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Abstract

Background Visceral leishmaniasis (VL) is among the world's most serious public health threats, causing immense human suffering and death. In Ethiopia, little is known about the barriers and facilitators of visceral leishmaniasis case management. This study aimed to explore such barriers and facilitators in the Amhara Regional State, Northwest Ethiopia.

Methods An exploratory qualitative study was conducted on 16 purposively selected patients and key informants from May 8 to June 2, 2023. The study participants were recruited using the maximum variation technique. The interviews were audio recorded, transcribed verbatim, and translated into English. Thematic analysis was employed using Atlas.ti 9 software with a blended approach of both deductive and inductive coding.

Results The study identified a variety of issues that hinder the success of visceral leishmaniasis case management. Treatment centers face frequent interruptions of medicinal supplies, a lack of funding, and a lack of trained healthcare providers. A lack of support from health authorities, including weak supervision and feedback systems, is also a source

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key characteristics, meanings, and implications. ese studies are useful for describing, comparing, evaluating, and understanding various aspects of a research problem [26]. e current study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) standards for ensuring comprehensive and transparent reporting of the study design, recruitment approaches, data collection, and analysis methods [27].

Participant selection

e interviewees were purposefully chosen using the maximum variation technique to gain insights from a diverse range of perspectives and to recount notable shared experiences among the various stakeholders [28]. A total of 16 participants took part in this study. Of these, eight key informants (two from each treatment center) were recruited by considering their role in the hospital. ese include hospital CEOs, heads of treatment centers, and healthcare providers. Key informants were selected for their ability to provide a wealth of information as well as their active participation in VL case management.

Eight VL patients were carefully selected for the in-depth interviews by healthcare providers based on their ability to provide valuable information and their experience in treatment centers. Patients who completed their treatment or were readmitted after relapse were selected because they were required to share their experiences based on their observations in the treatment centers. e nal sample size for both hospital CEOs and service providers, as well as patient groups, was determined based on data saturation, with no new information emerging from additional participants [29]. e principal investigator, who facilitated and conducted the data collection process, is based in an academic institution and had no prior relationship with the study participants or study sites.

Data collection

e data were collected between May 8 and June 2, 2023, using in-depth interviews (IDIs) and key informant interviews (KIIs), using a semi-structured interview guide that was developed for this study and reviewed by ve experts (Supplementary le.docx). It was designed to elicit the participants' perspectives through open-ended questions that were further probed to trigger more discussions. IDIs were conducted with current VL patients who completed their treatment course to explore their views and experiences concerning the disease and attempted treatment options, their health-seeking behavior, and the quality of the healthcare at the treatment centers. e interviews were conducted at a convenient location in the hospital just before they were discharged.

e KIIs were intended to explore the views of hospital CEOs and service providers concerning the support received from various stakeholders, program governance and integration issues, the quality of healthcare, and other factors that are both barriers and facilitators of the e ectiveness of VL treatment from the perspective of both the healthcare systems and the patients. Key informants were interviewed at their place of work during a predetermined meeting.

e interviews for this study were carried out by the lead investigator (YMG), a researcher with a master's degree in health systems management, a PhD fellow, and extensive experience in conducting qualitative interviews. All of the interviews were conducted face-to-face in convenient locations privately within the hospital setups to encourage openness and honesty. e interview sessions lasted between 25 and 60 min and were conducted in Amharic, the local language. With the participants' permission, all conversations were audio recorded using a digital voice recorder, and eld notes were taken during the interviews by one of the authors (MH). Everyone we contacted agreed to participate in the study.

Trustworthiness

We used various approaches to improve the trustworthiness of the data, such as re exivity, data triangulation, and thick description. ese data collection methods and data sources (method and source triangulation) helped to increase the credibility of the ndings [30]. roughout the research process, the principal investigator kept a re exive journal to record expectations, observations, interview experiences, options available, and decisions made, which helped to foster re exivity [31]. To enhance understanding and transferability, the research setting, process, and ndings were thoroughly described. We present a detailed account of the ndings, supported by su cient evidence in the form of quotes from the participant interviews [29].

