Accepted Manuscript

Revised date:

Accepted date:

Title: Perceptions, knowledge, attitudes and practices for the prevention and control of lymphatic filariasis in Conakry, Republic of Guinea

Authors: Bernard L. Kouassi, Aboulaye Barry, Kathrin Heitz-Tokpa, Stefanie J. Krauth, Andre Goépogui, Mamadou S. Baldé, Oumar Barry, Marie L. Niamey, Moses J. Bockarie, Benjamin G. Koudou, Jürg Utzinger

16-10-2017

1-12-2017



PII: DOI: Reference:	S0001-706X(17)30382-0 https://doi.org/10.1016/j.actatropica.2017.12.002 ACTROP 4516
To appear in:	Acta Tropica
Received date:	31-3-2017

Please cite this article as: Kouassi, Bernard L., Barry, Aboulaye, Heitz-Tokpa, Kathrin, Krauth, Stefanie J., Goépogui, Andre, Baldé, Mamadou S., Barry, Oumar, Niamey, Marie L., Bockarie, Moses J., Koudou, Benjamin G., Utzinger, Jürg, Perceptions, knowledge, attitudes and practices for the prevention and control of lymphatic filariasis in Conakry, Republic of Guinea.Acta Tropica https://doi.org/10.1016/j.actatropica.2017.12.002

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Perceptions, knowledge, attitudes and practices for the prevention and control of lymphatic filariasis in Conakry, Republic of Guinea

Bernard L. Kouassi^{a,b*}, Aboulaye Barry^c, Kathrin Heitz-Tokpa^{a,d}, Stefanie J. Krauth^{d,e,f}, Andre Goépogui^c, Mamadou S. Baldé^c, Oumar Barry^c, Marie L. Niamey^c, Moses J. Bockarie^g, Benjamin G. Koudou^{a,b,g}, Jürg Utzinger^{d,e}

^a Centre Suisse de Recherches Scientifiques en Côte d'Ivoire, Abidjan, Côte d'Ivoire

^b Unité de Formation et de Recherche Science de la Nature, Université Nangui Abrogoua, Abidjan, Côte d'Ivoire

^c Programme National de Lutte contre l'Onchocercose, le Trachome et les autres Maladies Tropicales Négligées, Ministère de la Santé Publique, Conakry, Republic of Guinea

^d University of Basel, Basel, Switzerland

^e Swiss Tropical and Public Health Institute, Basel, Switzerland

^f École Polytechnique Fédérale de Lausanne, Lausanne, Switzerland

^g Centre for Neglected Tropical Diseases, Liverpool School of Tropical Medicine, Liverpool,

UK

*Corresponding author at Centre Suisse de Recherches Scientifiques en Côte d'Ivoire, 01 BP 1303, Abidjan 01, Côte d'Ivoire.

E-mail address: loukou_kb@yahoo.fr (B. L. Kouassi)

A B S T R A C T

Little is known about the perceptions, attitudes and practices of lymphatic filariasis in Conakry, Republic of Guinea. Yet, such knowledge is important for an optimal design and implementation of setting-specific prevention and control measures. We conducted a crosssectional study using a mixed methods approach. Qualitative data related to people's general experience with lymphatic filariasis, their perception of the causes of the disease, the onset of elephantiasis, care-seeking behaviour and the socioeconomic impact of lymphatic filariasis were collected by in-depth interviews with 85 respondents. Quantitative data related to strategies for prevention and the knowledge of the causes of the disease were collected by interviewing 429 people. A total of 514 individuals (313 females and 201 males), aged 10-84 years, participated. Most participants were well aware of lymphatic filariasis and they recognized the disease mainly by its disfiguring manifestation, collectively termed "elephantiasis" or "leg-swelling disease". Morbidity patterns due to filarial infection showed an increase with age (from 30 to 50 years) independent of sex. Most patients with lymphatic filariasis abandoned their jobs (73.9%) or sought other work (21.7%). The main perceived causes of acquiring lymphatic filariasis were of supernatural origin (as stated by 8.7% of patients and 5.7% of healthy subjects), while mosquito bites were mentioned by fewer participants (4.3% of patients and 4.2% of healthy subjects). A number of other causes were reported that relate to both medical and non-medical conceptions. The study also identified socioeconomic impairments and stigmatization due to elephantiasis. Taken together, community perception of lymphatic filariasis in Conakry is influenced by sociocultural conceptions. Appropriate health education campaigns aimed at enhancing community understanding of the transmission of lymphatic filariasis are required to increase the success of mass drug administration implemented for the elimination of this disease. There is a need

for a morbidity management programme to alleviate lymphatic filariasis-related physical and emotional burden in Conakry.

