

PERSPECTIVES OF ELEPHANTIASIS IN AN ENDEMIC AREA OF BRAZIL

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Abstract

Background: The most advanced form of lymphoedema, known as elephantiasis, is one of the most distressing clinical presentations of lymphatic filariasis. **Aims:** The objective of this study was to explore women's experiences of elephantiasis. **Methods:** This study was conducted at the Center for Teaching, Research and Tertiary Referral for Bancroftian Filariasis (NEPAF) in Recife, Brazil. Ten open-ended questions prompted each subject to respond freely about their disease. **Results:** The content of the responses that was common to all 28 participants were grouped into nine themes, the most prominent being: patients referring to their disease as filariasis; the tremendous physical and emotional suffering that accompanied acute episodes; discouragement and hopelessness on hearing from physicians that 'filarial swollen leg' was an 'unavoidable disease'; poor access to medical assistance and drug treatments, particularly during acute episodes; the substantial negative effect of elephantiasis on daily life; and societal discrimination. **Conclusions:** There was a strong consensus from women with elephantiasis regarding their needs, perceptions of their condition, its treatment and its impact on their lives. **Conflict of interest:** The study was supported by the Amaury Coutinho Non-Governmental Organization, Recife, Brazil.

Key words

Elephantiasis
Bancroftian filariasis
Lymphatic filariasis
Patients' experiences
Access to medical services

One of the most distressing clinical presentations of lymphatic dysfunction in lymphatic filariasis (LF) in endemic areas is advanced lymphoedema, or elephantiasis. The estimated prevalence of patients with elephantiasis living in the 83 LF-endemic countries (World Health Organization [WHO], 2005b) is unknown. It has been reported that there are about 16 million patients suffering from all stages of filarial lymphoedema (Jamal and Pani, 2000)

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among the estimated 100 million and 20 million people infected with *Wuchereria bancrofti* and *Brugia* species, respectively (Michael et al, 1996).

In 2000, Dreyer et al demonstrated that overt clinical disease in bancroftian filariasis is a multifactorial process and, in the case of lymphoedema, bacterial superinfection is a key element for disease progression. This theory is supported by numerous studies (Shenoy et al, 1995, 1999; Olszewski, 1996; Olszewski et al, 1997; Dreyer et al, 1999). It is now accepted that avoiding recurrence of such bacterial infections can prevent the disease from progressing to elephantiasis. There is a possibility for thousands of individuals with subclinical lymphatic damage or incipient disease to prevent the recurrent acute episode through low-cost morbidity control programmes (Addiss and Mackenzie, 2004).

Many aspects of this condition remain poorly understood — as does its actual prevalence in endemic

areas. As part of a broader study to capture the life history of patients living in bancroftian filariasis-endemic areas (Mattos and Dreyer 2006b), the authors have explored the feelings and experiences reported by women with elephantiasis of the lower limb.

Methods

Setting

The study took place at a public tertiary referral service for bancroftian filariasis (NEPAF), located at the Hospital das Clinicas at the Federal University of Pernambuco in Recife, Brazil.

Data collection

Following approval by the ethics committee of Hospital das Clinicas, women with elephantiasis of the lower limbs who had agreed to participate in the study were recruited and signed informed consent forms were obtained. Patients were either referred to NEPAF or directly sought assistance themselves.

Inclusion criteria

Participants were included if they:

- ▶ Were females with lower limb elephantiasis (either uni- or bilateral)
- ▶ Were 19 years of age or older
- ▶ Were willing to participate in the study and signed the informed consent forms
- ▶ Were new patients at NEPAF and had no experience of the Hope Clubs support groups for patients with chronic disease living in LF-endemic areas (Dreyer and Addiss, 2000; Dreyer et al, 2006b).

