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“Whenever I tell her to wear slippers, she turns a deaf ear. She never listens”: a qualitative descriptive research on the barriers to basic lymphedema management and quality of life in lymphatic filariasis patients in a rural block of eastern India

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Abstract

Background Chronic lymphatic filariasis patients in Bihar, India, need management of lymphedema to live a disability-free life. For patients who have recurrent attacks of acute dermato-lymphangio-adenitis (ADLA), World Health Organization (WHO) has recommended simple home-based measures that include maintaining hygiene, skin care, and limb movement. However, patients in rural areas are unable to adopt them, resulting in a vicious cycle of ADLA attacks. There might be multiple realities from patients' and healthcare workers' perspectives that were unexplored. Qualitative research was deemed best suitable to identify the barriers to carrying out home-based lymphedema practices that adversely affected quality of life.

Methods The qualitative descriptive study was conducted in two villages in the rural field practice area under a tertiary care hospital in Bihar. Researchers purposively selected ten participants, including patients affected by lymphedema, their caregivers, the grassroots healthcare workers, and the block health manager. In-depth interviews were conducted using a semi-structured interview guide. Data were entered into QDA Miner Lite, where researchers did attribute, in-vivo, process, descriptive, emotion, and holistic coding, followed by content analysis, where categories and themes emerged from the codes.

Results Three themes emerged: the inherent nature of disease, patient-related factors, and healthcare system-related factors. The fifteen identified barriers were low awareness, low adherence, low health-seeking behavior, poor personal hygiene, and categories like signs and symptoms, seasonal factors, hampered activities of daily living, hopelessness from not getting cured, psychosocial difficulty, lack of capacity building and receipt of incentives by healthcare workers, unavailability of laboratory diagnosis and management of complications at the facility, inconsistent drug supply, and no financial assistance.

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Conclusions Accessibility to WaSH, regular training of home-based care, increasing the capacity and motivation of grassroots workers, and the generation of in-depth awareness among the patients are required to achieve the elimination of filariasis, with MMDP as a key component of that strategy for endemic districts across the whole country.

Keywords Lymphedema, Lymphatic filariasis, Elephantiasis, Morbidity management and disability prevention, Mass drug administration, Neglected diseases, Water sanitation and hygiene, Qualitative research, India

Background

Lymphatic filariasis (LF), a neglected tropical disease, is endemic in 257 districts of India, putting 650 million people at risk. They include all 38 districts of the state of Bihar [1]. Lymphedema is the most common morbidity among the chronic cases. To achieve elimination of LF, two-pronged strategies are used: annual mass drug administration (MDA) with diethylcarbamazine and albendazole, and morbidity management and disability prevention of lymphedema (MMDP) [1, 2].

Under MDA, there are biannual rounds of door-to-door distribution of tablet albendazole (which are be combined with diethylcarbamazine and/or ivermectin) followed by supervised consumption of the tablets by the healthy and afflicted alike. The grassroots healthcare workers supervise the distribution of the medicines in their respective areas. Under MMDP, an essential package of care is only provided to patients with filarial lymphedema, either by the healthcare workers or directly at the block health center. Washing the affected limb daily with soap and clean water at room temperature followed by drying with a clean cotton cloth is the recommended protocol. Interdigital lesions are usually treated with anti-fungal creams; proper footwear is to be used to avoid 'entry' lesions, while antiseptic or antibiotic creams are used for small wounds. For management of hydrocele, an important surgical complication, hydrocelectomy is the treatment of choice [3]. There is a huge burden of chronic cases in Bihar, which requires management of lymphedema to make patients' lives as free of disability as possible. However, these patients are not being followed up effectively under the present elimination program of LF: only 7155 MMDP kits had been distributed among the patients and 129 hydrocelectomies done in the block health centers in Bihar in 2021 [4].

For the patients who have recurrent attacks of acute dermato-lymphangio-adenitis (ADLA) in their limbs, WHO has also recommended simple home-based measures that include maintaining hygiene, skin care, and limb movement. Patients can do compressive bandaging, elevation of legs while resting, and careful washing with soap and water. However, patients in our rural practice area have been unable to adopt them, resulting in a vicious cycle of ADLA attacks. The water, sanitation, and hygiene (WaSH) component has also become

essential in the elimination of LF [5]. Despite this common knowledge, low health-seeking behavior, poor socioeconomic conditions, and low adoption of personal protection are some of the known reasons behind decreased lymphedema management practices. Moreover, there might be multiple realities from the patients' and healthcare workers' perspectives, which were yet to be explored. Based on this background, qualitative research was deemed best suitable to identify these barriers to carrying out home-based lymphedema practices in the rural area of Bihar, which were adversely affecting the quality of life of LF patients. Determining and building a comprehensive picture of the barriers, and understanding how these barriers affected quality of life would help both the patients and the healthcare system in addressing ADLA in rural areas of Bihar.

