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Exploring the Pathways of Leprosy Patients from Their Communities to a Diagnosis in the Districts of Mayuge, Yumbe and Kasese-Uganda

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Abstract

Background*:* Leprosy is known to cause disability that leads to severe outcomes like stigma, discrimination, mental health problems and participation restriction. Furthermore, in cases of infectious leprosy, longer delays increase the risk for the spread of the disease. Despite being preventable and curable, a significant proportion of new leprosy patients (39%) in 2019 had grade 2 (Described as Visible disability) at the time of diagnosis signifying late presentation. The aim of this study was to describe patient journeys from first symptoms suggestive of leprosy to a diagnosis and individual and community level factors associated with health seeking behavior of leprosy patients. **Methods:** This was a cross-sectional explorative study implemented in Kasese, Mayuge and Yumbe districts .A structured questionnaire was used to collect quantitative data. Qualitative assessment included patients, family members, health workers, voluntary health teams and the district health team. Descriptive statistics were presented in terms of percentages, frequency tables, pie Charts and graphs for easy interpretation and discussion. **Results:** The results indicate that 53% of the respondents identified as female. The median age of the respondents being 34 years, with a range of 1 to 76 years (Mean: 44.7, Mode: 65, Standard-Deviation: 19.6, Kurtosis: −0.6). The most common first symptom noticed by respondents was skin lesions (65%) followed by deformities (18%) (P value = 0.05%) occurring mostly in the feet (P-value = 0.48). Majority (52%) of the patients had taken more than 24 months (SD 18.72 OR

2.75) for a diagnosis to be made with a maximum delay of over 60 months. The most common cause of delay in seeking health care was lack of knowledge on leprosy (P value=<0.05) and inaccessibility of the health facilities (p value =< 0.05) due to long distances and poor means of transport. The first symptom recognized was mainly skin lesions (P value = 0.01) followed by deformities (P value = 0.06) first noticed by the patients (35%) followed by family members (35%). In regard to perceived causes and modes of transmission, the community's understanding of leprosy was linked to cultural and spiritual beliefs, associating it with curses from ancestors or gods. Other beliefs were that leprosy is hereditary and that it can be caused by witchcraft. Stigma caused humiliation and emotional distress and extended to family members and caregivers, leading to discrimination. **Conclusion**s: There was a delay of 2 years in seeking health care for the majority of the patients. Key barriers to early diagnosis were lack of knowledge and infrastructure. Community sensitization and strengthening capacity building are needed to achieve early diagnosis of leprosy and proper management.

Keywords

Leprosy, Patient Pathway, Skin Lesions, Disability, Discrimination, Delayed Diagnosis

1. Introduction/Background

Leprosy (Hansen's disease) is one of the world's Neglected Tropical Diseases and is recognized as "a disease of the poor" [1] [2] [3]. It is an infectious disease that is caused by the bacterium *Mycobacterium leprae*. This bacterium affects peripheral nerves and gives rise to deformities such as muscle wasting and injuries over anaesthetized areas of the body [2] [4] [5]. Leprosy is a leading cause of preventable disability worldwide. Early detection of the disease leads to prevention of disability. Despite having been eliminated as a public health problem in most countries by 2005, leprosy cases continue to occur globally with over 200,000 new cases reported in 2019. In Uganda, the leprosy burden has reduced over time. A recent retrospective study of spatial trends of leprosy in Uganda in 2019 by Aceng *et al*., 2019 reported a continued downward trend in new cases detected with an estimated annual decline of 7% between 2012 and 2016. The declining trend was driven by statistically significant decreases in the eastern and central regions of Uganda. However, the declines in the northern and western regions were not statistically significant. However, there was a growing trend of grade 2 disability proportions from 12% in 2017 to 39% in 2020 and the proportion of child leprosy cases increased from 6% in 2017 to 12% in 2020 (MOH Annual reports) signifying late diagnosis and continued transmission of leprosy. In Uganda, 234 people were diagnosed with leprosy in 2020, majority of them from the districts of Yumbe, Mayuge and Kasese districts.

Naturally, a decrease in disease is followed by dwindling clinical skills among health workers due to the "rareness" of the disease. In most regions of Uganda, this has been noted to be the case with leprosy, contributing to late diagnosis of leprosy. Delay in diagnosis of patients augments the transmission of infection and allows progression of disease and more severe disability. The late diagnosis implies that from a disease that initially presents with skin patches, the result is often time life-changing disability. In order to break the cycle of transmission and reduce the number of new cases detected with physical deformities, it is essential to diagnose and treat patients early, before these injuries occur [5] [6].

Demographic variables such as distance from the nearest health clinic and patient's highest level of education were found to be associated with delays in China and India. [7] [8]. Additionally, leprosy patients have been found to prefer visiting traditional healers, rather than trained medical doctors [7] [9] [10] It is important to study similar questions regarding this delay within Uganda [11]. The assumption of dwindling knowledge of health care workers is not substantiated in evidence.

For identification of "last mile stones" needed to achieve early diagnosis of leprosy and to prevent late presentation with disabilities, there is an urgent need for improved knowledge and insights to enhance the identification and implementation of innovative health promotion approaches with and by empowered communities for future public health interventions. There are no specific studies have been conducted in Uganda about the health-seeking behavior of leprosy patients and no published evidence of knowledge, attitudes and practices of communities towards the disease. In this study, we describe patient journeys from first symptoms to a diagnosis and individual as well as community-level factors associated with health-seeking behavior of leprosy patients.

1.1. Purpose of the Study

The purpose of the study was to determine health system delays in diagnosis of leprosy in the districts of Mayuge, Yumbe and Kasese. The study explored the relationship between the health-seeking behaviors of leprosy patients and their types of health beliefs in the districts of Mayuge, Yumbe and Kasese and described the differences in behavior and beliefs by leprosy disability status and by adult or child leprosy index case.

1.2. Rationale

Despite being preventable and curable, a significant proportion of new leprosy patients (39%) in 2019 had grade 2 (Visible disability) at the time of diagnosis. Several studies demonstrate inter-linkages between delays in seeking health care after observing the first symptoms, attitude of communities and attitudes of health care workers. In Uganda, there are no studies done to explore and understand health-seeking behavior of leprosy patients to understand the high number of Grade 2 disability. The presented study would help to examine patients' journey to health care; the attitudes of surrounding communities in three districts of Uganda that report high numbers of leprosy patients every year.

1.3. Objectives

1.3.1. Overall Objective

The overall objective of this study was to describe patient journeys from first symptoms suggestive of leprosy to a diagnosis and individual and community-level factors associated with health-seeking behavior of leprosy patients.

1.3.2. Specific Objectives

1) To describe the reasons for the delay in seeking health care for leprosy patients diagnosed in three districts of Mayuge, Yumbe and Kasese.

2) To describe the mechanisms and ease of recognition of skin changes by households and communities explored.

3) To describe the knowledge, attitude and practice among members of communities and health care providers in reference to leprosy.

4) To describe the recommendations for increased engagement and empowering communities in health promotion activities.

1.3.3. Secondary Objective

1) To explore the presence of different levels of discrimination.

2) To describe the timing of patient presentation related to the disease status.

3) To identify the possible cultural ways signs and symptoms of leprosy are interpreted.

1.4. Research Questions

1) What factors influence the decision of an individual noting skin changes to seek medical attention?

2) What are societal and health system factors that influence health care seeking in leprosy patients diagnosed with Leprosy? (VHT)

3) What are health system requirements for early diagnosis of leprosy, timely initiation and adherence to treatment?

