


# Lessons from integrating mental health as part of lymphatic filariasis morbidity management and disability prevention services in Jigawa State, Nigeria

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Lymphatic filariasis (LF) is a neglected tropical disease affecting >120 million people worldwide. LF has debilitating effects on humans and leads to morbidity and sometimes irreversible disability. A significant proportion of persons affected by LF morbidity also suffer from ill health, such as depression, anxiety, pain, stigma and social isolation due to disfigurement, as well as loss of mobility, livelihood and income. Mental health is often overlooked as a component of morbidity management and disability prevention (MMDP) services, despite the high prevalence of depression and anxiety among people affected by LF.

To address this gap, Christian Blind Mission (CBM) piloted a comprehensive approach providing morbidity management and disability prevention by integrating mental health as part of the MMDP care package. The participatory evaluation of the project reviewed the project documents and a review meeting, small group discussions and in-depth interviews with project stakeholders.

Findings suggest that project training and service delivery targets were exceeded in most cases. In addition, the disability and gender disaggregated data highlights the interplay of gender and disability in accessing care and the existence of unmet mental health needs. The financial cost of transportation to utilise referrals or access other MMDP services, such as replenishing treatment supplies, was a major constraint in accessing services for LF morbidity patients and low levels of awareness, fear of hydrocoele surgery and social stigmatisation were reported.

The project outcomes demonstrate the feasibility and effectiveness of integrating mental health as part of a comprehensive MMDP package of care. Integration strategies should target training of MMDP providers in basic mental health skills, screening for mental health issues and the provision of mental health services and other MMDP services within the same facilities. Integration is an important step towards comprehensive care for people affected by LF and other NTD morbidities and disabilities.

La filariose lymphatique (FL) est une maladie tropicale négligée qui touche plus de 120 millions de personnes dans le monde. La FL a des effets débilissants sur l'homme qui entraînent une morbidité et parfois un handicap irréversible. Une partie importante des personnes affectées par la morbidité de la FL souffre également de problèmes de santé tels que la dépression et l'anxiété, ressentent des douleurs, sont stigmatisés et isolés en raison de leur défiguration, et perdent leur mobilité ainsi que leurs moyens de subsistance et de revenus. De plus, la santé mentale de ces patients est souvent négligée. Pourtant, celle-ci devrait faire partie intégrante de la gestion de la morbidité et des services de prévention des handicaps, car on constate une forte prévalence de la dépression et de l'anxiété parmi les personnes touchées par la FL.

Pour palier à ce problème, CBM a piloté une approche globale de la gestion de la morbidité et de la prévention des invalidités en intégrant la santé mentale dans le paquet de soins du MMDP. L'évaluation participative du projet a permis d'examiner les documents du projet, d'organiser une réunion d'examen, des discussions en petits groupes et des entretiens approfondis avec les parties prenantes du projet.

Les résultats suggèrent que la plupart des objectifs du projet en matière de formation et de prestation de services ont été dépassés dans la plupart des cas. En outre, les données ventilées par handicap et par sexe sur les personnes atteintes mettent en évidence l'interaction du genre et du handicap dans l'accès aux soins et l'existence de besoins non satisfaits en matière de santé mentale. Le coût financier du transport pour utiliser les références ou accéder à d'autres services du MMDP tels que le réapprovisionnement en fournitures de traitement, a été une contrainte majeure dans l'accès aux services pour les patients atteints de morbidité due à la FL et de faibles niveaux de sensibilisation, la peur de la chirurgie hydrocoele et la stigmatisation sociale ont été signalés.

Les résultats du projet démontrent la faisabilité et l'efficacité de l'intégration de la santé mentale dans l'ensemble des soins du MMDP. Les stratégies d'intégration devraient viser à former les prestataires du PDMM aux compétences de base en matière de santé mentale, à dépister les problèmes de santé mentale dans le cadre des évaluations de la santé mentale et à fournir des services de santé mentale et d'autres services du PDMM dans les mêmes établissements. Cette intégration est une étape importante vers des soins complets pour les personnes touchées par la FL et d'autres maladies et handicaps liés aux MTN.

