDCap, and all were read and re-read prior to coding. Coding of transcripts and observation notes was performed by TC and AYA, each taking responsibility for data at one site, to identify patterns, construct themes and narratives, and detect differences in experiences between treatment settings. Senior researchers (MK, EG, JP & TM) also listened to sample audios or read transcripts to check the data quality and give input on the analyses. Observation notes and interviews from each setting were analyzed separately and then compared to identify patterns, assess consistency and highlight divergences in the data sources and enable us to ground accounts in the real-world hospital contexts. All quotes exemplifying themes are presented with labels for the hospital (AL-ALERT or BR-BMGH) where the interviewee was treated, gender and age in years. Participant demographic and clinical data were analysed with descriptive statistics.

First, we present a summary of the characteristics of the 22 participants and then qualitative data in two main parts: experiences of care-seeking prior to hospital admission and experiences after admission.

Results

Sociodemographic and clinical characteristics of participants

Twenty-two adults receiving treatment for CL were recruited and interviewed. 12 were recruited from BMGH and 10 from ALERT (3 were not part of the cohort study, Table 1 and Supplementary file S1). At BMGH, a higher proportion were men (9/12) compared to those at ALERT (5/10). The proportion of

participants with MCL was higher at Boru Meda (7/12) compared to 2/7 at ALERT. One participant at ALERT had DCL. The period between the first appearance of lesions and current hospital admission, as reported by participants, indicated substantial delays at both hospitals (ranging from 6–144 months at ALERT and 4–48 months at BMGH). Seven people had more than one lesion. Most participants (18 of 22) had facial involvement, two had lesions on their hands, and two had lesions at sites covered by clothing. At ALERT, the seven participants involved in the cohort study received IM SSG. Six of these individuals received additional lesion-directed (cryotherapy or paromomycin ointment) therapy. At BMGH, most (10/12) interviewees received systemic therapy (IM SSG or IM paromomycin), accompanied by oral allopurinol. One participant at ALERT and one at BMGH received two 28-day courses of systemic treatment. Among people with Day 90 outcome data available, the majority (5/6 or 83.33% at ALERT and 8/12 or 66.66% at BMGH) rated their lesions as ‘better’ after treatment (Table 1).

Care-seeking prior to hospital admission

Early symptoms

Many participants initially mistook their CL for less serious conditions such as acne, fungal infections, or a reaction to sunlight. One man, discussing why it took him 12 months to present to hospital, reflected on how the large lesion on his nose started: *“It [the first CL lesion] was small [...] just a pimple, and it was nothing to worry about. That is why I did not pay much attention”* (AL 060, male, 19 years).

Traditional medicine use

Most participants in both settings (9/10 at ALERT and 10/12 at BMGH) described using traditional remedies including plant-based preparations regardless of differences in religion or place of residence (rural or urban).

“One of the medications was leaf and the other was like a stem sap. The leaf was crushed and stuck to the surface of the lesion. [...] He [the traditional healer] dripped the milky fluid [sap] here [pointing to CL lesion on his cheek]. Then, he placed cotton on it. It formed a crust, and he removed the crust to apply again. It burned a lot and worsened my wound (AL 096, male, 18 years);

“The traditional healer mixed the acidic fluid from a car battery with leaf extract and applied it here [pointing to CL lesion on his hand], but I refused application on my nose. The mixture caused burning sensation to me. He [healer] said it would heal, but it severely damaged my hand, let alone healing it” (BR 002, male, 45 years).

Participants at both hospitals described being advised against using allopathic medicine for their CL, as it would only lead to a temporary cure, unlike traditional plant-based medicines: *“People [in my community] say modern treatment only cures the disease [CL] temporarily... and can’t permanently*

eliminate it. In contrast, they believe traditional treatment, despite causing temporary swelling, cures the disease permanently" (BR 089, male, 18 years).

Failure of traditional medicines and practices to improve lesions, however, were an important driver for individuals to seek care at the hospitals:

"I tried a lot of [traditional] medicine [...] for about six months. [...] It [CL] came back when I thought it was healed. Because of that, I gave up, and took a referral paper from a health centre to come here [ALERT]" (AL 060, male, 19 years).