4) What are recommendations for increased engagement and empowering communities in health promotion activities?

2. Methodology

2.1. Introduction

2.1.1. Study Scope

The project was implemented in Kasese, Mayuge and Yumbe districts.

2.1.2. Study Design

A mixed methods study in which both quantitative and qualitative data were concurrently collected; the findings of which were merged at the point of data analysis.

2.1.3. Study Population

All leprosy patients registered in 2019/2020 from the target districts were included in the study. (Yumbe – 27, Mayuge – 42 and Kasese – 28) due to high numbers of leprosy cases with grade 2 disability. The three districts together registered approximately 97 new cases. In addition, 58 prospective patients registered during the study period were included. At least 10 Persons affected by leprosy, 10 Health workers involved in leprosy diagnosis and management, and 10 Community members in each of the three districts participated in the Focus group discussions.

2.2. Quantitative and Qualitative Approach

2.2.1. Quantitative Approach

The questionnaires (translated into respective local languages) were administered to 155 leprosy patients by trained research assistants (DTLS, leprosy focal person and VHT).

2.2.2. Qualitative Approach

For the qualitative assessment, we included 10 patients and family members, 10 health workers and VHTs, district health officials including the District Tuberculosis and Leprosy Supervisors (DTLS) and Regional Tuberculosis and Leprosy Supervisors (RTLS) including in-charges of health facilities in each of the three districts as key informants. Three Focus Group discussions in each of the three districts were facilitated by a social worker (from NTLP) and a translator who used semi-guided themes and prompts accordingly.

2.3. Inclusion and Exclusion Criteria

2.3.1. Inclusion Criteria

All leprosy incident cases with Visible disability due to leprosy Participants who consented to be enrolled in the study.

2.3.2. Exclusion Criteria

Leprosy patients who refused to consent to participate in the study.
Incident leprosy cases without visible disability due to leprosy

2.4. Ethical Consideration

Ethical approval for this research project was sought from an accredited Institutional Review Board and from the Uganda National Council for Science and Technology. This research project only enrolled those participants, who gave their informed consent to participate in the study beforehand. Data collected from the study participants was kept anonymous to ensure confidentiality.

2.5. Limitations of the Study

Limitations of this study include accuracy of recall and social acceptability bias. Although measures were taken within the questionnaire to assist participant recall, data collection largely depended on participant-reported information. Furthermore, a sizeable proportion of participants were functionally illiterate and required verbal questionnaire delivery. These responses may have been influenced by social acceptability bias with participants reporting shorter patient delays.

This study was limited to three referral centers. This sample is likely to differ from simple leprosy cases, which are dealt with in the community and results from this study may not be generalizable throughout the country. Although delays were found to be independent of region in this study, previous research has indicated that the reason for delay can vary between regions of the same country, with some areas seeing long health system delays whilst others seeing longer patient delays.

3. Results

3.1. Participant's Characteristics

3.1.1. Respondents by Gender

Table 1 below shows the participants gender distribution.

There were more males in Kasese (63%) and Mayuge (54%) Districts while Yumbe had more females (71%) respondents.

3.1.2. Distribution of Participants by Age

Table 2 below shows the age distribution of the participants in the study.

The Most common age category of respondents is 50 years and above.

Table 1. Distribution of participants by gender.

Gender	Kasese	Mayuge	Yumbe
Male	26 (63%)	28 (54%)	18 (29%)
Female	15 (37%)	24 (46%)	44 (71%)
Total	41	52	62
p-value	less than 0.05	CI 95%	

Table 2. Age distribution of participants.

age group	**Freq**	**Percent**
>50 years	59	40%
31 to 40 years	27	18%
41 to 50 years	26	18%
11 to 20 years	15	10%
21 to 30 years	15	10%
0 to 10 years	5	3%
Total	**147**	**100%**

3.1.3. Leprosy Patients' Distribution by Religious Groups

Figure 1 below shows the religious distribution among the participants.

Religious distribution by respondents revealed that there were more Christians in Kasese and Mayuge while Yumbe had more Muslims

3.1.4. Participants and Monthly Income Distribution

Yumbe district had none of the respondents earning more than 50,000 /= per month with majority earning less than 10,000 shillings per month.

3.1.5. Timeliness in Diagnosis

Figure 2 below shows the time period distribution from the first symptom noticed by the patient to when the diagnosis was made.

Majority (52%) of the patients had taken close to 2 years for a diagnosis to be made. A significant proportion of 22% had disability grade 2 at time of diagnosis. Some respondents spent more than 5 years before a diagnosis had been made.

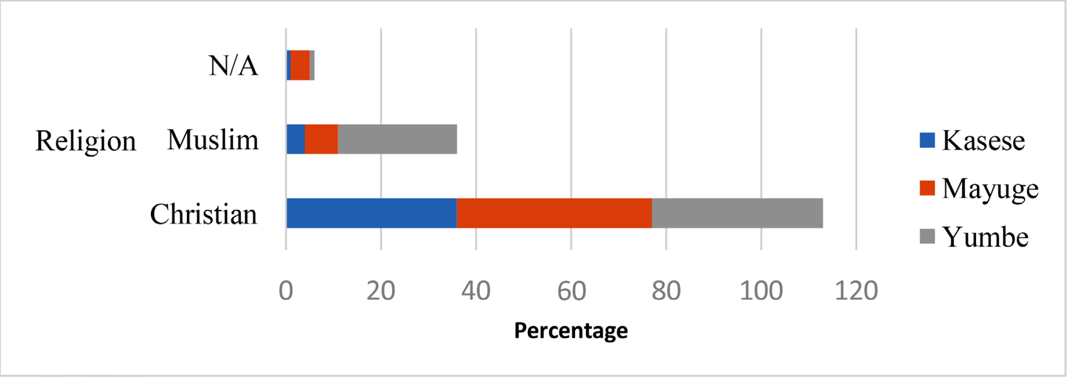

Figure 1. Leprosy cases among different religious groups.

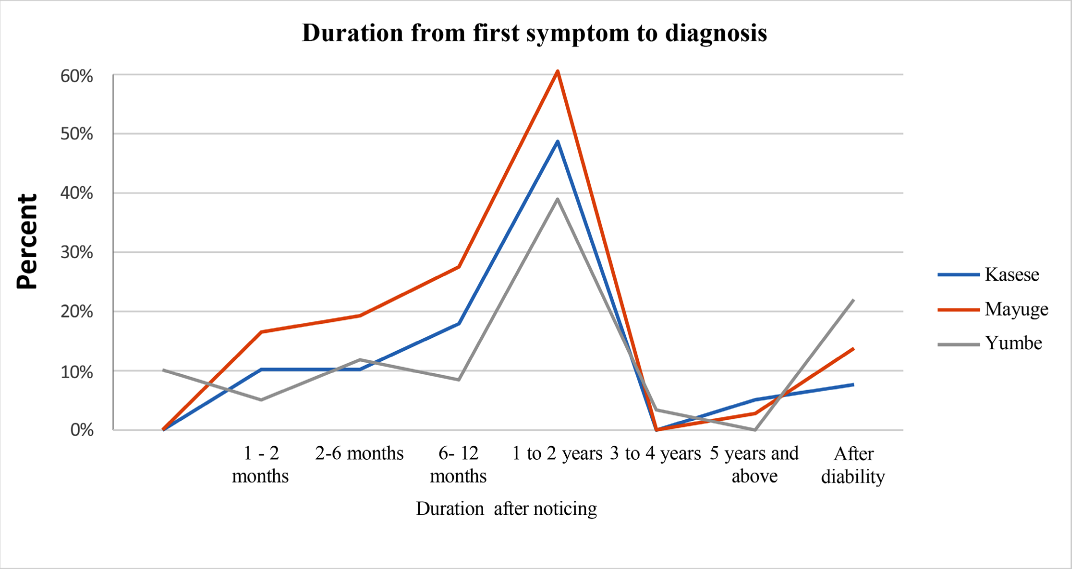

Figure 2. Timeliness in diagnosis.

