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Unveiling the gendered abyss: exploring the case of women with lymphatic filariasis and the path to inclusive care in India

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Abstract

Introduction Lymphatic filariasis (LF), a neglected tropical disease (NTD), affects tropical regions marked by poor socioeconomic conditions and often results in non-curable filarial lymphedema. The impact of LF is often disproportionate, adversely affecting women due to a multitude of intersecting disadvantages. There has been little effort to understand the unique illness experience of women with LF.

Methods To explore the interplay between gender and the illness experience of women afflicted with filarial lymphoedema, this qualitative study mapped the experience of 18 women and the perceptions of 18 men with lymphatic filariasis. Data collection involved 12 in-depth interviews and four focus group discussions, with equal gender separation. The content generated was analyzed using a hybrid thematic analysis approach.

Results The study shows that individuals with filarial lymphedema, regardless of gender, encounter numerous challenges. However, certain aspects, like cultural gender norms paired with socioeconomic disadvantages, exert a disproportionate burden on women, which adversely affects their physical health, health-seeking behavior, and mental health. While the study highlights the intersectional lived experiences of women with LF, its focus on women's experiences may limit broader generalizability across genders.

Conclusions Addressing the factors that impact the lived experiences of women with lymphatic filariasis is an essential but complex task that requires positive changes across various domains. Targeted mental health interventions and robust family support systems can play a pivotal role in improving the health outcomes of affected individuals. Also, gender-informed intersectional research on the illness experiences of women with LF can give valuable insights to tailor better morbidity management policies and practices.

Keywords Lymphatic filariasis, Gender, Health experience, Health sociology, Women

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Background

The impact of disease often goes beyond the biological plane, affecting the mental health and social functioning of an individual. This is particularly relevant in the context of neglected tropical diseases (NTDs), which are a group of 20 diverse conditions caused by various pathogens that disproportionately affect impoverished communities in tropical regions. These diseases, affecting over 1 billion people, pose significant health, social, and economic challenges due to their complex epidemiology and difficult control measures [1]. Lymphatic filariasis (LF) is one such neglected tropical disease, caused by parasites transmitted through mosquitoes, causing damage to the lymphatic system [1]. The early stages remain mostly asymptomatic with gradual damage of lymphatic channels, whereas symptomatic acute cases may present with fever, chills, skin rashes, limb edema, etc., and the chronic manifestations can involve lymphoedema, elephantiasis, and hydrocele, which can induce painful and disfiguring conditions that cause permanent disability [2, 3]. Once established, the lymphatic pathology is irreversible, promoting disease progression [2]. The repercussions of LF transcend mere physical disability, encompassing mental, social, and financial dimensions, thereby perpetuating stigma and poverty [3]. Apart from disfigurement, patients live with concerns of incapacitation, necessitating assistance even for basic personal tasks. Further, the patients are prone to recurrent skin and soft tissue infections of the affected limb, known as Acute Dermato-Lymphangio Adenitis (ADLA). Filarial lymphedema lacks a permanent cure, necessitating long-term management through Morbidity Management and Disability Prevention (MMDP).

While the epidemiological burden of NTDs is well-researched, understanding of the lived experience of chronic conditions, especially from an intersectional gender perspective, is limited. In diseases like LF that involve visible physical consequences (disfiguration), the illness experience can be highly influenced by stigma and cultural norms, as adverse societal perceptions can contribute to adverse health outcomes [4, 5]. Gender critically shapes these illness experiences, with gender stereotypes intersecting with elements like socioeconomic conditions to disproportionately impact women [6]. Data from UNDP indicates that while the prevalence of NTDs tends to be higher among men, the enduring consequences, particularly in the long term, may disproportionately affect women [7]. This skewed impact, affecting women, may be primarily due to the gender inequalities prevalent in low-resource settings. Understanding the nature of these intersections in shaping the illness experience is essential to ensure the inclusion of all stakeholders in the fight against the diseases of poverty [7]. For instance, the informal labor roles often assigned to women within households can significantly impair their functional capacity [8] and impact the morbidity management practices in the case of lymphatic filariasis. Cultural norms and caregiving expectations further exacerbate these challenges, creating a cycle of vulnerability that demands attention.

Puducherry, a Union Territory in the southern part of India, was endemic for lymphatic filariasis and has reported a considerable number of cases over the years. Though the state has neared the elimination targets [9], a sizable number of patients with filarial lymphoedema still reside in the setting. It is imperative to ensure that the care of this substantial number of patients still afflicted by the disease remains a priority within the program. Studies in the region have brought attention to the stigma and discrimination associated with this disease, as well as the socioeconomic and physical challenges that patients encounter [10, 11]. However, the intersectional impact of gender and socioeconomic factors on women with lymphatic filariasis has seldom been recorded. This study aims to explore the intricate interplay between gender dynamics, socio-economic disparities, and the illness experience of women afflicted with filarial lymphoedema.

