



The Influence of Social Support on the Utilization of Health Care Services by Patients with Chronic Lymphatic Filariasis in Goshi location, Malindi Sub-County, Kenya

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Summary

Background: Lymphatic filariasis (LF) caused by filarial worms and transmitted by mosquitoes is ranked as the second largest cause of disability in the world. Infection leads to clinical manifestations; lymphoedema of limbs and genitalia and elephantiasis. The disease causes considerable morbidity to affected individuals with consequent loss of income and social and psychological stress. To determine the influence of social support on the utilization of healthcare services by patients with chronic clinical signs of LF, a cross-sectional study was conducted in Goshi location, Malindi Sub-County, Kenya.

Methods: A total of 220 patients with chronic (LF) were purposively selected and interviewer-based questionnaires administered to them for quantitative data. Four focus group discussions (FGDs) with single sex adult and youth groups and 16 key informant interviews with purposively selected opinion leaders were conducted for qualitative data. The quantitative data was analyzed by SPSS version 16 and the qualitative data manually by study themes.

Results: Encouragement received by patients from family and friends was significantly associated with health care services utilization ($P < 0.001$). Most (68.2%) of patients who received such encouragement compared to 31.8% who did not, utilized health care services. Similarly, receiving encouragement from other patients with chronic LF was significantly associated with frequency of visiting health care facilities ($P < 0.001$). Majority (81.8%) of respondents who received encouragement from fellow patients compared to 18.2% who did not, visited the health facility more frequently. Feeling of being a burden to the family was significantly associated with utilization of health care services ($P < 0.05$). More than one half (57.1%) of those who felt that they were a burden to their family



compared to 42.9% who did not, utilized health care services. Being affiliated to a support group was also significantly associated with utilization of health care services ($P<0.001$). Most (85.7%) of respondents who indicated that they were affiliated to a support group compared to 14.3% who were not, utilized health care services.

Conclusion: Patients with chronic LF require encouragement from community members and fellow patients to remove the feeling of rejection and to seek health care services. Being a member of a support groups is an important contributor of increased health care services utilization and authorities should support patients to form such groups.

Key words: social support, health care services, chronic lymphatic filariasis

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Introduction

Lymphatic filariasis, commonly known as elephantiasis, is a neglected tropical disease. Infection occurs when filarial parasites are transmitted to humans through mosquitoes [1]. The disease manifests as progressive lymphoedema leading to disfiguring elephantiasis in both genders, hydrocoele, predominant manifestation in males, and loss of respiratory function due to tropical pulmonary eosinophilia (TPE). The other health problems due to filariasis include renal disease, arthritis, endomyocardial fibrosis [2]. Filariasis patients suffer from episodic of adenolymphangitis (ADL), which causes acute suffering and incapacitation [3]. Lymphatic Filariasis is the second most common cause of long-term disability after mental illness [4].

In sub-Saharan Africa, it is estimated that about 512 million people are at risk of infection, with almost 40 million men at risk of developing hydrocoele [1], whereas about 28 million are already infected. Of this number,

there are 4.6 million cases of lymphoedema and over 10 million cases of hydrocoele.

In Kenya, Lymphatic filariasis has been reported since 1910 [5] and the disease remains endemic in entire Coastal Kenya where about 3.4 million people are at risk of infection [6]. Estambale *et al* (1994) found 16.5% of the males over 14 years of age had hydrocoele and 2.4% of the adults of this age group had lymphoedema. In the same study the prevalence of hydrocoele increased with age (23.8%) among individuals older than 49 years. Prevalence and intensity of microfilaraemia varies distinctly between the geographical locations in Coast region [8]. Nevertheless, amicrofilaraemic and asymptomatic infections are not included in this estimate and the true number of affected people may even be higher.

Acute manifestations directly caused by live adult worms are usually rare. Acute filarial lymphangitis (AFL) is caused by death of the adult worm [9] and is characterized by lymphangitis that progresses distally or



in a 'retrograde' fashion along the lymphatic vessel, producing a palpable 'cord'. Rarely, AFL is accompanied by mild fever, headache, and malaise. Distal lymphoedema may occur, but is usually mild and reversible, that is, self-limited (Dreyer *et al.*, 1999). Acute dermatolymphangioadenitis (ADLA) is frequently associated with Group A Streptococcus bacterial infection. Little is known about the antimicrobial sensitivity of bacteria isolated from persons with ADLA in filariasis-endemic areas. Available experience suggests that the organisms most commonly involved are sensitive to penicillin; thus, penicillin is usually recommended for treatment (10). Patent asymptomatic infection (microfilaraemia) of lymphatic filariasis often leads to acute and then chronic disease and causes severe disability and incurs considerable treatment cost [11].