La filiarisis linfática (FL) es una enfermedad tropical desatendida que afecta a más de 120 millones de personas en todo el mundo. La FL tiene efectos debilitantes en los seres humanos que provocan morbilidad y a veces discapacidad irreversible. Una proporción significativa de las personas afectadas por la morbilidad de la FL también sufren problemas de salud como depresión y ansiedad, dolor, estigmatización y aislamiento social debido a la desfiguración, así como pérdida de movilidad, medios de vida e ingresos.

Aunque en los últimos años se han redoblado los esfuerzos mundiales para eliminar las ETD -los países están en vías de lograr la eliminación de algunas de ellas-, en la actualidad la atención a las necesidades de las personas que ya viven con la morbilidad de las ETD, como el linfedema y el hidrocele, es limitada; a menudo se pasa por alto la salud mental como componente de los servicios de gestión de la morbilidad y prevención de la discapacidad, a pesar de la alta prevalencia de la depresión y la ansiedad entre las personas afectadas por la FL. Para subsanar esta carencia, CBM puso a prueba un enfoque global de la gestión de la morbilidad y la prevención de la discapacidad mediante la integración de la salud mental en el paquete asistencial del MMDP. La evaluación participativa del proyecto revisó los documentos del proyecto, celebró una reunión de revisión, debates en pequeños grupos y entrevistas en profundidad con las partes interesadas en el proyecto.

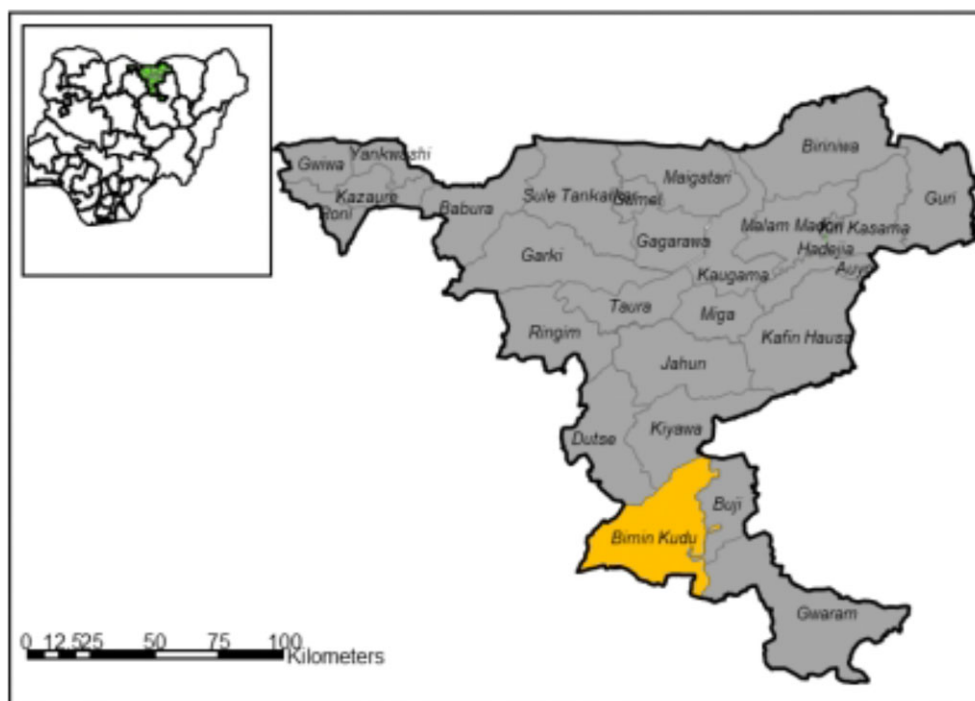
Los resultados sugieren que en la mayoría de los casos se superaron los objetivos de formación y prestación de servicios del proyecto. Además, los objetivos de datos desglosados por discapacidad y género de las personas atendidas ponen de relieve la interacción del género y la discapacidad en el acceso a la atención y la existencia de necesidades de salud mental no cubiertas. El coste económico del transporte para utilizar las derivaciones o acceder a otros servicios del MMDP, como la reposición de suministros para el tratamiento, fue una limitación importante para el acceso a los servicios de los pacientes con morbilidad por LF, y se informó de los bajos niveles de concienciación, la seguridad de las operaciones de hidrocoele y el miedo a la estigmatización social.