Exclusion criteria

Patients were not eligible for the study if they:

- ▶ Had an acute bacterial episode or venous ulcers at the time of first consultation
- ▶ Had a history of venous ulcers
- ▶ Had lymphoedema of the upper limbs with or without a history of mastectomy
- ▶ Had undergone surgery for lymphoedema
- ▶ Had any other medical condition that contraindicates the study (such as mental incapacity, chronic depression, renal failure, cancer, alcohol addiction, severe liver disease, leprosy, type 1 diabetes mellitus or type 2 diabetes which had progressed to require insulin)
- ▶ Had refused to participate in the study
- ▶ Had prior knowledge of the content of the study through interaction with patients who had already been included in it.

Diagnosis

The seven stages of lymphoedema described by Dreyer et al (2002a) were used as diagnostic criteria. Those patients with lymphoedema at stage 5 and above were diagnosed with elephantiasis.

Study design

To avoid potential bias through exposure to other study subjects, each patient was scheduled to arrive at NEPAF so as to not encounter other patients in the waiting room. Before a routine medical consultation and social interview and after informed consent, the participants were

encouraged to respond freely to the open-ended questions presented by the interviewer. They were informed that they could end the process at any time. The questions they were asked were:

- ▶ What disease do you have?
- ▶ How did your disease begin?
- ▶ How did it progress?
- ▶ What makes your disease worse?
- ▶ What information did you get from the doctors about your disease?
- ▶ What kind of treatment have you sought/received?
- ▶ What do you think about the care provided by the public health system to patients with your disease?
- ▶ What problems and/or barriers do you face because of the disease?
- ▶ What makes your life easier?
- ▶ Would you be willing to have another consultation to talk about your life history?

Those with an offensive odour were evaluated for initial antibiotic therapy before the first hygiene session. During this session the leg's status was assessed for cleanliness. Patients were taught how to carry out their own hygiene regimen...

All interviews were conducted by one investigator (GD) and were limited to one hour. The interviewer took care to avoid introducing phrases or words which might bias the participants' responses, such as acute episode, bad odour, prejudice, benefits from the government, filariasis, antifilarial treatment, free medication and benzathine penicillin.

Prompts on the part of the interviewer were limited to eliciting responses and clarifying points (both for the participants and for the interviewer); for example, 'Can you repeat, please?' 'Can you say that in a different way?' 'Is there anything else you would like to add?'. The interviewer proceeded to the next

question if the participant kept repeating, or when it was apparent that she had said all she wanted to. Following the interview, patients were invited to have refreshments. After that, those without offensive odour of the leg underwent medical and social consultations.

Those with an offensive odour were evaluated for initial antibiotic therapy before the first hygiene session. During this session the leg's status was assessed for cleanliness. Patients were taught how to carry out their own hygiene regimen and were corrected, where needed, on their skin care (from washing to applying the medicated cream and/or KMnO_4 [potassium permanganate]). The patients were also started on the 'self-skin' care programme. They then had time to practice at home and to identify any difficulties (including their own situation, such as lack of clean water) before the medical and social consultation a few days later at NEPAF, when any problems they had experienced could be addressed. The physical examination of the interdigital lesions is also easier if the patient's leg has been cleansed and there is less odour.

Audiotapes of the interviews were transcribed and were then printed out and re-checked against the audio and corrected if necessary. This was done by two different people, both of whom had not been involved in the interviews. The audiotapes were anonymised and coded by a number from one to 28. The transcripts were checked for words which might have introduced bias. The printed documents were independently analysed by the two authors. Those topics that were recognised by both analysts as being raised by all participants were categorised into themes. The authors also noted other topics reported by a number of patients that were considered relevant and/or interesting.