Lymphatic filariasis (LF) is an important public health and socio-economic problem worldwide [12] and it imposes considerable economic burden on patients, their families and communities. The disease is estimated to be responsible for the loss of about 0.63% of per capita GNP in India [13]. In Haiti, lymphoedema patients reported decreased ability to walk, difficulty in finding appropriate footwear, and sometimes inability to sell at the market or do household chores [14]. As a result, many men switched to less demanding occupations that require less energy. In a study conducted by Ramu *et al.* (1996), the productivity of male weavers with chronic LF was found to have reduced by as much as 27.4% in the cloth weaving industry and thus reducing wage earning. In China where LF has been eliminated, the primary motivation behind the elimination campaign was the

impact of the disease on agricultural productivity [16]. In non-endemic villages in Ghana, considerable stigma was associated with hydrocoele and lymphoedema, much more than in hyper-endemic villages [17]. In some countries, they believe that hydrocoele has supernatural causes which lead people to seek treatment from traditional healers or sorcerers instead of modern medical care [18]. A study in Kenya conducted by Amuyunzu, (1997) found out that 36% of men with hydrocoele interviewed responded that they were laughed at, while 29%, mostly patients with small hydrocoele reported no reaction from the community.

Lymphatic filariasis has been identified as one of the six diseases (among over hundred considered), targeted for elimination based on considerations that human beings are only reservoir of infection [20]. Improved therapies and diagnostic methods have led to the realization that it is possible to interrupt transmission and eliminate LF by repeated, annual cycles of Mass Drug Administration (MDA) [21]. Ivermectin and diethylcarbamazine (DEC) have been the drugs of choice for the treatment of onchocerciasis and LF [22]. Plaisier *et al.* (1999) have shown that a dosage level of 400 micrograms/kg of ivermectin as a single dose irreversibly reduces mf production by 65%. Beach *et al.*, (1999) in a study, which combined albendazole and ivermectin for the treatment of intestinal helminthes, and *Wuchereria bancrofti* in schoolchildren, reported that combination therapy reduced the prevalence of *Trichuris* and the prevalence of mf more than placebo or ivermectin alone.

Kenya initiated its National LF Elimination Programme in 2002 and several rounds of MDAs have been conducted



in at least 4 of the 6 LF endemic Counties. Malindi Sub-county in Kilifi County has received 4 MDA rounds but nothing much has been done with regards to addressing objective 2 i.e. morbidity control. This study is an attempt to explore the social support factors that could be used as a platform for implementation of a disability management programme in the LF endemic areas of Kenya. Suggestions from the affected communities on social support factors can be used as an entry point in addressing morbidity control issues. The study specifically examined six aspects: encouragement from fellow patients, family and friends; feeling of rejection; perception of role of spiritual intervention; disease burden; fear of being noticed by others and role of support groups in morbidity control. It is intended that this research will provide information necessary to address the gaps and provide suggestions to make the programme responsive to the needs of LF patients.

Methods

Ethics statement

Scientific and ethical approval of the study was received from the Kenya Medical Research Institute (KEMRI) through its Scientific Steering Committee and Ethical Review Committee as SSC No. 2385, and written informed consent sought from all the study participants. All the participants were adults above the age of 18 years and therefore provided their own consent to participate in the study.

Study area

The study was carried out in Malindi Sub-County, Kilifi County, in the coastal region of Kenya which lies between 2° 20' and 4° South, and 39° 5' and 40° 14' East, covering an area of 15,500 km². The county comprises the former Kilifi and Malindi districts. It borders Tana River County to the North, Taita Taveta County to the West, Kwale to the South West, Mombasa County to the South and the Indian Ocean to the East. The County has a population of 1,134,856 with 569,906 male, 611,072 female and 191,318 less than five years of age [6]. Administratively, Kilifi County has six sub-counties namely; Malindi, Magarini, Ganze, Rabai, Kaloleni and Kilifi/Bahari. The four main livelihoods include; marginal mixed farming (MMF) which comprises 44 percent of the population, ranching (two percent); food cropping (11 %) and cash cropping/dairy (22 percent). Other livelihood zones are fishing and mangrove which comprises of three percent of the population; formal employment (14 %) and forest /tourism and casual labor each of which comprises 2% of the population.