Keywords

Attitude

Control

Lymphatic filariasis

Mixed methods study

Perception

Practice

Republic of Guinea

1. Introduction

Lymphatic filariasis is a major cause of chronic morbidity of the lymphatic system that – left untreated – may lead to elephantiasis and hydrocele. This filarial disease remains an important public health problem that inflicts a considerable social and economic burden on many tropical and sub-tropical countries (WHO, 2000; Babu et al., 2006) where it affects primarily poor rural communities (Upadhyayula et al., 2012). An estimated 120 million people are infected across 73 countries, and some 1.3 billion are at risk of acquiring the infection (Rebollo and Bockarie, 2014). The economic impact of lymphatic filariasis is composed of the costs borne by infected individuals (loss of employment) and their relatives (caring for infected people) and the costs for individual patient management and communitybased control approaches by the government (Haddix and Kestler, 2000).

Recognizing the importance of the disease, the World Health Organization (WHO) launched the Global Programme to Eliminate Lymphatic Filariasis (GPELF) in 2000, with the goal to eliminate lymphatic filariasis as a public health problem by 2020 (WHO, 2010). The main strategy to interrupt transmission and to eliminate lymphatic filariasis as a public health problem is through repeated rounds of mass drug administration (MDA) (WHO, 2010). Depending on human and financial resources, complementary strategies (e.g. vector control) are being implemented (Ottesen et al., 1997). Morbidity management is being facilitated by improved access to health care for those suffering from lymphatic filariasis (Ichimori et al., 2014).

Since the launch of the GPELF, laboratory research and quantitative field evaluations of the impact of lymphatic filariasis, including local prevalence studies of parasite-infected humans and vectors, have been promoted (Wynd et al., 2007). In the meantime, MDA programmes have been implemented successfully in 60 out of the 73 lymphatic filariasisendemic countries (WHO, 2016). Detailed studies on the burden of lymphatic filariasis-

related morbidity are scarce and appropriate programmes for clinical management of lymphatic filariasis are relatively few (WHO, 2013). WHO recently recommended that national programme managers assess the number of cases of elephantiasis, lymphedema and hydrocele in implementation units as a first step to improve morbidity management strategies (WHO, 2013). This is of importance in all lymphatic filariasis-endemic areas, as the chronic sequelae of the disease will continue to cause morbidity, even after transmission has been interrupted. However, in order to achieve community participation that is necessary for increasing success of elimination strategies, a deeper understanding of the relevant socialecological systems is required (Wynd et al., 2007). Any strategy intended to impact on a given community will have to take into account the range of people's knowledge and perceptions and how these are rooted in local settings (Rath et al., 2006). It is widely acknowledged that disease control programmes in low- and middle-income countries often fail to meet their objectives because the strategies pursued are inappropriate for the community involved or they challenge local perceptions of aetiology, prevention and control (Wynd et al., 2007). With regard to lymphatic filariasis, poor knowledge and local belief systems that contradict the scientific reality contribute to high-risk and inappropriate illness prevention and treatment (Rauyajin et al., 1995). The dearth of sociocultural information about local beliefs, perceptions and behaviours in relation to the disease has been highlighted previously (Coreil et al., 1998).

The lymphatic filariasis elimination programme in the Republic of Guinea was initiated in 2000 and a plan of action was developed, which includes mapping of lymphatic filariasis, developing strategies for MDA (Diallo et al., 2005) and management of morbidity related to lymphatic filariasis. In the Republic of Guinea, while epidemiological data are available for rural areas, there have been virtually no studies of the state of lymphatic filariasis in the capital city of Conakry. In view of the absence of epidemiological data, WHO recommended

a new mapping of lymphatic filariasis in Conakry in order to decide whether or not there is a need to conduct MDA. Addressing community knowledge and perception of lymphatic filariasis, including social and economic implications, patients-itinerary, prevention and treatment-seeking behaviour and burden of disease may help to conduct setting-specific sensitization campaigns and to provide locally adapted strategies to monitor national lymphatic filariasis control and elimination activities.