Results

Twenty-eight women with elephantiasis participated in the

study. Demographic and medical information related to the participants was obtained from their medical charts (see *Table 1* and *Figures 1 and 2*). When assessing the quality of the interview audiotapes, no bias was found in the way the questions were posed. Among 21 patients with unilateral elephantiasis, the contralateral limb was considered normal in eight of them (38%). The remaining 13 had lymphoedema (or oedema) grade 2 and 3 in the contralateral limb (Dreyer et al, 2002a). Seven patients (25%) were promptly recognised as not having lymphoedema related to filariasis based on their epidemiological data. Six of them (21.4%) were born and lived in non-endemic areas and moved to an endemic area after the onset and progression of swelling, but before the development of elephantiasis. Of these six, one presented with bilateral elephantiasis. One patient with unilateral elephantiasis denied having spent even one night in an endemic area. These patients with non-filarial lymphoedema still participated in the 60-minute consultation with the physician. All patients at the end of the first interview were willing to have a second consultation to continue discussing their life history. The results of sequential interviews were not part of the current study. The chronology of the themes elicited did not necessarily follow the order of the questions asked, or the patient's responses, with the exception of the first question – what disease do you have? Nine main themes were reported by all participants:

- ▶ Patients referred to their disease as filariasis
- ▶ They stated having difficulty understanding why they experienced no improvement after several courses of antifilarial treatment (a full course of diethylcarbamazine) and/or vaccines (*Corynebacterium parvum* [Imunoparvum], an intramuscular preparation used for long periods, around 12 months), for the prophylaxis of the acute episodes in the earlier phase of the disease. Twenty-three patients — six

from non-endemic and 17 from endemic areas — received several full courses of antifilarial treatment with diethylcarbamazine after presenting with chronic swelling. They had been investigated for filarial infection several times in the past, reporting recurring negative results. They used diverse hot preparations made from local herbs to treat the acute episodes. They also related to having used at least two or more other popular remedies, such as rubbing frog's urine, clay, ashes and/or mud into the limb or burying the affected leg in their backyard. This involved patients remaining outside, whatever the weather conditions, with their leg buried in the ground. Relatives would bring them food and water and they would urinate in a special container. The temperature of the earth helped to decrease the patient's pain.

- ▶ All patients emphasised that they were 'taken by surprise' by the recurrent bacterial acute episodes and the tremendous physical and emotional suffering they experienced during the process. Their lives were considered much easier when they were not having an acute episode. The popular name used by the patients for the acute bacterial episodes were *maldita* and *crise* (equivalent to acute dermatolymphangioadenitis or ADLA for describing the acute bacterial episodes of the skin seen in bancroftian filariasis-endemic areas) (Dreyer et al, 1999). They all referred to the number of acute episodes in their life as 'many' and/or 'countless' and/or 'so many I cannot remember'
- ▶ The message from doctors was that 'filarial swollen leg' is an 'unavoidable disease' and that medicine and doctors can do little for the feelings of despair and lack of hope that women with elephantiasis have
- ▶ Patients felt that they had the right to financial support from the government due to their disability, but this was systematically denied. All the patients had applied at least twice for such aid



Figure 1. A 47-year-old woman with unilateral lymphoedema, stage 5 (with normal contralateral limb), of eight years duration.



Figure 2. A 79-year-old patient who has had bilateral elephantiasis (stage 6) for approximately 30 years (right and left leg disease started at the ages of 46 and 56 years, respectively).

- ▶ The patients considered that the access to medical assistance and free drug treatments in public hospitals was poor, especially during the acute episodes when intramuscular benzathine penicillin would be prescribed but only when a medical consultation had been possible
- ▶ Patients were told by the doctors, nurses or other patients that they should be permanently under the

care of physiotherapists. However, accessing such care in the public system was extremely difficult, if not impossible

- ▶ Patients commented that the effects of elephantiasis on their daily life profoundly interfered with work and simple tasks, such as day-to-day home activities and self-care
- ▶ Patients felt that they were victims of discrimination in society and from doctors, in particular, because their legs or feet were not touched during medical consultations.

Patients primarily reported that leg swelling began in one of two ways: painless swelling with no fever and after repeated episodes of *maldita/crise*. Among 25 patients who had separated from their husbands, only one cited reasons other than the swollen leg as responsible for

the breakdown of their marriage. Two patients claimed that they had a husband who accepted them as they were, despite their swollen leg. One patient was alone before the overt disease began and remained single. Three patients reported that their husbands had asked them to sleep in another room, but they did not spontaneously explain why.