Study design and setting

The study design was cross-sectional and utilized both qualitative and quantitative methods for data collection. Based on records from the LF Programme Manager, Goshi Location was selected for the study as cases of hydrocele and lymphoedema are reported to be high, approximately 1 in every 4 households.

Study population

Five sub-locations (Kakuyuni, Madunguni, Mongotini, Malimo and Paziani) were purposively selected with help of the Chief of Goshi Location and a total of 220 patients



with chronic LF purposively sampled from with the help of the Assistant Chiefs of the 5 sub-locations and interviewed by use of a structured questionnaire for quantitative data. For qualitative data, 4 FGDs were carried out with single sex adult and youth groups who were relatives of the patients. Additionally a total of 16 in-depth interviews were carried out with purposively selected key informants (chiefs, sub chiefs, teachers, church leaders and health care workers). Observational checklists were used to capture Lymphoedema characteristics of the patients who took part in the study.

Statistical analysis

Quantitative data from questionnaires were checked daily for completeness after the interview. At the end of interviews, the responses from closed and open-ended questions were coded for appropriate computer entry. The data was then cleaned and entered into Epi- info version 6 and analyzed in SPSS version 16. Equivalent responses were pooled to arrange the responses in different categories. Cross tabulations was used to test association between social support factors and health care service utilization among patients with chronic LF. A P value of ≤ 0.05 was considered statistically significant. The quantitative data was collected before the qualitative data. This was mainly to generate meaning for the various patterns observed from the preliminary quantitative data analysis. The qualitative data from various sources were analyzed manually according to the themes of the study and triangulated for cross verification. The triangulation helped increase the credibility and validity of the results by continuously cross-checking the data from the various sources.

Background Characteristics of the Study Participants

A total of 220 participants from the five sub-locations were interviewed. Majority (27.7%) of participants were from Kakuyuni Sub-location (Table 1). Out of the total participants interviewed 34.1% had swollen lower limbs, 1.4% swollen upper limbs, 6.8%, swollen both limbs, 57.2%, swollen scrotum, 0.5% swollen other body parts.

The mean age of the study participants most (70%) of whom were male was 55.15 years, (SD=16.7), median, 54 and mode 60. The youngest interviewed participant was 20 and the oldest 102 years. The mean number of years with which the patients had lived with the disease was 13 years, (SD=11.292), median and mode were 10 while the minimum number of years was 1 and maximum was 50 years. Majority (71%) were in marital unions, over one-half (54.1%) were non-practicing while 41.4% were Christians. Nearly one-half (47.5%) of the study participants had primary school education and more than one half (56.4%) were peasant farmers and almost three-fifths (59.5%) earned less than 31.25 \$ per month with only (3.6%) having enough to eat (Table 2).

A total of 16 in-depth interviews were conducted with opinion leaders from 5 sub-locations. Ten of the participants were male and eight female. The respondents mean age was 39, the youngest was 24 years old and the oldest was 56 years old. Majority (6) of respondents were health care workers (nurses, doctors and counselors) while 5 were village elders and 4 social group leaders. All (16) respondents were Christians and 13 were married and 5 were single.



The FGDs participants included single sex adult (35 years and above) and youth (18 to 34 years) male and female respondents of homogenous characteristics. Each FGD contained a minimum of 8 and a maximum of 12 participants and standard procedures (25) were adhered to.

Results

Patients perception of available assistance

Majority (93.6%) of the respondents were residing with their family. A high proportion (68.2%) of patients indicated that people living with them encouraged them to seek health care services. Slightly more than two-fifths (41.4%) of the patients received support to seek health care services from a religious charity organization, Mission of Mercy while 37.9% received support from a humanitarian relief organization such as Kenya Red Cross Society (Table 3).

Encouragement from family and friends and its association with utilization of Health Care Services

The psychological help based on encouragement that patients received from those around them was significantly associated with utilization of health care services ($P < 0.001$ ($\chi^2 = 22.15$, $df = 4$)). Most (68.2%) of the patients who indicated that they were encouraged by those around them compared to 31.8% who did not receive any encouragement reported that they utilized health care services.

Encouragement from fellow patients and its association with utilization of health care services.