The current study investigated lymphatic filariasis-related perceptions, knowledge, attitudes and practice with regard to causation, transmission and chronic manifestation. It is hoped that the experiences and lessons learned will contribute to enhance the national control programme against lymphatic filariasis.

2. Materials and methods

2.1. Ethical considerations

This survey received ethical clearance from the National Ethics Committee for Research in Health (CNERS) from the State's Ministry of Health in Conakry, Republic of Guinea (reference no. 20/CNERS/12), based on the study protocol approved by the Institutional Review Board of the Liverpool School of Tropical Medicine (Liverpool, UK) and was approved by the Centre for Neglected Tropical Diseases Control of Liverpool. Written informed consent was obtained from all participants aged 18 years and above. For minors (aged <18 years), written informed consent was obtained from their parents or legal guardians, while minors provided oral consent. Oral rather than written informed consent was obtained in some households due to high rates of illiteracy. CNERS explicitly approved our consent procedures. The procedures and likely benefits and inconveniences of the study were explained to all participants. The purpose of the interview and the key topics addressed in the questionnaire were explained. Interviews were conducted at people's household in French or local languages for participants not fluent in French.

2.2. Study area and population

Data for the present study were collected from Conakry, the capital of the Republic of Guinea. The country is divided into four ecological zones: (i) Lower Guinea along the west coast, mainly inhabited by the Susu ethnic group; (ii) Middle Guinea with the highland region Fouta Djalon that runs north to south through the centre of the country, where the majority of the population belongs to the Poular ethnic group; (iii) Upper Guinea to the northeast dominated by the Manding ethnic group; and (iv) Forest Guinea in the southeast, with a mix of different ethno-linguistic groups with a forest-based economy.

Conakry is a peninsula of 308 km², with a length of 34 km and a width of 1-6 km. At the time of our study in 2012/2013, the number of people living in Conakry was estimated at 2.5 million of whom 52% were female according to the 1999 census and extrapolations. Hence, Conakry accounts for about a quarter of the total population and 60% of the urban population of the Republic of Guinea (Calvertoń, 2000).

2.3. Design and study procedures

2.3.1. Sampling of study participants

People with lymphatic filariasis were progressively registered from November 2012 to February 2013. In preparation of concomitant entomological and serological surveys, an information and awareness campaign was carried out by the research team in health districts, communes and quartiers, particularly in places where mosquito collection would be carried out. On this occasion, patients were registered and their households identified. Subsequently, instructions were left to local authorities (e.g. local chiefs and religious leaders) to continue sensitization in places of worship that were readily accessible by the majority of the population. Information was regularly collected from quarter and sector leaders and community health workers (CHWs). Of note, CHWs were tasked to register all presumptive

cases affected by elephantiasis, lymphedema and hydrocele. Moreover, some of these patients were approached by study team members who inquired about their address details so that they could be examined at their residency. The clinical profile of patients, involving the degree of lymphedema, was registered by the study clinician. An edema was identified when, after gently pressing by a finger, the skin formed an indent, which remained for several seconds after the pressure was released and which was spontaneously reversible on elevation. The different stages of elephantiasis were recorded (Dreyer et al., 2001).

The study pursued a mixed methods approach, combining qualitative and quantitative methods for data collection. Patients were interviewed in household surveys. In each patient household, 1-3 people (spouse or husband, son or daughter, brother or sister or other close relatives and/or friends or neighbours from a nearby household) were interviewed about their relationship with the patient and their perception about elephantiasis. Furthermore, health personnel, traditional healers and staff from non-governmental organisations (NGOs) and CHWs were interviewed about their experience with elephantiasis. Beyond these target subjects, consenting persons aged ≥15 years living in households close to those of the patient were administered a questionnaire. The questionnaire was pre-tested in the area of Ratoma and interviewers were trained. An additional investigation to determine how the population prevents mosquito bites was conducted in sentinel households, where mosquito collections were implemented.

