Lepr Rev (2024) **95,** e2023108 doi:10.47276/lr.95.3.2023108

Participation of people with disabilities due to Leprosy, Lymphatic Filariasis (LF), and other causes in Uganda

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Submitted 27 December 2023; Accepted 18 June 2024

Summary Leprosy and lymphatic filariasis (LF) not only cause disfigurement and disability but also create social stigma hindering participation and inclusion of affected individuals. This is largely attributed to the limited knowledge and information about these conditions which contributes to misconceptions, exacerbating the stigma. This research project conducted in 2018–2019 investigated the participation of people with disabilities due to leprosy, LF, and other causes.

A mixed-methods approach was applied, using the participation scale (v6.0), focus group discussions, observation, and semi-structured interviews to attain comprehensive conclusions on the various aspects of the study.

Although the higher percentage perceive their disability to be moderate, 19.8% perceive their disability to be severe. A majority (59.4%) of the people affected by leprosy reported the need for protective footwear and other assistive devices. Although 26.5% experienced no participation restrictions at individual, family or community level, 24.8% experienced severe restrictions and 17% extreme participation restrictions. The study revealed that education played a pivotal role in mitigating participation restrictions across all categories. Those with higher education levels reported fewer restrictions, highlighting the need for targeted interventions to address educational disparities. 42.9% of persons with disabilities with vocational/tertiary

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education indicated no participation restrictions while 37.3% of people affected by leprosy with no education reported severe participation restrictions. The assessment also explored various aspects of participation, including equal opportunities and responsibilities, social interaction and confidence, and personal wellbeing and health. Disparities were observed, with individuals affected by LF exhibiting higher levels of social interaction and confidence compared to those affected by leprosy and other disabilities.

Knowledge and information, attitude, hygiene and lack of funds are key determinants of participation and inclusion of people affected by leprosy, LF, and disability due to other causes, while lack of information restricts effective planning for their inclusion. Improving self-care practices, providing knowledge and information on these conditions, and promoting equal access to resources and opportunities were identified is vital in enhancing participation and inclusion of the people affected by leprosy, LF and other disabilities. Accurate documentation, community-based rehabilitation, equal access to assistive devices, and advocacy efforts to combat stigma and promote understanding, are recommended to enhance participation and inclusion.

Keywords: Participation restriction, disability, inclusion

Author summary

Disability is estimated at 15% of an average population.[1] Disability inclusion is prioritized on the development agenda. It is explicitly mentioned in six out of the 17 goals.[2] Leprosy and lymphatic filariasis are neglected tropical diseases that disfigure the affected persons and cause disability. However, it is not clear how these conditions affect their participation at individual, family and community level.

This study was implemented in 2018–2019 to establish the nature and level of participation of people with disabilities due to leprosy, LF and other causes. It also intended to establish a foundation upon which stigmatized people such as those affected by Leprosy, LF and disabilities due to other causes can be assured of participation at individual, family and community level.

This mixed method study was implemented in five districts of Northern Uganda aimed at establishing the nature and level of participation of people with disabilities due to leprosy, LF and other causes. Document review, the participation scale, focus group discussions and semi-structured interviews were used to collect data.

This study revealed that people affected by leprosy, people with disabilities due to other causes and the people with lymphedema, experience more participation restriction than the males with hydrocele. The key determinants of participation are education attainment, knowledge and information, attitude, hygiene, and funds to afford services.

Introduction and background

Approximately 15% of the worldwide population are persons with disabilities attributed to different causes. 80% of people with disabilities live in developing countries.[1,2] In Uganda, the Uganda Bureau of Statistics Census Report indicated that 12.4% of the Ugandan population lives with some form of disability.[3]

Africa is reported to account for almost 40% of the global NTD burden.[4] According to the Ministry of Health, Uganda continues to carry a heavy burden of NTDs including leprosy and lymphatic filariasis (LF), both of which cause disfigurement and disability.[5] People with

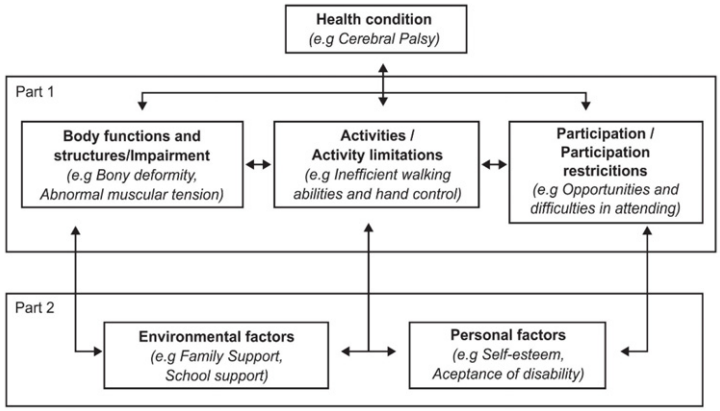

Figure 1. The ICF Model and its application in the consequence of disease and disability Adapted from WHO.[6]

disabilities experience multifaceted challenges that restrict their participation in community and social activities as illustrated by the International Classification of Functioning, Disability, and Health (ICF) model (Figure 1).[6]

The ICF diagram illustrates how impairment from a disease like leprosy or LF interacts with personal and environmental factors to cause disability. Disability is viewed as an interplay between an individual's health conditions and the barriers attributed to society. By categorizing disability into impairments, activity limitations, and participation restrictions, the ICF framework highlights its incorporating nature, including challenges relating to bodily function, task performance, and the barriers to daily activities. Barriers include physical obstacles, discriminatory attitudes, and limited access to services and opportunities.[6]

In 2018, 208,619 new cases of leprosy were reported from 127 countries compared to 211,009 cases in 2017 indicating a 1.2% global decrease.[7] According to the WHO fact sheet, 10,816 new cases were detected with grade-2 disabilities (G2D), a 1.4 per million population G2D rate.[7] Visible disabilities like damage to hands and feet are often used as an indicator for the severity of the leprosy disease and timeliness of detection.[8]

Leprosy is endemic in Uganda, with 40% of the districts affected in 2016[9] and 231 new cases reported across 50 districts in 2018/19, with an annual case detection rate of 0.06/1000,000 population. Northern Uganda accounted for over 60% of all newly notified leprosy cases.[10]

In 2018, 51 million people were reported to live with LF.[7] LF impairs the lymphatic system followed by abnormal enlargements of body parts, causing pain, severe disability, and social stigma. According to the MOH 2009/2010 survey, LF was endemic in 54 districts in Uganda. Several districts in Northern Uganda were classified as needing surveillance.

This research project sought to establish the nature and extent of participation of people with disabilities attributed to leprosy, LF, and other causes and identify strategies to enhance their participation. By employing the ICF model, this study sought to inform development of inclusive policies and interventions that promote the active engagement and well-being of persons with disabilities in Uganda and other parts of the world.