Methods

Study setting and design

LF is one of the six diseases covered under the National Vector Borne Disease Control Programme (NVBDCP), which is an umbrella program of the Government of India dealing with vector-borne diseases, namely malaria, LF, dengue, kala-azar, chikungunya, and Japanese encephalitis. All 38 districts of Bihar are highly endemic for LF, and it has the highest caseload in India. In 2021, as many as 89,970 lymphedema and 19,566 hydrocele cases were reported by NVBDCP in Bihar [4]. This qualitative descriptive study was conducted in two villages, Chakiyapar and Maharajganj, in the rural field practice area (Naubatpur block) under a tertiary care hospital in the state of Bihar. The researchers selected these villages under the rural field practice area because they have highly reported caseloads.

Research members

The research was led by Pragya Kumar (PK) and Shamsad Ahmad (SA), who are senior faculty at the Department of Community and Family Medicine at a tertiary care institution of national importance in India. Both researchers are well trained and experienced in carrying out qualitative research methods. The other members of the team, Ditipriya Bhar (DB), Ria Roy (RR), and Bhavna Singh (BS), are trained in interviewing techniques, transcription, translation, and coding procedures

in qualitative research. All the members are fluent in the regional language and were involved in conducting in-depth interviews with the study participants.

Study tool

A semi-structured in-depth interview guide was developed by the researchers PK and SA for each stakeholder (Additional file 1: Text S1). The interview guide was formed initially with a deductive framework but with room to include any new emergent theme during the process of data collection or data analysis. The questions were asked in order for the first patient and caregiver but later modified according to severity of the health condition or any new theme detected.

Study population

The LF patients affected by lymphedema, their caregivers, and the healthcare workers working in the rural field practice area were considered the study population. The caregivers were unpaid members of the patients' family or social network who help them with the activities of daily living and live within an hour from their homes. One cadre of healthcare workers considered here was the grassroots healthcare worker, namely accredited social health activist (ASHA) in these villages, with one worker looking after the basic health assistance of 1000 rural people. They are the first point of contact for healthcare delivery system in the area. The other cadre was the block health manager who supervised the overall service delivery for LF to all the villages covered under the block primary health center (BPHC) of Naubatpur, including Chakiyapar and Maharajganj. All the MMDP kits and MDA drugs were distributed from the BPHC. For our study, the inclusion criteria were: (i) patients > 18 years old, living with lymphedema for > 1 year, (ii) caregivers of filariasis patients with lymphedema who were present at the patients' residence during the study, and (iii) the grassroots healthcare workers and the block health manager of the rural field practice area.

Study technique, data collection, and analysis

Following the informed consent, PK, SA, DB, and RR conducted in-depth interviews, in teams of two, using the interview guide. Each interview lasted around 8–10 min, and their responses were further probed. The teams organically explored new areas of inquiry in the interviews as they emerged from the answers. The audiotape of each interview was played several times, paying close attention to remove any unnecessary phrase. The audiotapes were first transcribed exactly verbatim by DB, RR, and BS by listening to a clip every 10 s before transcribing it. Each audiotape took around 40 min to transcribe in the local language (Hindi) and then 1 h to translate to

English on the same day after the interview. This helped in capturing any hesitation or emotion behind the words spoken by the participants. The names of interviewees (and of other people mentioned during their interviews) were removed from the transcripts. The researchers DB, RR, and BS re-read the transcripts several times, and important aspects, which were immediately striking, were marked.

Data were collected from ten participants: four patients suffering from lymphedema, three caregivers of LF patients, two grassroots healthcare workers, and the block health manager of the rural area. The transcripts were entered into QDA Miner Lite software, where two of the researchers independently performed mainly attribute, in-vivo, process, descriptive, emotion, and holistic coding. If any coding process hit a block, DB, RR, and BS listened to the audiotapes again to understand the intended meanings of the participants. The data collection and data analysis happened concurrently to revise the interview guide and draw upon the emergent areas of inquiry. The codes were shared among all the researchers, and disagreements were resolved. PK, SA, DB, and RR continued to purposively sample the patients, caregivers, and healthcare workers until saturation of the codes was reached by agreement among all the researchers. Then, DB, RR, and BS did a content analysis where categories and themes emerged from the codes. In this way, they identified the categories pertaining to lymphedema management and uncovered the relationships between categories by iterative reading. Then, they harmonized the themes and reconciled any matter of disagreement. Finally, a thematic codebook was made as the final coding template (Additional file 2: Table S1), which was re-applied to the data to check consistency.