2.3.2. Qualitative study

For the qualitative aspect of the study, elephantiasis patients were subjected to in-depth interviews about their experiences with the disease. The interviews were conducted by pairs of interviewers; one conducting the interview and the other recording responses manually. Lymphatic filariasis patients' migration history was investigated to gather information on

their place of origin and their places of residency before the first symptoms of lymphatic filariasis occurred. The status of migration was determined through questions about the place of birth, the place where they spent their childhood and the time and place where they first recognized the signs and symptoms of the disease. The next step was to encourage patients to tell their story, beginning with the first symptoms and ending with their current state. Care seeking behaviour, including the first medical support during the early stage of the disease, changes in their socio-professional life and personal experiences from the time since the disease occurred were the main issues inquired during the interview.

Ten traditional practitioners selected in different districts of Conakry were interviewed about their knowledge of lymphatic filariasis and elephantiasis, their relationship with patients and their experience as healers. Health authorities, including two private clinics, three government hospitals and the infectious diseases department from the university hospital in Conakry were interviewed about their knowledge of lymphatic filariasis and elephantiasis in relation to patients received in their medical centres.

2.3.3. Quantitative study

For the quantitative study, a semi-structured questionnaire was developed to assess the knowledge, attitude and perception of the participants with regard to the causes, prevention and treatment of lymphatic filariasis and the means of personal protection to avoid mosquito bites, indicating the reasons for specific preferences.

2.4. Statistical analysis

Based on the defined input masks, quantitative data gathered were entered and codified in Excel (version 2010) and processed in Stata version 13 (Stata Corporation; College Station, TX, USA). Qualitative data were transcribed and processed using MaxQDA version 10 (Verbi

Software Consult Sozialforschung GmbH; Marburg, Germany). After data entering, a series of internal consistency checks were made to ensure completeness and integrity of the information. The transcripts of the interviews were first entered in the Word software before being imported into the MaxQDA software. We then proceeded to the coding after defining the different variables that emerged from the interviews. After the coding, the data was transferred into the Word software where it was analyzed and interpreted.

3. Results

3.1. Profile of study population

A total of 514 individuals (313 females, 60.9%), aged 10-84 years, were interviewed, consisting of different target populations (Table 1). Among these, 187 individuals (92 females, 49.2%), aged 17-84 years, were subjected to a more in-depth lymphatic filariasis awareness survey (Table 2). Lymphatic filariasis awareness was found associated with the private services-exercising group (odds ratio (OR) 2.04; 95% confidence interval (CI) 1.23-3.40) and remained lower in the non-employment group (OR 0.17; 95% CI 0.07-0.38) in merchants (OR 0.35; 95% CI 0.13-0.91) and in the Poular ethnic group (OR 0.36; 95% CI 0.18-0.73).

<Table 1 near here>

<Table 2 near here>

There were 23 patients (10 females, 43.5%) with lymphedema and elephantiasis identified among 30 initially listed with these conditions (Tables 2 and 3). Of these cases, 11 (47.8%) were suffering from elephantiasis of the right foot, in nine (31.1%) the left foot was affected and in three (13.0%) both feet were affected. The identified lymphedema were classified as stage 3 (21.7%), stage 4 (43.5%), stage 5 (17.4%) and stage 6 (17.4%) of elephantiasis evolution. The age of patients ranged from 30 to 80 years with a peak of onset of

lymphedema at 20-50 years (n=17, 73.9%; Table 3). In 8.7% of cases, a secondary infection of affected limb was observed and 4.3% of all patients expressed mental depression because of the harsh conditions imposed by the disease. Although the hydrocele is a common clinical manifestation of lymphatic filariasis in endemic areas, none of the participants was found with hydrocele.

Table 1. Target populations, number of people interviewed and data collection methodsto determine perceptions, knowledge, attitudes and practices of lymphatic filariasis inConakry, Republic of Guinea in late 2012 and early 2013

Targeted population	Number	Data collection method
Community health worker	5	In-depth interview
Member of NGO	2	In-depth interview
Traditional practitioner	10	In-depth interview
Close relative and/or friend or neighbour of patient	45	In-depth interview
Lymphatic filariasis patient	23	In-depth interview
Consenting ≥ 15 year-persons living in households close to those of patients	119	Questionnaire
Interviewed for mosquito bites prevention	310	Questionnaire
Total	514	

Table 2. Distribution of the lymphatic filariasis questionnaire respondents in Conakry in

late 2012/early 2013.

