ORIGINAL RESEARCH PAPER
Volume - 10 | Issue - 06 | June - 2021 | PRINT ISSN No. 2277 - 8179 | DOI : 10.36106/ijsr

INTERNATIONAL JOURNAL OF SCIENTIFIC RESEARCH

LIVED EXPERIENCES OF PATIENTS WITH LYMPHATIC FILARIASIS: A QUALITATIVE STUDY

Nursing

Prof Alice Daniel MSc(N), MPhil (N) Principal, Malik Deenar College Of Nursing Kasargodu, Kerala.

ABSTRACT

A qualitative phenomenological study was conducted to find out the lived experiences of patients with lymphatic filariasis and to develop a guideline to promote self-esteem, self-efficacy and compliance to different treatment regimens. The study was conducted at Institute of applied dermatology which provides an integrated approach in treatment of LF, in Kasargodu district of Kerala state. Sample size was eight patients with LF recruited using purposive sampling, were undergoing treatment and met the inclusion criteria. Data was collected using socio demographic proforma and a semi structured interview schedule, recorded using both audio tapes and field notes. Data analysis was planned to conduct based on Husserl's phenomenological approach. Six themes emerged primarily in this study: Physical disabilities due to the illness, Low self-esteem, Financial burden, Effect on the marital relationship, Emotional problems and Feeling towards treatment. These findings were portrayed in many previously published studies which were done qualitatively and quantitatively.

KEYWORDS

Filariasis, Qualitative study, Lived experiences.

INTRODUCTION

Lymphatic filariasis (LF) is a chronic and disfiguring condition that can lead to significant disability. Lymphatic filariasis is found among persons residing in rural areas and at the periphery of communities predominantly in developing countries in the tropics. Global estimates project that infection with the filarial parasite, which causes LF, is present in at least 120 million persons, with about 40 million people exhibiting clinical symptoms and signs. Thus, the condition is now recognized as a public health priority, along with other neglected tropical diseases (NTDs).

Several studies have explored stigma and its associated socioeconomic consequences among affected persons living with LF and other NTDs. Recent estimates conservatively estimate that 50% of clinical patients with LF have co-morbid depression. Others have also postulated that stigma and discrimination lead to co-morbid mental health problems and to a reduction in health-related quality of life. The wider burden of LF is therefore likely to be considerably higher if these co-morbidities are taken into account.

About 31 million people are estimated to be the carriers of mF and over 23 million suffer from filarial disease manifestations in India. The state of Bihar has highest endemicity (over 17%) followed by Kerala (15.7%) and Uttar Pradesh (14.6%). Andhra Pradesh and Tamil Nadu have about 10% endemicity. Goa showed the lowest endemicity (less than 1%) followed by Lakshadweep (1.8%), Madhya Pradesh (above 3%) and Assam (about 5%). *B. malayi* is prevalent in the states of Kerala, Tamil Nadu, Andhra Pradesh, Orissa, Madhya Pradesh, Assam and West Bengal. The single largest tract of this infection lies along the west coast of Kerala, comprising the districts of Trichur, Ernakulum, Alleppey, Quilon and Trivandrum, stretching over an area of 1800 sq km. The infection in the other six states is confined to a few villages. Surveys undertaken recently in Kerala and a few villages in other states revealed either a reduction of foci or complete elimination of the parasite as well as the vector(s) in many villages which were known to be endemic for *B. malayi* infection four decades back.

A better understanding of such experiences is an important first step upon which to premise advocacy for a rights-based approach to address the identified problems. Our study sought to fill this gap. Specifically, it explored aspects extremely related to their lived experiences.

MATERIALS AND METHODS

A qualitative phenomenological study was conducted to find out the lived experiences of patients with lymphatic filariasis and to develop a guideline to promote self-esteem, self-efficacy and compliance to different treatment regimens. The study was conducted at Institute of applied dermatology which provides an integrated approach in treatment of LF, in Kasargodu district of Kerala state. Sample size was eight patients with LF recruited using purposive sampling, were undergoing treatment and met the inclusion criteria. Data was collected using socio demographic proforma and a semi structured interview schedule, recorded using both audio tapes and field notes. Data collection duration was thirty days during the OPD timings in the counseling centre of institute. Data analysis was planned to conduct based on Husserl's phenomenological approach.

DATA CODING AND ANALYSIS

Researcher transcribed and translated into English the audiotapes of the interviews, paying special attention to removing mentions of people's names and descriptions of specific individuals who may be identifiable from such descriptions. The final transcript data was analyzed based on the Husserl's phenomenological method, using a sequential combination of deductive and inductive coding. Researcher subsequently harmonized their themes and reconciled areas of disagreement.