Results

The researchers tried to elucidate the factors responsible for the decrease in quality of life of the LF patients in the study through in-depth interviews. Three themes emerged in this study that provided detailed descriptions of the findings: "inherent nature of disease," "patient-related factors," and "healthcare system-related factors" (Fig. 1). The factors that were already assumed in the epistemology, such as low awareness and adherence, low health-seeking behavior, and not maintaining personal hygiene, due to either poverty or non-use of WaSH facilities, are shown differently than the newer categories that emerged (shown in blue) under patient-related factors.

The inherent nature of disease played a major part in the difficulty faced by participants, as evident by the frequency of its appearance in the transcripts (Table 1). The codes under signs and symptoms occurred 55 times (35.3%), while seasonal factors also accounted for 14 (9%)

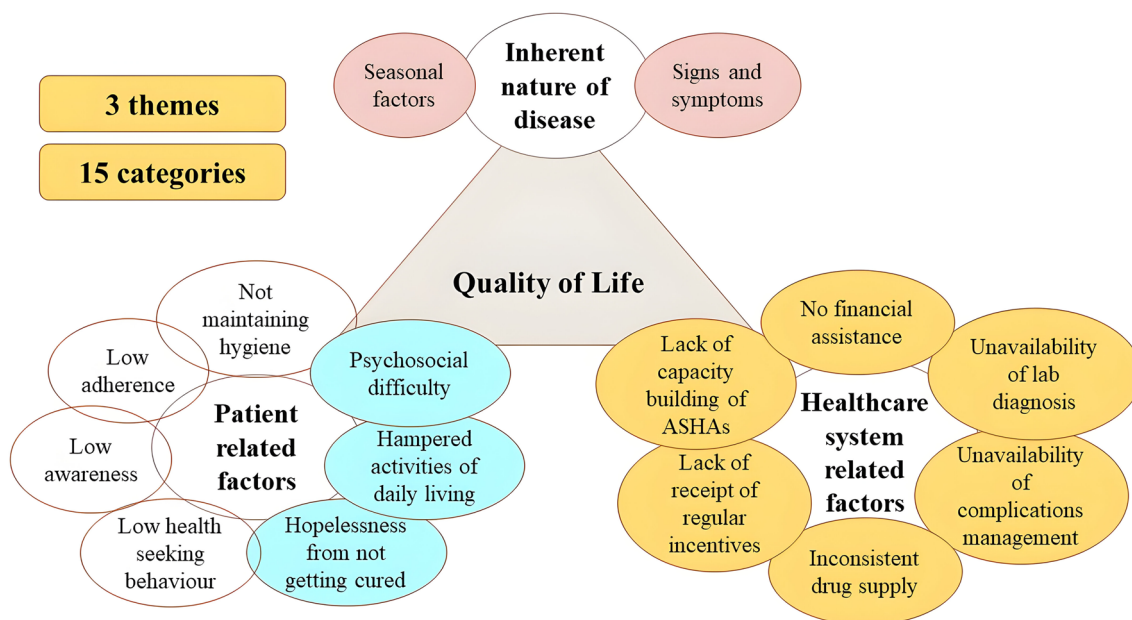


Fig. 1 Categories and themes from the qualitative descriptive analysis

Table 1 Content analysis of the categories in the study

Categories	n (%) of total codes
Symptoms and signs of the disease	55 (35.3)
Seasonal factors	14 (9.0)
Low awareness in patients and relatives	14 (9.0)
Low adherence	12 (7.7)
Low health-seeking behavior in modern medicine	5 (3.2)
Hopelessness from not getting cured	3 (1.9)
Not maintaining personal hygiene	18 (11.5)
Hampered activities of daily living	5 (3.2)
Psychosocial difficulty	5 (3.2)
Lack of capacity building for grassroots workers	3 (1.9)
Lack of receipt of regular incentives for grassroots workers	4 (2.6)
Unavailability of laboratory diagnosis of filariasis at health facility	6 (3.8)
Unavailability of management of complications of filariasis at health facility	2 (1.3)
Inconsistent drug supply in the community and health facility	4 (2.6)
No financial assistance	6 (3.8)
Total	156 (100)

codes among participants. Following the category of not maintaining personal hygiene (18, 11.5%), low awareness (14, 9%) and low adherence (12, 7.7%) were mentioned most often by patients. The healthcare worker cadres complained about the lack of capacity building (3, 1.9%) and twice as much about the lack of receipt of regular incentives (4, 2.6%). Most participants complained about the unavailability of laboratory diagnosis and no financial assistance (6.8%). Inconsistent drug supply was

mentioned at least four times (2.6%) by both patients and healthcare workers.