3.1.6. Seeking Medical Help

1) Causes of Delay in Seeking Medical Help

The reasons for delay in seeking health care for leprosy patients diagnosed in Mayuge, Yumbe and Kasese included Lack of knowledge and difficulty in accessing the health facilities as seen in Table 3 and Table 4.

2) Limited knowledge and understanding of leprosy

Asked whether the participants knew about leprosy, Table 3 shows the following responses.

Lack of knowledge about leprosy at the time they noticed the skin changes on their bodies was reported by 75% of the respondents.

3) Participants Knowledge about Leprosy per District

Figure 3 below is the percentage response to knowing what leprosy is.

The results show that more patients in Yumbe did not know what leprosy is compared to those in Mayuge and Kasese District where the proportion of those who knew was more than those who did not know.

4) Difficulty in Accessing Health Facilities

The response to accessibility to health facilities is as follows as seen in Table 4.

63% of respondents reported difficulty in accessing health facilities.

Figure 4 below shows the proportion distribution of accessibility to the health facilities.

Participants from Kasese reported a bigger proportion of difficulty in accessing health facilities. The problem of inaccessibility was less reported by the Yumbe and Mayuge Districts.

Table 3. Knowledge about leprosy.

Knowledge on Leprosy	Freq	Percent
No	116	75%
Yes	34	22%
Nonresponse	5	3%
Total	155	100%
P-value	<0.05	CI 95%

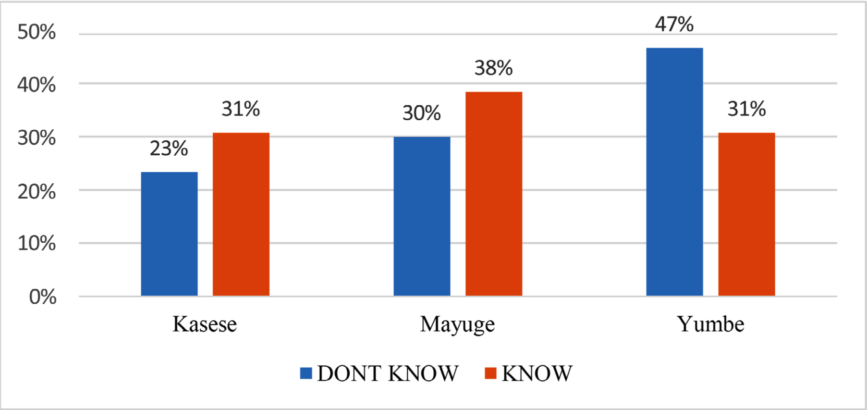

Figure 3. Response to knowing about leprosy.

Table 4. Reported level of accessibility of health facilities for patients in the three districts.

Do you find health facilities accessible for persons affected with leprosy?	Freq	Percent
Difficult to access	98	63%
Easily accessible	51	33%
Nonresponse	6	4%
Total	155	100%
P value	=< 0.05	CI 95%

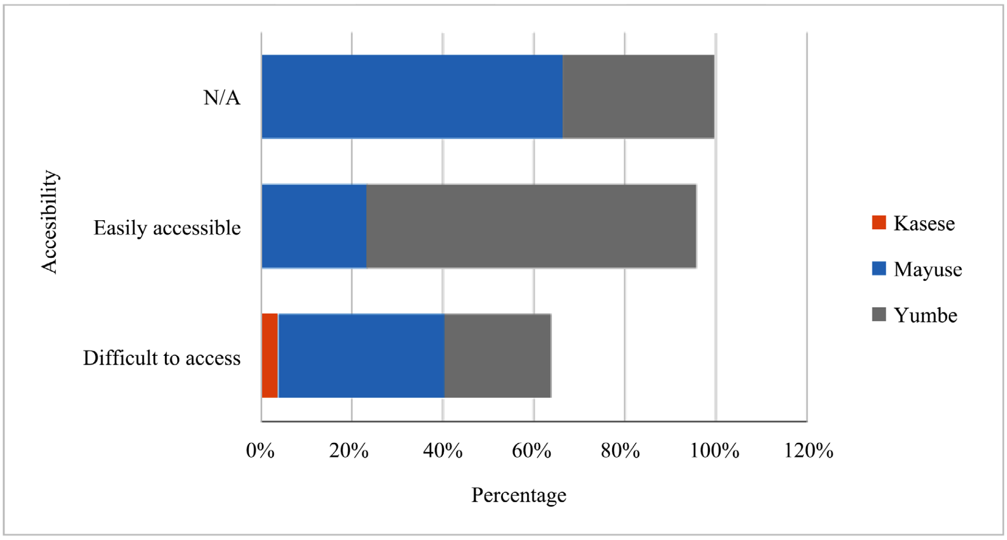

Figure 4. Reported level of accessibility of health facilities for patients in the three districts.

5) Reasons for difficulty in accessing Health facilities

The findings in Table 5 suggest several reasons why health facility services are not accessible to individuals affected by leprosy.

Figure 5 below is the response to the reason for inaccessibility by district.

The most commonly reported barrier was the long distance to the health facility, mentioned by 39% of the respondents. This indicates that the geographical distance between individuals and healthcare facilities poses a significant challenge in accessing services. Limited transportation options further compound this issue, with 15% of participants mentioning poor means of transport as a barrier to accessibility. Another significant barrier reported was the perception by the Persons affected by leprosy that health care workers were unskilled to manage leprosy, with 15% of respondents. High lighting this issue.

3.2. Mechanisms and Ease of Recognition of Skin Changes by Households and

Communities.

3.2.1. First Symptom Noticed by Patients

The first symptom recognized was mainly skin lesions followed by Deformities as seen in Figure 6 below.

Table 5. Reasons for inaccessibility of health centers.