Methods

STUDY DESIGN

The study adopted a descriptive research design utilizing both qualitative and quantitative data. Qualitative data was used to establish the nature of participation, enablers, barriers to participation, challenges experienced, and strategies to promote participation and inclusion. Quantitative data was used to establish the various demographic aspects of the people with disabilities due to Leprosy, LF, and other causes, the magnitude of disability, and the level of participation to inform effective conclusions on the various aspects of the study.

STUDY SITES

The study was conducted in Kitgum, Alebtong, and Gulu (Northern Uganda), and Arua and Koboko (North Western Uganda) regions. According to the 2014 national census, disability in northern Uganda accounts for approximately 16% of the population. This region is still recovering from a 20-year civil war with the "Lord's Resistance Army" which forced 90% of the population to abandon their homesteads for a life confined to the squalid internment camps.[11] The war increased poverty and vulnerability, leading to a general breakdown in social service provision resulting in delayed detection of NTDs and disability. On the other hand, North Western Uganda often gets an influx of refugees from the Democratic Republic of Congo and South Sudan, who have equally experienced war over the years and have a burden of other NTDs.[12]

SAMPLING PROCESS AND RECRUITMENT STRATEGY

Due to the lack of reliable record, the study employed a mixed-methods approach utilizing snowball sampling and purposive sampling techniques. The study initially identified people affected by leprosy based on available records. These individuals served as key informants to identify additional participants through snowball sampling. With the support of district TB leprosy supervisors (DTLS), village health teams, community development officers (CDOs), local leaders, and communities, snowball sampling was utilized to identify and recruit individuals affected by leprosy, persons with disabilities, and individuals affected by lymphatic filariasis (LF) who were not documented in official records. Efforts were made to match participants across the three targeted categories (people affected by leprosy, people with LF and persons with disabilities) to ensure representation and comparability within the study sample.

District TB leprosy supervisors (DTLS), Vector Control Officers, health personnel, village health teams, community development officers (CDOs), leaders of organizations of persons with disabilities, disability council members, and local leaders were selected using purposive sampling based on their roles and responsibilities relevant to the study's objectives.

INCLUSION CRITERIA

- People affected by leprosy: Included individuals with a confirmed diagnosis of leprosy based on available records or community identification by the DTLS during the study.
- Persons with disabilities: People identified by the community development officers, self-identified or identified by community representatives and confirmed to have a disability such as; physical (difficulty in moving body parts), sensory (visual impairments, hearing impairment or deaf-blind), intellectual (learning difficulties or severe developmental delays) impairments.

- People affected by LF: People self-identified or identified by community representatives as having a hydrocele or lymphedema.

All this was explained to the DTLS, vector control officers, village health teams, the community development officers and community members who supported identification of study participants through training at the beginning of the study.

EXCLUSION CRITERIA

The study excluded people affected by leprosy, LF, and disability living outside the study are and those living in the study are but do not have the conditions listed that is:

- People without leprosy: that is without a history or current diagnosis of leprosy.
- People without disabilities: without physical (difficulty in moving body parts), sensory (visual impairments, hearing impairment or deaf-blind), intellectual (learning difficulties or severe developmental delays) impairments.
- People not affected by LF: without hydrocele or lymphedema.

DATA COLLECTION

Document review: Data collection started with an exhaustive document review encompassing records from various entities including health centers, NTD offices, community development offices, organizations of people with disabilities, and National and district TB Leprosy Program offices. This served as a foundational step in gathering information relating to persons with disabilities due to leprosy, LF and other causes as well as details on their participation and inclusion at the different levels.

Questionnaire: A questionnaire with a participation scale (v6.0) developed by the Participation Scale Development Team was used. This tool, was specifically used to measure (social) participation at individual, familial, and communal levels among people affected by leprosy, LF, and those with disabilities due to other causes. The questionnaire had specific questions on the demographic profiles, nature and extent of disabilities (informed by the Washington group of questions) and use of assistive devices since they are all critical for participation of persons with disabilities.

The questionnaire was administered by a team of trained research assistants, many of whom were graduates in the field of education, social work, community development and community based rehabilitation residing in the respective areas of study. The validity of the participation scale had been established prior to its utilization in this study. The technical team leader had previously employed the same tool to evaluate the participation levels of learners with visual impairment in secondary schools, thereby ensuring its efficacy and reliability.

In the selection of research assistants for each study area, emphasis was placed on their proficiency in translating data collection instruments into indigenous languages. This was imperative due to the prevalence of linguistic diversity across various regions of Uganda. For instance, Arua district had a multitude of languages spoken within its boundaries, necessitating the recruitment of research assistants from different sub-counties proficient in various language varieties. This strategic approach enabled the seamless translation of the questionnaire, ensuring accessibility and comprehension among respondents across linguistic backgrounds.

Semi-structured interviews: Were conducted with health personnel, district community development officers, local leaders, leaders of organizations of persons with disabilities and

the disability councils at different levels and a few community members to identify appropriate strategies for change. This allowed probing to obtain details on participation and inclusion of the persons with disabilities due to leprosy, LF and other causes.

The TB leprosy supervisors are responsible for leprosy programs at national and district level respectively, they are instrumental in diagnosis and treatment of people with leprosy while the vector control officers are responsible for strategies to mitigate the spread of vector-borne diseases including LF, community development officers are responsible for all programs for community empowerment including support for persons with disabilities while local leaders are known for community mobilization. Based on this, they were believed to have adequate information for identification of enablers, barriers and challenges to the participation of people affected by leprosy and LF and people with disabilities and propose appropriate strategies to enhance participation of persons with disabilities due to leprosy, LF and other causes.

The semi-structured interview guide was systematically developed to gather insights from the study participants. Its questions were based on ICF to enable effective assessment of activity limitations, participation restrictions, and contextual factors. The questions were designed to allow probing into physical, attitudinal, and systemic barriers as well as supportive factors such as access to services, attitudes of community members, and policy support. The guide also included questions eliciting perspectives on effective strategies to enhance participation and inclusion.

The guides for the different stakeholders also considered the roles and responsibilities of different study participants for instance for the TB Leprosy Supervisors, questions focused on their experiences in leprosy diagnosis and treatment, and their insights into challenges faced by people affected by leprosy. For the Vector Control Officers, questions explored existing strategies for the control of LF and other vector borne diseases, their role in community health and any strategies to help the people affected by LF. For the Community Development Officers, questions centered around community empowerment programs, support services and systems for persons with disabilities, including challenges and successes while for the local leaders, focus was on their in community mobilization, their perceptions of inclusion, and their involvement in promoting participation of individuals with disabilities.