Inherent nature of disease (theme 1)

Symptoms and signs of the disease

Patients had experienced fever, pain, and discomfort in their whole body: pain, burning sensations, and swelling in the lower limbs, including the ankles; red eyes; vomiting; weakness; and complications such as hydrocele.

Thus, these multiple symptoms made the patients unable to maintain their health and increased their hardships in life, as quoted from two participants below:

"In a month, fever comes four times. Only on sweating it becomes alright." (patient, homemaker in her 40s)

"Once fever came. It was so severe that my legs were swelled up, it was even more severe compared to current swelling. And blisters appeared...it was like blisters that appear after burn.... There was severe burning sensation, that I couldn't sleep due to this." (patient, Anganwadi worker for 15 years).

All these symptoms not only had a great effect on the quality of life but also portrayed symptoms that caused severe suffering due to ADLA. Their persistence over multiple years had added to the difficulty faced during the disease. Sometimes the disease was resistant to the usual treatment, and this made the condition chronic for years, as described by the patient:

"In 2013, I went to see the doctor (at) hospital... they prescribed an injection from there. I do not remember the name. They gave 12 injections daily at morning and evening. At that time some swelling diminished, but after that gradually swelling appeared (again)." (patient, Anganwadi worker for 15 years).

Seasonal factors

Bihar has a very high temperature of around 40° C during the summer season, a heavy monsoon during the months of June to September, and a harsh winter from November to February. A wide variation in the occurrence of ADLA has been noted, with difficulty mainly occurring during the summer.

"In winter discomfort used to be less, but in summer the discomfort increases. Swelling also increases in summer. The burning sensation in my legs become more severe and sometimes my whole body becomes swollen...in one leg, swelling persists throughout the year but in another leg, swelling occurs only in the summer. During winter season, this leg (showing her leg that swells in summer and currently swollen) becomes normal, but in summer it becomes like this (by showing her other swollen leg)." (patient, Anganwadi worker for 15 years).

There was reporting of a high fever and a flare-up of swelling in the lower limbs in two patients during the winter. Cold weather is unfavorable for the development of microfilariae but favorable for the breeding conditions of the vector mosquito, and vice versa. This results in

more injection of microfilariae into the bloodstream and accumulation of the pathogen in the lymphatic system, which may explain the discomfort felt by these patients in our study during the winter.

"(Swelling of leg) creates more problems for him in winter, and less in summer...He doesn't have any problem doing anything in summer. But if he overexerts himself, then everything swells up." (caregiver, in her 30s, of a vegetable seller).

Patient-related factors (theme 2)

Low awareness in patients and relatives

The participants had some basic knowledge about the nature of the disease; however, around half of the respondents were not aware of prevention and treatment available in the community, and health facilities were lacking. One respondent reasoned that she was not formally educated, even though she was an Anganwadi worker.

"Not much information about filaria...Nowadays, social media is there. Like, whenever pain is there, I open YouTube and see, what could be done." (caregiver, a hospital attendant).

The caregiver was also unaware about how to maintain hygiene of the affected limb of the patient:

"Whenever I tell her to wear slippers, she turns a deaf ear. She never listens...(I know) nothing regarding cleaning her leg."

Regarding the MDA program, their low trust in government services had led them to find other options, one of which was buying over-the-counter medicines and self-medicating without a doctor's prescription. They had been slowly discouraged from taking the MDA supply because of false information about their effectiveness, which has clearly deterred the implementation of the program.

"I have not been to any doctor. (I have taken) medicines, like, these small tablets, something like that." (patient, farmer in his 40s).

"No, I didn't take it. Earlier where I used to live, I had taken the medicines. I remember. I ate the drug once or twice for filaria. You know, ASHA and ANMs; they only gave the drugs." (caregiver, a hospital attendant).

"Some people go to medical shops and show their drug there and that shop owner says that the drug is of no use and he gives another drug saying his drug would work better." (health care worker).

Low adherence

The low adherence was in relation to preventive chemotherapy (MDA). There was a lack of trust in the government's supply of free MDA drugs. Some said straightaway that they did not consume the medicine given to them biannually by healthcare workers. This problem has been shown from the perspectives of a patient, a relative, and a health care worker:

"I was taking another medication, how could I take another? When they gave medicine (MDA), I thought I will take it, but the same night I got fever and chills." (patient, homemaker in her 70s).

"He doesn't listen (to anyone). He says it (MDA) doesn't work. Taking only those medicines (from private) work. If it's for deworming, then he takes it (from the Government supply)." (caregiver, in her 30s, of a vegetable seller).

"When I meet those people, I ask them whether they took the drug or not...few reply yes while the rest say no...most people don't take it in front of me, and I don't know what they did with the drug." (health care worker).