Los resultados del proyecto demuestran la viabilidad y eficacia de integrar la salud mental como parte del paquete integral de atención del MMDP. Las estrategias de integración deberían centrarse en la formación de los proveedores del MMDP en habilidades básicas de salud mental, la detección de problemas de salud mental como parte de las evaluaciones de salud mental y la prestación de servicios de salud mental y otros servicios del MMDP dentro de las mismas instalaciones. La integración es un paso importante hacia la atención integral de las personas afectadas por esta enfermedad y otras enfermedades y discapacidades derivadas de las ETD.

## Background

Neglected tropical diseases (NTDs) are a group of infectious diseases that thrive in impoverished settings in tropical and subtropical countries.<sup>1</sup> Some of these diseases have debilitating effects on humans that lead to morbidity and disability, and lymphatic filariasis (LF) is one of the NTDs that causes morbidity.<sup>2</sup> LF, also

known as elephantiasis, is a parasitic infection caused by filarial worms that are transmitted to humans through the bites of infected mosquitoes; the adult worms live in the lymph system where they cause chronic inflammation and damage to the lymphatic vessels, leading to swelling and enlargement of the limbs, genitalia and breasts<sup>3</sup>. According to the World Health Organization (WHO)<sup>4</sup> LF continues to threaten about 882 million people in



**Figure 1.** Map of Jigawa State, with the project location highlighted.

44 countries across the tropics and subtropics of Asia, Africa, the Western Pacific and parts of the Caribbean and South America.

Most individuals infected with LF are asymptomatic; however, when LF develops into chronic conditions it leads to lymphoedema (tissue swelling) or elephantiasis (skin/tissue thickening) of the limbs and hydrocele (WHO, 2022). Approximately 40 million people suffer from the debilitating effects of chronic infection and a significant proportion of persons affected by LF morbidities suffer depression, anxiety, pain, stigma and social isolation due to disfigurement and loss of mobility, livelihood and income (WHO, 2022).<sup>5,6</sup> These challenges can exacerbate physical symptoms and reduce quality of life, hence the need for mental health as a component of care.

Nigeria is estimated to have the highest burden of LF globally, with 583 endemic local government areas (LGAs), putting >141 million Nigerians at risk of the disease.<sup>5,7</sup> Jigawa State is one of the 36 states in Nigeria endemic for LF, the 27 LGAs of Jigawa State are endemic for LF, putting a population of >6 million people at risk of the disease and its related morbidity and disability (FMoH, 2022).

The current twin approach recommended by the WHO for LF elimination is preventive chemotherapy involving mass drug administration (MDA) and morbidity management and disability prevention (MMDP) to reduce the suffering of those already infected and prevent further disability.<sup>8</sup> However, this approach does not address the mental health component (anxiety and depression), thus increasing the mental health challenges faced by persons affected by LF morbidities and disabilities.

The WHO NTD road map 2021–2030 recommends a paradigm shift in the implementation of NTD programs towards a holistic,

cross-cutting, integrated and intersectoral approach. The holistic NTD program piloted by Christian Blind Mission (CBM) collaboration with the Health & Development Support Programme (HANDS) in Jigawa State, Nigeria, integrated mental health as a component of MMDP services provided for persons identified with LF morbidities.

## Project overview

The 18-month project was conducted in Birnin Kudu LGA of Jigawa State, Nigeria (Figure 1). Jigawa State is one of the 36 states of Nigeria with a population of >6 million people (2006 census projected population).