Others described avoiding traditional medicine altogether, because they feared adverse effects or had observed others experience harm: *"Others with CL used traditional treatment, but I didn't, as I saw their lesions worsen. Despite people saying modern treatment doesn't cure CL, I ignored them [...] and chose injections [at BMGH] despite the pain"* (BR 052, female, 47 years).

Use of prayer or religious practices

Participants indicated that they visited religious places or persons for prayer and application of holy water or holy soil from the grounds of churches or mosques to heal their lesions before seeking hospital care. Some participants took comfort in religion to cope with the psychosocial impacts of CL and both Muslim and Orthodox Christian participants used prayer ('*dua*' or '*tselot*') to assist the treatment process and sometimes requested others at the hospital to pray for them.

Experiences at other health facilities

Participants, especially those at ALERT, described care-seeking journeys involving multiple visits to other health facilities, receiving incorrect diagnoses, and being referred by health workers who had not considered CL as a differential diagnosis:

"I went to a health center and got medicine, but the wound didn't improve. They referred me to [hospital name censored], where I had minor surgery and was given drugs, but the disease [the CL lesion] worsened. I then went to [...] [another] hospital, where they diagnosed it as skin tuberculosis and gave me anti-TB drugs for six months, but it didn't work. Finally, I returned to [the first] hospital, and they referred me here [ALERT]" (AL 185, female, 18 years)).

One participant at ALERT was correctly diagnosed and referred at a private clinic by a clinician who also worked at ALERT.

Lay person referrals

Former hospital patients and other community members with knowledge and experience of CL services sometimes played a role in encouraging others to seek care at both treatment centres:

“My brother-in-law had the same illness [CL]. He initially sought treatment from a health centre, and then from traditional healers [...] Then, he came here [ALERT] and got cured. He is the one who advised me to come” (AL 058, female, 18 years).

Competing priorities

Family and community members often encouraged participants to delay visiting ALERT or BMGH until important seasonal work was completed, due to the time they would be away from home: *“My husband said that my illness was not fatal and I should not rush for treatment early. He said I should [...] get treatment after we finished our work”* (BR 088, female, 32 years). Moreover, single parents and those who lacked support from relatives also found it difficult to seek timely care.

Insecurity

Participants at both hospitals reported that their conditions worsened due to their inability to travel to facilities because of armed conflict. A woman who was eventually treated at BMGH said: *“When I decided to come here [BMGH], the war started. I couldn’t come and had to flee my village. During the war, my lesion worsened”* (BR 056, female, 42 years). Another man treated at ALERT described initially being diagnosed and treated for CL at the hospital but delaying his follow-up by two years after the trauma of being detained for days by an armed group on his way home from the hospital.

Patient experiences of hospital CL care

Diagnosis

Patient experiences of receiving a CL diagnosis at the hospital depended on whether they had considered CL as a cause of their lesions prior to arriving and how they interpreted the need for admission to treat their CL. Experiences of the slit-skin smear test for confirmation were commonly mixed in with patient accounts of other tests needed to assess their suitability for receiving SSG. Some participants described pain when laboratory staff took samples from their lesions: *“When blood was taken, it hurt me so much, making me lay on the bed”* (ALNC1, male, 50 years). Discussion of these topics are integrated into the subsequent sections.

Hospital admission

Shock and miscommunication

Individuals reported a range of emotional and psychological reactions to the need for prolonged hospital admission for CL treatment, particularly shock at first. Patients at both hospitals expressed surprise and distress, anticipating a simpler, outpatient-based solution. Some even feared they had a more serious condition like cancer due to the need for hospitalization: *“I didn’t expect admission. When I was told that I should be admitted, my family and I thought it was another [more serious] disease. Because we did not know about such a treatment for it [CL], and we thought it [the diagnosis] had been changed to cancer”* (BR 002, male, 45 years).