Methods

Study design and participants

Since the focal point of the inquiry was on exploring the illness experience, a qualitative approach was employed. Participants of this study were recruited from a lymphatic filariasis clinic functioning under a central government-funded research institute in Puducherry, India. The clinic primarily serves patients from low-income backgrounds, with a significant portion being either unemployed or engaged in daily wage labor. The participants were recruited using a purposive sampling technique to ensure that the information captured was most appropriate and useful to address the research question [12]. Only patients with visible lymphoedema (grade 2 or above) seeking morbidity management at the filariasis clinic were recruited for the study, as physical symptoms have a significant role in shaping the illness experience of individuals with lymphatic filariasis. A combination of qualitative methods was used for the study. Initially, 4 Focus Group Discussions (FGDs) were conducted to understand the overarching perceptions of patients, providing the necessary context and language to formulate individual interviews. The FGDs were equally separated by gender, and each focus group consisted of six members. The insights garnered from the FGDs were pivotal in shaping the interview guides for the subsequent In-depth Interviews (IDIs), enabling a deeper exploration of the themes identified in the FGDs. Separate interview guides were used for male and female respondents. IDIs were conducted among 12 participants, of which six were women, and six were men. None of the members who were part of the FGDs was recruited for the IDIs in order to make sure that the data gathered from the IDIs did not lead to repetition of responses and/or a tendency to shape the answers based on the discussions in the FGDs. This also made sure that the data gathered was robust enough to attain data saturation [13].

Data collection

Participants were provided with a clear understanding of the study objectives and the voluntary nature of their participation. The IDIs and FGDs were conducted in the counseling facility of the clinic in Tamil–the vernacular language of the participants. A semi-structured open-ended interview topic guide was used to conduct in-depth face-to-face interviews to facilitate the narration of lived experiences by the participants. The guide included probe questions to ensure participants stayed on track while sharing their perspectives. Three subject experts reviewed the interview guide to ensure content validity, and the modified tools were piloted to confirm clarity and smooth flow of conversation. The investigators received training on handling sensitive topics and culturally appropriate rapport-building strategies were employed before the interviews. Additionally, regular debriefing sessions among the research team helped identify and resolve any emerging issues, ensuring the robustness of data collection methods. IDIs of female participants were conducted by a female investigator to facilitate better rapport considering the cultural factors. This approach was chosen to foster a more conducive environment for women respondents to express themselves freely, aligning with cultural norms. Nonetheless, it is important to acknowledge that this methodological choice may introduce bias regarding the perspectives of men. An important attempt towards overcoming this bias was made by ensuring the participation of a male and female investigator in the transcription, coding, and analysis of the data collected. Each IDI lasted from 40 to 60 min, and the FGDs lasted from 90 min to 2 h. All interviews were audio recorded after obtaining due consent from the participants. The content generated was translated into English verbatim and then assessed by a bilingual expert to ensure the precision of the translated content.

Data analysis

The content generated was analyzed using a hybrid thematic analysis approach [14], which is a combination of data-driven inductive thematic analysis [15] and a theory-driven deductive approach [16]. In the inductive thematic analysis, the data gathered from the FGDs and IDIs were analyzed to derive open codes to understand provisional topics based on the participants' narratives, i.e. the experiences of patients with filarial lymphoedema [17]. These codes were then clustered as themes [15], which codified the meaning of multiple open codes into an argument regarding the phenomenon, i.e. the role of gender in shaping the illness experiences of women with filarial lymphoedema. Deductive thematic analysis was applied to explore the mental health aspects of the respondents using the theoretical evidence generated by Person et al. [18] regarding the categories of stigma. To ensure intercoder reliability, intercoder agreement percentage statistics were employed. The segments of text coded in the initial analysis were assigned with codes from the code pool, by two of the investigators independently. 100% intercoder agreement was ensured by eliminating segments of disagreement.

Ethical considerations

The study has adhered to the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants [19]. Ethical clearance for the study was obtained from the Institutional Human Ethics Committee of [redacted for anonymity]. Participation in the study was voluntary. The participants were explained the purpose and objectives of the study verbally, and a printed Participant Information Sheet (PIS) was provided. To honor the data privacy of the respondents, alphanumeric codes were assigned to each respondent instead of personal identifiers. Each code constituted information about the IDI or FGD, the respondent/participant number, and gender separated by underscores. Hence alphanumeric code of a female IDI participant would be IDI_R_n_F, and that of a female FGD participant would be FGD_F_n_P_n. Throughout the study, strict adherence was maintained to the Standards for Reporting Qualitative Research (SRDR) guidelines.

Findings

In-depth interviews were conducted among 12 participants, six male, and six female, to capture the opinions of both sexes on the research question. Focus groups had six members each across four groups, adding up to 24 members, two groups for male participants and the other two for female participants. Thus, the study had 36 participants, whose socio-demographic details are provided in Table 1.

