

Quality of life of people living with lymphoedema: A cross sectional community based study in selected districts of Nepal

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Abstract

Introduction: Lymphatic Filariasis (LF) is the second most common cause of physical disability worldwide with 40 million people chronically disabled by the disease and about twice that number suffering from covert lymphatic changes or kidney diseases. The most common chronic manifestations of the disease are lymphoedema and hydrocele. The objective of this study is to evaluate the quality of life (QOL) of lymphoedema patients in Nepal.

Methods: We sought the help of female community health volunteers, health workers working in peripheral health centers in selected sentinel surveillance sites in listing out the names of patients with lymphoedema. The researcher obtained details of a 205 cases of lymphoedema (49 cases of Elephantiasis and 156 cases of hydrocele) in three districts (Dhading 74, Kapilbastu 78, Kailali 53). A total of 205 healthy individuals were selected from same locality (Dhading 68, Kapilbastu 66, Kailali 71) for comparison. World Health Organization Quality of life questionnaire brief version (WHO QOL-BREF) was used for data collection.

Results: The mean age of the respondents was 45.95 years with standard deviation of 17.96 years. In four domains, physical domain scored highest (14.28±2.52) and environmental domain scored the lowest (12.19±1.69). Patients with lymphoedema had significantly low QOL scores in physical ($p<0.001$), psychological ($p<0.001$), social relationship ($p<0.001$), environmental ($p<0.001$) compared to their healthy counterparts. Similarly, the overall QOL score was lower in patients with lymphoedema than healthy control and it was statistically significant ($p<0.001$).

Conclusion: This study reports significantly low QOL scores in all four domains in patient with lymphoedema denoting low quality of life compared to their healthy counterparts. It is recommended that current Lymphatic Filariasis elimination program of Nepal should focus to initiate morbidity management program specifically to patients with lymphoedema and hydrocele.

Keywords: Lymphoedema, filariasis, quality of life, cross sectional studies, Nepal

Introduction

The prevalence of Lymphatic filariasis (LF) cases is 2.0% globally¹. LF is the second most common cause of physical disability worldwide². Approximately 40 million people are chronically disabled and twice the number are suffering from covert lymphatic changes or kidney diseases³.

There are three nematodes causing LF in human: *Brugia malayi*, *Brugia timori* and *Wuchereria bancrofti*⁴. *Wuchereria bancrofti* is the only recorded parasite for transmitting LF in Nepal. These nematodes are transmitted by different mosquito hosts varying geographically in Nepal. The mosquito, *Culex quinquefasciatus* is the most commonly recorded vector for LF in Nepal⁵.

The Global Programme to Eliminate Lymphatic Filariasis (GPELF) was started in 2000 with the aim to interrupt the transmission of parasite and alleviate the suffering of those with chronic manifestations of LF through a mass drug distribution of Diethylcarbamazine and Albendazole or Ivermectin in endemic communities^{6,7}. The MDA programme has now reached 42 of 83 endemic countries³ of which 26 of the 81 now has morbidity programs, specially focusing on addressing physical impairments⁸.

LF is a well-recognized public health problem in Nepal. Prevalence rates of LF range from a low of 0.1% to a high of 40% in certain endemic districts in Nepal⁹. The government of Nepal initiated mass drug administration (MDA) from Parsa district in 2003. Since then the programme has been expanded to other 46 districts by 2011⁵.

The most common chronic manifestations of LF are Elephantiasis and hydrocele. Acute adenolymphangitis and bacterial infections that cause significant pain and fever also occur in phases. Other less reported clinical expressions include lymphoedema of the breast, swelling of the vulva, and rheumatic and respiratory problems¹⁰. Lymphoedema denotes Elephantiasis and Hydrocele in this study. The chronic condition of LF may impede the quality of life (QOL) of Lymphoedema patients. But the impact of LF on quality of life of lymphoedema patients remains largely unknown with very few studies available¹¹⁻¹³. The several studies regarding QOL have been conducted in Nepal¹⁴⁻²⁰ but none of such studies has been conducted to explore QOL of Lymphoedema patients in Nepal. The objective of this study is to describe and quantify the QOL of patients with chronic filarial lymphoedema in Nepal.

Methods

Study setting

A cross sectional study was carried out in three of the sixty endemic districts of Lymphatic Filariasis in Nepal. The selected districts were Dhading, Kapilbastu and Kailali districts and had a population of 336067, 571936, 775709 in 2011 respectively²¹.