The encouragement that the respondents received from fellow patients was significantly associated with the rating of health care services provided ($P < 0.05$ ($\chi^2 = 11.014$, $df = 4$)). Seventy two percent of the respondents who received encouragement from fellow patients compared to 28.2% who did not rated the health care services highly. Similarly, encouragement from patients with similar chronic disease condition to look for medical care was significantly associated with frequency of visits to health facilities ($P < 0.001$ ($\chi^2 = 44.630$, $df = 10$)). Majority (81.8%) of the respondents who received encouragement from fellow patients compared to 18.2% who did not sought health care services more frequently. All the in-depth interview respondents stated that there was improvement in community involvement in elimination of LF in Malindi Sub-county due to awareness activities that had been created.

"Yes there is improvement since we don't have new cases about the disease and patients do attend hospitals fearlessly" 56 year old, village elder.

"Some patients feel shy, others are not able to walk to the venues and others did not get the treatment due to large number of patients." 56 year old, village elder.

Rejection and its Association with the Utilization of Health Care Services

The interest to seek health care services was significantly associated with experience of rejection by the family and friends because of the sickness; ($P < 0.001$ ($\chi^2 = 18.187$, $df = 1$)). Ninety three per cent of those respondents who did not experience rejection in their family compared to 7% who did had the interest to seek health care services



in future. In addition, the interest to seek health care services in future was significantly associated with rejection at events and gatherings because the sickness; ($P < 0.05$). Eighty eight percent of those respondents who did not experience rejection at gatherings compared to 11.7 % who did had the interest to seek health care services in future.

Spiritual intervention and its Association with the Utilization of Health Care Services

Utilization of health care services was significantly associated with the thinking that only spiritual intervention without medical care was helpful in reducing the disease burden ($P < 0.001$ ($\chi^2 = 20.006$, $df = 4$)). Sixty seven percent of respondents who did not think that only spiritual intervention helps compared to 32.6% who thought so utilized health care services.

Disease burden and its Association with the Utilization of Health Care Services

The frequency of visiting the health care facility per month was significantly associated with respondents' feeling of being a burden to the family because of the sickness; ($P < 0.05$ ($\chi^2 = 22.818$, $df = 10$)). Slightly more than half (57.1%) of those respondents who felt that they were a burden to the family compared to 42.9% of those who did not visited health facilities more frequently.

Fear of others noticing swollen limbs and its Association with the Utilization of Health Care Services

The frequency of visiting health facility per month was significantly associated with fear of others noticing the

swollen limbs; ($P < 0.05$ ($\chi^2 = 20.347$, $df = 10$)). Eighty eight percent of respondents who did not fear others noticing swollen limbs compared to (11.7%) who feared visited health facilities more frequently.

Support groups and its Association with the Utilization of Health Care Services

The feeling that support groups are important to improve health care services utilization was significantly associated with the frequency of visiting the health facility per month; ($P < 0.001$ ($\chi^2 = 33.724$, $df = 10$)). Most (85.7%) of respondents who felt support group are important compared to 14.3% who did not visited health facilities more frequently. However, the study results showed that experience of diminished marriage prospects was not significantly associated with the utilization of health care services ($P = 0.620$).

A large majority of the participants in the 4 FGDs stated that the reasons why patients did not seek health care services included: lack of money; family discrimination; fear and shyness while explaining the condition to physicians; myths that the disease is not for hospital and being attended to by untrained doctors.

"We believe that we cannot use medicine or cannot be injected." Respondent 4, youth male FGD

"We cannot walk to the health care facilities as they are very far and we feel shy and as a result, we remain at home." Respondent 5, adults' women FGD

A majority of the FGD participants further indicated that health care services utilization can be improved by having more health centers caring for LF patients,



provision of free operation in government hospitals, proper education on the importance of seeking healthcare services and frequent visit to treat patients.

“Kenya Medical Research Institute should continue to visit the patients and counsel them on the importance of taking medicine and going to hospital.” Respondent 4, Youth female FGD,

“We need to be supported by the government and to be taken to hospital for the free operation. We also need to be educated on the importance of medicine and visiting the hospitals.” Respondent 7, adults’ women FGD.

Discussion

The current study results show that psychological help based on the encouragement that patients received from those around them (families and communities) was significantly associated with utilization of health care services ($P < 0.001$). Patients who indicated that they were encouraged by those around them (family and community) utilized health care services. Patients lived within the family setting and family members provided care, assisted in daily domestic activities and socially encouraged respondents to seek health care services in hospital. The current finding corresponds to that of Amuyunzu, (1997) who observed that people who had patients in their households expressed sympathy and understanding, whereas those who had no relationship with victims joked and laughed about it. Family members are normally more united during time of sickness by providing tangible support such as care for individuals who are ill. When serious illness or disability strikes a

person, the family as a whole is affected by the disease process and by the entire health care experience. Emotional support from family members is a protective factor for psychological distress (26). Therefore, family relationships are a critical component of daily life. Family members are the people who know the patient best and those who, simply by their presence, can help to reassure patients in times of uncertainty, anxiety or vulnerability.