Gendered illness experience in lymphatic filariasis

This study sought to understand how gender intersects with other socio-cultural factors to shape women's experiences of lymphatic filariasis. Biologically, the 'female body' can itself induce a differential experience of health outcomes from that of the 'male body', with each of these 'biological bodies experiencing its own unique set of difficulties. Our investigation was more social and cultural

Table 1 Socio-demographic details of the participants

Focus group discussions					
FGD No.				Participants	Age Range (years)
FGD M1				Six male patients	42–78
FGD M2				Six male patients	39–70
FGD F1				Six female patients	40–69
FGD F2				Six female patients	41–65
In-depth Interviews					
IDI No	Gender	Age	Social Class	Occupation with remuneration	Marital status
1	Female	48	Lower	Nil	Married
2	Male	67	Lower	Daily wage labourer	Married
3	Male	40	Lower	Nil	Unmarried
4	Female	58	Upper middle	Teacher	Married
5	Female	59	Lower	Daily wage labourer	Married
6	Female	67	Upper lower	Housemaid	Widow
7	Male	53	Lower	Daily wage labourer	Married
8	Male	78	Lower	Nil	Married
9	Female	49	Lower	Nil	Married
10	Male	76	Upper lower	Nil	Widower
11	Female	69	Upper lower	Nil	Married
12	Male	70	Lower	Nil	Widower

rather than biological. However, there was no watertight compartmentalization between the 'biological' and the 'social' components. The complex interactions between these components could be observed across the experiences of the participants of the study. The study gathered data from male and female respondents to see how the outlook on the gendered illness experience was perceived by both categories. The analysis of the data generated three major themes, viz. a) Economic and occupational burden, b) Lymphatic filariasis-induced stigma, and c) Social and cultural burden. A graphical representation is provided in Fig. 1.

Economic and occupational burdens impacting physical health

One of the major themes that emerged from the open coding process was the fact that women experience unequal economic and occupational burdens compared to men. While men are thought to be engaging in physically demanding jobs, women's labor is often unaccounted for as they often engage in non-remunerated household work and, in some cases, engage in additional remunerating jobs in addition to household work. While labor provides economic independence to most men, at least to some extent, labor that women engage in does not provide economic independence in most cases. Even when the male participants did not have a job, they had significant control over the financial resources of the family in comparison to female patients. This economic and occupational burden adversely affected the physical health of the respondents, which in turn plays a pivotal role in shaping their illness experience. The economic and occupational burden that the participants of this study were undergoing emerged in four major domains. The open codes that represent these domains are discussed in the following section.

a. Workplace discrimination

While few reports of workplace discrimination were noted, they underscored the potential impact of lymphatic filariasis on employment. This discrimination may force the patients to give up their jobs, jeopardizing their income and ultimately affecting their physical health. For instance, a focus group participant cited having to abandon her business due to illness.

> *I used to prepare some sweets at home and sell them at shops. I could do things at my own pace, and everything was well again. But some shopkeepers refused to buy sweets from a 'yanaikkal' (elephantiasis) patient. I was so saddened that I stopped all my efforts. I wanted to support my family in the best way possible, but this society denied me the right. (FGD_F2_P4)*

Such discrimination at the workplace can not only add to the occupational and economic burden but also create stigma towards patients with lymphatic filariasis. A respondent from FGD recounted how discrimination at the workplace led her to cease seeking medical care.

> *Previously I used to work and earn for myself, but after my legs started visibly swelling, my colleagues started to treat me differently. I was called for lesser*