Data analysis

e audio recordings of the interviews were transcribed verbatim and then translated into English. e transcriptions also included a summary of the eld notes.

ematic analysis was conducted based on the nalized translated data. e coding process was facilitated using the Atlas. ti 9 software package. First, all interview transcripts were read and reread to gain a comprehensive understanding of the data set. A blended approach involving both deductive and inductive methods was used in the coding process. e deductive approach was used to rst identify preliminary themes and sub-themes based on a review of the existing literature and research questions. e themes that emerged during the coding process were incorporated inductively rather than by trying to t them into a prede ned coding framework. e principal investigator independently generated the initial

coding schemes, and he classi ed them into subthemes and themes. e preliminary results were reviewed and revised with the coauthors to ensure that the ndings

and ll gaps. ey argued that the e ectiveness of a VL treatment center is attributable to the strength of the hospital management and felt that the support from higher o cials was weak. Some of the e orts that hospitals undertook, according to the respondents, included better control and e cient use of supplies to prevent shortages, the continuous supply of food despite budget constraints, resource mobilization for capacity-building activities, and knowledge transfer between sta .

> *“ e support of the hospital management is good. For example, when there are patients who lack food, the hospital provides the necessary food and treatment. ey decide what needs to be done and do it on time. e regional state can replace the budget later.” [KII-1, service provider].*

Contrary to the above statements, respondents disclosed a number of administrative concerns in hospitals where the VL treatment centers are located, including immediate responses to problems, the cleanliness of treatment rooms, and the supply of food. In particular, patients and service providers in all treatment centers expressed great concern concerning the quality of food available for VL patients, as this is highly linked to the e ectiveness of the treatment.

> *“… the response to problems is not su ciently swift; for me, the response is too late. I’m the one who is close to the case and facing it. e management will probably only nd it in the report.” [KII-4, service provider].*

> *“ ere are problems concerning cleanliness and the food. ere should be a variety of food. We are the ones who clean the room we are in; they don’t clean it for us.” [IDI-8, VL patient].*

Integration and referral system

e extent to which the VL treatment center works cooperatively with other units of the hospital and has received support from the hospital management was another area of discussion. In this regard, the VL treatment centers are well integrated, and it is such integration that has largely contributed to the e ectiveness of VL case management, as stated by most of the interviewees.

> *“Healthcare is a collaborative e ort. Without the pharmacy, laboratory, and other departments, this department cannot be e ective. e kala-azar service provision is shared; everyone knows what to do. e coordinated approach is one of the reasons for our e ectiveness.” [KII-1, service provider].*

e situation in one of the VL treatment centers is different. Due to the fact that the treatment center has its own independent team, budget, and support from an aid organization, it is viewed by the hospital community as a separate entity that is not part of the hospital in many ways. For this reason, center sta are not invited to participate in hospital affairs and meetings, such

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every month, both quantitatively and qualitatively." [KII-2, Hospital CEO].

e monitoring and evaluation system becomes looser as one goes higher up in the health system hierarchy. Rare review meetings were organized by the Ministry of Health approximately three years ago but were then interrupted. Accordingly, the study participants recommend that a well-organized and system-based monitoring and evaluation strategy be established and that actions be based on the results of such monitoring and evaluation.

" e medical center must be organized with an organized monitoring and evaluation system. Periodic indicators should be set, and the results need to be measured based on them. Second, there should be an actively programmed evaluation and revision of neglected issues by the regional health bureau. At the regional level, it was done only once this year, and there is no continuous monitoring or support. Evaluation implies attention to the program. [KII-3, Hospital CEO]

Structural inertia and lack of focus

Structural inertia

Another issue that impedes the e ectiveness of VL case management is that the existing structure does not allow care providers to perform comprehensive activities. Despite the program being budget intensive and placing a great deal of pressure on healthcare providers, hospitals are running the program without additional human resources or budget allocation. As a result, their e ort is limited only to curative services; despite that, they are expected to participate in preventive activities, such as screening. For better functioning and e ectiveness of the program, there should be a separate treatment center with its own independent team and budget, as suggested by the respondents.

"It is an additional responsibility for the existing structure. After the introduction of this program,

"*Yes, they did not know about it; now, in our district, people do not know about kala-azar. People in our district should get health education about the disease.*" *[IDI-2, VL patient].*

Belief in and the use of traditional drugs

Although the first choice of VL patients is to visit the nearest primary healthcare facility, the next option is to visit traditional healers because of their lack of confidence in traditional healthcare facilities. These range from stabbing and/or heating parts of their body, drinking herbal products, and visiting witch hunts to the use of holy water in religious places.