Why do you think health facility services are not accessible?	Freq	Percent
Long distance to the health facility	61	39%
Poor means of transport to the health facility	24	15%
There are no skilled personnel who handle leprosy patients	23	15%
There are always no drugs	21	14%
Nonresponse	20	13%
Negative attitudes by the health workers	3	2%
Financial difficulty	2	1%
Persons with leprosy are less considered	1	1%
Total	155	100%
P-value	=< 0.05	CI 95%

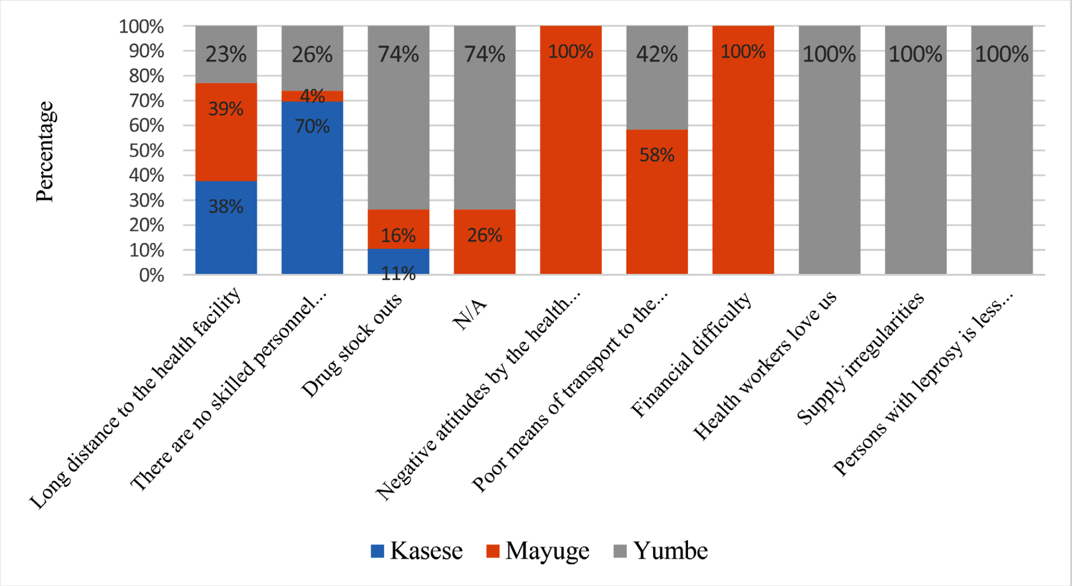

Figure 5. Proportions of reasons for inaccessibility by district.

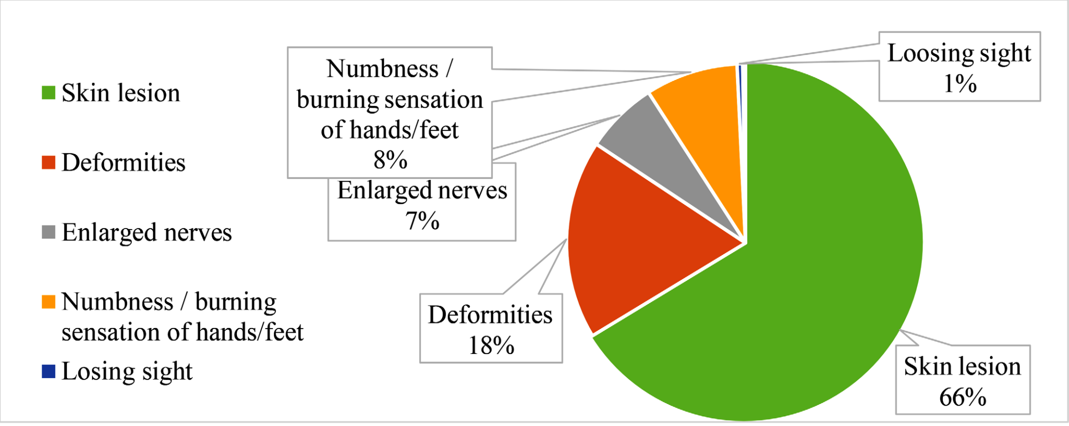

Figure 6. First symptom noticed by patients.

3.2.2. First Symptom Noticed per District

The distribution of the initial symptom noticed by patients per district is presented in Table 6 below.

The most common first symptom noticed was skin lesions followed by deformities.

3.2.3. Specific Individuals That Noticed the Symptoms

Figure 7 shows the distribution of the people who recognized skin changes among leprosy patients in the communities explored.

Most of the recognition of skin changes was done by patients themselves (35%) and family members (31%). Community health workers (9%) as well as Volunteer Heath teams (VHTs) also participated in suspecting and referring Leprosy cases.

Table 6. First symptom noticed by the patients per district.

First Symptom	Kasese	Mayuge	Yumbe
Skin lesion	63%	55%	54%
Deformities	31%	35%	29%
Enlarged nerves	2%	3%	9%
Numbness / burning sensation of hands/feet	3%	7%	7%
Losing sight	2%	0%	0%
Value	<0.05 CI 95%		

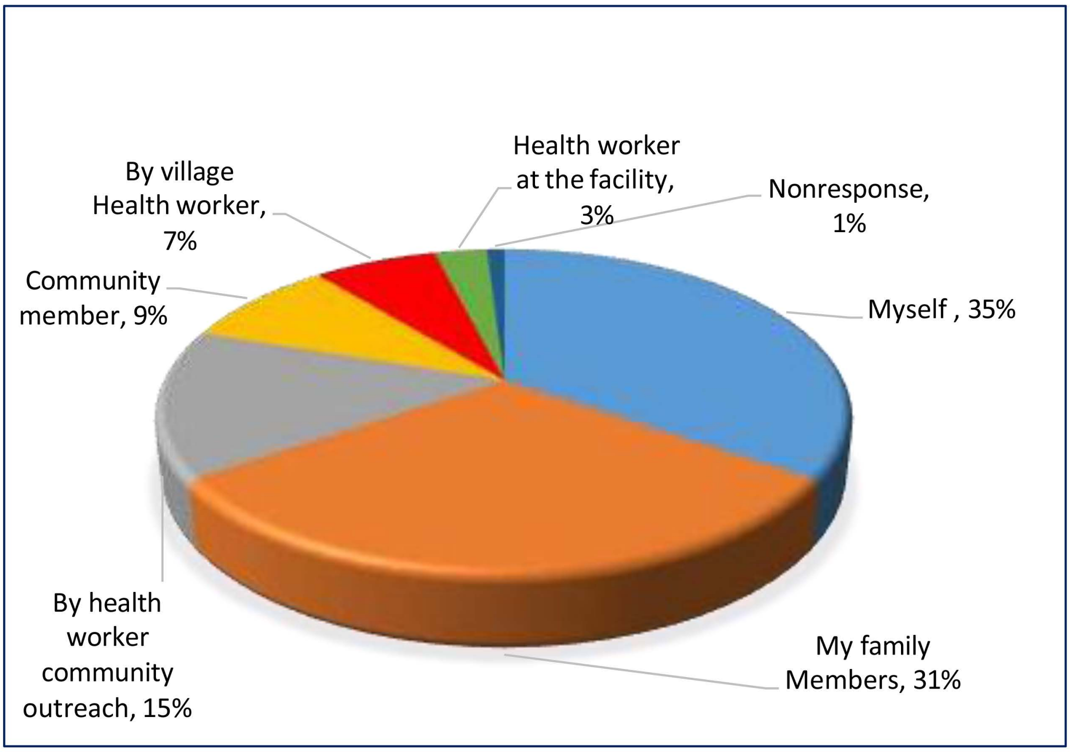

Figure 7. Specific individuals that noticed the symptoms.

3.2.4. Duration of Time from First Symptom to Diagnosis

Table 7 below shows the proportions of the different length of time from first symptom to diagnosis.

The average duration from the first symptom to diagnosis was 12-month t0 24 months. Some participants described having taken longer to be diagnosed with leprosy even up to more than 5 years from the time they developed symptoms until when they saw deformities in the feet or wound.

3.2.5. Duration from First Symptom to Diagnosis per District

The line-graph in Figure 8 below shows the distribution of length of time before diagnosis per district.

The most common duration was a period of 1 to 2 years across all the districts with Yumbe having the highest proportion of patients who presented after disability had set in.

Table 7. Duration of time from first symptom to diagnosis.