Characteristic	Stratum	Females	Males	Awareness of
				lymphatic filariasis
		Number	Number	OR (95% CI)
		investigated	investigated	- (,
Age group (years)	10-20	2 (28.6)	5 (71.4)	0.75 (0.17-3.35)
	21-30	5 (31.2)	11 (68.7)	1.33 (0.22–7.98)
	31–40	39 (71.7)	17 (28.3)	1.00 (0.20-4.89)
	41–50	21 (67.7)	10 (32.2)	3.26 (0.60-17.59)
	51-60	18 (40.0)	27 (60)	1.16 (0.23-5.82)
	61–70	5 (21.7)	18 (78.3)	1.45 (0.26-8.01)
	>70	2 (22.2)	7 (77.8)	1.06 (0.14–7.82)
Sex	Female	92 (100.0)		-0.02 (-0.59–0.55)
	Male	-	95 (100.0)	0.04 (-0.86–0.94)
Occupation	Private service	21 (31.3)	46 (68.7)	2.04* (1.23-3.40)
	Without employment	49 (98.0)	1 (2.0)	0.17* (0.07-0.38)
	Merchant	11 (45.8)	13 (54.2)	0.35* (0.13-0.91)
	Public service	10 (22.7)	34 (77.3)	0.70 (0.32-1.55)
	Student	1 (50.0)	1 (50.0)	1.00
Ethno-linguistic	Susu	43 (51.2)	41 (48.8)	1.47 (0.95–2.27)
group	Poular	29 (48.3)	31 (51.7)	0.36* (0.18-0.73)
	Manding	12 (48.0)	13 (52.0)	0.53 (0.21-1.31)
	Forest ethnic group	8 (44.4)	10 (55.6)	1.36 (0.46–3.97)
Religion	Muslim	92 (49.7)	93 (50.3)	1.03 (0.77–1.37)
-	Other	0 (0.0)	2 (100.0.)	1.00
Residence status	Tenant	45 (56.9)	34 (43.1)	1.20 (0.46–3.15)
	Owner	47 (43.5)	61 (56.5)	0.89 (0.49–1.59)
Participant status	Without lymphedema	83 (50.6)	81 (49.4)	0.76 (0.56–1.04)
	With lymphedema	10 (43.5)	13 (56.5)	1.00

* *P* value based on likelihood ratio test (LRT) <0.05

Crude odds ratio (OR)

Table 3. Distribution of elephantiasis patients in Conakry in late 2012/early 2013,

Age	Females		Males		Total	
group (years)	Presence of lymphedema	Appearance of lymphedema	Presence of lymphedema		Presence of lymphedema	Appearance of lymphedema
10-20	0	1	0	0	0 (0.0)	1 (4.0)
21–30	0	3	0	4	0 (0.0)	7 (30.0)
31–40	2	2	1	2	3 (13.0)	4 (17.4)
41–50	2	2	3	3	5 (21.7)	5 (21.7)
51–60	3	1	4	1	7 (30.4)	2 (8.6)
61–70	2	1	2	3	4 (17.4)	4 (17.4)
>70	1	0	3	0	4 (17.4)	0 (0.0)
Total	10	10	13	13	23 (100.0)	23 (100.0)

3.2. Dynamic and migration of elephantiasis patients

Questions regarding patients' dynamics showed that people originated from different regions of the country. Most of the patients (82.6%) were born in the central parts of the Republic of Guinea, 17.4% were born in Conakry where they had also grown up. Some of the patients from the central regions migrated to Conakry later on. A proportion of 70% of patients spent at least 10 years in Conakry before the onset of the disease and for 82.6% of them, the disease onset occurred while living in Conakry.

3.3, Knowledge and perceptions about the cause and mode of transmission of lymphatic filariasis

Regarding knowledge of the causes of lymphatic filariasis, 65.2% of the healthy subjects and 87.2% of patients responded that they did not know the exact cause of the disease.