> *"They come late having tried many traditional treatments; they go to witch hunts, try holy water, try different drinking potions, and stab their tongues when they develop jaundice or 'bird disease', which exposes them to anemia." [KII-1, service provider].*

> *"This disease does not allow anyone to go early, including me. I did not come early because I used holy water one time and went to a witch hunt another time. There was no place I would not go to. Later. I decided to come here after I tried other things and understood that I had no other option." IDI-3, VL patient]*

Signs and symptoms of VL are given different names and reasons in society. When patients show signs of jaundice at the late stage of the disease, it is traditionally referred to as "woche" or "bird disease," whereas enlargement of the spleen and liver is known as "Lava". In the community, it is believed that such ailments are cured only by traditional drugs.

> *"Another symptom is that their eyes turn yellow because VL affects the liver. Traditionally, this is called 'bird disease'. People try various alternatives to traditional drugs for such diseases." [KII-7, Head, treatment center].*

Adherence to treatment and doctors' advice

Most of the time, VL patients adhere well to the treatment plan and doctors' recommendations because they reach the treatment center with various complications and understand the severity of the disease. However, there are instances of nonadherence due to the pain and suffering associated with anti-*Leishmania* drugs. In particular, this is common among those who have no social support and those who are young.

> *"Because of the pain caused by the drug, occasionally some people stop. The injection is very painful. Recently, one of our patients defaulted and was lost due to fear of the pain after taking the drug for three days." [KII-8, service provider].*

In addition to the medication, patients are also required to adhere to some professional recommendations. These include maintaining a balanced or high-protein diet, maintaining one's health, and avoiding harmful practices, such as alcohol intake. VL patients disclosed that some do not follow these recommendations due to various reasons, including a lack of awareness or inattention.

> *"There are patients who drink alcohol knowing that it is harmful. Some patients died due to the intake of prohibited things. I remember a person who was on kala-azar treatment, drank alcohol and smoked cigarettes who is now dead, although I told him not to do so." [IDI-2, VL patient].*

Despite both healthcare providers and VL patients placing a great emphasis on the importance of maintaining a balanced diet for the effectiveness of VL case management, it is not usually practical. The inability to maintain a balanced diet is related to the economic status of the patients and their families. Most VL patients are migrant workers who travel to VL-endemic areas to earn money and do not have assets. They may fall ill before they earn enough money, or they may spend their money on various treatment options before reaching the VL treatment center. Apart from their economic background, the disease and its treatment modality put a great burden on patients and their families in terms of both direct and indirect costs.

> *"Now, I have spent a lot of money; I have spent no less than 5 thousand Birr, and that is only in a month. Now I am spending the money that I get from the seasonal agricultural work for the treatment of this disease." IDI-8, VL patient]*

> *"The payment is difficult for us; there are those who have nothing, but it is for a cure, which is a matter of life and death. Now, there is a patient here who has no money to pay, so he is very stressed. Now, it is sent from his family. We pay for not only VL but for additional diseases; it costs a lot." IDI-1, VL patient]*

Social support

The support patients receive from their social networks,

they were migrant workers who were far from their families. In this situation, it is the additional responsibility of the healthcare provider to provide the required support.

> *"It is di cult for a patient without a caregiver. Most of the patients are migrant workers and do not have family supporters. Patients support each other; some friends bring them, but their friends do not want to stay more than three days." IDI-2.*

> *"Most of the migrant workers are far from their families; only a few have family members nearby; patients who are accompanied by family members can get good care of when food is not easy to obtain; but most of them have no family around." [KII-5, service provider].*

Nature of the disease and its treatment modality

VL-HIV co-infection and other co-morbidities

VL-HIV co-infection is another challenge that impedes the e ectiveness of VL case management, as stated by both service providers and VL patients. High rates of relapse and mortality are observed among these patients. Such patients usually receive repeated treatment and are admitted two or three times per year.

> *" ese patients experience treatment failure. e relapse rate is very high; it is about 50%. It compromises their quality of life, and they are admitted at least twice a year." [KII-8, service provider].*

> *"VL-HIV management is a big challenge for us. It is a very big challenge because, to your surprise, there is a person that we have treated 52 times. He comes three times a year, and we treat and discharge him; he can't be cured, and the parasite does not decrease." [KII-7, Head, treatment center].*

Moreover, the presence of other co-morbidities and conditions, such as chronic diseases, tuberculosis, anemia, and severe malnutrition, is another challenge that a ects the e ectiveness of VL case management. Sol5080566tions

are mostly willing to support them. ey try to relieve the pain associated with the drug injection using analgesics and encourage patients to boost their tolerance with friendly approaches.