Length of time before a diagnosis was made	Percentages	Count
1 - 2 months	11%	13
2 - 6 months	15%	18
6 - 12 months	18%	22
1 to 2 years	52%	62
3 to 4 years	2%	2
5 years and above	3%	3
P-Value	0.05	CI 95%

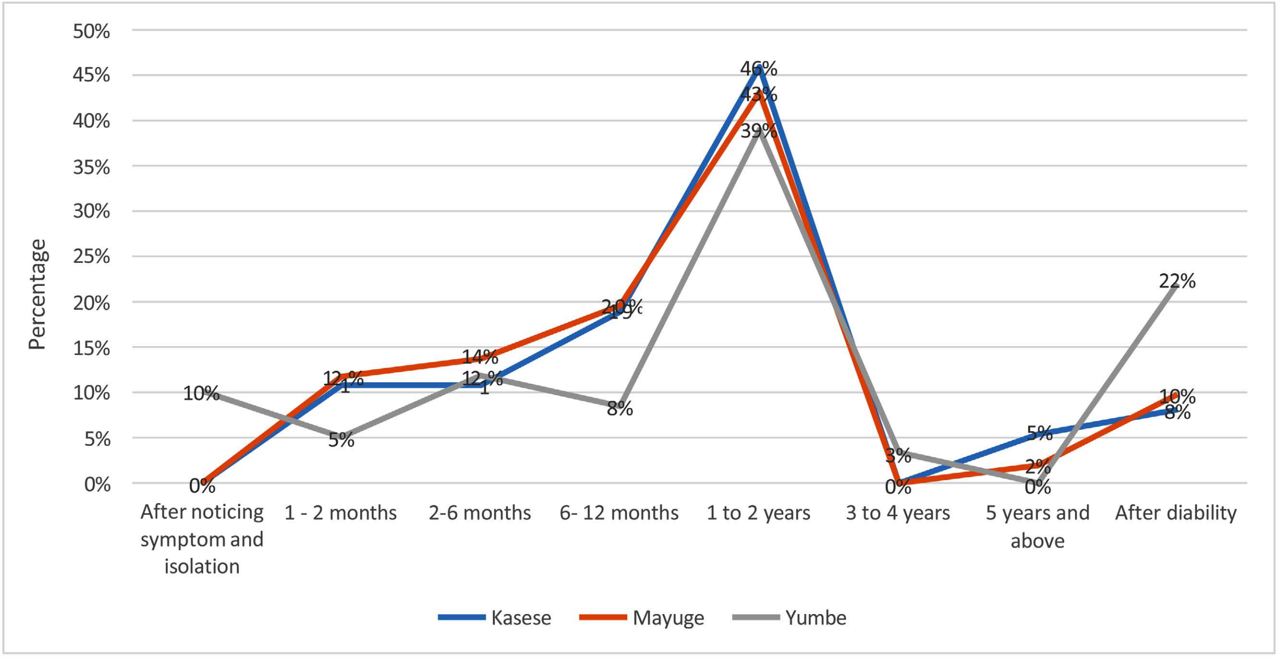

Figure 8. Distribution of length of time before diagnosis per district.

3.2.6. Place of Preference for Treatment

In response to patients' preference of place of treatment being a health facility after noticing skin changes, the following were the answers as represented in Figure 9 below.

Majority of the patients in Kasese (93%) preferred first seeking treatment outside the health facilities. after noticing the skin changes while more than 60% of the patients in Yumbe and Mayuge preferred seeking medical help from the health facilities.

1) Where Patients Sought for Help after Noticing Skin Changes before going to the health facilities.

Table 8 below shows the distribution of where patients seek help after noticing skin changes.

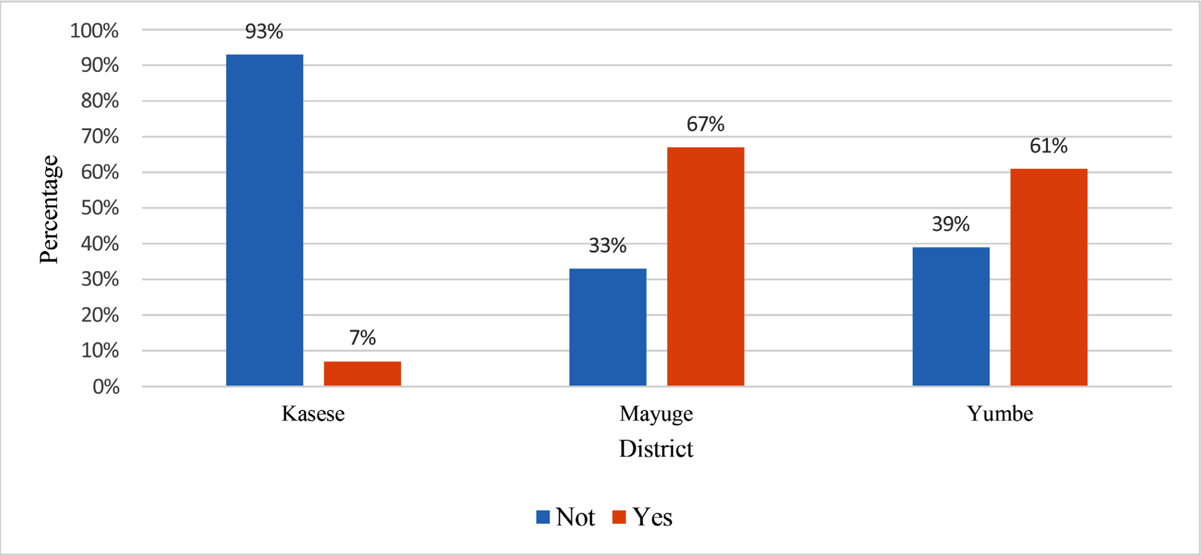

Figure 9. Proportion of patients who preferred treatment at health facilities and those who preferred treatment elsewhere.

Table 8. Proportion distribution of where Patients Sought for Help after Noticing Skin Changes.

Where did you seek for help after noticing these skin changes?	**Proportions**		
	Kasese	**Mayuge**	**Yumbe**
Went to a witch doctor	3.0	0.0	3.2
Talked to my family members	81.8	14.0	25.8
Talked to a religious leader	6.1	2.0	0.0
Went to a health center	9.1	70.0	61.3
Somebody referred her to hospital	0.0	2.0	0.0
Went to a health center, Health facility visited seemed not to know about leprosy	0.0	2.0	0.0
Went to a traditional healer	0.0	10.0	8.1
She talked to her father who advised her to go to the health center	0.0	0.0	1.6
P-value	**0.05**		**CI-95%**

Only 9.1% of the patients in Kasese went to health facility after noticing skin changes while majority in Mayuge and Yumbe went to the health facility.

2) Investigating the Reasons for delaying to seek medical Attention

Figure 10 below shows the proportion distribution of reasons for delay to going to health facilities.

The most common reason delay in seeking medical attention immediately after noticing the skin changes was the belief that there are no skilled personnel who handle skin issues in the facilities.