The sentinel surveillance sites in these districts constituted the sampling frame at the first stage. The peripheral health care centers in these sentinel sites constituted the sampling frame (clusters) at the second stage of sampling. Each village development committee has a peripheral health center in Nepal.

Sampling technique and data collection

The Lymphoedema cases are hidden in Nepalese society and they are difficult to get recruited for data collection. So the researchers sought the help of female community health volunteers (FCHVs) and health workers working at peripheral health centers in selected sentinel surveillance sites. Cluster random sampling was used to recruit study participants into sampling frame in three districts. Assuming that the desired width of the 95% confidence interval is 0.25, intra cluster correlation=0.01, and number of clusters 3, the number needed in each cluster is 60, corresponding to a total sample size of 180. It is considered for the non-response rate of 10% resulting 198 total samples. But for convenience, 205 Lymphoedema patients are enrolled in this study. The FCHVs listed out the names of individuals with lymphoedema and the researcher obtained a list of 205 cases (patient with filarial lymphoedema) in three districts (Dhading 74, Kapilbastu 78, Kailali 53). The researcher himself being a medical doctor ascertained the medical condition of a filarial lymphoedema. Similarly the individual who doesn't have any filarial lymphoedema and also other chronic diseases that hamper quality of life were selected as healthy individual. The researcher prioritized selecting the healthy individual from the same household. Thus, the researcher obtained a total of 205 healthy individuals as control in this study.

WHO QOL-BREF is a shortened version of the WHO QOL instrument consisting of a 26 items questionnaire that is comparable across different languages and cultures²². Pertinent demographic characteristics such as age, sex, educational and marital status were also included in the WHO QOL-BREF. WHO QOL-BREF has been used for measuring quality of life in people living with several diseases and health conditions across different settings and cultures. The WHO QOL-BREF has four domains such as physical, psychological, social relation and environmental. The domain scores denote an individual's perception of QOL in each QOL domain. The researcher used the Nepalese version of WHO QOL-BREF used by Giri et al in Nepal¹⁴. The questionnaire was pretested among 10 Lymphoedema cases and 10 healthy individuals in Salyantar Village Development Committee of Dhading district to ensure cultural adaptability.

Defining variables

WHO QOL-BREF has 26 items grouped under four domains²²: (i) physical health, (ii) psychological well-

being, (iii) social relations, and (iv) environmental. Each item is categorized into a five point Likert scale. The items under the domains are summarized in Table 2. There are two other items that are measured separately:¹ patient's overall perception of QOL, and ² overall perception on his/her health. Domain scores are scaled in a positive direction; higher scores denote higher QOL. The mean score of items within each domain is used to calculate the domain scores compatible with the scores used in WHO QOL-100 and subsequently transformed to a 4-20 scale²³.

Data analysis

Data were analyzed using SPSS version 20 (IBM Corporation, Armonk, NY, USA). Descriptive variables such as mean and standard deviation (SD) were calculated as the primary method of data analysis. Normality of the distribution of the data was ascertained using the Shapiro–Wilk test, and Person Chi square test was used to test the association between variables. We compared the socio-demographic characteristics of respondents and individual domain scores among cases and healthy individuals. The level of significance chosen was 5%. The domain scores were categorized into two based on mean domain scores. The physical, psychological, social relation, and overall domain scores were categorized as <15 and >15 where as environmental domain was dichotomized into <12.5 and >12.5.

Research Ethics

Ethical clearance was obtained from Institutional Review Board of Institute of Medicine, Kathmandu, Nepal. Verbal informed consent was obtained from each participant before starting interview. The list of details gathered about lymphoedema cases were kept only for study purpose and personal identifiers were removed after data collection. The purpose of the interview was clearly explained to all participants before interview. Participants had the liberty not to answer any question or leave the interview any time.

Results

The mean age of the respondents was 45.95 years with standard deviation of 17.96 years. The mean age of cases was slightly greater than of healthy individuals and it was statistically significant ($p=0.020$). One in three respondents belonged to each of the three study locations as such Dhading (34.6%), Kapilbastu (35.1%) and Kailali (30.2%). Seven in ten (70.5%) respondents were male. A total of 42% of respondents were illiterate and majority of the respondents were married (88.3%). There was statistically significant difference between cases and healthy individuals by age ($p=0.010$), sex ($p<0.001$) and educational status ($p<0.001$) (Table 1).