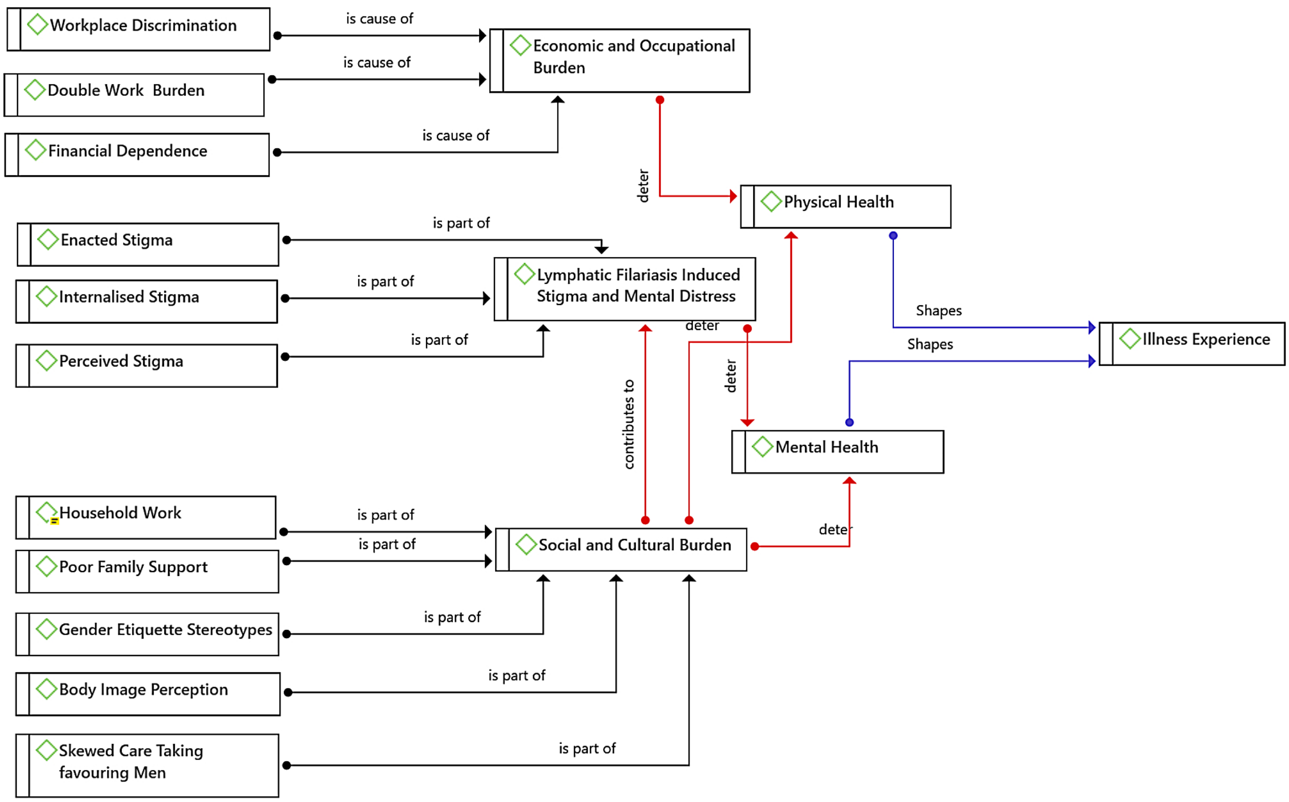

Fig. 1 Network representation of gender dynamics in illness experience of LF patients

> *and lesser jobs, and ultimately, I was left with no work. Now I depend on my husband even for medical expenses and I feel very reluctant to ask him for money frequently...I just left my follow-up at the clinic. (FGD_F1_P4)*

Workplace discrimination forces patients to quit their jobs, resulting in a financial strain impacting their health-seeking behavior. Although participants perceived this issue as equally devastating for both men and women, cultural stereotypes surrounding female body image were believed to exacerbate workplace discrimination against women, discussed in detail in subsequent sections.

b. Double work burden

Some of the women bore a dual responsibility of household chores and employment. While some solely managed household duties, others juggled both roles. This workload imbalance was particularly pronounced among female patients, potentially affecting their physical health.

> *Yes, I come from a very poor background. My husband is blind and cannot work. As the only earning member of the family, I have no time to take care of myself as I have to take care of others in the family. (IDI_R5_F)*

To aggravate the situation, women often receive little to no help from their partners in the household chores and manage both works themselves despite the illness. Respondent 6 from the IDIs expressed feeling trapped between dual roles.

> *If there was someone to help me, I could have better taken care of myself. Now, I have to do all the household chores and work as a maid in other houses for my living. (IDI_R6_F)*

The male participants also tend to agree that women are overburdened by employment and household responsibilities. For instance, a male respondent from the FGDs commented:

> *Typically, men are hesitant to take on household chores as they are traditionally viewed as women's responsibilities. Many women dedicate their lives to these tasks. While some women are now employed, I doubt men in those households will equally share these responsibilities...though there may be exceptions. (FGD_M1_P5)*

c. Financial dependence

As discussed earlier, many respondents in the study were primarily engaged in household chores rather than paid employment. Economic dependence emerges as a significant challenge for women patients, impacting their ability to access healthcare. This dependency can hinder health-seeking behavior, as financial resources play a crucial role in accessing medical services. For example, one participant expressed her husband's opposition to her receiving medical consultations and treatments because of financial concerns.

> *We have a lot of financial issues. I am considered a burden by my husband as I don't contribute to the income of my family. My husband even dislikes me taking medical treatment. If my husband knows that I am coming for treatment, he will even scold me for that. (IDI_R9_F)*

Further, few male participants commented that they never liked their wives going for a job outside.

> *Our wives may wish to go to job, but we won't allow them to work. If they go to work outside, who will take care of the family? (FGD_M2_P4)*

This highlights a notable stereotype associated with financial independence in the local culture. Further, few women commented that despite earning themselves, women are economically dependent on their spouse as they are unable to spend without the approval of their spouse.

> *"It doesn't matter whether I or he (husband) earns the money, he decides on spending. I simply hand over what I earn to him. I have been taught so... women are always financially dependent on their husbands, even for medical expenses we have to ask him" (IDI_R5_F).*

Lymphatic Filariasis Induced Stigma and Mental Distress Impacting Mental Health

Lymphatic filariasis-induced stigma was one of the key themes that emerged from this study, which affected both genders but in different degrees and ways. The codes for this theme were adapted from Person et al., who studied the nature of stigma experienced by women lymphatic filariasis patients [18].

a. **Enacted Stigma**: It refers to the experience of unfair treatment by others [18]. The participants of this study, both men and women, enumerated their experiences of unfair treatment from others.

> *Everyone who sees my leg asks what happened. Some people stare and some people walk away. Even children ask me questions regarding this and pass comments. (IDI_R11_ F)*

Even the families of the respondents were experiencing courtesy stigma due to the disease. One of the participants recalled how her family was at the receiving end.

> *People were making fun of me, and my family was in a state of shock. The psychological recovery was gradual and difficult. People still make comments about my legs to me and my family. (IDI_R1_F)*

The resulting stigma often leads to individuals facing bans in public places due to their illness, largely stemming from community ignorance. During the focus group discussions, one participant recounted her gradual exclusion from public spaces.