Unclear communication about the need for hospitalization and method of treatment sometimes compounded distress:

“What I came up for was to be given something to be easily swallowed or applied and I thought it would easily heal. [...] the professional [doing an ECG test requested for CL treatment monitoring at a private clinic] told me that I would be his customer, mentioning that I would stay for 28 days. That shocked me! [...] My father was very shocked too. Then I was in a very bad mood” (AL 060, male, 19 years).

Interviewees were worried about the impact of a long hospital stay on their daily lives, including work and family responsibilities, and anticipated financial and logistical challenges. Some expressed concern that they would be isolated and confined to the hospital grounds. One man who had previously experienced stigma and been isolated in his community stated: *“I thought that I would be admitted alone in a separate room. I worried a lot about [...] being here] for 28 days without contact with other people, spending day and night in bed”* (BR 007, male, 20 years).

Delays in starting treatment

Most participants were not admitted at the time the diagnosis of CL was made, due to drug stock-outs or insufficient bed capacity.

Patients prescribed IM SSG required blood tests assessing kidney and liver function and an electrocardiogram prior to and during treatment. At BMGH, these tests were available in the hospital at a low price with a mean total out of pocket cost of 179.83 birr (USD 3.15 at the exchange rate during the study period), while ALERT required patients to have these done at a nearby private clinic costing 1269.9 birr (or USD 22.28). Participants at ALERT struggled to afford them, with some delaying or omitting necessary tests, further delaying their treatment. For example, a man who delayed treatment initiation for two years said: *“I couldn’t come back [to ALERT] because I didn’t have money. Thus, it [CL] got worse making me look like this [indicating his disfigured nose]”* (AL NC1, male, 50 years).

Patients reported waiting up to six months to be admitted. At ALERT, some patients had to wait because of a lack of bed capacity, while at BMGH, the main issue was interruption of CL drug supplies. Delays were compounded by challenges with the hospitals’ patient communications procedures or telecoms infrastructure:

“They [healthcare workers] said they would call us when a bed is available. But they didn’t call us. So, we came again on our own and fortunately got a bed” (AL 058, female, 18 years);

“I was waiting for the phone call. Later, I learned that they were trying to reach me when the drug was in stock, but my phone was not working as I live in a rural village. So, I missed the chance [to get treated earlier]” (BR 056, female, 42 years).

Overall, the pre-treatment phase was described as challenging and tedious, marked by miscommunication from healthcare professionals and a lack of immediately available solutions. This contrasted with more positive experiences once treatment began: *“It’s very good after starting the medical care. But what was before that [treatment initiation] was not good. I had been here several times without anything [test results or admission]. It [the process] was very tedious”* (AL 036, female, 45 years).

Treatment experiences

Hope in CL treatment

Many participants expressed hope that the treatment would heal their lesions without leaving scars: *“I do not have worries now because I am hoping the lesion will heal [...] that the treatment here will cure me”* (BR 052, female, 47 years). While some initially felt anxious or hopeless due to the severity of their condition, hope and the desire for normalcy were key motivators for acceptance and completion of CL treatment:

“I will return to my farm, which I share with others. If I recover, I want to go back to my village; [...] improve my life and marriage. Yes, I’ll reconnect with the community, attend funerals and weddings with my wife. If my body returns to normal, I can achieve all this. I want this” (AL NC1, male, 50 years).

Many also found reassurances through observing positive outcomes in other patients.

“Like what I have seen on other patients [whose CL lesions are healing], I hope it [the CL lesion on my face] will disappear too” (AL 058, female, 18 years).

Pain related to injections

Many participants felt the treatment process was difficult, especially the daily IM injections of SSG and paromomycin which were often reported as painful and hard to endure:

“I have no words to describe the pain that I feel when I take the medicine [through injection], the pain still comes to my mind” (BR 007, male, 20 years, treated with IM-SSG and oral allopurinol);

“The pain after I took the injection persisted for hours. It is not the disease that is painful, but the treatment is more painful than the disease. I find it difficult to walk [right after taking the injection]” (BR 075, male, 52, treated with IM-SSG and allopurinol).

An observation note by the research team describes how the pain was experienced and managed by a group of women at BMGH:

“A young woman with a CL lesion on her lip was crying outside the female dermatology ward while a middle-aged woman joined in crying. A female caregiver of another patient started reassuring both. Both were massaging their injection sites, walking around to relieve pain, and described it as ‘intolerable’” (BMGH, January 24, 2023).