3.3. Knowledge, Attitude and Practice among Members of Communities and Health Care Providers in Reference to Leprosy

3.3.1. Knowledge of Leprosy

Participants had limited awareness and understanding of leprosy before diagnosis, associating it with symptoms like numbness, skin hardening, and loss of sensation. The study findings are further complimented by individual attestations below:

"*It was my first time to hear about leprosy yet I came with a big world under my foot*"**—Said female leprosy survivor MR5-Buluba HC.V**. Mayuge District

At first when I saw the patch on my left hand, I thought it was a normal skin change which will disappear with time. I did not even give it attention for many years until the number of patches increased that's when I asked the VHT who referred me to Okubani health centre III"—Said Female YR2-Okubani HCIII. Yumbe district

"*A classmate of mine in primary seven was the first person to tell me about the brown patch on top of my left eyebrow. When he asked me about it, I laughed it off. I did not follow it after*"—Said female YR5 Swinga HC.III. -Yumbe

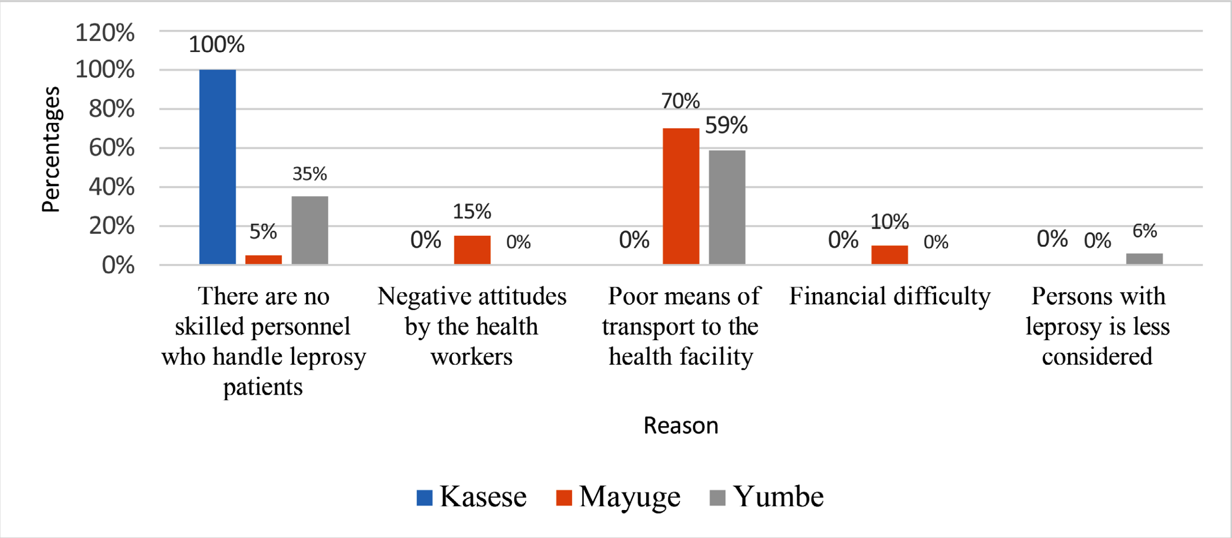

Figure 10. Proportion of reasons for delay to seek medical attention.

3.3.2. Perceived Causes and Modes of Transmission

The community's understanding of leprosy was linked to cultural and spiritual beliefs, associating it with curses from ancestors or gods. Some believed in hereditary transmission, seeing leprosy as a familial curse. Others thought it was caused by witchcraft or insect bites.

Below are some of the responses by respondents in the community.

"When I started getting the patches on my skin, I was told that the disease is associated to persons who have spirits" **said female leprosy survivor-MR3-Buluba HC. IV**.

"*I first thought my condition was witchcraft so I first invited spiritual people to my home to offer prayers for me" "I then started visiting clinics/drug shops where I was given prednisone to swallow and it helped the swelling on the face to reduce. Finally, when I visited Kumi hospital, I was right away diagnosed with leprosy and given treatment" this was now after 6-8 years*". FR1-Kagando Hospital.

3.3.3. Impact of Diagnosis

Receiving a leprosy diagnosis was often met with shock, fear, and feelings of impending death. Stigmatization led to isolation and rejection, with individuals being avoided by friends and family members. Participants faced significant social and emotional challenges, leading to feelings of loneliness and depression. Some resorted to seeking spiritual solutions, believing leprosy was a result of demonic attacks or witchcraft. Below are some responses by members of the community on the impact of having a leprosy diagnosis.

I feared mixing freely with people because I was embarrassed with the way my skin was with patches on face-Response from YR4 -Yumbe district.

"When I started getting the patches on my skin, I was told that the disease is associated to persons who have spirits" **said female leprosy survivor-MR3-Buluba HC. IV**.

3.3.4. Treatment Seeking Behavior

Delays in seeking treatment varied based on factors like lack of awareness, fear, and misdiagnosis of symptoms. Some participants visited multiple health facilities before receiving a proper diagnosis. Access to health facilities, especially in remote areas, was a challenge, leading to delays in receiving care as testified by participant below.

"When my child fell sick, I started from Kagando hospital and it treated my child who did not respond positively to treatment. Bwera hospital diagnosed a fungal infection, gave medicine but the infection was not healing. I was referred to Kasanga PHC Health center 111, *and it also referred me back to Kagando hospital. At this point, the child had started having wounds on the feet at hands. They referred me to Mr. Kaze Jackson who confirmed leprosy".*—**Said female care taker -Kagando Hospital**

3.3.5. Stigma and Discrimination

Whereas Majority (60%) in Yumbe felt discriminated, those in Kasese (3%) and

Mayuge (25%) perception on discrimination was low. Stigmatizing terms like "leper" were used to describe affected individuals, causing humiliation and emotional distress. Stigma extended to family members and caregivers, leading to discrimination against them as well. Social interactions were negatively impacted due to the fear of contagion, leading to isolation and loss of relationships.

Below are some statements made by two of the respondents about stigma and discrimination. "*It is an abuse/insult and we feel embarrassed.*"**—MR3 from Mayuge district**

*"Currently discrimination/Isolation of Leprosy Patients have reduced because the Government and NGOs conducted massive awareness of TB/Leprosy and the facilities treat Leprosy patients and the drugs are free of charge, however, when the patient has deformities/Disabilities and poor hygiene, then they are isolated".***—Said R2 from Yumbe district.**

3.4. Community Engagement as Recommendation to Address Limited Knowledge and Understanding as Well as Socio Economic Status of Affected Persons and Members of Respective Communities

Participants suggest that the community should be sensitized on the signs and symptoms of leprosy

Disseminate leprosy messages through funeral gatherings, village meetings, spiritual gathering, etc. **Commented majority (55%) of the respondents***.*

Health facilities should integrate leprosy treatment into routine schedules.

They also suggest that the community should support leprosy patients in counseling to encourage them to take their medications and follow routine appointments.

Some participants also highlighted the importance of continuous health education, decentralization of services, and equipping small facilities with trained specialists to help leprosy patients.

4. Discussion

The study explored the pathways of leprosy patients from their communities to a diagnosis in the districts of Mayuge, Yumbe and Kasese from the first symptom to diagnosis that could be contributing to the overall delayed diagnosis of leprosy in Uganda. Delays in diagnosis of leprosy occurred at many stages from the development of the symptoms to consultation of health care services. there are several reasons why individuals do not immediately seek healthcare at a health center when they notice skin changes.

The most (65%) common first symptom noticed was skin lesions followed by deformities. The fact that skin lesions are painless, coupled with lack of knowledge people tend to pay little attention to them until the deformities appear. This is similar to a study by Chen X, *et al.* [12] that found that the most common symptom was painless non pruritic skin lesions.