> *I used to go to the temple frequently, but one day some people told me that I would not be allowed into the temple because of the disease. I was considered an outcast. I cried a lot on that day. Gradually I was restricted from many other public places. (FGD_F2_P1)*

While stigmatizing experiences were not excluisve to women, female participants predominantly shared narratives about such encounters.

b. **Perceived Stigma**: Perceived stigma involves "expectations of prejudicial reactions, discriminatory behaviours, being shamed, feeling fearful, feeling uncertain, and being teased" [18]. Often arising from enacted stigma, perceived stigma shapes individuals' pessimistic views of societal attitudes toward them. Although responses on this issue were limited, they seemed to profoundly affect the mental well-being of the patients.

> *If anyone sees it as disgusting, it is difficult for me. I think over it and my mind gets disturbed...I feel ashamed of myself. (IDI_R4_F)*

Sometimes, the perceived stigma has roots in the religious and cultural beliefs of the participants and their communities. For instance, a participant recalled how her disease was attributed to sins from a previous life.

> *People pass comments linking my disease to sins from my previous life...I used to think about what mistake I had made to suffer all this. (IDI_R11_F)*

c. **Internalized Stigma**: Internalised stigma involves "internalized feelings of personal shame, guilt, sadness, diminished self-worth, depression, and fear" [18]. It emerges as the culmination of enacted and perceived stigma. Individuals grappling with internalized stigma often experience issues such as depression and stress, significantly impacting their mental health. The sustained 'stigmatizing gaze' of the community over time serves as one of the contributing factors, as noted by a respondent.

> *I have changed as a person after getting this illness. I am no longer confident to go out to public places and meet people, I prefer staying indoors and always try to stay discreet to avoid attention. (IDI_R1_F)*

This sense of internalized stigma can affect the social life of the patients and even tend to isolate them from social gatherings, inducing loneliness and further mental distress. A participant commented how the internalized stigma made her avoid even family gatherings.

> *What hurts me the most is when someone gives me a revolting look and moves away from me during some family functions like marriages. I stopped going to gatherings to avoid this. (FGD_F2_P6)*

The narratives showed the depth of internalized stigma so deep as to self-isolate oneself from one's own children. Internalized stigma was also found to adversely affect the perceived self-esteem and self-worth of the individuals, pushing them into mental agony.

> *My daughter helps me with all the work. But I never allow her to touch my legs. Even if someone comes to me for a blessing, I will not allow them to see and touch my legs, thinking that they may feel it is nasty. (FGD2_P4_F).*

Stigma, originating as 'enacted', gradually precipitated to 'internalized', especially in the context of poverty and poor social support. All three levels of stigma had a significant impact on the mental health of individuals, as it induced distress and low self-esteem. Stigma and mental distress essentially play an adverse role in shaping the illness experience of lymphatic filariasis patients. Social and cultural aspects have a deciding role in shaping the stigma and mental distress, which is discussed in the following section.

Social and cultural burden impacting physical and mental health

As discussed in the previous sections, social and cultural components can shape the individual's experience of an illness. The nature of the social roles and the associated 'role-stereotyping' associated with the cultural practices can influence the illness experience. The findings of this study show that women with lymphatic filariasis were experiencing social and cultural burdens that significantly influenced their illness experience. There were four major axes under which the social and cultural burden were categorized.

a. Body Image Perception: Body image refers to the attitude and perception of an individual towards their own body [20]. Individuals with lymphedema commonly experience a negative body image, feeling dissatisfied with their physical appearance. This perception is influenced by cultural beliefs and stereotypes, particularly affecting women with lymphedema. One of the respondents commented on how this body image perception curtailed her social participation.

> *I feel disgusted about this disease. I'm not able to attend any functions. I feel bad when someone looks at my legs. I can see an aversion in their eyes…Once, my sister-in-law told me not to come with her to a wedding. She even said I should stay away from such things because I'll only get upset when people comment about my looks. (IDI_R6_F)*

Most respondents of the study considered their physical appearance as the most difficult part associated with the disease and opined that they would have experienced better life outcomes if their physical appearance was not affected by the disease.

> *You see these dark, bumpy things on my skin. Even I feel bad about them, so I can only imagine how others feel. I'm not trying to meet all the beauty expectations society throws at me, but I just wish people didn't find me disgusting. That's why I avoid being around people. I've heard them make hurtful comments…if people would not have been always looking at my leg, it would have given me a better social life. (IDI_R1_F)*

However, the negative body image was not just the product of the perception of the female body in its isolation but rather the product of beliefs reinforced by societal perceptions regarding the female body as well. As one of the male participants from the FGDs observed, women are expected to be part of ceremonies and functions in the local culture where their bodily shortcomings will be amplified by the on-looking crowd.

> *I think women have more difficulties. They go to functions, and they wish to wear good dresses. Physical appearance may affect them more as people comment on their physical appearance more than they do on us. They are soft-hearted and may feel more worried than men. (FGD_M2_P3)*

Women, in particular, face vulnerability to lymphatic filariasis-induced stigma due to the pervasive male gaze and societal expectations regarding bodily appearance. The relentless scrutiny and comparison with societal standards of femininity contribute to the experience of stigma.

b. **Gender Etiquette Stereotypes**: A whole set of behavioral norms exist in society in the form of gender etiquette, often pronounced essential for the smooth conduct of societal functioning. However, women are often at the receiving end of such institutionalized social norms. Illness experience can be highly shaped by adverse gender etiquette that puts indiscriminate demands on the sick person. For instance, one of the participants recalled how she was expected to stand for long hours when visited by her husband's friends.