Low health-seeking behavior in modern medicine

There was an overall low health-seeking behavior among the patients. It could have been due to self-medication, as mentioned before. It could also be rooted in some barriers to receiving adequate treatment, such as the high cost of private healthcare services. Some patients tried alternative therapy for filarial lymphedema. However, the cure eventually failed, which has further aggravated their suffering:

"I tried in ayurvedic, allopathy, homeopathy. Everywhere, but it wasn't successfully treated...no medicines are available. I don't have such information." (caregiver, a hospital attendant).

The management of complications such as hydrocele in a patient gave an insight into how these factors can affect their decision to use healthcare services related to lymphadenitis.

"He never used to go for consultation. I forcefully took him, and they did an ultrasound. He was diagnosed with ripe filaria. Then only we went for surgery, it took around forty to fifty thousand rupees. Then he took 6 months rest. Then only (the treatment) worked." (caregiver, in her 30s, of a vegetable seller).

Hopelessness from not getting cured

Because of all these barriers affecting the patients' suffering, they experienced strong feelings of dissatisfaction about never getting cured of filariasis and ADLA. Different modes of therapy had failed in the end to improved the quality of life for some of the patients.

"There was a homeopathic doctor in the colony. Many people used to say that the treatment is effective, but it didn't work for me. There was another doctor who used to give some zaributi (plant-based) medicine; he said not to take food throughout the day after taking the medicine and to take curd in the evening. The whole day I had to starve. But nothing happened. Then I became tired of it and left it...the disease was not cured, so how could one be satisfied?" (patient, Anganwadi worker for 15 years).

This could adversely impact their mental well-being, affecting even the caregivers, who had spent a great proportion of their time caring for the disabled individuals. They had witnessed the pain and suffering of their loved ones, which rendered them disgruntled and hopeless about the whole situation.

"See, some disease has no cure, like AIDS. (It's possible) only if you take precautions. I know this disease (filariasis) can't be cured. But treatment must cure the pain. Like, pain occurs as if it may kill you. So, to avoid that, government should do something to reduce the pain." (caregiver, a hospital attendant).

Hopelessness led to expectations for better intervention from the government. This situation points to the existing gap between guidelines and the reach of successful ground-level interventions of the MDA-MMDP program, which had not managed to prevent the occurrence of filariasis in the community.

Not maintaining personal hygiene

Some patients in the community were not using soap to clean the affected limbs, even though a water supply was present in their household. Instead, they were using ashes to care for the infected leg. Another necessity was taking adequate rest. However, most of them were either involved in doing work without any break or not fulfilling the basic requirements of foot care, skin care, exercise, and leg elevation.

"It becomes very difficult to do farming in the cold...I go without (slippers)." (patient, farmer in his 40s)

"This thing, I always tell her. That whenever you sit, wherever you sit, always have your legs raised up... She never listens." (caregiver, a hospital attendant).

Maintaining hygiene is the most important requirement for ADLA patients who are suffering for prolonged periods of time. This aspect had been much neglected by most of the respondents, which continued to add to the healthcare costs and burden of filariasis in the community.

Hampered activities of daily living

Patients reported difficulty in maintaining balance, walking, standing up or sitting down, or doing the basic household chores like cooking, washing, or cleaning. The main culprits were pain and swelling of the lower limbs, which hampered the normal movements of the patients. One of the patients expressed her plight in facing severe difficulty in doing chores at home, with no one to help her at all:

"I am not able to do cold related work. What else!... Like, work related to water, I have to do it whether other family members are at home or not. Even if I worry, what can I do! If there are no daughters or daughters-in-law at home, one has to do it. At least cooking and cleaning have to be done, who will do all these things? No one is here." (patient, homemaker in her 70s).

Psychosocial difficulty

Few respondents reported that they had decreased socializing in their neighborhood because of physical difficulty. One respondent reported about financial difficulty because of filariasis in the past while his children were still dependent. Though there was no stigma in the study community regarding filariasis and ADLA, some patients seemed to become reclusive or even delve into addiction once they were known to be afflicted with this disease.

A caregiver reported that the patient did not consume MDA given by ASHA and only took medicine from a private facility, even though his whole family took MDA. He also did not take care of his lymphedema in the lower limb. However, since he had filariasis, the main problem reported was his addiction to alcohol:

"He stays outside, goes to the village. Now he goes astray and then drinks (alcohol). Now when he drinks, only that can bring some relief. This is the main problem, nothing else. If only his alcohol addiction was managed, then there would be no problem." (caregiver, in her 30s, of a vegetable seller).

Perhaps the consumption of alcohol by this patient reflected a much deeper problem in this setting. The feeling of never getting out of the 'abyss' of filariasis can negatively impact the quality of life of whole families, not just the patients.