FOCUS GROUP DISCUSSIONS (FGDS)

At least two FGDs were conducted in the respective districts of study. Each group had a total of 15 participants each category represented by 5 participants. Participatory learning approaches including problem identification and analysis and stakeholder mapping and vulnerability assessment were utilized in the FGDs to harness existing knowledge and skills and awaken participants to identify their role and contribution to ensuring participation of the persons with disabilities due to leprosy, LF and other causes in addition to complementing strategy development to enhance their participation.

OBSERVATION

Observation was made of the people affected by leprosy, LF and persons with disabilities due to other causes in their natural environment to identify their difficulties, existing barriers and their coping strategies, existing resources, and hygiene practices since all these are vital for their participation and inclusion in society.

The use of a variety of data collection methods was aimed at obtaining comprehensive and quality data on the various aspects relating to participation of all three categories of respondents.

Data collection for the study started soon after ethical approval was confirmed. It was conducted between 28th October 2018 and 18th January 2019 while data analysis started in February.

Data analysis

Information from the Participation scale was coded, analyzed using Statistical Package for Social Science (IMB SPSS 25), and descriptively presented in response to the study objective. Information from the interviews and focus group discussions was transcribed, arranged based on emerging themes and subjected to content analysis and used to complement that from the Participation scale. The output from the document review was triangulated with data from all other data collection methods for a comprehensive understanding of the key aspects and a comprehensive conclusion of the study.

ETHICAL CONSIDERATIONS

The research proposal was assessed by Gulu University Research Ethics Committee before submission to the National Council of Science and Technology for approval (SS4994) and implementation. Informed consent was obtained from the participants and for children aged between 2–18 years and people with severe disabilities, both verbal and written consent was also obtained from their respective legal guardians. Informed consent was also obtained from the participants whose photos were used for the study.

Results

Although 1020 persons with disabilities due to leprosy, LF and other causes participated in the study, analysis was made for 1011 individuals, excluding 4 with incomplete questionnaires. 5 other respondents; 2 people affected by leprosy and lymphedema, 2 deaf persons with hydrocele and 1 person with Down syndrome and lymphedema were excluded from the analyses for inconsistency in reporting. This decision aimed at minimizing potential distortions or outlier effects that could compromise the reliability of the findings. By maintaining uniform criteria for inclusion in the analysis, researchers sought to enhance the coherence and comparability of results, to facilitate more accurate interpretation and generalization of findings.

Of the 1011; (n = 294) people with disabilities due to leprosy who were released from treatment between 1996 and 2017, (n = 11) on treatment, and (n = 5) new cases. People with different symptoms like lymphedema (n = 169) and hydrocele (n = 173), and people with disabilities due to other causes (n = 359). TB/leprosy supervisors (n = 10), vector control officers (n = 5), chairpersons of the disability council (n = 5), chairpersons of the disabled people's unions (n = 5), community development officers (n = 5), health officers (n = 5), and health personnel (n = 8) were included for interviews. 18 focus group discussions (FGDs) were conducted each with 15 participants including persons with disabilities, people affected by leprosy, and LF.

Results from the participation scale are summarized using graphs, complemented with output from observations and interviews.

In terms of gender distribution; 62.4% of respondents were male. Of these males, 79.8% had LF (lymphatic filariasis). Among those with LF, 63% reported having hydrocele. In terms

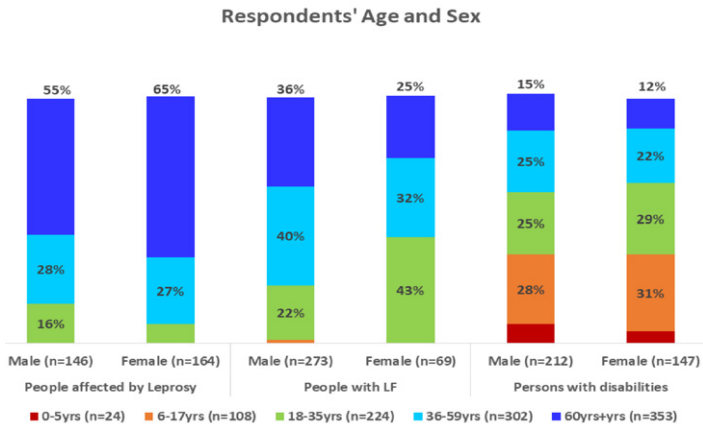

Figure 2. Distribution of age and gender among respondents.

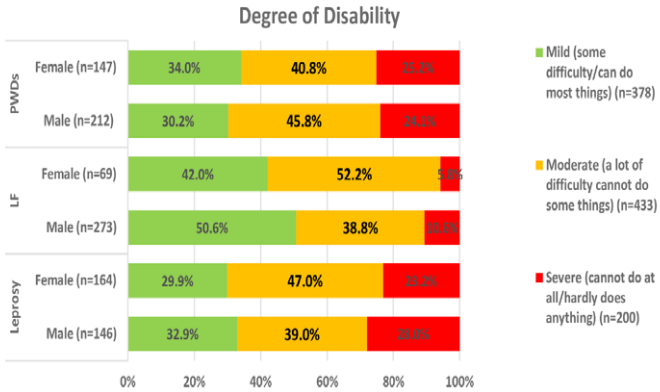

Figure 3. Perspectives of degree/severity of disability for the three categories differentiated by gender.

of age distribution, 132 children (7.7%), 526 (52%) respondents in the productive age (18–59 years), and 353 (34.9%) above 60 years as detailed in Figure 2.

A majority of the people affected by leprosy were older persons (60 yrs+). The children of 6–17 yrs with LF were identified with lymphedema. They were found in Gulu, Amuru and Alebtong districts.

Participation of persons with disabilities is sometimes determined by the degree/severity of disability and use of assistive devices. Details are presented in Figure 3 and Figure 4.

In total, 42.8% of the respondents indicated that they perceived their disability as moderate. Among females affected by LF, 52.2% fell into this category. A slightly lower percentage, 37.4%, perceived their disability as mild. 50.6% of the males affected by LF were in this category, while 19.8% considered it severe. Notably, individuals affected by leprosy and persons with disabilities comprised the majority of respondents who classified their disability as severe.

It's important to recognize that the assessment of disability severity was based on individual perception. However, this perception can serve as an indicator of one's intrinsic attitude, which is a significant determinant of participation in various aspects of life.