> *I used to do tailoring work in my husband's shop. If any customers or friends of my husband come to the shop, I shouldn't sit on a chair in front of them. If I sit, my husband scolds me and insults me, which makes me feel worried…Generally, in our community, women are not allowed to sit in front of men and elders. When affected by such a disease, which makes it difficult to stand for a long time, the trouble is huge. (IDI_R9_F)*

Regrettably, these practices exhibit a bias towards women, who are expected to adhere to certain norms solely based on their gender. Such practices are inherently patriarchal in ideology and simultaneously detrimental to individuals living with lymphatic filariasis. Consequently, they create a double burden for women affected by the condition. Moreover, in their daily lives, women with lymphatic filariasis often bear the weight of cultural expectations that assign the majority of household chores and caregiving responsibilities to them. In many instances, women internalize these cultural norms, considering them as commonplace. For instance, a woman participant commented:

> *You can't expect men to help you in all the activities you do. Our culture is like that. We have to take care of the household chores. Men have their own work to do. (IDI_R11_F)*
> *If both husband and wife are working, we can expect some help from the husband in household activities. Otherwise, how can we expect him to help us after his work outside? It doesn't matter if we are ill; we have to take care of the household work. Who else would do that? (FGD_F1_P4)*

These cultural dictates were ingrained in the perspective of some male participants as well.

> *Women may adjust and help us. But, males will not help women with this disease as they do not have the patience to do it. Men are born to be hard and do manual work, they do not have the soft and caring hearts that females have. Even if we feel like helping, we feel reluctant as we think it is their duty to take care of the family's needs.(FGD_ M2_ P5).*

The caretaking roles of women in the family are shaped by cultural dictates, which can essentially induce a burden on women with lymphatic filariasis. They are expected to manage their 'duty to family' even when they are sick.

> *Women have to take care of the household, they have more work to do than men. But, the fact is that those unpaid works are never considered 'work.' So, it is difficult when women have this disease. We face several difficulties in daily activities, yet we take care of the family. We are not supposed to complain and we won't do that. (IDI_R5_F)*

Patriarchal cultural norms can adversely shape the illness experience of women with lymphatic filariasis, as evident from the responses of the participants.

c. **Poor Family Support**: Family support is a key element that shapes the illness experience of individuals. While good family support can help individuals overcome the difficulties posited by the disease, poor support from family can play a detrimental role. Women with lymphatic filariasis often do not receive adequate support from their spouse and family, both materially and morally. For instance, one of the participants from the IDIs commented on how the support level from the family was gendered.

> *I suffer since I am a woman. If I were a man, things would have been easier. Men are taken care of at home by their wives, but women patients like me have to take care of myself and others. (IDI_R1_F)*

Female patients hailing from poor conditions are even more vulnerable as they have to take care of the survival of their families and manage the discomfort of the disease. For instance, one of the participants narrated how she was the sole breadwinner of the house.

> *As I'm taking care of 3 granddaughters and my blind husband, and also doing all household work, I do*

> *not find enough time to take care of myself. I wish I had someone to support me… (IDI_R5_F).*

Some participants were facing huge discrimination and adverse behavior within their families, including spouses and children.

> *My husband asks me to die rather than be a burden to him and society. (IDI_R9_F).*

In contrast, participants who received good support from their families appeared to have better mental health outcomes and illness experiences.

d. **Skewed Care Taking Favoring Men**: Cultural elements often favor men when it comes to caretaking practices. Male patients are often cared for by the family, mainly the spouse, perpetuated by patriarchal traditions. Conversely, female patients with lymphatic filariasis often receive limited care from their immediate circle. A respondent from the IDIs highlighted how these cultural beliefs surrounding caregiving favor male patients while discriminating against women.

> *If a man gets this disease, they will be taken care of by his wife, but if a woman gets this disease, most men won't help us. (IDI_R6_F)*

These skewed caretaking-related cultural practices are beneficial to male patients but highly detrimental to women patients, as opined by participants of both genders.

> *Women will face more difficulties…If a man is affected, it is only up to him, and his wife will surely take care of him But if a woman is affected, she has to take care of her husband, child, and also herself. (IDI_R7_M)*
> *I feel that if my wife was there, she would have helped me. But women with this kind of disease will face difficulties. We expect the women in the family to help us. But, I feel, men will doubt helping a woman with this illness. (IDI_R12_M)*

Such patriarchal norms regarding caretaking practices even impact the self-care practices of women patients. For instance, one of the participants from the IDIs commented that her self-care practices would have been better if she had a proper support mechanism.