Despite these challenges, some patients stoically acknowledged that the injections were necessary and effective: *“The injection might be very difficult, but nothing compares to the challenge of dealing with poor health”* (BR 088, female, 32 years).

Disruptions in day-to-day life

Inpatient treatment significantly disrupted patients' educational or working lives, compounding the effects of the disease.

Interruption of educational opportunities were associated with anxiety about being left behind by their peers:

“This disease started last year. [...] they [my grandparents] took me to their home in the lowland village for traditional treatment. So, my education was interrupted when I went there. [...] I continued travelling to find other medications like tsebel [holy water] and I discontinued the school after that. Still, I didn’t get better, I am here [ALERT], I left the school totally” (AL 096, male, 18 years).

“My religious learning stopped. My friends excelled, but I’m not at their level. I hope to reach it if I regain my health ” (BR 007, male, 20 years).

Similarly, CL and its treatment significantly disrupted patients' ability to work, leading to financial instability, loss of livelihoods, and dependence on others. Many participants reported that prolonged hospital stays further undermined their income and livelihood, leaving already vulnerable families worse off due to physical limitations, stigma, and the challenges of seeking treatment.

“My illness [with CL] prevented me from carrying out my daily routine. For example, I am here [at BMGH] during the ploughing season, but I have no son to plough my farmland, only daughters who, despite being able to perform other tasks, cannot plough. This creates a significant deficit, and the impact of the disease on my work and livelihood is substantial.” (BR 091, male, 50 years)

Experiences of hospital domestic services

The cleanliness of the facilities, proper care once admitted, and provision of food were frequently commended: *“The rooms are clean, and we are served food according to a schedule. I did not rush to get discharged because everything is good here”* (BR 091, male, 50 years). However, other participants at both hospitals complained about the taste or variety of hospital food served. A group of women at Boru Meda

said they sometimes cooked their own sauce to accompany injera. At ALERT, women and men believed they needed to supplement hospital food to manage adverse effects of treatment such as pain, dizziness, and nausea, referring to SSG as ‘powerful’, requiring body-building foods as understood it may affect their internal organs:

“Patients in the CL wards expressed dissatisfaction with the quality and nutritional value of the hospital food, noting that it does not meet the dietary needs to manage drug side effects [of SSG]. They often supplemented meals with food brought by visitors, take-away items, fruits, or purchases from the cafeteria to improve their diet” (Observation, ALERT, August 24, 2022).

Treatment progress

Despite all these challenges, most participants reported significant improvements in their symptoms and overall health. Participants described a variety of improvements including reduced swelling, weeping and resolution of secondary infection of lesions. A man with MCL who rated his clinical outcome ‘better’ at follow-up said, *“it [my CL lesion] is showing an improvement from day-to-day. When I finish [treatment in] 10 days, I hope I will become normal”* (BR 070, male, 64 years).

Similarly, a young girl who received IM SSG and cryotherapy for localized CL at ALERT said:

“At the beginning of medication, there was pus like discharge. Now, it is dry and no discharge.” (AL 098, female, 18 years). The emotional and psychological impact of these improvements was evident. Patients who previously felt frustrated, isolated, or self-conscious due to their condition expressed newfound confidence and happiness as their symptoms improved. The absence of scarring in some patients, particularly compared to traditional treatments, was another source of satisfaction, marking ‘full recovery’ and the possibility of social reintegration:

“Many people have scars and lose their beauty after traditional treatment, but I have no scars [...] because I used injections, thanks to Allah. [...] If they [my family] see me now, they’ll be surprised. [...] I hope those who refused to eat with me before will do so now. I’m fully recovered” (BR 007, male, 20 years, treated with IM-SSG and allopurinol).