A significant proportion (52%) of participants with suspected lepromatous lesions experienced a delay of close to more than two years before a diagnosis could be made. Nadeeja Roshini *et al.* observed an overall delay of 17.5 months in Ethiopia [13]. Similar findings were got from a study by Lockwood DN *et al.*, Cross H. and Samraj A *et al.* in India which showed a delay of 24 months and suggest an important need to educate patients regarding the early symptoms of leprosy, in order to encourage them to present early [1] [5] [8]. Lack of knowledge may force patients to look for other means of addressing their health problem and inaccessibility discourages participants from seeking medical help and could be seen as a measure of effectiveness of public health programs at early diagnosis through various information and education activities can prevent deformities via implementation of treatment. Early diagnosis and treatment of Leprosy remains the main means of preventing the development of physical disability. [14]

Many patients were ignorant of early symptoms of leprosy. More than half of the participants in this study (75%) did not know about leprosy at the time of diagnosis. This is due to the fact that information on the signs and symptoms of leprosy is not available to the public. About 19% thought that leprosy is caused by evil spirits and 10 percent knew that it is hereditary. These findings support research in Indonesia and a need for more health education, based on a multidisciplinary approach and consideration of cultural and religious views [15]. Inaccessibility due to distance challenges was highlighted as one of the challenges leading to delay in seeking health care services. This supports the research findings in Brazil by Murto *et al.* that inaccessibility may represent an important barrier and suggested that continued efforts to improve access to care, have the potential to improve leprosy treatment outcomes and disease control [12]. Factors such as lack of transport, long distances to health facilities, and financial constraints were significant barriers faced by leprosy patients. Efforts should be made to address these barriers and ensure equitable access to healthcare services for all individuals affected by leprosy.

There were more males in Kasese (63%) and Mayuge (54%) Districts while Yumbe had more females (71%) respondents. This is most likely due to the fact that Yumbe district has more females than males. [15]

The most (40%) affected age group of participants were those above 50 years making age as well as duration of symptoms risk factors for visible disability. The high likelihood of visible disabilities in this age group is similar to previous studies done in Brazil [16].

Findings from the study show that socio-economic status of leprosy-affected persons and members of their respective communities contributed to delay in seeking health care by diagnosed leprosy patients. In the study, it showed that 34% representing majority respondents were unemployed in addition to being over aged (>50 years). This is in contrast to study findings from Brazil [14] noting that, delay in leprosy case detection was not associated with income status among other factors like health insurance

Regarding attitudes and practices, the study found that the majority (90%) of respondents recognized skin conditions as important health problems in their community. However, there were variations in the treatment practices reported. The use of drugs obtained from health facilities was the most common treatment approach, aligning with recommended standards. However, a significant proportion of participants reported using medicinal herbs and engaging in dietary modifications, reflecting the influence of traditional or complementary therapies. Some participants also mentioned practices such as patient isolation and religious or witchcraft rituals as treatment.

5. Conclusions

In conclusion, there was delay in seeking health care service of up to 5 years in some instances. Majority of the respondents lacked a basic understanding of leprosy, its cause, and transmission.

The study also highlighted variations in attitudes and practices related to leprosy. While the majority of participants recognized skin conditions as important health problems in their community, there were diverse treatment approaches reported. While the use of drugs obtained from health facilities aligned with recommended standards, a significant proportion of participants reported using traditional or complementary therapies, such as medicinal herbs, and engaging in dietary modifications. Addressing misconceptions and promoting evidence-based medical care is crucial to ensure effective leprosy treatment and management.

Collaboration with traditional healers, community leaders, and health workers is essential to promote evidence-based treatment and foster supportive attitudes towards leprosy patients. By addressing these gaps in knowledge, attitudes, and practices, effective leprosy control and management can be achieved, ultimately improving the outcomes and quality of life for individuals affected by leprosy.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix 1: A CRONYMS

CI	Confidence Interval
DTLS	District Tuberculosis and Leprosy supervisor
IRB	Institution Review Board
NTLP	National Tuberculosis and Leprosy Program
OR	Odds Ratio
RTLS	Regional Tuberculosis and Leprosy supervisor
SD	Standard Deviation
VHT	Voluntary Health Team

Appendix 2*

Adapted from: Henry M, *et al.* (2016), Factors Contributing to the Delay in Diagnosis and Continued Transmission of Leprosy in Brazil—An Explorative, Quantitative, Questionnaire Based Study. *PLoS Negl Trop* Dis 10(3): e0004542. https://doi.org/10.1371/journal.pntd.0004542

Thank you very much for agreeing to complete this questionnaire. Your involvement in this study is greatly appreciated and will help us to understand more about leprosy and the effects of this disease.

Please try and answer all questions as truthfully as possible—all answers will remain completely anonymous.

Please complete the following questions:

Fill in the blank spaces or where there is more than one option; please tick the correct boxes (as seen in the example below):

Example: ☑ Yes ☐ No

1) Age:____________________________________

2) Gender: ☐ Male ☐ Female

3) In which city and in which state do you live?

____

4) Current Employment Status:

Unemployed	☐
Part--time work	☐
Full--time work	☐
Self--employed	☐
Retired	☐

5) Occupation:____

6) Highest Level of Education received:
Never studied ☐
Pre--school Education ☐
Primary School I (years 1 - 5) ☐
Primary School II (years 6 - 9) ☐
Secondary School ☐
Higher education ☐

7) Marital Status:
☐ Single
☐ Married
☐ In a Relationship
☐ Living with Partner
☐ Separated
☐ Divorced
☐ Widowed

8) Number of children:
0 ☐
1 ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐

9) Who do you currently live with?
☐ Alone
☐ With a partner/spouse
☐ With children
☐ With partner/spouse and children
☐ With other family
☐ Other *Please specifiy*:

____

____

10) Personal Income:
Less than 1 minimum salary ☐
1 minimum salary ☐
1 - 2 minimum salaries ☐
2 - 3 minimum salaries ☐
3 - 4 minimum salaries ☐
4 - 5 minimum salaries ☐
Other ____ ☐

11) Household Income:
Less than 1 minimum salary ☐
1 minimum salary ☐
1 - 2 minimum salaries ☐
2 - 3 minimum salaries ☐
3 - 4 minimum salaries ☐
4 - 5 minimum salaries ☐
Other ________________________________ ☐

12) How old were you when you received a diagnosis of leprosy? In what year was this?

____

13) Does anybody else in your family have leprosy?
☐ Yes ☐ No

14) Apart from leprosy, do you have any other illnesses?
☐ Yes ☐ No

If yes, what?

____

____

Section 2

Before starting this section, please take time to try and remember back to when you first noticed symptoms for leprosy. Think about the time of year it was and how old you were to help you remember. I'd like you to remember what you thought at the time.

1) In what month and year did you first experience symptoms to do with Hansen's disease?

____

2) How old were you when you first experienced this symptom?

____

3) What were the first symptoms you noticed? (Choose only 1 option)
o Pale patches on your skin
o Pale patches on your skin with no sensation
o Lumpy or thickened skin
o Runny nose or nose bleed
o Difficulty seeing

- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*)

4) a) Had you heard about Hansen's disease at that time?

☐ Yes ☐ No

b) If you hadn't heard about Hansen's disease, what about leprosy? Had you heard about leprosy?

☐ Yes ☐ No

5) Did you think that your symptoms could be due to Hansen's disease or leprosy?

☐ Yes ☐ No

6) Some people like to tell others soon after they experience symptoms (within 2 weeks). Did you do this? (You can select more than one option)

- I did not tell anyone
- Family member or friend
- Priest
- Any other religious leader oLocal healer
- I went straight to a medical practitioner
- Other (*please specify*) ____

7) At the time you noticed your first symptoms, roughly how far away was the nearest health centre from your home?