> *If there was someone to help me, I could have taken care of myself better. (IDI_R6_F)*

Table 2 Participant perceptions across themes

IDI/FGD code	Economic and occupational burden	Lymphatic filariasis induced stigma	Social and cultural burden	Total
IDI_1_F	4	3	3	10
IDI_2 _M	4	0	0	4
IDI_3_M	1	0	0	1
IDI_4_F	0	1	0	1
IDI_5_F	3	0	3	6
IDI_6_F	2	1	5	8
IDI_7_M	2	0	2	4
IDI_8_M	2	0	0	2
IDI_9_F	5	1	8	14
IDI_10_M	2	0	1	3
IDI_11_F	1	2	1	4
IDI_12_M	2	0	0	2
FGD M 1	5	1	2	8
FGD M 2	2	1	4	7
FGD F 1	3	2	6	11
FGD F 2	7	7	4	18
Total	45	19	39	103

Such trends related to caretaking practices can be detrimental to the physical and mental health of women with lymphatic filariasis. Cultural beliefs and practices, due to some of the ingrained patriarchal norms, can influence the caretaking availability for women. The norms of caretaking in most societies are gendered and favor men.

To understand the groundedness of the narratives and the gender differences in the narratives, the axes generated by the qualitative coding were cross-tabulated with the IDI and FGD transcripts using Atlas.ti (Table 2). The findings showed 25 recorded instances of female participants narrating the economic and occupational burden, while male participants made 20 such narrations. In terms of stigma, 17 instances of narrations were recorded from the female participants, while only 2 instances were recorded from the male participants. However, this uneven distribution could also be due to the traditional gender stereotypes and reluctance to respond to female interviewers by male participants. In terms of social and cultural burden, a total of 27 instances were recorded from the narratives of the female participants but only 9 such instances were recorded from the male participants. The findings show that some of the aspects, like economic and occupational burden, can be relevant across genders, but aspects like stigma and social and cultural burden affects women disproportionately.

Discussion

Towards a gender-informed intersectional outlook to illness experience in lymphatic filariasis

The classifications based on gender that are part of the social system pave the way to gender norms, which are culturally defined characteristics to judge individuals of specific gender groups [21]. These gender norms influence how individuals experience social realities in their day-to-day lives, and women, in particular, often face adverse life experiences owing to these cultural constructs dictating 'appropriate behaviors'. These norms can pair with the disease and multiple intersectional disadvantages to create a unique 'illness experience' for women. As the findings of this study suggest, the illness experience of women with lymphatic filariasis is highly shaped by the intersection of gender and other social elements, including economic and occupational factors, family and social support, cultural norms, education, discrimination, and stigma. Researchers noted two decades ago that embarrassment, shame, cultural constraints, and social taboos hindered Indian women from seeking help for lymphatic filariasis [22]. Despite advancements in women's health-seeking behavior over time, it is disheartening that they remain ensnared in the cycle of gender-specific intersecting disadvantages, heightening vulnerability to adverse mental and physical health consequences. Gender-based cultural practices and social norms directly interfere with the physical and mental health outcomes of women with lymphatic filariasis in different ways compared to their male counterparts.

Lymphatic filariasis, a disease that affects people from poor and marginalized settings, induces an experience of illness that is highly shaped by the cultural mandates of the settings. Women in most marginalized settings are known to be vulnerable to multiple overlapping disadvantages, and a disability adds to the burden [23]. The notable influence of family structure and gender inequalities on the intersectionality of disability, poverty, and race in the United States was asserted by Pokempner and Roberts [24]. In the context of a neglected tropical disease like lymphatic filariasis, economic and occupational burdens are common in the settings, and women have even more difficulty in terms of financial and occupational factors. The vulnerability of women cannot solely be attributed to their disadvantaged position in the job market but also to the disproportionate burden of domestic responsibilities placed upon them. Particularly for women from marginalized backgrounds, their identity is often intertwined with their marital roles and obligations [25]. This identity is often a construction of stereotyped female roles involving patriarchal outlooks on female body image and social position. Certain cultural norms, perceived as gender-specific etiquette in some societies, can constrain women's freedom and autonomy as individuals [26]. These factors can exacerbate the burden on affected women, leading to internalized stigma, depression, and heightened psychological vulnerability. Moreover, the current study revealed a widespread endorsement of gender stereotypes among participants of both genders. Women were expected to fulfill the caregiving role in the family, even when they were ill and in need of caretaking themselves. The instance of lymphatic filariasis serves as a poignant illustration of the gendered dimensions within caretaking norms, wherein women frequently encounter insufficient support while also being obliged to fulfill their familial duties despite grappling with physical afflictions.