Table 1: Socio-demographic characteristics of respondents

Variables	Total	Cases (205)	Healthy individuals (205)	P value
Study Location				
Age	45.95+17.96	48.67+18.14	43.22+16.56	0.020
<45 years	202(49.3%)	88(42.9%)	114(55.6%)	0.010
>45 years	208(50.7%)	117(57.1%)	91(44.4%)	
Study location				
Dhading	142(34.6%)	74(36.1%)	68(33.2%)	0.145
Kapilbastu	144(35.1%)	78(38.0%)	66(32.2%)	
Kailalai	124(30.2%)	53(25.9%)	71(34.6%)	
Sex				
				$p<0.001$
Male	289(70.5%)	178(86.8%)	111(54.1%)	
Female	121(29.5%)	27(13.2%)	94(45.9%)	
Educational status				
				$p<0.001$
Illiterate	172(42.0%)	114(55.6%)	58(28.3%)	
Primary	112(27.3%)	45(22.0%)	67(32.7%)	
Secondary	80(19.5%)	29(14.1%)	51(24.9%)	
Tertiary	46(11.2%)	17(8.3%)	29(14.1%)	
Marital status				
				0.759
Unmarried	48(11.7%)	25(12.2%)	23(11.2%)	
Married	362(88.3%)	180(87.8%)	182(88.8%)	

The different domain scores are shown in table 2. In four domains, physical domain scored highest (14.28 ± 2.52) followed by Social relationship domain (13.62 ± 2.18) and Psychological domain (12.93 ± 2.58). Environmental domain scored lowest (12.19 ± 1.69). In cases, social relationship domain (13.15 ± 2.48) scored highest and psychological domain scored lowest (11.58 ± 2.54). Among the healthy individuals, Physical domain (15.75 ± 1.84) scored highest and environmental domain scored lowest (12.91 ± 1.13). There was statistically difference between cases and healthy individuals by domain scores. Cases scored lower than healthy individuals and it was statistically significant in terms of physical ($p < 0.001$), psychological ($p < 0.001$), social relationship ($p < 0.001$) and environmental ($p < 0.001$) domains. Similarly, the overall domain scores was lower in cases than healthy individuals and it was statistically significant ($p < 0.001$) (Table 2).

Table 2: Mean domain scores by cases and Healthy individuals

Domain Scores	Total	Cases (205)	Healthy individuals (205)	P value
Physical	14.28 ± 2.52	12.83 ± 2.24	15.75 ± 1.84	$p < 0.001$
Psychological	12.93 ± 2.58	11.58 ± 2.54	14.27 ± 1.80	$p < 0.001$
Social relationship	13.62 ± 2.18	13.15 ± 2.48	14.10 ± 1.71	$p < 0.001$
Environmental	12.19 ± 1.69	11.46 ± 1.84	12.91 ± 1.13	$p < 0.001$
Overall QOL score	13.25 ± 1.92	12.25 ± 1.94	14.25 ± 1.27	$p < 0.001$

Slightly more than a half (57.80%) of the respondents had <15 score in physical domain. Three quarter of respondents (74.6%) had <15 score in psychological domain. Slightly less than four in five (77.3%) respondents had score <15 in social relationship domain. A total of 59% of respondents had score <12.5 % in environmental domain (Table 3). Three quarter (75.6%) of respondents had overall domain score between 12 and 16 and it was statistically significant ($p < 0.001$) (Table 4).

Table 3: Individual Domain Scores by cases and Healthy individuals

Domain Scores	Total	Cases (205)	Healthy individuals (205)	P value
Physical				$p < 0.001$
<15	237(57.8%)	175(85.4%)	62(30.2%)	
>15	173(42.2%)	30(14.6%)	143(69.8%)	
Psychological				$p < 0.001$
<15	306(74.6%)	186(90.7%)	120(58.5%)	
>15	104(25.4%)	19(9.3%)	85(41.5%)	
Social relationship				$p < 0.001$
<15	317(77.3%)	174(84.9%)	143(69.8%)	
>15	93(22.7%)	31(15.1%)	62(30.2%)	
Environmental				$p < 0.001$
<12.5	242(59.0%)	158(77.1%)	84(41.0%)	
>12.5	168(41.0%)	47(22.9%)	121(59.0%)	
Overall QOL Domain				$p < 0.001$
<15	74(18.0%)	6(2.9%)	68(33.2%)	
>15				