Healthcare system-related factors (theme 3)

Lack of capacity building for grassroots workers

The reason healthcare workers were not taking adequate care of patients could be attributed to infrequent training regarding the disease. One grassroots healthcare worker, when asked if she had attended any meeting or training on filariasis, replied that she had attended only one meeting regarding managing filariasis in the community:

"Yes, a long time ago, but I don't remember much about it now...I tell them (patients) to keep wet warm cloth over the limb, but it has not been told how long they should do it." (health care worker).

Unfortunately, there had been no formal training program for capacity building of the healthcare workers on the management of filariasis and ADLA in the community. The only times 'meetings' were held were on "surveys regarding how many patients are positive" for filariasis.

Lack of receipt of regular incentives for grassroots workers

One of the major problems in managing patients with filariasis was a lack of motivation and disappointment, which stemmed from the fact that healthcare workers were not getting any incentives for taking filariasis patients to health facilities, especially the BPHC.

"Yes, if we would get something for filariasis obviously we would pay more attention to those patients and bring them to BPHC." (health care worker).
"No incentive for taking patients to hospital. We get an incentive during the program, for house to house, mass drug administration in people starting from more than 2 years old." (health care worker).

On the contrary, the block health manager of the BPHC told a different story:

"Yes, a hundred rupees for bringing a patient...yesterday all ASHAs who brought patient, they all got a hundred rupees. They get incentives for all work."

Because of the lack of regular incentives for healthcare workers, some patients reported very few visits from the grassroots workers. Even if they mobilized the patients, all they did was give the MMDP kits to the patients at the BPHC every Monday. They did not have any information on how to clean the ADLA-affected limbs to decrease the chances of ADLA attacks.

Unavailability of laboratory diagnosis of filariasis at health facility

Laboratory diagnosis of LF by examination of blood at night is an important follow-up method for detecting any active traces of infection in patients. The investigation by microscopic examination was not available at any nearby health center or even the BPHC, while management of the disease was based mainly on clinical diagnosis. The need for laboratory diagnosis and advice for management of the disease sequelae was very much felt at the village level by the patients and their relatives.

“No such test was there. As you people are saying, there is no treatment for filaria. Doctor said, there’s no any internal problem. So, we didn’t do anything else. They didn’t tell anything as such (about taking care of swollen leg).” (caregiver, a hospital attendant).

Unavailability of management of complications of filariasis at health facility

Treatment of complications was not available at the BPHC. On OPD visits, they were not given advice regarding how to take care of the affected limb at home. Thus, patients had to travel long distances to a tertiary health center to avail of such services, which made even the healthcare workers apprehensive.

“Most people don’t go to block, even at my home there are two filariasis patients but they don’t go to the hospital. It would be better if more facilities for treatment would be provided at the center!” (health care worker).

This was a dangerous precedent for the growing burden of complications in the community. An urgent need was noted to scale up the services and initiate minor surgical and dressing procedures in the peripheral health facilities of the area for care of the affected limbs and complications like ADLA and hydrocele.

Inconsistent drug supply in the community and health facility

The treatment component of filariasis was mostly symptomatic among the respondents. Diethylcarbamazine, ivermectin, and albendazole had not been administered to many patients because of their inconsistent availability at the BPHC. A patient relative remembered that besides not getting tested in a laboratory, the patient also did not receive the main chemotherapeutic management of the disease from a tertiary hospital, which was quite alarming.

“One year back, I sought treatment (for the patient). We got only calcium. Nothing else. Calcium and BP”

(caregiver, a hospital attendant).

The block health manager, though, recounted differently:

“Filariasis is very common here. Yesterday we distributed kits, as many patients came. The patient presents with fever, cough, swelling of limbs. Even if slight swelling is there, we start DEC 6 mg/kg. Suppose a 70-kg male presents with swelling, then the dose will be 420 mg. So we give 100 mg thrice daily with levocetirizine, which prevents drug allergy.”

The healthcare workers took the patients to the BPHC where they received adequate treatment only when there was a supply of diethylcarbamazine and albendazole. Certain areas in the community could have been missed during the MDA implementation, too. One patient in the study area complained about not receiving the MDA drugs from the healthcare workers during the biannual deworming days.

No financial assistance

Most of the patients had to buy preventive measures like long-lasting insecticide nets (LLINs) from shops, although they were supposed to receive them from the public distribution system or from the health facility under NVBDCP. However, both the healthcare workers and the block health manager corroborated that the BPHC did not receive any supply for the LLINs.

“They (patients) have to purchase mosquito nets.” (health care worker)

“They do not get LLINs from here. They get them from the government supply. They just get medicines, bath tubs, mugs, antifungals, soap, and povidone iodine from here.” (block health manager).