Approximately one in 10 (9.2%) of the healthy respondents stated that elephantiasis was a natural disease. Furthermore, 8.7% of patients and 5.7% of healthy people linked the disease to supernatural facts and related its cause to witchcraft. According to a 63-year-old woman *"This disease is not natural; I went to a funeral for a week in good health. Suddenly I got fever that made me lie for two days with pain in the legs and then swelling started."* This explanation of the disease is also supported by 70% of the traditional healers who claim that this type of disease is the result of a curse from evil spirits or an enemy. *"I am convinced that elephantiasis is not a natural disease. It affects man when he is bewitched by another man; that is why it cannot be treated in hospital"* said one of the traditional healers. Other causes such as lack of cleanliness (4.9%), heredity (3.7%), microbial infections (2.4%) and malnutrition (1.2%) were also reported. Only 4.3% of healthy subjects and 4.4% of patients attributed the causes of elephantiasis to mosquito bites (Table 4).

Most of the interviewees with appropriate knowledge of lymphatic filariasis were informed by CHWs. In the opinion of one of the health authorities, lymphatic filariasis develops in warm areas characterized by a special microclimate and temperature promoting the life cycle of the parasite. It was noted, however, that the precise cause of the disease is poorly understood, even by CHWs. A 55-year-old male patient reported: "*When I went to the hospital, I was informed that this disease was caused by diabetes. I was prescribed medication and subjected to dietary restriction for the treatment of diabetes. Five months later, my leg was swollen again and became very painful.*"

	Without		Patient	s with
Cause	lymphedema elephantiasi		ntiasis	
Don't know	107	65.2	20	87.0
Natural	15	9.2	0	0.0
Supernatural	9	5.5	2	8.7
Dirtiness	8	4.9	0	0.0
Mosquito bites	7	4.3	1	4.3
Heredity	6	3.7	0	0.0
Microbe	4	2.4	0	0.0
Malnutrition	2	1.2	0	0.0
Swelling	1	0.6	0	0.0
Total	164	100.0	23	100.0

Table 4. Knowledge about the mode of transmission of lymphatic filariasis in Conakry,in late 2012/early 2013.

3.4. Attitude towards mosquito bites and means of protection

In all communities, mosquito bites were reported to be a problem throughout the year and the respondents indicated the presence of mosquitoes in their households. Mosquitoes are believed to develop in dirty water of gutters (48.2% of respondents), because of the garbage that can be found everywhere (39.4%), in the surrounding ocean water (6.7%) and during the mango period towards the end of the dry season (4.7%), mainly because mosquitoes are attracted by rotting mangoes. Mosquitoes disturb not only by their bites but also by their noise, so they prevent people from a good night's sleep. Participants reported that mosquitoes are dangerous for various reasons, involving painful bites (19.9%), sleep disturbances (13.9%), disease transmission (66.4%) and, particularly, malaria (93.2%).

Regarding the means of protection against mosquito bites, 42.2% of the subjects reported the use of insecticide sheets, 22.8% used fans and 2.8% used air conditioners. Insecticide-

treated nets (ITNs) and insecticide sprays were used by 12.6% and 16.1%, respectively, of those interviewed (Table 5). These protection measures were primarily used to avoid disruptions of sleep, rather than to prevent transmission of lymphatic filariasis. The reasons for not sleeping under an ITN involve heat or perceived suffocation under the net (41.4%), inaccessibility (44.8%), bad odor because of the insecticide and tingling (8.6%) and the perceived high price (GNF 35,000-50,000; approximately US\$ 3.9-5.5) (5.2%). The odor of insecticide spraying was reported as the main deterrence for their use. Most nets were provided by NGOs and governmental donations. However, 96% of the surveyed people considered nets useful and necessary for the protection of children and themselves and stressed that they would use nets if they were available.

Method used	Number of respondents (%)		
No protection	10 (2.3)		
Bed net	54 (12.6)		
Insecticide sheet	181 (42.2)		
Insecticide spray	69 (16.1)		
Fan	98 (22.8)		
Air conditioning	12 (2.8)		
Vegetable fumes	5 (1.2)		
Total	429 (100)		

Table 5. Protection against mosquito bites in Conakry, in late 2012/early 2013.