Table 4: Overall QOL score by cases and Healthy individuals

Overall QOL score	Total	Cases (205)	Healthy individuals (205)	P value
4-8	2(0.5%)	2(1.0%)	0(0.0%)	$p < 0.001$
8-12	90(22.0%)	78(38.0%)	12(5.9%)	
12-16	310(75.6%)	123(60.0%)	187(91.2%)	
16-20	8(2.0%)	2(1.0%)	6(2.9%)	

Discussion

It is found that lower QOL scores in all four domains denoting lower quality of life among patients with lymphoedema. Similarly, the overall, general QOL scores were higher in healthy individuals than patients with lymphoedema. The lower quality of life among patients with lymphoedema has been described earlier^{11, 24}. An earlier study in Sri Lanka showed that only the environmental and spiritual domains were significantly affected by the maximum grade of lymphoedema. A similar trend was reported by Babu et al. in 2006 using the DLQI questionnaire where the differences in scores across various grades of lymphoedema were not significant²⁵.

The lower QOL scores in all domains can be explained in the light that the chronic pain, discomfort, sleep disturbance, difficulty to perform physical activities of daily living, dependence on medication, less working capacity, less social support accompanied by recurrent acute adenolymphangitis attack/s leads to low health related quality of life scores compared to their healthy counterparts²⁶. Lymphoedema patients are often neglected in family, are not provided with good care and family support. The districts selected for this study represent rural villages of the Terai and Hill region of Nepal. Motorable roads are not available in many villages, and transportation facilities are seldom available. Slowly, the traditional joint family structure is being replaced by nuclear families^{27, 28}. We assume that the traditional joint family is better than nuclear family in terms of providing psychological support to Lymphoedema patients. This typically maintains strong bond between Lymphoedema patients and their family members and attempt to provide economic and emotional support.

The findings revealed an important public health issue in Nepal. From the study, it can be affirmed that lymphoedema patients suffered a definite negative impact on their QOL in all aspect of life has also been reported in earlier¹¹. LF is one of the most neglected diseases in terms of prevention, morbidity management and research in developing countries. Lymphoedema which comprise Hydrocele and Elephantiasis may have increased suffering among the patients adding disability adjusted life years in developing countries²⁹. Everyone strives for better quality of life. Therefore governments of all over the world are increasingly concerned about improving the quality of life of their people by reducing morbidity and mortality, providing primary health care and enhancing physical, mental and social well-being.

Historically, Nepalese people are regarded much caring

towards their families and neighbors. In villages of Nepal, there are social structures like youth clubs, mother associations and religious groups who support the people in debilitating conditions like Lymphoedema, paralysis and other chronic conditions. These social structures should be capitalized in management of patients with lymphoedema. Moreover, the government needs to initiate morbidity management of Lymphoedema.

This study had a number of strengths such as use of robust study design, having a comparison group, representative samples from three study locations and validated questionnaires. The researcher selected the healthy persons from the sample household who accompanied patients may have reduced the actual differences between the two groups. An earlier study described taking a healthy individuals from the same home environment as patients; the long-term consequences of a chronically ill patient in reference to psychological domain under their care can be underestimated¹¹. QOL is an inclusive concept incorporating all factors that impact upon an individual's life, and gives good approximation to the QOL experienced by people³⁰. Though this study being carried out among a representative sample representing three geographically distinct population, it can only be generalized beyond the study locations with caution. QOL was self-reported; hence there is high possibility of reporting bias of close personal issues¹⁴.

The government of Nepal Epidemiology and Disease Control Division has formulated a National Plan of Action (2003-2020 AD) for the Elimination of Lymphatic Filariasis in Nepal through i) Interruption of transmission by yearly Mass Drug Administration using two drug regimens (Diethylcarbamazine and Albendazole) and ii) morbidity management by self-help and using intensive but simple, effective and local hygienic techniques⁵. However, there is not any morbidity management program specific to Lymphoedema management existed in Nepal. This study will contribute to the public health programs and further research in the field of Lymphatic Filariasis. The lower quality of life among Lymphoedema patients reported in this study needs to be addressed.

Conclusion

This study reported significantly low QOL scores in all four domains in patient with lymphoedema denoting low quality of life compared to their healthy counterparts. It is recommended that the current Lymphatic Filariasis elimination program of Nepal should focus to initiate morbidity management program specifically to patients with lymphoedema.

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Authors Contribution

RKA conceived this research work. SRM and KR helped RKA in carrying out field work. RRW and JBS are RKA's supervisors and contributed to all aspects of this study from making proposal to finalization of the manuscript.

Conflict of interest: None declared.

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