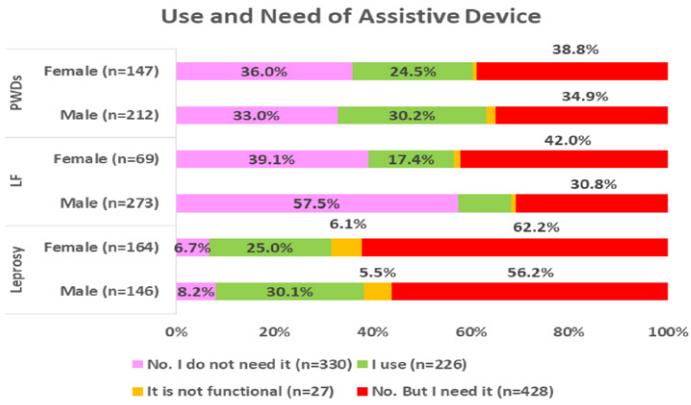

Figure 4. Use and need of assistive device of the three categories differentiated by gender.

(a) (b)

Figure 5. People affected by leprosy in need of protective footwear.

In most cases, persons with disabilities need appropriate assistive devices to mitigate functional limitation. The study therefore sought to establish the use and need of assistive devices for all three categories of respondents.

In total, the higher percentage, 42.3% of the respondents expressed need for assistive devices. Among those are people affected by leprosy with a significant majority (59.4%) who expressed need for protective footwear and other mobility aids. This emphasis on footwear stems from the impact of leprosy on sensory perception which makes the affected individuals highly vulnerable to injuries, particularly in the feet and hands.

The picture in Figure 5(a) illustrates a concerning state; an individual wearing rubber sandals with a significant hole at the bottom. Within this deep cavity lies a rusty metal piece he did not notice due to loss of sensation as a result of leprosy. Similarly, in Figure 5(b) another individual is shown walking barefoot, exposing themselves to potential injuries and infections. The continuous wounds have eaten away at her toes. Most people affected by leprosy were found without protective footwear and often identified by the bad odor due to inadequate

Figure 6. Wound of a youth with Lymphedema.

wound care. These descriptions underscore the terrible consequences of inadequate protective footwear for people affected by leprosy.

People with lymphedema encounter similar challenges. In most communities, most people with lymphedema resort to wearing rubber gumboots in an attempt to conceal their condition which increases their vulnerability to injuries. Youths with lymphedema often adopt coping mechanisms such as wearing tight jeans to blend in among their peers. A youth with lymphedema found wearing a pair of tight jeans and canvas shoes despite the evident difficulty in mobility. Figure 6 illustrates what he was attempting to conceal, providing evidence of his condition.

Interestingly, this youth perceives his disability as mild and sees no need for assistive devices. Instead, he utilizes his choice of clothing as a form of disguise to mitigate social exclusion, as he openly expresses:

> *"Look! I am a youth. Like all my peers, I would like to marry someday. But who can accept a man with this swollen ugly leg? I wear jeans like all youths in this village to be admired by girls. Who knows! I could get a wife soon"* (male youth with lymphedema in Awach sub-county, Gulu district)

This moving statement reflects the social stigma and pressure faced by people with lymphedema, particularly in relation to societal expectations and perceptions of attractiveness. Despite the youth's efforts to disguise his condition, his challenges persist, exacerbated by the rejection triggered by the unpleasant odor coming from his wounds. Additionally, the use of tight clothing and shoes does not address the underlying health issues instead, it increases the risk of injuries.

Participation was assessed at the individual level, family and community level using an overall participation scale (v6.0) developed by the participation development team. The results on overall participation restriction by conditions are shown in Figure 7.

Approximately half people with lymphatic filariasis (LF) reported no significant participation restrictions, which may not be surprising since majority of LF patients were male (79.8%). Half (50.6%) of the male with LF perceive their disability as mild and 57.5% of the same population indicated that they do not need assistive devices. In contrast, people affected by leprosy (96) 31%, persons with disabilities (89) 24.8%, and the female with lymphedema 30.4% reported severe participation restrictions. While 19%, 24.5%, and 8.7% of people affected by leprosy, persons with disabilities, and the female lymphedema respectively reported extreme participation restrictions.

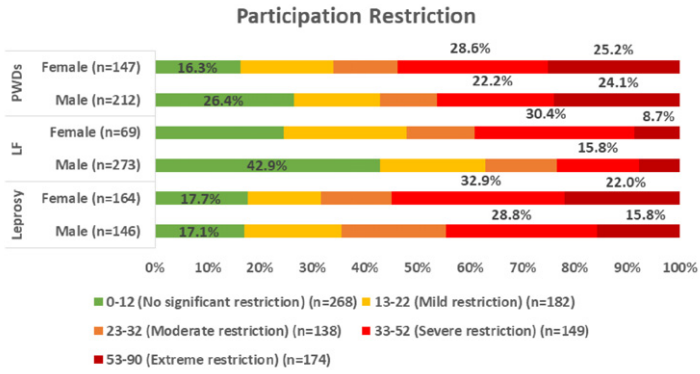

Figure 7. Grading of participation restriction for the three categories differentiated by gender.

The mean scores for the "Condition" (leprosy, LF, and disability), were 2.41, while that for the participation "Score" was 2.88, indicating moderate participation levels on average. However, there was greater variability in participation score compared to the "Condition", as evidenced by their standard deviations and variances. Both sets of variables demonstrated skewness values close to 0, indicating approximately symmetrical distributions, with kurtosis values below 3, suggesting relatively flat distributions compared to a normal distribution.

Across all categories, females reported more participation restrictions than males, particularly among those indicating severe restrictions, who also perceived their disability as severe and expressed a need for assistive devices. Most individuals with extreme participation restrictions were either children or individuals with severe disabilities. Overall, both genders exhibited similar trends in restriction levels, with males averaging a slightly higher overall mean of 20.4% compared to females at 19.8%, resulting in a combined average across all categories for both genders of 20.1%.

Despite moderate mean scores, qualitative findings revealed substantial proportions of individuals reporting severe and extreme participation restrictions, particularly among those affected by leprosy, disabilities, and lymphedema. This underscores the significance of addressing the diverse participation challenges faced by individuals with these conditions through targeted interventions and support services to enhance their inclusion in society.

Low participation restrictions amongst males with LF could be attributed to the patriarchal nature of these communities and people's receptive attitude to hydrocele as mentioned by a respondent below:

> '*Traditionally, a man with a hydrocele is believed to be very fertile. He can make any woman pregnant. It is a pride for the man to have that condition. It is also a sign of wealth since you make many children and girls fetch cows in this community*' (a female respondent in an FGD in Omoro sub-county, Alebtong district)

Such an attitude most likely makes the affected individuals attractive, increasing chances of their participation and inclusion.

In some cases, education is reported to be a determinant of participation. Based on the results above, analysis was made of education attainment and participation restriction for the three categories as shown in Figure 8.