Making sense of poor outcomes

A minority of participants, particularly those with the more severe MCL and DCL, experienced poor outcomes necessitating additional treatment and a corresponding extension of their hospital stay or re-admission. A young man with LCL who experienced relapse following treatment attributed this to the long (36 month) duration of his lesion prior to treatment: *“Before, I was admitted for two months. I improved a lot except for a feeling of mild burning. I think it is because the illness [CL] lived with me for a long time”* (BR 014, male, 24 years). At BMGH, some patients attributed relapses after treatment to engaging in taboo behaviours. In this part of Ethiopia, CL is commonly said to worsen with agricultural work, sexual intercourse, or social interactions in busy places, where the ‘shadow’ of people who have recently had sex can fall on someone with CL: *“As I told you, sexual intercourse, ploughing, meeting with*

people in the mosque and market places caused the relapse and [contributed to] exacerbation of the [CL] lesion" (BR 091, male, 50 years).

Relationships within the hospital

Relationships with staff

Patients had largely positive experiences of healthcare delivery, with people at both hospitals praising healthcare staff for their compassionate, respectful, and supportive approach: *"The nurses are very happy and hopeful for us. Even when we get upset, they never let us feel alone. They [nurses] and the doctors always check on us, offering great hospitality and touching me and every patient with their hands"* (AL 060, male, 19 years).

Relationships with other patients

Participants reported they formed strong bonds with other inpatients receiving treatment for skin conditions, but particularly others with CL. Patients frequently mentioned how they supported, encouraged, and cared for one another, creating a sense of belonging. For example, a woman at BMGH explained: *"When I had discomfort overnight, they [other females with CL and other skin conditions in the ward] cared and showed sympathy. [... We] even celebrated a woman's discharge yesterday"* (BR 056, female, 42 years). These relationships often formed quickly, with patients referring to each other as 'brothers', 'sisters', or 'family,' despite coming from different regions or religious backgrounds:

"I have a lot of friends here. All of us came from different places but we are living together as friends and relatives" (AL NC3, female, 53 years);

"We pray for each other and plan to stay connected after discharge, by phone or other means. Meeting here makes us one as a community, conversing and discussing [our issues] together" (BR 070, male, 64 years).

Talking, joking, and sharing experiences eased boredom, sadness, and worry:

"When I asked patients [about treatment] here on my first day, they reassured me that it's simple, saying they played football and spent the day refreshing themselves. Their support made me feel relaxed. On the second day, we exchanged our life stories, socialized, and grew close. [...] I also reassured newly admitted patients, sharing my first-time experience and telling them not to worry" (BR 007, male, 20 years).

Patients actively exchanged knowledge about their illness, treatments, and coping strategies. They discussed lesion progression, medication effectiveness, and lifestyle adjustments. These peer discussions empowered individuals to manage their condition and make informed decisions: *"We promised one another that we will call one another even if we are discharged from this hospital. If one of us is cured, we will follow the same path to get cured. [...] For example, there was a boy discharged [from*

ALERT] and I called and asked him about the progress of his wound. He assured me that he was recovering well and the lesion didn't relapse. This communication made me happier and I found it important." (AL 60, male, 19 years)

Resource-sharing was central to building this caring community of solidarity, as patients exchanged food, drinks, spare syringes and medication, and helped with tasks such as meal preparation or going for tests: *"We all have the same disease [CL]. So, we understand and help each other as friends"* (AL 096, male, 18 years).

Discussion

This study highlights the complex experiences of people with CL in Ethiopian specialised referral hospitals. Failure of traditional medicines to improve lesions, as well as referrals from former patients and health facilities, were important drivers for individuals to seek care at the study hospitals, while misdiagnosis, reliance on traditional remedies, competing social or economic priorities and political insecurity delayed care seeking. At hospitals, the financial costs of treatment monitoring tests at ALERT, drug stockouts and insufficient bed capacity delayed initiation of treatment, while CL-affected people's lack of prior knowledge about the requirement for a long hospital admission, sometimes combined with unclear communication by hospital staff, contributed to initial confusion and anxiety. Long hospital stays contributed to disruptions in education, livelihoods, and social roles. The daily IM injections of SSG were extremely painful. Despite these difficulties, participants expressed optimism in hospital-based CL treatment, drawing strength from compassionate healthcare staff and the support of other inpatients with CL who had become 'like family', sharing resources and forging bonds across different cultural and religious backgrounds. The ways people bonded was sometimes gender-specific, with men talking about the benefits of football they played near the wards and women enjoying cooking together. After treatment, 13/18 participants rated their lesions as 'better' (and an additional 4 rated them as 'somewhat better'), with poor outcomes attributed to taboos associated with delayed healing and prolonged untreated disease. These findings highlight both gaps and opportunities to strengthen CL care.