> *“ eir care in kala-azar treatment is good; they accept us, they don't complain, and they don't get bored when we go there all the time. ey are never tired of patients, according to my observation. ey help us with what they have. So, I think it is good.” [IDI-6, VL patient].*

> *“As far as I can see, they encourage you, they take care of you, they ask us questions, and they respond to us quickly. Not the government hospital, even a private one, will help in this way. ey take great care of those who are sick.” [IDI-1, VL patient].*

As a result, patients have a thankful attitude when they leave the hospital and provide positive feedback.

E ectiveness of care

As part of the quality dimension, the points explored in the interviews included the extent to which patient care is based on the management protocol and scienti c

Although occasional health education campaigns have been undertaken in urban settings of VL endemic areas, the primary target population of interest was not reached. In particular, health education e orts are limited along the Ethio-Sudan border, where many migrant workers, the most vulnerable populations, are engaged in seasonal agricultural activities. In accordance with our ndings, a prior study in Ethiopia found that migrant workers were substantially less aware of VL than the resident population in endemic lowland areas. Health education was insu cient and primarily facility-based, and when it did reach the community, it was either devoid of VL information, too vague, or presented inconsistently [18]. Although there were health education e orts supported by external partners in Sudan, their sustainability was a concern because there was no clear funding available [17].

Overall, it is apparent that the disease is still neglected, with little government attention or engagement. e responsibility is left to donor organizations and treatment centers and the e orts by the Ministry of Health are minimal. Overreliance on partner organizations is a concern, even for maintaining current levels of VL management. ese ndings essentially corroborate what has already been reported in the literature. In East Africa, national control programs are underfunded and deprioritized, and most work to address the problem has long relied on external support [3, 32]. on the contrary, domestic nancing and good leadership and governance, as well as a strong political commitment, were shown to result in the successful elimination of VL in Nepal [35]. is could be due to the strong support of the WHO for South-East Asia VL elimination e orts [33], which may have inspired governments to prioritize the disease as a major public health issue.

Despite the importance of early detection and treatment in the VL elimination strategy [38], we observed signi cant delays in care-seeking, diagnosis, and the initiation of treatment for a variety of reasons. e delay in seeking care was mainly attributed to a lack of awareness among patients and the general population, a lack of an e ective surveillance system, and misdiagnosis due to healthcare workers having insu cient knowledge at lower-level health facilities. Patients initially seek treatment at lower-level healthcare facilities and are frequently misdiagnosed with other febrile illnesses, most

Several factors, including poverty and food insecurity, lead to malnutrition among the VL-vulnerable population [16].

VL is a cost-intensive disease, incurring both direct and indirect costs, and places hospitals under a signi cant nancial strain because treatment must be delivered over a long period on an inpatient basis. On the one hand, the therapy is extremely expensive, while on the other, hospitals experience serious budget constraints due to a lack of additional funding. In this context, hospitals are challenged to strike a balance between the two issues, which may jeopardize the quality of care. is is corroborated by the ndings of a systematic review, which found that the cost of VL places considerable pressure on the healthcare system [47].

Despite the program's inherent constraints, it is not without features that enhance the e ectiveness of the treatment. e extent to which the VL treatment center collaborates with other hospital units and is integrated within the hospital has an important bearing on the success of VL case management. Healthcare workers showed a caring attitude and a positive interaction with VL patients, attempting to understand their concerns, responding to their needs, and providing courteous service. Because the treatment modality places a signi cant strain on individuals, healthcare providers are frequently willing to help them. Furthermore, the fact that the treatment is free of charge and that external donor support is available is an added opportunity.

Although the study provides valuable insight to service providers, health authorities and other relevant stake-

Institute and a support letter was sent to each study hospital. Each study participant provided verbal informed consent. During the interviews, consent was obtained for the use of a voice recorder. Con□dentiality was ensured by collecting anonymous data and informing participants that their identi□ers would not be disclosed to a third party.

Competing interests
The authors declare no competing interests.

Consent for publication
Not applicable.

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