RESULTS

- **Socio demographic data of participants**

(n=8)

Variable		Frequency	Percentage
Age	30-49	04	50
	50-69	04	50
Gender	Male	04	50
	Female	04	50
Religion	Hindu	04	50
	Isam	04	50
Educational status	Illiterate	01	12.5
	Primary	03	37.5
	Secondary	01	12.5
	Graduate	03	37.5
Marital status	Married	08	100
Occupation	House wives	02	25
	Unskilled	01	12.5
	Skilled	03	37.5
	Semi skilled	01	12.5
	Professional	01	12.5
Income	Above 5000	07	87.5
	3000-5000	01	12.5
Type of family	Nuclear	06	75
	Joint	02	25
Residence	Rural	04	50
	Semi urban	04	50

- **Themes derived from significant statements**
- **Theme 1: Physical disabilities due to the illness** – they cannot do religious rituals, washing the legs before prayer, unable to bend knee joint, lymphedema, unable to do self-care activities, repeated attacks of fever with chills and weakness.
- **Theme 2: Low self-esteem** – All patients had altered body image such as appearance related concerns and low self-esteem because of the disfigurement of the body, huge lower limbs, infected wounds and discharge from wounds.
- **Theme 3: Financial burden** – Patient expressed that had taken treatment from many doctors, shifted from hospitals to hospitals, and spend lot of money for travelling, staying in hostels and surgeries.
- **Theme 4: Effect on the marital relationship** – The chronic and irreversible nature of LF affected not only affected the patients but

also the spouse and family members. One patient reported that her spouse divorced her and one patient said her husband was in severe stress because of this disfigurement.

- **Theme 5: Emotional problems -** Six participants experiences depression, sadness, frustration, irritability, anger, anxious about their future, about children marriage, treatment, and they were in a opinion that nobody should get this disease. Two patients coped well with the disease process.
- **Theme 6: Feeling towards treatment –** Patients had negative feelings towards the previous hospitalization and treatment. They expressed that doctors were not able to diagnose the disease, treated with many drugs, surgeries, referred to many hospitals and so on which created irritation.

Based on findings that patients are having low self-esteem and low self-efficacy a guideline was prepared after consultation with experts.

DISCUSSION

Six themes emerged primarily in this study: Physical disabilities due to the illness, Low self-esteem, Financial burden, Effect on the marital relationship, Emotional problems and Feeling towards treatment. These findings were portrayed in many previously published studies which were done qualitatively and quantitatively.

Several studies showed lymphatic filariasis to have an impact on quality of life of the person affected. In contrast, the quality of life of family members has not received much attention, despite evidence that families are also affected and play a crucial role in most societies around the world. Individual quality of life broadly encompasses an individual's perception of the 'goodness' of multiple aspects of their life, such as mental, physical, role, environment and social functioning. Family quality of life, a natural extension of individual quality of life, is not focused on individuals but rather on all family members in the family unit.

Ethical considerations

Researcher obtained ethical clearance from the Ethics and Research Committee of the Institute of applied dermatology. Privacy and confidentiality were ensured for all participants in the interview settings, and these issues were discussed prior to conducting the interviews. Written informed consent was also obtained from the participants.

CONCLUSION

Given the pervasive life experiences as experienced by persons affected by LF, and the associated emotional consequences, interventions that address stigma and the psychosocial consequences of this condition must be considered an essential component of LF-related services. Such interventions can be supported through the enactment of a legislative framework that promotes and protects the human rights of affected citizens. The training of health workers, the provision of accessible services via primary care, and public education campaigns are additional steps that can be taken by the government and civil society organizations alike. The screening, identification, and treatment of mental health needs, as well as social and economic inclusion, should gain prominence as rights-based considerations during policy discussions on contemporary challenges for LF in particular and NTDs in general.

REFERENCES

1. World Health Organization, Working to overcome the global impact of neglected tropical diseases (Geneva: WHO, 2010).
2. World Health Organization, Managing morbidity and preventing disability in the Global Programme to Eliminate Lymphatic Filariasis: WHO position statement (Geneva: WHO, 2011).
3. M. Zeldenryk, M. Gray, R. Speare, et al., “The emerging story of disability associated with lymphatic filariasis: A critical review,” PLoS Neglected Tropical Diseases 5/12 (2011).
4. World Health Organization, Global Programme to Eliminate Lymphatic Filariasis: Progress report 2000–2009 and strategic plan 2010–2020 (Geneva: WHO, 2010).
5. Brady, “Seventh meeting of the Global Alliance to Eliminate Lymphatic Filariasis: Reaching the vision by scaling up, scaling down, and reaching out,” Parasites and Vectors 7/46 (2014).
6. Eigege, D. S. Evans, G. S. Noland, et al. “Criteria to stop mass drug administration for lymphatic filariasishave been achieved throughout Plateau and Nasarawa States, Nigeria,” American Journal of Tropical Medicine and Hygiene 97/3 (2017), pp. 677–680.
7. Goffman, Stigma: Notes on the management of spoiled identity (Harmondsworth, Middlesex: Penguin Books, 1963); G. Scambler, “Stigma and disease: Changing paradigms,” Lancet 352/9133 (1988), pp. 1054–1055.
8. Thornicroft, D. Rose, A. Kassam, and N. Sartorius, “Stigma: Ignorance, prejudice or discrimination?,” British Journal of Psychiatry 190/3 (2007), pp. 192–193.
9. G. N. Ton, C. Mackenzie, and D. H. Molyneux, “The burden of mental health in lymphatic filariasis,” Infectious Diseases of Poverty 4 (2015), p. 34.
10. Litt, M. C. Baker, and D. Molyneux, “Neglected tropical diseases and mental health: A perspective on comorbidity,” Trends in Parasitology 28/5 (2012), pp. 195–201; K. T. Harichandrakumar and M. Kumaran, “Health related quality of life (HRQoL) among patients with lymphatic filariasis,” International Journal of Health Sciences and Research 7/3 (2017), pp. 256–268.