☐ 0 - 1 km
☐ 1 - 3 km
☐ 3 - 5 km
☐ 5 - 10 km
☐ 10 - 20 km
☐ >20 km

8) Many people wait a while before visiting a medical practitioner about their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms?

☐ 0 - 2 weeks
☐ 15 days - 4 weeks (1 month)
☐ 1 - 3 months (including 3 months)
☐ More than 1 year. How many? ________________
☐ 3 - 6 months (including 6 months)
☐ 6 months - 1 year (including 1 year)

9) Why was it that you waited before seeing a medical practitioner? (you can select more than one option)

- I did not wait, I went straight away

- o I lived too far away from a health centre
- o I couldn't get an appointment
- o I couldn't afford to pay for an appointment
- o I could not afford to take time off work to visit a health centre
- o I did not think my symptoms were serious
- o I thought my symptoms would go away on their own
- o I was not in pain
- o Family member/friend told me not to tell anyone
- o I was afraid it was something serious
- o I was afraid it might be Hansen's disease but didn't want anyone to know
- o I thought it was Hansen's disease but didn't want to be isolated from my community
- o I knew it was Hansen's disease but did not think anything could be done to help
- o Other (*please specify*)

____

10) Was there anyone else in your household with known Hansen's disease at the time? Tick appropriately.

☐ Yes ☐ No

The next questions are about when you made contact with the health service and about your first consultation:

11) a) What year was it when you visited a doctor (medical practitioner) for the first time for your symptoms?

____

b) How old were you when you visited a doctor (medical practitioner) for the first time for your symptoms?

____

12) Where? Please state the city/state that you were in and the health centre.

____

13) What encouraged you to go to a health centre and see a medical doctor? (You can select more than one option)

- o My symptoms didn't go away
- o My symptoms got worse
- o My symptoms got so bad I couldn't hide the condition anymore
- o A friend or family member encouraged me to go
- o My local healer told me to visit a medical doctor

- The treatment I was using was not working
- I was visiting the doctor for another reason and I mentioned it whilst I was there.
- I was visiting the doctor for another reason and they noticed my symptoms.
- Other (*please specify*):

____

____

14) a) What symptoms were you experiencing when you first saw a medical doctor? (More than one can be selected)

- Pale patches on your skin
- Pale patches on your skin with no sensation
- Lumpy or thickened skin
- Runny nose or nose bleed
- Difficulty seeing
- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*) ________________________________

b) Which symptom were you most concerned about out of all your symptoms? (Select only the main symptom)

- Pale patches on your skin
- Pale patches on your skin with no sensation
- Lumpy or thickened skin
- Runny nose or nose bleed
- Difficulty seeing
- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*) ________________________________

15) Did the doctor suspect that you might have Hansen's disease?

☐ Yes ☐ No

16) Did the doctor examine you?

☐ Yes ☐ No

(if you selected "No", please skip to question 18)

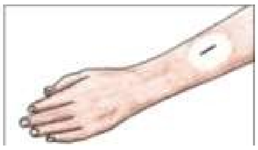
17) Did the doctor perform any of these examinations on you? (On your first visit)

o They looked at my skin

o They tested the feeling in my skin (often done over a pale skin patch)

o They felt my nerves (e.g. at the elbow or in my legs)

o They took a sample of skin (cut made in skin usually at the earlobe or arm)



18) Did the doctor diagnose you with leprosy on this first visit?

o Yes (If you marked this option, you do not need to continue answering the questionnaire)

o No

19) It is easy for Hansen's disease to be mistaken for a different condition. Did your doctor diagnose you with another medical condition instead? (Please only select one option).

o No
o Bone condition
o Nerve condition
o Blood vessel condition
o Other (*please specify*) ____

20) Did your doctor refer you to another doctor?

☐ Yes ☐ No

23) How many different doctors did you see before being diagnosed with leprosy? (Including the doctor that diagnosed you)

o 1
o 2 - 3
o 4 - 5
o More than 5

20) When were you diagnosed with Hansen's disease (leprosy)? (Please give month and year if possible)

____

21) How long after your first visit to a health centre were you diagnosed with leprosy?

☐ 0 - 2 weeks ☐ 3 - 6 months (including 6 months)
☐ 15 days - 4 weeks (1 month) ☐ 6 months - 1 year (including 1 year)
☐ 1 - 3 months (including 3 months)
☐ More than 1 year. How many? ___________________________________

Appendix 3: Proposed Knowledge and Attitude Form

Urgesa *et al*., (2020), Knowledge of and Attitude Toward Leprosy in a Leprosy Endemic District, Eastern Ethiopia: A Community-Based Study. Risk Manag. Health Policy. 13: 1069-1077 **Knowledge Questions**:

1) Have you heard about leprosy?
2) Where did you hear about leprosy?
3) What causes leprosy?
4) What is/are symptoms of leprosy?
5) What is/are means off leprosy transmission?
6) Is leprosy cured?
7) What is/are treatment of leprosy?

Attitude Questions:

1) Would you admit to sitting beside a leprosy patient in public transport?

2) Would you be ashamed if someone has leprosy in your family?
3) Would you admit to sharing a plate with a leprosy patient?
4) Would you admit to owning a child who married someone from a family with a history of leprosy?
5) Would you be ashamed to work with a leprosy patient in the same environment?
6) Would you allow your own child to play with a child from leprosy family?
7) Would you admit to helping if someone gets leprosy in the family?
8) Would you share items with a leprosy patient?

Appendix 4: Focus Group Discussion (FGD) Guide for Family /Community Members

Hello… My name is I would like to thank you all for agreeing to be part of this discussion. We are having this discussion because one or more members of your family were diagnosed with leprosy. No answer is right or wrong; we just want to have a discussion about leprosy and what people in this community think about leprosy and how they seek for treatments.

No	Questions
1	What is your understanding of Leprosy? (Probes: How did you come to learn about leprosy? Since you in constant contact with a person affected by leprosy, what is your experience managing leprosy?
2	What in your opinion is the main sign of leprosy?
3	If you find-out that you or your family member has developed any of these skin problems, where would you FIRST advise them to seek care? (Why?)
4	When did you realize that your family member had been infected with leprosy? Probes: what main signs did they have?
5	What do you think motivates persons affected by leprosy to seek for medical treatment?
6	In your opinion, is leprosy curable?
7	Why do you think persons affected by leprosy delay to seek for medical help?
8	What are the challenges facing persons affected by Leprosy in accessing health services?
9	In your opinion, how should community members assist Person Affected by Leprosy in accessing health services? (Probes: do they, do it? Why, why not? What other kind of support should people affected by leprosy get from the community and community members?)
10	According to you, where should persons affected by leprosy receive treatment from? (Probes: How about at health facilities? how about with other patients? why? why not?
11	According to you, what should health centers be like to ensure persons with leprosy access health care services on time?
12	How do you think community members should support persons affected by leprosy in accessing health services on time?
13	What do you think should be done to improve early diagnosis and retention in care for persons affected by leprosy?
14	Have you ever felt isolated/discriminated against because of Leprosy? Probe: Chased away from Home/work, Isolation Camps, etc.
15	Why do you think people affected by Leprosy are Isolated? Probe: Considered an incurable disease, high degree of stigmatization, Because of deformities