Acute episodes were thought to be caused by emotional distress and 'dangerous food' (chicken, pork and shrimps) in 26 and 23 patients, respectively. Six of them claimed that trauma of the affected leg also contributed to the cause of the acute episode. One claimed that a mosquito bite had caused an acute episode. Difficulties in buying clothes were emphasised by 16 patients, while problems with shoes were raised by

22 of them. Sexual difficulties were brought up by 11 patients, while six reported that because of their swollen leg they had accepted that their husbands had relationships with other 'normal women' outside of the marriage. Three women said, 'my husband deserves someone normal since this is not his fault'.

Several women described the employment difficulties in two ways:

- ▶ They could only perform a limited amount of work and, therefore, could only earn a very low income
- ▶ No one would accept them as an employee because of their condition.

A variety of other issues were raised by a few individual patients, such as their children's shame, loss of employment, feelings of guilt for not performing well as a housewife, sadness, shame, presence of a mother or an aunt in the family with the same disease and fear of their daughter(s) inheriting the disease, which was expressed by the patients as 'swollen leg woman'. Bad odour was only briefly mentioned by two patients. The issue of 'family support' was not mentioned directly during the consultation by any patient. Only the two women with stable marriages indirectly touched on the subject, mentioning their husbands' support.

Discussion

A clear similarity of feelings and problems was found among these 28 women with lower-limb elephantiasis. It was possible to select nine very similar or identical themes reported by women with elephantiasis, bringing to light the major difficulties they faced from their own point of view.

The results might help to improve the public healthcare system in Brazil and, hopefully, in other endemic areas by using a similar or improved approach for data collection. This study confirms the anecdotal idea in Brazil that the word elephantiasis is a synonym for filariasis, whether the condition is caused by a filarial parasite or not.

Table 1

Characteristics of patients with elephantiasis (stages 5 and 6) within this study group

Total number of women	28 (100%)
Bilateral elephantiasis	7/28 (25%)
Unilateral elephantiasis	21/28 (75%)
• Right limb	10/21 (48%)
• Left limb	11/21 (52%)
Mean age at first consultation (years)	56 (range=29–78)
Mean age of swelling onset (years)	35 (range=12–66)
Mean (range) duration of the disease (years)	21 (range=5–65)
Swelling started as:	
Non-inflammatory (%) (painless swelling without redness and fever)	7/28 (25%)
• Non-endemic area	3/7 (1 bilateral)
• Endemic area	4/21 (2 bilateral)
Inflammatory (<i>maldita</i>) (dermatolymphangiadenitis, Dreyer et al, 1999)	
• Non-endemic area	4/7
• Endemic area	17/21 (4 bilateral)
Lymphoedema staging	
• Stage 5	22/28 (78.6%)
• Stage 6	6/28 (21.4%)

WHO also acknowledges this in the statement: 'Lymphatic filariasis, known as elephantiasis, puts at risk more than a billion people in more than 80 countries' (WHO, 2000). Patients who developed lymphoedema outside filarial-endemic areas also referred to their condition as lymphatic filariasis. Similarly, several other patients from outside endemic areas were routinely referred to NEPAF for treatment of 'filarial lymphoedema or filarial elephantiasis' (Dreyer, personal communication).

The term 'filarial elephantiasis' also covers other beliefs, such as:

- ▶ In patients living in LF-endemic areas, the differential diagnosis should not necessarily prevent the possibility of exploring other potential causes and/or treatment for lymphatic dysfunction (Wijeyaratne and Sherifdeen, 2002)
- ▶ Progression is understood to be unavoidable
- ▶ Social exclusion is anticipated, and recurrence of acute episodes is expected to be a life-long problem for the patients.