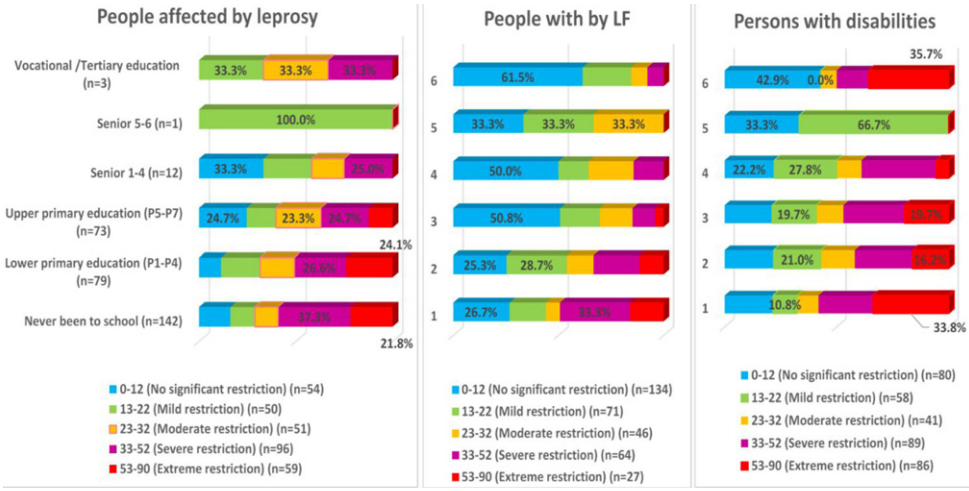

Figure 8. Comparison of participation restriction for the three categories differentiated by education attainment.

Overall, educational attainment appears to be a pivotal factor influencing participation levels among all three categories. Notably, participation restrictions are more prevalent among those who have never received formal education. Among the people affected by leprosy, a substantial percentage (37.3%) of those who have never been to school reported severe participation restrictions, with an additional 21.8% experiencing extremely severe restrictions. The prevalence of low education levels among people affected by leprosy may be linked to age, as the majority of them are older adults aged 60 years and above whom could have experienced leprosy before education became popular.

In the case of persons with disabilities, those with vocational/tertiary education (42.9%) indicated no participation restrictions. However, a significant percentage of individuals with no education reported extremely severe participation restrictions (33.8%), along with a considerable portion experiencing severe restrictions (24.3%). This lack of education among persons with disabilities may be attributed to the severity of their impairment or disability. It is intriguing to note that even among the people with disabilities who have achieved vocational or tertiary education, 35.7% reported extreme participation restriction possibly due to intrinsic attitude and various barriers in society. Persons with disabilities often get opportunities for skills development from various the government vocational rehabilitation program under the ministry of Gender, labor and Social Development and civil society organizations as part of economic empowerment. Some individuals utilize the opportunity and start enterprises while a few remain dependent.

For the people with LF, while a significant percentage (33.3%) of those with no education reported severe participation restrictions, the majority (50.8%) of those with upper primary education reported no participation restrictions. Notably, a considerable number of individuals with LF who experienced participation restrictions were women with lymphedema.

These findings underscore the critical role of education in mitigating participation restrictions and the need for targeted interventions to address educational disparities and enhance participation for all individuals, regardless of their health or disability status.

Participation is often determined by individual perspectives, attitudes, and readiness to participate.

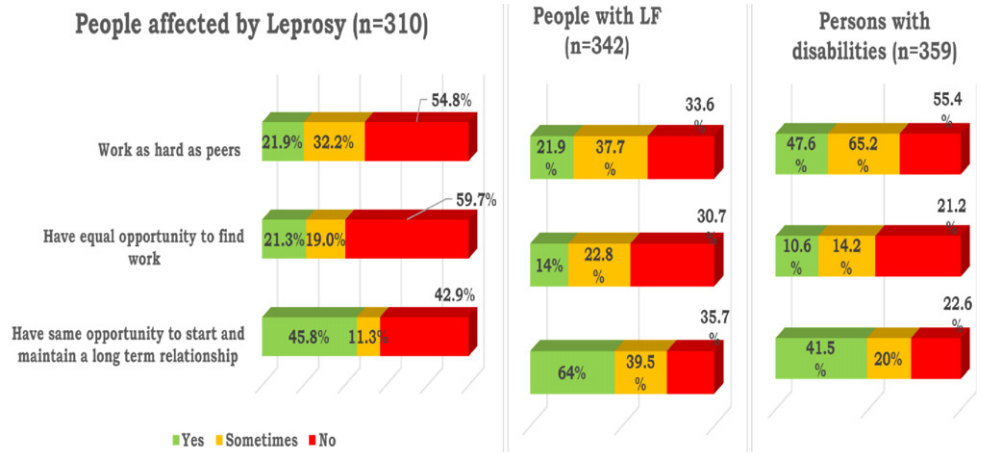

Figure 9. Assessment of participation restriction - Equal opportunities and responsibilities.

The intervention for people affected by leprosy, LF, and other disabilities requires a thorough exploration of the areas where they face participation restrictions. A comprehensive assessment was conducted to evaluate their participation and wellbeing, by categorizing the various aspects into three categories equal opportunities and responsibilities, social interaction and confidence, as well as personal wellbeing and health. This aimed to reveal societal structures affecting participation and wellbeing, to inform development of appropriate strategies to enhance inclusion and dignity for all.

PARTICIPATION RESTRICTION IN TERMS OF EQUAL OPPORTUNITIES AND RESPONSIBILITIES

Involved exploration of the intricate social structures and norms that dictate access to resources, opportunities, and fundamental rights within society. Every individual has a right to access these resources and opportunities, irrespective of their background or circumstances. Whereas individuals are responsible for actively seeking and seizing opportunities, society bears the responsibility of creating an environment where these opportunities are equally accessible to all. By recognizing and fulfilling these responsibilities, we lay a foundation for an equitable and inclusive society. Assessment of participation restriction in regards to equal opportunities and responsibilities is presented in Figure 9.

According to Figure 9, a majority (64%) of the people with LF and 45.8% of the people affected by leprosy reported that they have opportunity to start and maintain long-term relationships. Although all three categories indicated limited opportunities to find work, a significant percentage (47.6%) of the persons with disabilities indicated that they work as hard as others, possibly as they have tertiary/vocational skills and express no restriction as indicated earlier.

The overall mean of approximately 33.07% suggests that about one-third of the respondents do not enjoy equal opportunities (equal opportunities in starting and maintaining long-term relationships, finding work, and working as hard as their peers). This underscores the need for strategies to enhance attitudes and support systems for empowerment of people with disabilities.