This study had some limitations. Interviews with some participants were conducted early in their treatment course, preventing us from capturing their experiences of treatment effectiveness and after discharge. The perspectives of healthcare workers and children were not included. Since only a small proportion of CL-affected people in Ethiopia reach hospitals and receive allopathic treatment, our findings on care-seeking do not represent the broader CL-affected population. While we recognised some cultural concepts about CL lesion healing (related to exposure to soil and sexual intercourse) from our previous research in communities served by BMGH [1, 5, 12], we could not explore all the disease-specific discourses about CL healing in the diverse populations seeking care at ALERT. However, our study's careful, phenomenological approach to documenting patients' multifaceted experiences associated with facility-based treatment for CL in two important dermatology centres in different parts of Ethiopia, with purposeful sampling ensuring diversity in clinical presentation and gender, revealed important insights that complement ongoing clinical, economic and health system studies that seek to

improve CL care in the country [4, 5, 12, 22, 29]. Unlike some other Neglected Tropical Diseases (NTDs) of the skin including leprosy, Buruli ulcer and lymphatic filariasis [30–32], there is very little documentation of how management processes and relational interactions within specific hospital and health facility settings contribute to affected people's experiences of CL disease and care.

The challenges faced in hospital-based care for CL echo findings related to other NTDs. Globally, late presentation and diagnostic delays for CL arise from a lack of awareness, reliance on traditional medicine, centralized specialist services, limited hospital capacity and high treatment costs [1, 2, 5, 12, 33, 34]. Community engagement strategies in West Africa, such as involving traditional healers, have improved hospital service utilization for Buruli ulcer [35]. Our findings on lay referrals and peer networks align with evidence highlighting the role of social capital in navigating healthcare, as seen case detection for rarer NTDs like human African trypanosomiasis [36]. Long inpatient stays for CL disrupt daily routines and impose significant financial burdens due to transportation, food and treatment-related costs, straining household resources [5, 10, 14, 34, 37]. Limited access to effective treatment and insufficient disease knowledge contribute to uncertainties and psychological distress among those affected by CL [1, 12, 37–40]. Poor communication from providers exacerbates this anxiety; another study at ALERT showed only 39% of CL-affected people felt their doctor adequately explained their treatment [41]. Traditional lesion-based treatments for CL such as cauterization and application of caustic plant sap often worsen pain and lead to scarring [1, 2], while allopathic lesion-based treatments like IL-SSG or cryotherapy offer quicker healing with less discomfort [41–43]. Supportive relationships between peers and healthcare workers are vital for improving outcomes in leprosy, fostering trust and patient-centered communication that enhance adherence and psychosocial well-being [44]. These connections are crucial not just for addressing clinical needs but also for sustaining motivation and emotional resilience during prolonged treatment [45, 46].

The ineffective communication by providers at the time of diagnosis that we have reported along with drug stockouts, insufficient bed capacity and out-of-pocket expenses for treatment monitoring tests highlight ongoing gaps in policy implementation for CL. This is despite Ethiopia's commitment to universal health coverage and strengthening of primary healthcare systems to support NTD control and reduce CL-affected people's reliance on traditional medicine [47,48]. Policy and practice implications are clear: improving provider communication, ensuring reliable drug supplies, and reducing out-of-pocket treatment costs are needed to prevent additional delays and mitigate suffering. Out of pocket payments, for example, could be reduced through ensuring all necessary treatment monitoring laboratory services and supplies are available in public hospitals so that patients don't need to purchase them from the private sector. Promoting community-based health insurance will also reduce hospitalisation costs for CL-affected people. Strengthening diagnostic knowledge of staff at primary healthcare centres, referral pathways and community engagement in endemic areas could counter lack of knowledge and misconceptions about hospital-based CL treatment and CL healing. People hospitalized for CL treatment are an important source of knowledge about CL and CL services which shape future patient expectations and experiences. They are key stakeholders for the national CL program to understand and engage in their plans to strengthen and decentralise services. BMGH and ALERT hospitals should build