A study from Nepal has explored the intersection of social stratifiers on lymphatic filariasis with a focus on disease prevention and health care seeking. This study highlights the need for gender-sensitive interventions to combat the heightened stigma faced by female patients, driven by societal perceptions of women's productivity and family impact [27]. Also, compliance with MDA for lymphatic filariasis prevention is highly influenced by gender relations, social hierarchy, and decision-making patterns in communities on compliance with MDA for lymphatic filariasis prevention [28]. Their discussion on gendered roles in disease prevention underscores the potential exacerbation of power disparities among women with the disease, compounded by factors such as disability, discrimination, stigma, and economic burden. Transcending this adverse illness experience is well beyond the immediate scope of health sciences. While disease prevention remains the most impactful intervention in medical and public health initiatives, it is important to recognize that once a chronic disease develops, enhancing the lived experience of individuals can significantly support their well-being. Addressing the cultural and economic factors that impact the lived experiences of women with lymphatic filariasis, as indicated by the data from this study, is a complex and long-term task that requires positive changes across various domains. women reported experiencing significant stigma-induced distress, rooted in restrictive gender norms and societal expectations. However, it was heartening to note that many women, despite their vulnerabilities in the family and community, exhibited good mental strength to be resilient enough to face the challenges. In our study, men were found to express higher levels of suicidal ideation, which contrasts with the existing literature indicating that although men typically have a higher incidence of suicide, women often report more suicidal ideations [29, 30]. The higher suicidal ideation among men observed in this context may have cultural underpinnings, potentially stemming from societal expectations and the pressure to fulfil their roles as providers. A perceived lack of respect or failure to meet these expectations may exacerbate their distress. This underscores the need to recognize and address challenges faced by men, which are equally significant. While women require support to combat stigma, interventions aimed at enhancing resilience may benefit men. While acknowledging the unique challenges faced by men, it's evident that women experience a multitude of issues that disproportionately impact their well-being. The interplay of these intersecting factors warrants further exploration to better understand the underlying dynamics and inform targeted interventions.

As mentioned, the WHO recommends hygiene-based home care for managing morbidity in lymphatic filariasis. However, limitations persist due to insufficient knowledge and motivation among patients and family members regarding this home-based care approach. The situation further worsens in the context of women, as the majority of them lack a caretaker in the family. Hence, to enhance the health experience of women with lymphatic filariasis, it is crucial to initiate efforts at the immediate family level, ensuring the availability of improved caregiving and psychological support. The experience of illness is personal, beyond all the other contributing elements. Support groups, mental health interventions, and family support can help individuals free themselves from potential internalized stigma and poor mental health. Moreover, incorporating an intersectional gender lens into the outlook of the illness experiences of women with lymphatic filariasis can help in gender-sensitive policy formulation. Policies should prioritize gender-informed tailoring of health interventions, including health education and care services, to address the unique challenges faced by women. Training healthcare professionals to recognize and address cultural factors influencing illness experiences and health-seeking behavior is essential. Additionally, culturally relevant communication strategies should be integrated to enhance compliance with morbidity management programs. Establishing community-based support systems and mental health services can further assist vulnerable populations in navigating the intersectional disadvantages they face, fostering more equitable and effective healthcare outcomes. This is particularly important in the context of low and middle-income countries where women are marginalised and face the double burden of the disease and other socio-economic disadvantages. Many of the countries with a burden of NTDs have limited resources leading to poor attention to NTDs [31], let al.one implementing gender-informed care. Hence, policies and programmes in such settings should take resource constraints into consideration and employ community-based sustainable practices.

Limitations of the study

The study primarily focuses on the perspectives of patients visiting a filariasis clinic, which may restrict our understanding of the full extent of challenges faced by individuals outside the healthcare system. The individuals outside the healthcare system may face unique barriers or challenges that remain unexplored in our study. The study reflects the specific socio-demographic and cultural characteristics of Puducherry, India which might differ from other regions in terms of healthcare accessibility, cultural perceptions, and socioeconomic conditions. Additionally, IDIs were conducted by a female investigator to encourage open communication among female participants, considering the cultural context. This approach could potentially introduce a bias in the representation of male perspectives. the potential influence of interviewer characteristics, such as gender and professional background, on participants' willingness to share sensitive information must be considered as a limitation, as it may have subtly shaped the depth and direction of the responses. Nonetheless, as mentioned earlier, we made every effort to mitigate this bias by obtaining training on interviewing skills and rapport building, ensuring culturally sensitive communication, and involving both male and female investigators in the transcription, coding, and analysis of the collected data. The study focused on mapping the lived experience of the participants from a constructivist worldview. We acknowledge that a mixed methods approach would have enhanced the robustness of the study findings.

Conclusion

This study illuminates the pressing need to address the gendered health disparities that afflict women with lymphatic filariasis in India. Our research has unveiled the stark and troubling reality of women with this neglected disease, facing a multitude of intersecting disadvantages stemming from deeply rooted cultural norms and economic inequities. These disparities, compounded by the psychological distress associated with the illness, manifest as a significant burden on both the physical and mental well-being of the affected women. This research highlights the importance of gender-informed intersectional studies to inform more effective healthcare policies to foster a more effective and inclusive healthcare landscape for all individuals.

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Author contributions

The study was conceptualized and designed by AR, ACC and VSK. AR, ACC, DG, GV and SA were involved in designing the interview guides and its translation to local language. AR, DG and ACC conducted the interviews and discussions for data collection. AR, ACC, DG, GV, SA and VSK participated in the transcription and data analysis. ACC and AR drafted the first manuscript which was further improved with comments from other authors. All authors read and approved the final manuscript.

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Data availability

The data that support the findings of this study are available on request from the corresponding author.

Declarations

Ethics approval and consent to participate

The study has adhered to the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (Indian Council of Medical Research, 2017). Ethical clearance for the study was obtained from the Institutional Human Ethics Committee of ICMR-Vector Control Research Centre (IHEC/IRB No: IHEC-1122/N/J).

Consent for publication

Written informed consent for participation and publication was obtained from every participant after obtaining the study objectives and methods and the participation was voluntary.

Competing interests

The authors declare no competing interests.

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