Results of the current study also showed that experience of rejection by community members as a result of diseases was significantly associated with utilization of health care services ($P < 0.001$). Community members accepted patients in social gathering and events. This removed the element of stigmatization as patients participated in community social activities. These current findings correspond with study conducted in Philippine which reported that filariasis sufferers were not excluded from social activities by the community (27).

Although the patients felt accepted in social gatherings, some still shied away depending on the severity of the diseases. They either perceived themselves to be smelling or feared to be laughed at as a result of oozing pus. A study conducted in Tanzania similarly reported that the disease was considered to be socially unacceptable and shameful in the community and people with hydrocoele were embarrassed and led a restricted life making them unable to visit hospitals (28). In addition, Kumari *et al.*, (2005) in Indian observed that social participation in community was affected by large hydrocoele. Therefore, social interpretation of particular disease may be important especially with a disfiguring



disease where people are reluctant to expose their body part. Objectively patients' acceptance by the community members positively influenced utilization of health care services.

The results of the current study further showed that formation of support groups was significantly associated with utilization of health care services ($P < 0.001$). Those patients who perceived the formation of support group as important visited health facilities more frequently. This could be because support groups can play an important role in coping with and overcoming problems. The study respondents preferred forming social support groups for encouragement by sharing of experiences, advice and support each other. Members of a support group typically share their personal experiences and offer one another emotional comfort and moral support.

This finding relates to that of Coreil *et al.*, (2002) where participation in patient support groups was shown to decrease the number of ADLA episodes and improve quality of life among lymphoedema patients in Haiti.

A study conducted in Ghana by Gyapong *et al.*, (1996) found out that the degree of stigma appeared to be associated with the severity and visibility of the disease and that filariasis sufferers were not excluded from social activities.

However, these findings differ with that of Remme *et al.*, (1995) and WHO, (1994) observation where advanced chronic manifestations such as elephantiasis of the extremities, genitalia, and breast can have important psychological implications and can inflict grave social wounds which hinder formation of support groups.

According to Dreyer *et al.*, (1999) there are serious psychosocial consequences, sexual/social dysfunction of men with hydrocoele, genital abnormalities and lymphedema of the breasts or genitals. This could be because when elephantiasis or hydrocoele becomes very big, people suffering from the disease may not feel comfortable when they move around. A study conducted in Indian found patients' usual activities and social participation was affected by hydrocoele, those with larger hydrocoele felt themselves being a burden to family (29).

The results reported in this paper also indicate that feeling of being a burden to the family was significantly associated with utilization of health care services ($P < 0.05$). Those patients who felt they were a burden to family visited health facilities more frequently. This burden could be emotional, physical, social, and financial aspects. The family members fully supported the patients although the patients felt they were burden to them. Patients with illnesses face grief and fear not only for their own future but also for their families' future that only the spiritual intervention helps utilized health care services. Spiritual believes influence patient roles, expectations on health and how much information about illness and treatment is desired. This finding agrees with the observation of Suma *et al.*, (2003) where with networks of public healthcare facilities, most of lymphoedema patients utilized medical care from modern medical practitioners, although a minority used home remedies first. In contrast, in Ghana modern medical care often is avoided due to lack of interest from health care



workers and a belief by patients that lymphoedema treatment requires spiritual interventions (24).

Conclusions

The finding revealed that respondents had psychological support from community, family and fellow patients which enhanced health care utilization. According to the finding most of patients did not experience stigmatization because of diseases in family although smaller number of patients feared visiting the hospital when they are sick. Formation of support group was found to be an important contributor of increased health care utilization in hospital.

Author Contributions

Social mobilization: DM and DWN. Read and approved the manuscript: DWN, DAM and ZWN. Guarantor of the paper: DM. Conceived and designed the methodology DM, DWN DAM and ZWN. Performed the experiments; DM, DWN, DAM and ZWN. Analyzed data: DM, DWN and DAM. Contributed materials/analysis; DM, DWN, DAM and ZWN. Wrote the paper: DM

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