All 27 LGAs in the state are endemic for LF. In 2020, CBM designed and implemented a comprehensive pilot project in Birnin Kudu LGA. The goal of the project was to ensure that people who are being treated through the MDA program can access comprehensive and inclusive services for the management of LF and other NTD-related morbidities. The project components comprised training of health workers and community volunteers to identify and refer LF-related morbidity (lymphoedema and hydrocele) during house-to-house MDA, strengthening the referral system and the provision of hydrocele surgeries and limb care and management services. Other components were advocacy for inclusive water, sanitation and hygiene (WASH) services; psychosocial support for mental health; and community-led awareness raising, sensitisation and advocacy to demystify mental health and disability and to reduce stigma.

**Table 1.** Personnel trained by the project.

Personnel trained	Target	Males without disability	Females without disability	Males with disability	Females with disability	Total
Training of health workers and DPO on DID and WASH	25	13	4	16	3	36
Training of CDDs on inclusive and comprehensive NTDs	350	542	38	9	3	592
Training of CDDs on rapid survey of people with disabilities using the WG questionnaire	350	561	15	9	3	588
Training of health workers and CDDs on referral for morbidity management and mental health services	150	632	32	11	2	677
Training of mental health nurses on mental health GAP (mhGAP)	25	19	6	0	0	25
Total	900	1767	91	45	11	1918

CDD: community drug distributors; DID: disability inclusive development; DPO: disability persons organization; WG: washington group.

This article provides the lessons and challenges of incorporating mental health as part of MMDP services and provides insights on the lived experience of persons affected by LF morbidities.

## Methods

The assessment utilised a mixed method design, comprising a review of project documents and reporting tools, a review meeting with key stakeholders, in-depth interviews and small group discussions. The quantitative method used was a review of project reports, documentation analysis and project key performance indicators to assess the level of achievement of the targets. This information was tabulated and analysed using Excel (Microsoft, Redmond, WA, USA). The qualitative method gathered information through a project review meeting with key stakeholders, two small-group discussions and in-depth interviews with four persons affected by LF morbidities, two health workers and two community leaders to gain insights into project achievements and perspectives on the successes, challenges and outcomes of the holistic NTD pilot project. A question guide was developed to facilitate discussions. Participants were selected based on their roles in the project.

## Data management and analysis

Data from the review meeting, small-group discussions and in-depth interviews were conducted in the local language, documented without any personal identifiers and stored in password-protected computers. The in-depth interviews were recorded using an end-to-end encrypted device. The data collected were transcribed and translated into English for analysis. The data were organised into codes, categories and themes based on emerging patterns using Nvivo software (Lumivero, Denver CO, USA).

## Results

### Project achievements

#### Training

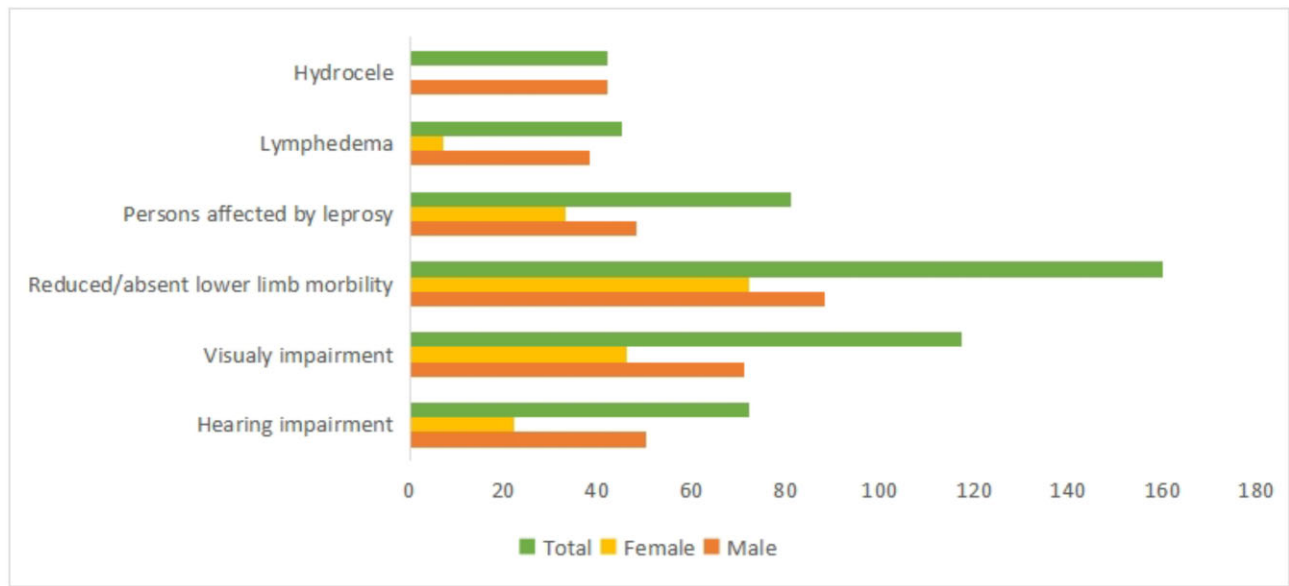
Table 1 is a summary of personnel trained to ensure inclusive implementation. The trainings included disability inclusive development, inclusive and comprehensive NTDs, use of Washington Group Questionnaires for rapid surveys of disability and the Mental Health Gap Action Programme (mhGAP)<sup>9</sup> to ensure the availability of knowledgeable healthcare providers for effective and comprehensive project implementation.