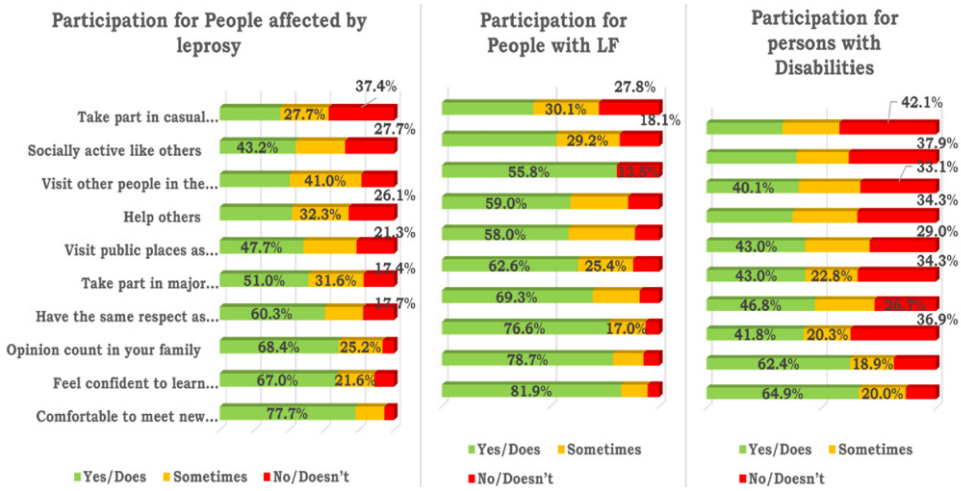

Figure 10. Participation restriction - Social interaction and confidence.

PARTICIPATION RESTRICTION IN TERMS OF SOCIAL INTERACTION AND CONFIDENCE

Involved exploration of interpersonal dynamics and psychological aspects of inclusion, building upon the premise of equal opportunities. It included exploration of the quality of relationships, social networks, and individuals' confidence to actively participate in social interactions, as presented in Figure 10.

Overall, the people with LF indicated higher levels of social interaction, confidence, and integration compared to those affected by leprosy and the persons with disabilities. For instance, the people with LF exhibit a significantly higher comfort level in meeting new people, with an overall mean of 81.9%, whereas those affected by Leprosy and persons with disabilities scored 77.7% and 64.9% respectively in the same category. Similarly, the people with LF reported greater confidence in learning new things (78.7%) compared to those affected by leprosy (67%) and persons with disabilities (62.4%).

In terms of feeling respected within their families, people with LF lead again with 76.6%, followed by those affected by leprosy (68.4%) and persons with disabilities (41.8%). Since majority of the people affected by leprosy were older persons, many of them could be having families and children from whom they get the respect. Furthermore, people with LF are more likely to participate in major festivals and rituals as their peers with 62.6%, compared to people affected by leprosy (51%) and persons with disabilities (43%).

This highlights the disparities between the three categories of respondents and underscores the need for targeted interventions to empower persons with disabilities and enhance confidence, social skills, and community connections.

PARTICIPATION RESTRICTION IN TERMS OF PERSONAL WELL-BEING AND HEALTH

This is a comprehensive framework to assess individual holistic wellness, including physical, mental, and emotional health. Access to healthcare services, robust support systems, and avenues for personal development and self-care are all essential. Prioritizing personal well-being not only ensures access to vital resources but also enhances resilience in overcoming

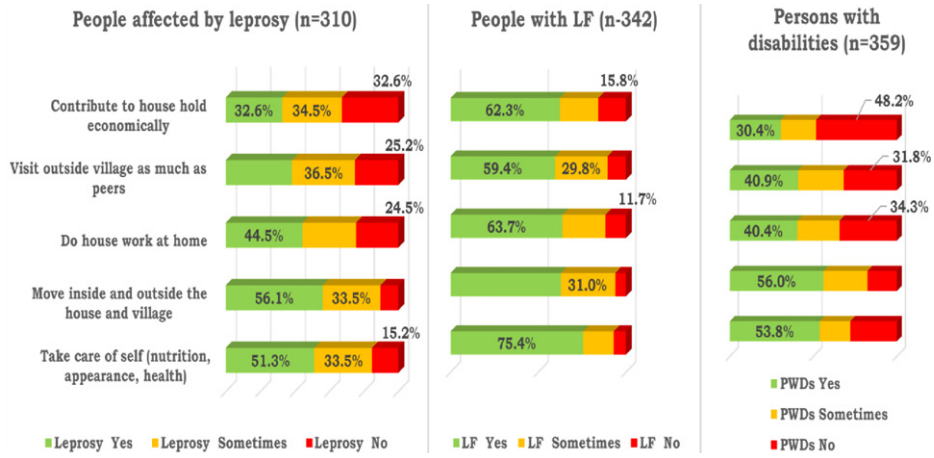

Figure 11. Participation restriction – Personal wellbeing and health.

life's inevitable challenges, to foster active participation and inclusion within society as presented in Figure 11.

In general, the majority of people with LF expressed engagement in various aspects related to personal well-being and health. Among those affected by leprosy and persons with disabilities, a significant portion indicated participation in self-care (51.3% and 53.8% respectively), as well as mobility within their homes and communities (56.1% and 56% respectively). However, notable percentages were noted for their lack of contribution to household finances (32.6% and 48.2% respectively). The 48.2% of persons with disabilities who do not contribute economically could be attributed to age and severity of disability as shown in Figures 2 and 3 above.

Despite reporting self-care practices, people affected by leprosy were found with inadequate hygiene practices. During interactions and focus group discussions, many were identified by foul odors and the presence of flies. Attempts to conceal their condition, such as wearing canvas shoes in public, were futile as the buzzing of flies gave them away. In some instances, colleagues even expressed discomfort, urging affected individuals to sit separately due to their odor as illustrated in this moving example from Kuluva, Arua district:

> *"Let her sit there alone!"* the group unanimously shouted.
> *"How can a normal woman be that smelly? You are the reason we get rejected in the community. Why don't you clean up and wash those wounds? We all have them but no… you will have to sit there alone,"* a group of women affected by leprosy in Kuluva, Arua district unanimously shouted.

When she joined the group, members held their nose and wanted her to be far from them because of her bad smell. This lady wears stockings to hide her condition and prevent flies on the wounds on her feet.

Such encounters highlight the profound impact of hygiene on the participation of people affected by leprosy and lymphedema, significantly contributing to their social exclusion.

Compared to those with hydrocele, people affected by leprosy, disabilities, and lymphedema reported greater participation restrictions. This could be attributed to differing community attitudes, as hydrocele is sometimes perceived positively due to its association with wealth and fertility, as expressed by a youth from Alebtong district:

> *"In this community, this is a treasure (pointing at his scrotal area) why operate it when I can make any woman pregnant? Who doesn't treasure children?"* (Youth with hydrocele in Abako sub-county, Alebtong district)

Interaction with the District TB/Leprosy supervisors and other health personnel revealed that many people only become aware of their leprosy when the disease has progressed significantly, leading to disabilities. As emphasized by a medical professional in Koboko district:

> *"Patients usually come to the health facility when leprosy has advanced and with deformity. In such cases, we treat leprosy but the disability is left for life unless intervention comes in to address it. Raising awareness of leprosy will inform people so that they report to health facilities early. It will help to reduce new cases and reduce disabilities due to leprosy"* medical officer in Koboko district.