According to the participants, the term also conjures up a loss of hope for an optimistic prognosis of living with filariasis and they have either experienced or expect to experience social isolation. The greatest concern of the patients was worry about the 'inevitable' recurrence of acute episodes, since these periods in their lives were a great burden for them. They perceived that the condition would inevitably progress in time to a more severe condition. Based on the medical history of patients with lymphoedema/elephantiasis referred for treatment at NEPAF and Centro de Pesquisas Aggeu Magalhães, Fiocruz, Brazil (Dreyer, personal communication), it is clear that these patients tend to receive little or no attention from the public healthcare system in the early stages of the disease. There are several reasons for this, including:

- ▶ Lack of patient information on how to recognise and prevent

interdigital entry lesions (Dreyer et al, 2006a)

- ▶ Difficulty in accessing regular medical appointments
- ▶ Patients are rarely prescribed appropriate antibiotics to treat the acute bacterial episodes
- ▶ The absence of an infrastructure to provide physiotherapy.

These circumstances increase the patient's risk of the lymphoedema worsening and its progression to the grotesque form of the disease. The use of traditional, hot herbal preparations, as well as other popular practices during the acute episodes can also increase their risk, thus contributing to the rapid progression to elephantiasis (Dunyo et al, 1997).

The feeling that the government had abandoned them was expressed very strongly. The overall situation faced by patients with elephantiasis in Greater Recife must be addressed by the Brazilian government. The socio-economic and educational status of the patients, however, does not suggest that they would be effective advocates for their care.

These factors may contribute to the higher prevalence of elephantiasis in endemic areas compared with non-endemic, more developed countries where prompt, appropriate care for lymphatic dysfunction (lymphatic malformation, and other forms of secondary lymphoedema) is provided. The patients in the current study perceived that the public healthcare system was not adequately prepared to provide assistance to patients with lymphatic dysfunction. It has been observed at NEPAF that, in addition to extreme difficulty associated with accessing physiotherapists, the barrier to appropriate management is related

to the cost of compression garments (or similar materials), and other issues, such as transportation. Patients living where LF transmission exists are probably not able to afford these additional costs. As pointed out by Durrheim et al (2004), the association between LF and poverty is evident, as 73% of low income countries and 94% of the countries listed as having lowest human development index (HDI) were endemic for LF. Supported by the Non-Governmental Organization Amaury Coutinho (2007) as part of the transdisciplinary approach at NEPAF (Mattos and Dreyer, 2006a), the provision of physiotherapy has been noted to be the most expensive in the management of patients with lymphoedema (Dreyer, personal communication). Similar findings have been described in Haiti (Addiss, personal communication).

The overall situation faced by patients with elephantiasis in Greater Recife must be addressed by the Brazilian government. The feeling that the government had abandoned them was strongly expressed by the patients but their socio-economic and educational status does not suggest that they would be effective advocates for their care.

Odour was almost a 'forbidden' subject, only verbalised briefly by two patients, although it was evident to the interviewer during data collection. During the subsequent medical consultation, the patients themselves confirmed that bad odour was a routine condition for them (data retrieved from their medical charts). This temporary lack of perception of the odour that accompanies the condition by the participants was not a surprising finding.

The authors' experience from several decades of seeing patients with elephantiasis, especially those with mossy foot (stage 6), confirms that it is quite common for patients not to mention the issue of odour as a complaint until after it has diminished or been eliminated by improvements in hygiene. Few patients had the

courage to report embarrassing situations and, when they did, it was mentioned retrospectively after the odour had improved due to routine limb hygiene. One patient reported a visitor asking whether there was a dead animal in the house in response to the leg odour. Some patients with lymphoedema find the odour very offensive, making it difficult for healthcare professionals to deal with the problem in a sensitive and reassuring way. They also have to overcome their own feelings of revulsion and some healthcare professionals are simply unable to cope with this problem.

The 'absence' of family support in the current study was somehow also expected by the authors. In general, there is an inverse relationship between family support and the degree of the disease. In the early stages it is much easier for the family to be involved and to better support the affected person. As time goes by and the disease worsens, family difficulties seem to deteriorate as well. These difficulties include:

- ▶▶ Shame from the relatives (and from the patient)
- ▶▶ Increasing financial demands for the patient's new needs, which comes at a time of less job opportunities and subsequent lower family income
- ▶▶ Being less able to contribute to domestic tasks, thus overloading other family members and becoming dependent on a helper for simple tasks such as body hygiene.