This was an added burden for those who could not even afford three meals every day as the majority of the filariasis patients in the study area belonged to a very poor socioeconomic class. Both patients and grassroots workers complained that the afflicted are not benefited in any way by attending the BPHC. Because of the dearth of so many services in government health facilities, some patients were forced to resort to treatment in the private sector.

“We went (to a doctor) in 2016 only. Did ultrasound and then did operation (for hydrocele). Yes, it’s private. We take medicines from private doctors. They give medicine for hundred or fifty rupees; only then he becomes fine, otherwise not.” (caregiver, in her 30s, of a vegetable seller).

All these factors contributed to increased out-of-pocket expenditures. Households with patients with LF

can incur huge costs, especially if they are in the low-income group or if they are seeking medical care in the private sector instead of a government health facility.

Discussion

Lymphatic filariasis (LF) is a debilitating disease causing permanent disfigurement in the afflicted, making it the second-most common cause of long-term disability worldwide [6]. Patients repeatedly suffer in agony because of symptoms that vary with temperature and humidity [7]. A study in Ghana showed that most of the symptoms occurred in the rainy season, as the maximum infection of filariasis happens in the period of minimum vector density due to flushing of the breeding places, whereas the attacks are less prevalent in the dry season [8]. Similarly, in the North Indian and East Indian states, several factors increase the probability of filarial transmission in the summer. Tropical climate, poorly maintained drainage, and increased vector-human contact attributed to using fewer clothes and sleeping in the open or outside the room at night are responsible [9]. Only two of our respondents suffered in the winter compared to five in the summer. However, a study done in Tamil Nadu, South India, has shown no significant variation between the summer and winter seasons [10]. The survival of the vector *Culex quinquefasciatus* was less in the summer, and infective stage larvae were not encountered until the early monsoon. The highest rate of parous mosquitoes has been recorded in the winter months (November–March) in this part of India, leading to maximum transmission that declined with a rise in temperature [11]. Geographical differences seem to play an important role; however, our respondents showed mixed variation. The best way to prevent LF is to avoid mosquito bites, followed by the biannual MDA program, while the WaSH strategy has been increasingly recognized as crucially important in the prevention of morbidity and disability for filariasis-related lymphedema [5, 12].

In our study, the respondents had low awareness regarding treatment and prevention of the disease, resulting in low MDA adherence. In an endemic town in Nigeria, 85% did not know about MDA, and 36% did not know its role in preventing LF [13]. Joseph et al. conducted a study among health workers in Karnataka, India, where they found poor awareness scores in 37.2%, average in 57.7%, and good scores in only 5.1% of participants [14]. The patients might fear its side effects, be absent at the time of distribution, not consume the drug because they forget or misplace it, or suffer from a concurrent illness [15]. They also feel mounting hopelessness that lymphedema is incurable, so there is no use in diligently following management practices once

they contract filariasis. However, increased community participation in WaSH needs to gain traction. Maritim et al. have concluded that adherence and health-seeking behavior were even driven by negative beliefs and myths about the disease and a lack of awareness about available homecare morbidity kits and WaSH facilities [16]. WaSH programs can also help reduce the breeding grounds for the mosquito vectors that breed in the open sewers [17]. In a study by Mues et al. in Odisha in 2014, overall compliance with lymphedema management techniques due to a community-based management program was negatively associated with difficulty accessing water and soap, emphasizing that lymphedema management is incomplete without WaSH facilities [18]. In Nepal, even though patients suffering from lymphedema had home-based care as their first treatment, their first point of contact was the traditional healers; only later did they seek Ayurvedic or modern hospital-based treatments during complications [19]. Also unfavorable interactions between the provider and client reduce acceptability. The low health-seeking behavior among the patients regarding modern medicine found in this study has been attributed to low trust in government facilities, leading to failure to cure and mounting hopelessness. Sometimes, misconceptions and rumors can spread like wildfire, obstructing the program and community participation [20].

The other problems in the study were that patients and caregivers were unable to work productively, leading to loss of earnings from reduced work hours, catastrophic and inappropriate health costs leading to debt, not being able to pay for the schooling of children in the family, and an overall reduced societal role. The younger the cohort, the greater the economic losses that accumulate over their years of productivity [17]. This is because patients whose lymph vessels are already damaged experience lymphedema and ADLA episodes for the rest of their lives. They also undergo increased travel costs coupled with lost productivity in both paid and unpaid labor [21]. All these surely affect their mental health as well, as evidenced by filariasis being related to depression and other psychosocial difficulties [22]. The social stigma of lymphedema can cause barriers to both adherence and health-seeking behavior, as seen in several studies [5], though this study did not find any such complaints.