on the strengths of the existing, informal peer support networks that have emerged in their dermatology wards and the compassionate care of their staff by fostering more structured patient support systems. In-hospital interventions may also help address misinformation about healing taboos. Dermatology departments at other hospitals in endemic area should also engage CL affected people to help assess their own patient management practices and issues relevant to their particular contexts. Further research is also needed to identify better CL treatment regimens that reduce pain, the length of and need for hospital stays and improve outcomes for all patients.

Abbreviations

ALERT: ALERT Comprehensive Specialized Hospital

BMGH: Boru Meda General Hospital

CL: cutaneous leishmaniasis

CL: cutaneous leishmaniasis

DCL: diffuse cutaneous leishmaniasis

IDIs: in-depth interviews

IL: intralesional

IM: intramuscular

LCL: localized cutaneous leishmaniasis

MCL: mucocutaneous leishmaniasis

N/A: not available

NTDs: neglected tropical diseases

REDCap: research electronic data capture

SSG: sodium stibogluconate

USD: United States Dollar

Declarations

Membership of SHARP collaboration

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Declaration of Competing Interests

The authors have declared that no competing interests exist.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the declaration of Helsinki with observance of ethical principles. Ethical approval was obtained from the London School of Hygiene and Tropical Medicine (Ref: 26421 dated 11.10.2021), the Ethiopian National Research Ethics Review Committee (Ref:722-506/m259/35/2021), Armauer Hansen Research Institute (AHRI) and All-Africa Leprosy, Tuberculosis, and Rehabilitation Training Centre (ALERT) ethics review committee (Ref: PO/26/20/2021), and the Institutional Review Board of University of Gondar (Ref: VP/RTT/05/946/2022). Written informed consent was obtained from all participants.

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Consent for Publication

Consent for publication was obtained from all participants for the use of anonymized data; no identifying images or personal or clinical details that could compromise anonymity are included in this manuscript.

Availability of Data and Materials

The datasets generated and/or analysed during the current study are not publicly available due to the presence of potentially identifiable and sensitive information from research participants. In line with ethical obligations to protect participant confidentiality, as approved by the relevant Ethics Committees, and in accordance with national data protection regulations, these data cannot be made publicly available.

De-identified data may be made available to qualified researchers upon reasonable request, subject to review and approval by the institutional Ethics Committee to ensure that the proposed use is consistent with the original ethical approvals and participant consent.

Requests for access to the data should be directed to:

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Authors' contributions

TC and AYA contributed to the conceptualization, data collection, formal analysis, drafting of the original manuscript, and addressed comments from reviewers. TC, AYA, YH, DEW, DBD, FAK, DD, SC, BH, TN, and GM were responsible for data collection and curation. SLW, EG, MK, MM, JP, and SL acquired funding for the study and provided overall supervision. All authors contributed to reviewing and editing the manuscript and approved the final version.

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Tables

Table 1. Summary of participant characteristics

		ALERT (n=10)	BMGH(n=12)	Total (n=22)
Gender	Men	5	9	14
	Women	5	3	8
Age	Range	18-53	18-64	18-64
Residence	Urban	1	4	5
	Rural	9	8	17
CL phenotype*	LCL	4	5	9
	MCL	2	7	9
	DCL	1	0	1
Time between first lesion appearing and hospital admission	Range (in months)	6-144	4-48	4-144
Patient reported outcome at Day 90	Better	5	8	13
	Somewhat better	1	3	4
	Same	0	1	1

*Some data (CL phenotype, lesion duration and patient-reported outcomes) were collected only from the 19 participants enrolled in the cohort study. One person from the cohort study was missing on day 90 follow-up.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryfileS1demographicclinicalfiles.docx](#)
- [SupplementaryfileS2IndepthInterviewGuide.pdf](#)