These situations lead to patient isolation, building a wider cleft among patients and family members. In a recent publication, similar feelings were reported among 188 patients with lymphoedema in Togo: 17% felt they were being avoided by their family and 36% by their community (Richard et al, in press).

From the patient's point of view, the long-term effect of elephantiasis on their lives can be devastating. Tasks that are usually enjoyable for any

woman can become unpleasant and difficult, for example, finding clothing that fits in an 'acceptable way' and shoes for the deformed foot.

WHO has an ambitious goal of eliminating lymphatic filariasis as a public health problem by 2020 (WHO, 1997), and has succeeded in increasing the scale of mass drug distribution to interrupt transmission (WHO, 2005a; Gyapong and Twum-Danso, 2006), yet it is clear that the Global Alliance to Eliminate Lymphatic Filariasis must pursue the commitment of the endemic countries to guarantee care for those who already have overt disease, particularly patients disabled by elephantiasis. It is important that people with elephantiasis, although fewer in number, are prioritised in the *Global Programme to Eliminate Lymphatic Filariasis* and that they do not become hidden or forgotten.

Recently, Mattos and Dreyer (2006b) reported a humanistic understanding represented by two patients, Maria and José, as a prototype of patients with lower-limb and scrotal elephantiasis, respectively. The importance of this disease was highlighted, with particular focus on its terrible psychosocial repercussions, physical characteristics, and emotional consequences. For people with elephantiasis, recovery of 'citizenship' and human dignity can be a powerful strategy for overcoming prejudice and stimulating socially responsible action. Hope Clubs are a powerful instrument for generating action that encourages social inclusion for people with elephantiasis (Dreyer and Addiss, 2000; Dreyer et al, 2002b; 2006b). It is also imperative to prepare healthcare professionals to better assist the patients in the earlier phases of lymphatic dysfunction and, therefore, avoid disease progression to grotesque stages. Being born and living in a filariasis-endemic area does not sentence individuals to becoming elephantiasis carriers.

The authors acknowledge that their findings may have differed in a

'control group' formed of patients with elephantiasis but belonging to a higher socio-economics status. However, during the authors' years of experience of working in a filariasis-endemic area, no patients in the higher socio-economic categories have been seen. On the other hand, patients with non-filarial lymphoedema living in the wealthier socio-economic districts of Greater Recife do exist but they receive better private care in the earlier phase of the disease and, therefore, have different outcomes from the patients in this study with a similar condition of non-filarial elephantiasis.

Not all the important problems common to these patients could be identified using the approach described in this study. As recently reported in the Dominican Republic by Person et al (2006), due to the complexity of the subject and the diversity found in the distinct endemic areas, different study designs are necessary to address other questions in similar and different places.

Conclusions

There was a strong consensus from the patients regarding their needs, perceptions of their condition, its treatment, and the impact elephantiasis had on their lives. It was clearly recognised by the patients, as well as by the authors, that resources for proper elephantiasis management are inadequate for the identified needs of women living in Greater Recife, Brazil. The availability of a specialised sustainable programme to support this group of people and their special needs is imperative. Although our findings are specific to the city of Recife, the authors speculate that this situation is not unique to this endemic area. Programme managers must recognise the dramatic burden of elephantiasis and work to provide the services for patients who have the disease to run alongside a scheme of mass drug distribution to interrupt transmission. **JL**

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Key Points

- ▶ When questioned about their condition, women in Brazil with elephantiasis of the limb described the tremendous physical, emotional and social suffering that accompanied acute episodes.
- ▶ The diagnosis of filarial elephantiasis may be too readily made for patients living in LF-endemic areas, thus significantly hindering the possibility of exploring other potential causes and/or treatment for lymphatic dysfunction.
- ▶ All the patients in the study felt that access to medical assistance and free drug treatments in public hospitals was very poor, especially during the acute episodes.
- ▶ Programme managers must recognise the dramatic burden of elephantiasis and work to provide better services and better access to medical care to run alongside planned mass drug distribution to interrupt transmission.

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