The filariasis elimination program had faced severe implementation challenges for years. The innovative efficiency was initially slow, and the focus was rarely on the disease impact on endemic regions. Thus, the WHO expanded its technical support to address these issues from 2017 until 2019. Microplanning and social mobilization might have improved in the case of dispensing MDA, but training on home-based care was

still lacking. The two healthcare workers in our study had only attended refresher meetings held on annual surveys or before the distribution of MDA. There was no formal training on how to manage lymphedema. It seems the state health authorities have placed more importance on the transmission of microfilariae but side-lined how to improve the quality of life in patients with severely affected lymphatics and cutaneous inflammation. Once established, the disease is irreversible even after treatment or spontaneous death of the microfilariae, which promotes insidious progression [23]. Initial ADLA attacks due to bacterial proliferation worsen the lymphedema, leading to elephantiasis. This creates a vicious cycle favoring more such attacks due to a lack of local hygiene [24]. Implementation at the administrative level is only strengthening the MDA administration and not the second pillar of the elimination strategy, which is managing the morbidity [25].

Many studies have elaborated on the physical, social, psychological, sexual, and economic problems caused not only by the deformities but also by the acute febrile episodes [26–28]. Even then, the administration faced several problems. During the rollout of IDA round 1 in Bihar in 2019–2020, there was a local strike by ASHAs at booths established in Anganwadi centers and schools. Only 58–61% of the total population had consumed the triple drug regimen, which was soon interrupted when Anganwadi workers also joined the strike [29]. During the study period, subsequent strikes occurred at the BPHC because of the non-payment of any incentives by the government over a prolonged period. This demotivated the grassroots healthcare workers, who were already burdened with mobilization and drug distribution under different community health programs. Hydrocelectomy surgery is not conducted at the BPHC, which forced one patient to go to a private clinic, resulting in catastrophic expenditure. There, only MMDP kits were distributed every Monday, with no training on how to use them to prevent ADLA. Lessons can be learned from Kerala State regarding this. The State Health Administration of Kerala conducted intensive training sessions for doctors and staff nurses from each Taluk hospital to provide care for lymphedema patients. They were given training in MMDP, including information, hands-on demonstrations, and specific lymphedema care plans. This increased the registration of previously unidentified lymphedema patients. Undertaking a policy decision to achieve elimination with MMDP in addition to MDA is the key component of that strategy, which should be the goal for endemic districts in all of India [3].

Conclusions

The main barriers affecting the quality of life of patients with LF and lymphedema were the inherent nature of the disease, including symptoms and seasonality, patient-related factors, and healthcare system delivery issues. These grassroots problems helped our understanding of the impact that lymphedema and ADLA had on patients' quality of life and highlighted the issues that needed to be addressed to increase home-based care for LF. Accessibility to WaSH, regular training of home-based care for both patients and their caregivers, increasing the capacity and motivation of grassroots workers, and generation of an in-depth awareness are required to achieve the elimination of filariasis, with MMDP as a key component of that strategy for endemic districts across the whole country.

Abbreviations

LF	Lymphatic filariasis
MMDP	Morbidity management and disability prevention
MDA	Mass drug administration
WaSH	Water, sanitation and hygiene
WHO	World Health Organization
ADLA	Acute dermato-lymphangio-adenitis
ASHA	Accredited social health activist
BPHC	Block primary health center
ANM	Auxiliary nurse midwife
NVBDCP	National Vector Borne Disease Control Programme
LLIN	Long-lasting insecticidal net

Supplementary Information

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Additional file 1: Text S1. Interview guide.

Additional file 2: Table S1. Content analysis of the categories in the study.

Additional file 3: Annexure S1. Participant information sheet. **Annexure S2.** Participant informed consent form.

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Author contributions

PK, SA, and DB contributed equally to this work in framing the concept, background and protocol of the study, data collection, and manuscript drafting. RR contributed to data collection, analysis, manuscript drafting, and reviewing. DB and BS contributed equally to this work in data analysis and manuscript reviewing. All authors read and approved the final manuscript.

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Availability of data and materials

All the quotes, codes, and categories described in the manuscript will be available to any scientist wishing to use them for non-commercial purposes. The confidentiality of the participants will be maintained.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Institutional Ethical Committee of the All India Institute of Medical Sciences, Patna (AIIMS/Pat/IEC/2019/351). Informed consent was obtained from all participants for their interview to be recorded before beginning the conversation (Additional file 3: Annexures S1 and S2). The participants were first explained in detail about the nature of the study, following which it was conveyed that participation is voluntary and they are free to withdraw from the study at any time, without citing any reason. There were also no risks involved in the study, which the participants were informed about. The consent forms, audiotapes, and transcripts were stored on a password-protected computer, which was only accessible to the researchers. Any report, presentation, or publication resulting from this research does not contain any information, such as names, that could identify the participants or their relatives.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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