Insufficient knowledge, negative attitudes, and financial constraints emerged as barriers to participation for the people affected by leprosy, LF, and disabilities from other causes. Community leaders and development officers highlighted the lack of information and data on affected individuals as hindrances to effective planning for their inclusion. There were no records of people affected by LF while scanty records existed for leprosy and fragmented documentation for persons with disabilities. Several programs working with persons with disabilities have lists of their beneficiaries.

To address these challenges, various strategies were proposed during interviews and focus group discussions:

Enhancing self-care, particularly through improved hygiene, is vital for the inclusion of people affected by leprosy and LF.

> *"The Ministry of Gender, Labor, and Social Development offers programs such as the Youth Livelihood Program, Senior Citizens Grant, and Disability Grant to support affected individuals. These initiatives aim to provide skills training, financial support, and promote socio-economic inclusion. People affected by leprosy and LF can benefit from them if they join groups"*, District Community development Officer, Kitgum district.

Empowerment and hygiene are crucial to overcoming negative attitudes for the people affected by leprosy and LF to access and benefit from these programs.

Providing knowledge and information on leprosy, LF, and disabilities was identified as crucial for early identification and referral for appropriate interventions. Empowering individuals with self-advocacy skills and offering training in self-care at both individual and group levels were also proposed as effective measures.

During discussions, the people affected by leprosy and LF emphasized the need for self-care training to mitigate unpleasant odors associated with their conditions.

> *"Yes, we are not wanted by people in the community but these people like us who go around smelling make us be abused for leprosy. Cleanliness is important and may help us be accepted in the community"* an older lady in Layibi division, Gulu distirtc.

Recognizing the similarities between leprosy, LF, and disabilities, community leaders and development officers pledged to promote the inclusion of affected individuals in community development programs.

Discussion

This study sought to assess participation of people affected by leprosy and lymphatic filariasis. 42.8% perceived their disability as moderate while 42.3% expressing need for assistive devices 59.4% of these were people affected by leprosy in need of protective footwear which increases their vulnerability to injuries. Although mean participation levels were moderate, substantial proportions reported severe and extreme restrictions. Females reported more restrictions, particularly among those with severe disabilities while the patriarchal attitudes in LF-affected communities positively influenced participation among males with hydrocele. Lack of formal education correlated with higher participation restrictions across all categories while vocational/tertiary education showed lower participation restrictions among persons with disabilities. Participation restriction was attributed to societal attitudes, and limited access to opportunities. Lack of awareness, negative attitudes, and financial constraints hinder participation and inclusion. Insufficient data and fragmented documentation impede effective planning for inclusion programs hence the need for targeted interventions.

Findings shed light on the challenges faced by people affected by leprosy, lymphatic filariasis (LF), and disabilities, revealing significant participation restrictions and vulnerabilities. These groups experience limitations in various activities,[13,14] with notable disparities between genders. Approximately 31% of people affected by leprosy, 24.8% of persons with disabilities, and 31.4% of females with lymphedema reported severe participation restrictions, while 19%, 24.5%, and 8.7% respectively reported extreme restriction which could be attributed to severity of disabilities and other barriers. Across these categories, females reported higher participation restrictions than males, underlining gender-based disparities consistent with broader research.[1]

The patriarchal attitudes towards conditions like hydrocele in some communities reflect wider societal beliefs affecting the social status and participation of people with some of these disabilities.[15] Factors such as negative attitudes and inadequate hygiene contribute to the exclusion of people affected by leprosy, emphasizing the need for targeted interventions.[16] Furthermore, limited access to assistive devices exacerbates participation restrictions, with 42.3% of respondents citing a lack thereof.

Education is a great empowering tool since it enlightens individuals, builds confidence, and breaks barriers to opportunity.[17] It is a crucial factor in mitigating participation restrictions, r with disparities evident among those who have never attended school, particularly among older women affected by leprosy.[18] It is vital to invest in targeted interventions for older persons to enhance their participation and benefit from the existing social protection programs.

Participation restrictions transcend mere economic factors, extending into social interactions and overall well-being. While some individuals demonstrate resilience and successful social integration, pervasive stigma and inadequate hygiene practices persist, resulting in exclusion. This resonates with existing literature on disability and participation, highlighting the complex interplay among individual characteristics, attitudes, and environmental factors in shaping participation outcomes.[1,6]

A similar study found that participation restrictions, along with stigma, shame, marital issues, and employment difficulties, were among the most commonly reported challenges faced by individuals disabled by leprosy.[19] This underscores the multifaceted nature of barriers to participation faced by those with disabilities, emphasizing the need for comprehensive support strategies that address both societal attitudes and environmental factors.

These findings highlight the existing gaps in accessibility that require urgent attention to ensure equitable support for persons with disabilities. People affected by leprosy require protective footwear and hand gloves to prevent ulcers, a common complication of the disease.

However, it's crucial that these devices are not just available but also appropriate for effectiveness, as emphasized by.[20] This underscores the critical importance of ensuring that assistive devices cater to the specific needs of individuals affected by leprosy to effectively mitigate risks and enhance their quality of life.

Furthermore, the demographic profile of respondents in the productive age bracket highlights the economic ramifications of these conditions, particularly on the country's workforce.[21] The financial implications of disability further exacerbate these challenges, underscoring the imperative for accessible rehabilitation and assistive technologies, as emphasized by the.[16]

Comparison with existing literature underscores the complexity of disability dynamics, emphasizing the need for context-specific interventions.[22] Despite limitations in self-reported data, the findings offer valuable insights into participation barriers and advocate for inclusive policies and practices.

Individual perceptions of disability severity play a pivotal role in shaping participation outcomes and social interactions.[23] Barriers to participation, such as insufficient knowledge, negative attitudes, and financial constraints, necessitate multifaceted interventions aimed at promoting self-care practices, knowledge dissemination, and inclusion in community development programs. A study by underscored the significance of knowledge and information in facilitating attitude change towards leprosy.[24]

Enhancing the participation of people with disabilities and other vulnerable groups demands a holistic perspective that recognizes socio-cultural, economic, and environmental factors. Targeted interventions that address socio-cultural, economic, and environmental barriers are essential to enhance participation and inclusion. Education emerges as a critical factor in facilitating participation, warranting investments in inclusive education programs. Furthermore, gender disparities in participation outcomes call for the formulation of gender-sensitive policies and approaches to foster equity and social justice for marginalized populations.