#### Disability and gender disaggregated data

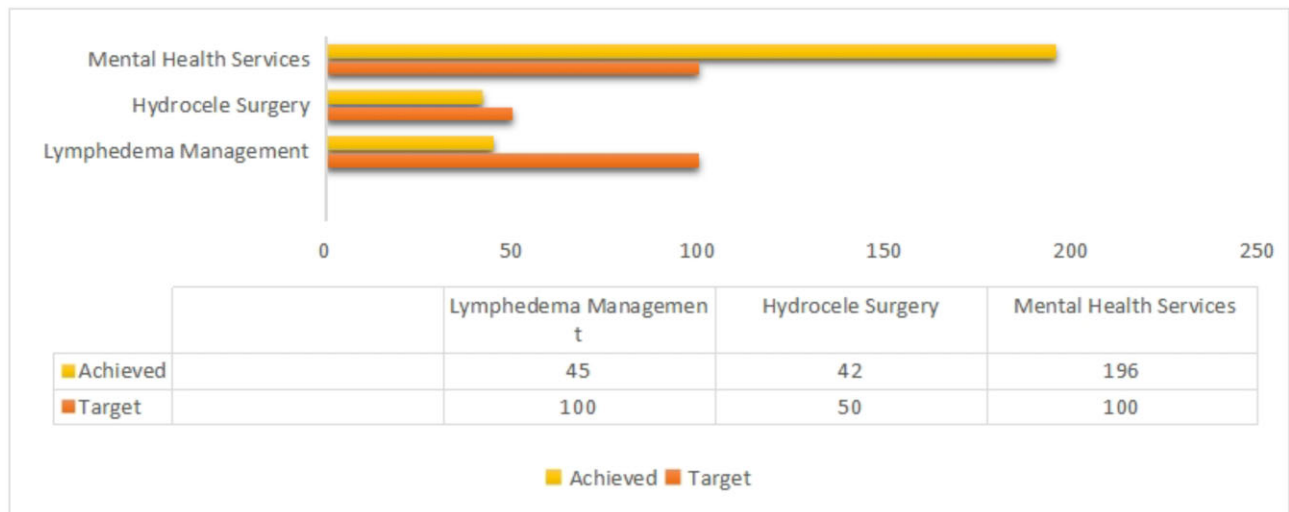
One of the objectives of the project was to collect data disaggregated by gender and disability type, as this is information that can intersect with other social and economic factors. The data in Figure 2 show that more men were reached. This could be due to how gender and disability status may reinforce barriers and social exclusion, especially for women in the project context.