The study sheds light on the complex challenges and inequalities encountered by people affected by leprosy, LF, and disabilities. Its comprehensive approach, including in-depth demographic analysis covering crucial aspects such as disability severity and the utilization of assistive devices, which are vital for understanding disability inclusion are commendable. Moreover, the study offers intervention strategies to enhance disability inclusion efforts. Nevertheless, it grapples with limitations such as reliance on self-reported data and a cross-sectional design, which has potential for biases due to variations in respondent characteristics at the time of data collection. These could restrict the study's generalizability.

Future research endeavors should delve into longitudinal trends and assess the effectiveness of interventions to advance inclusion and social justice further. Advocating for evidence-based interventions and policy reforms is crucial in our collective effort to build a more inclusive society where everyone has the opportunity to fully participate and contribute. Overcoming the challenges highlighted in the study could indeed strengthen its credibility and relevance, ultimately facilitating the development of more impactful interventions and policies aimed at promoting inclusion, equity, and social justice for marginalized communities.

Recommendations

In 2017, Disability-Inclusive Planning Guidelines[25] were developed to inform mainstreaming of disability in all government programs for inclusion. People affected by leprosy and LF ought to benefit from these like other persons with disabilities however, there is a pressing need for

accurate documentation of the people affected by leprosy, LF, and other disabilities which is currently lacking. This is imperative to inform targeted planning and interventions to ensure their full participation and inclusion in society.

The Community-Based Rehabilitation (CBR)/Community based Inclusive Development (CBID) approach as outlined in the WHO CBR Matrix, is paramount.[22] Its multisectoral nature will not only help to improve self-care and rehabilitation service provision but also empower and enable participation and inclusion of the people affected by leprosy, LF and other disabilities. CBR/CBID thrives with use of local resources to facilitate ownership and sustainability of interventions.

Lobby and advocate for inclusion of people affected by leprosy and LF in the production of assistive devices and other technologies to enhance their participation and inclusion. Incorporation of protective footwear into the list of assistive devices for persons with disabilities is vital. Through community systems and existing facilities, effort may be invested in enhancing local capacity for production and repair of some of the devices to mitigate some of the challenges identified by this study.

Lobbying and advocacy for gender responsive and targeted policies and programs is vital to address disparities in participation outcomes, particularly for individuals affected by conditions like leprosy and LF.

Government has vocational rehabilitation centers operated by the Ministry of Gender, Labor, and Social Development, in Ocoko (Arua district), Kireka (Kampala district), Lweza (Wakiso district), Ruti (Mbara district) and Mpunudee (Jinja district). These play a vital role in cost free skills development for youths with disabilities. The youths affected by leprosy and LF can equally benefit from them for economic empowerment. Through networking and collaboration, these centers can be further utilized for the production of assistive devices, leveraging their existing infrastructure and resources.

Education and awareness programs are indispensable in combating stigma and fostering understanding of leprosy, LF, and disabilities. Accurate diagnosis, self-care practices, and inclusive attitudes must be promoted to facilitate the acceptance and inclusion of affected individuals in government programs.

Training the people affected by leprosy, LF and disabilities in in self-care and self-advocacy is a crucial steps towards fostering their active participation in community development programs. Mobilizing them into groups to benefit from existing disability and mainstream programs further enhances their empowerment and enablement.

Capacity building of village health team, the medical personnel and communities in the identification, assessment, basic management, and referral of suspected cases of leprosy is essential. Health education initiatives and community-based approaches can help demystify leprosy, LF, and disabilities, bridging the existing knowledge gap.

Engaging the disability community in collective advocacy efforts, recognizing the intersectionality of education, gender, and disability, and ensuring equal access to resources and opportunities for all genders are indispensable in advancing the agenda of disability inclusion and contributing to sustainable development goals.

Conclusion

The study explores participation levels among people with leprosy, LF and disability, emphasizing similarities in activity limitation and exclusion across these conditions. While approximately half of LF patients, mainly males, reported no significant participation restrictions, significant proportions of those affected by leprosy, disabilities, and female lymphedema

patients faced severe and extreme limitations. Despite moderate mean scores, variability in participation levels was noted, with slightly greater variability in the participation "Score" compared to the "Condition" (leprosy, LF and disability). Both genders exhibited similar trends in restriction levels, with females generally reporting more limitations. Overall, targeted interventions are essential to address the diverse participation challenges and foster inclusion for individuals affected by these conditions.

Key determinants influencing the participation and inclusion of people affected by leprosy, LF, and disabilities include knowledge and information, attitudes, hygiene practices, and financial constraints. Additionally, the lack of reliable documentation poses a significant barrier to effective planning for their inclusion in societal programs and initiatives. Addressing these determinants is essential for fostering a more inclusive environment for all individuals, regardless of their health conditions or disabilities.

Adoption of multi-stakeholder collaboration, targeted and gender-sensitive approaches, we can effectively address the diverse needs of people affected by leprosy, LF and persons with disabilities. This synergistic approach not only promotes equitable support and opportunities for all individuals but also plays a pivotal role in reducing the burden of leprosy, lymphatic filariasis (LF), and disabilities in the community and the country at large.

Acknowledgements

The Research Team expresses sincere gratitude to the Leprosy Research Initiative for the opportunity, technical and financial support to successfully implement this study. Appreciation goes to German Leprosy and TB Relief Association for the coordination of this study; UNALEP team for the support throughout data collection, enlightening communities on leprosy and contributing to the fight against leprosy; the District Health Officers, District TB Leprosy Supervisors, NTD personnel, Community Development Officers, the leadership in the disability unions and disability councils, the health personnel, members of the village health teams and local leaders who greatly committed time to support the study.

Special gratitude goes to the people affected by leprosy, Lymphatic Filariasis and persons with disabilities, their families and the community for the time committed and the willingness to share the details presented in this report. Mr Okello Edwin and Mr Faraday M. Michael Faraday for the tremendous skills, determination and resilience throughout data management to facilitate successful completion of the assignment.

Finally, we also acknowledge all colleagues who have helped to review draft offering useful advice.

Author contributorship

Conceptualization: KM, BBS; CK research concept and methodology, MCS, CK; data collection MCS, BBS, KM; data management and analysis MCS, CK; report writing MCS; validation and technical guidance WHV, CK; logistics and administration CM; review of report and writing article AS, CK, AF, SP and WHV.

Financial disclosure statement

This research project was implemented with financial support from the Leprosy Research Initiative *with grant number 706.18.46*.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests

All the authors declare that there is no competing interest.

Related manuscripts

All the authors certify that the article is their original work and has not been submitted for publication or review in any other journal.

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