#### MMDP services provided

The project's aim was to identify LF morbidity cases and provide lymphoedema management, hydrocele surgeries and mental health services. A total of 196 persons received mental health services, thus exceeding the project target by almost 100%, demonstrating a high demand for mental health services. Additionally, the projects reached 42 and 45 persons for hydrocele surgeries and lymphoedema management, respectively, as shown in Figure 3. Table 2 also provides information on services received, disaggregated by gender. The details of more males receiving lymphoedema management and mental health services could



**Figure 2.** Morbidity, disability and gender disaggregated data of persons treated during MDA who received MMDP services (including mental health).



**Figure 3.** MMDP services provided.

be due to the sociocultural dynamics around gender participation in the project context.

*Qualitative analysis*

*Review meeting.* The review meeting was attended by intersectoral stakeholders who were part of the planning and project implementation. Participants included representatives from the Jigawa State Ministries of Health, Environment, Education and Water Resources, persons affected by LF morbidity, disabled persons’ organizations and non-governmental organizations.

Participants agreed that the pre-implementation advocacy activities, involvement of disabled persons’ organizations and the intersectoral collaboration during planning and implementation facilitated project acceptance and successes.

*Increased awareness and mental health services.* The feedback from LF morbidity patients suggests that there is increased awareness about MMDP services. Persons affected by LF morbidities have been reintegrated into their families and the project communities are now aware that mental health issues are not

**Table 2.** MMDP services provided disaggregated by gender.

MMDP services provided	Target, n	Achieved, n		Total, n	Achieved, %
		Males	Females		
Lymphoedema management	100	42	3	45	45
Hydrocele surgery	50	42		42	84
Mental health services for 100 persons	100	124	72	196	196
Total	250	208	75	283	113

a curse from God. Below are quotes from the review meeting. A bilateral hydrocele patient stated:

I can now walk straight and can do everything I wasn't able to do due to the hydrocele including having intimacy with my wife.

Unavailability of mental health drugs was one of the challenges of the project. In some instances where the medicines were available, they were out of date and would cause side effects if used. According to one of the participants, mental health drugs are either unavailable at the clinic, forcing people to travel to hospitals when referred, or are older-generation drugs with side effects. The community now understands that mental health issues are not a curse from God and may require drugs or psychological support through counselling. Involving the families during the counselling helped a great deal to demystify mental health and encouraged their support, thus reducing stigma.

In instances where patients with morbidity depended on traditional medicines for managing lymphoedema, the training and awareness equipped them with the knowledge of how to manage their limbs at home. A female patient who has depended on using traditional treatment attested that her leg pain and swelling improved due to the treatment at the primary health facility and the training she received in home-based limb care and management.

*In-depth interviews.* The Jigawa State Deputy NTDs Coordinator affirmed the role played by the state government in ensuring that the primary healthcare (PHC) facilities are adequately equipped to manage patients with LF/hydrocele in the Birnin Kudu LGA. He said that health workers from the LGAs and communities were invited to the state capital for training on how to manage LF morbidity and care for patients.

The PHCs were supplied with the necessary items needed for their activities. If you visit the PHCs, these items are there for you to see.

Hydrocele and lymphoedema patients are inclined to anxiety and depression due to a number of factors, including fear and social isolation as a result of stigma associated with cultural beliefs about these conditions. Patients, especially those with

hydrocele, mentioned social stigmatisation and fear prevented patients from accessing MMDP services. Some respondents revealed that fear of stigma prevented them from accessing services, while others feared dying during surgery. They were of the view that it is best for death to come naturally rather than subjecting themselves to death through the 'opening of their balls' (i.e. surgery; male in-depth interview respondent). For others, it was a story of restoration of hope and the ability to dream again, as recounted by a 24-year-old male hydrocele patient who is happy that the surgery has restored his dream of joining the military.

*Impact of poverty and sociocultural factors on access to services.* Poverty continues to play a role in the ability of patients to access services. The responses of participants provides insights on how a lack of resources aggravates the situation, as patients are often unable to access care due to the cost of transportation and the hospital. One hydrocele patient mentioned that he was referred to a secondary health centre (general hospital), however, he could not access care due to a lack of transportation. In his words:

I could not go to the place because of the distance and the cost. It would have cost me about 1300 naira [approximately US\$2] and I do not have such money.

This patient's situation is not unusual, as other respondents also mentioned the same issues.

Some sociocultural factors may affect who receives services, especially when women observe various customs to maintain their modesty and privacy and there are restrictions on interactions with men who are not family members. Female lymphoedema patients affirmed that inadequate awareness of the program impedes access to MMDP services. Men have access to information because they attend meetings, trainings and other events. According to a respondent:

As a married woman, I know only what my husband tells me, and this is applicable to all women in this community.

This highlights the need to develop contextually appropriate approaches in messaging and community awareness to ensure women have access to correct and timely information.



## Discussion

The goal of the project was to ensure that persons identified with LF morbidity during MDAs have access to comprehensive MMDP services. For this goal to be achieved, training targets were set; the findings from this review show that the target for training was exceeded in most cases.

The disability and gender disaggregated data highlighted the success of reaching more persons with decreased mobility who would often face the barrier of accessing care due to their specific disability.<sup>10</sup> This also demonstrates the interplay between gender and disability, where persons with disabilities may face discrimination and exclusion.<sup>11</sup> Additionally, involvement of women in the project is influenced by some sociocultural factors that shape their roles, access and participation.<sup>12</sup> The region's conservative cultural norms and gender inequalities intersect to create unique challenges and opportunities for women's engagement and accessing of services, including mental health services.

Mental health patients are often not prioritised because their condition is not perceived as life threatening.<sup>13</sup> Integrating public health and mental health can be complex due to the different approaches, however, recognizing the interconnectedness of physical and mental well-being calls for a multifaceted approach involving policy changes, cultural shifts and collaborative efforts to ensure the delivery of holistic and equitable services.<sup>14</sup>

Despite the existing barriers to accessing mental health services, the trained mental health nurses provided psychosocial intervention and counselling, and in some cases treatment with antidepressants was provided and severe cases were referred to a specialist at a secondary or tertiary health facility. However, the unavailability of first-line treatment medicines at the primary facility necessitated referral in most cases, thus increasing the cost of accessing care.

The cost of transportation to health facilities and other challenges such as lack of awareness of MMDP services and fear of social stigmatisation and surgery as reported here are similar to experiences of patients from other endemic parts of Africa.<sup>15</sup> Depending on the severity of the morbidity, some could have difficulty walking to the local health clinic servicing his/her community. Birnin Kudu, where the project was implemented, is largely an agrarian economy with periods of intense drought, so families have to prioritise food. Lack of awareness regarding hydrocoele surgery could also impede motivation. If patients are knowledgeable about the causes and available treatments for the different forms of LF morbidity, they are more likely to respond positively to MMDP services. Another plausible inference from the lack of awareness about MMDP services reported by our evaluation would be that husbands may not share certain information with their wives. There is a need to improve advocacy and health education programmes so that they leverage on innovative cultural channels<sup>16</sup> so that information trickles down to every member of the community regardless of gender or class.

## Conclusions

The project outcomes demonstrate the feasibility of integrating mental health as part of comprehensive MMDP packages of care. Integration strategies should target training of MMDP providers in basic mental health skills, screening for mental health issues as

part of health assessments and providing mental health services and other MMDP services within the same facilities. The number of persons reached with mental health services suggests that there is a high demand for services, however, it is crucial to develop a contextually appropriate program to ensure equitable access to all persons requiring services, irrespective of gender or disability status.

Comprehensive MMDP services have the potential to improve both physical and mental health outcomes for people affected by LF. However, significant challenges exist, including limited resources and a lack of expertise in mental health among health workers at the primary level, siloed programs and inadequate intersectoral collaboration. Addressing these challenges will require collaboration between public health and mental health sectors, investment in training and integration.

Integration is an important step towards comprehensive care for people affected by LF and other NTD morbidities and disabilities. Addressing both physical and mental health needs would improve quality of life and reduce the burden of LF on individuals and communities.

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**Data Availability Statement:** The data that support the findings of this paper are available in the article.

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