3.5. Onset of elephantiasis and care-seeking behaviour

Elephantiasis is usually termed *Bhuuri* in Poular, *Foyé* in Susu and *Tonnin* in Manding.

All three ethno-linguistic groups have the same interpretation of elephantiasis. The

aforementioned terms reflect a dysfunction of the blood circulation that generates small swellings developing gradually to the feet. According to patients, the disease appears suddenly after a fever. The development of lymphedema in elephantiasis occurs gradually and is accompanied by fever and pain. The swelling and the leg pain last for about 2-3 weeks. Afterwards the size of the affected leg reduces and the leg skin thickens and exfoliates. However, the leg volume does not reach its original size. Respondents explained that the feet develop elephantiasis, as the acute episodes occurred.

There are no defined steps in search for care among patients interviewed. The patients reported using home-based care, consulting traditional healers or seeking professional help when a first episode of lymphedema occurs. At the first signs of the disease, most patients visit a hospital to treat their infection. Yet, 8.7% of respondents reported having first visited traditional healers because they relate the cause of the disease to supernatural reasons. Many patients reported being treated by medical services without success. Subsequently, they only seek care at hospital when they experience pain and acute inflammation. Nearly 85% of patients with elephantiasis reported that they sought no treatment to reduce the swelling of the foot. This view is shared by health officials who indicate that they receive mainly patients experiencing acute attacks.

At health care facilities, treatment mostly consists of analgesic remedies to relieve pain. One option of treatment reported is 'scarification' – the surgical reduction of the size of the leg followed by scarification. One patient confused by different treatment approaches, resorted to this treatment option. However, due to secondary infections and pain, he reported not to be able to undergo this procedure again: "*Last year, a doctor suggested I practice scarification of which I'm carrying the wound until today. I was proposed to return a second time to do another scarification. But I cannot do because of the pain; in addition it does not improve my condition.*" All patients were ignorant of specific hygiene measures suggested by

WHO, that consist in elevating and regular washing of the infected leg(s). However, some patients reported that they felt better when they rest.

Interviews involving traditional healers indicated that none of them had specific knowledge of lymphatic filariasis that they ascribe to any outgrowth of the scrotum, breast or other body parts. The products mentioned that can be used for therapeutic purpose varied according to the healers. The best known were: the roots of small bamboo, bark and roots of papaya mixed with other "products" they apply on the affected body part. All healers claimed to be able to cure elephantiasis. One said "*I have a very effective recipe with incantations to be recited during all stages of acquisition of the treatment product in the bush. Sometimes I heal this disease if the patients follow all my instructions and avoid totems that I defend. However, I receive patients when the legs are completely swollen and in this case, it is difficult to cure the disease. Doctors do not trust us and they don't refer patients to us. They take us for fetishists yet we are just as helpful."*

3.6. Perception of patients' close relatives and neighbours about lymphatic filariasis

The interviews with close relatives or neighbours of the lymphatic filariasis patients revealed that the majority of them recognized elephantiasis as a serious disease. Patients generally weakened by elephantiasis were considered by close relatives, friends or neighbours as helpless victims to whom they express sympathy and compassion. According to them, the victims of this disease are in a pitiful and pathetic situation. Some respondents believe that the disease is an unavoidable fate and divine work, which requires God's help to rescue victims. In some cases, patients were stigmatized by their close relatives or neighbours. Some parents expressed feelings of reluctance against lasting wounds related to superinfections. One respondent said: *"Sometimes, I'm scared of approaching my father because I think that I can get the same disease if I touch him. But I cannot help, he is my father, I pray for him."*

Other respondents consider lymphatic filariasis as a disease that only infects "*bad people*" and they think that the disease appears as a result of curse or sometimes as divine punishment, since it cannot be cured and condemns individuals to a life of continual seclusion. Furthermore, none of the respondents were aware of the possibility of healing lymphatic filariasis and most considered elephantiasis patients as permanently dependent. These people express the grievances of social assistance and effective management of patients.

3.7. Socioeconomic impact of lymphatic filariasis

The development of elephantiasis drives patients to precarious socioeconomic conditions (Table 6). Indeed, 73.9% of patients were unemployed and 21.7% were forced to seek other employment, except for an accounting officer, who was able to remain on his job despite elephantiasis. The main reasons for job losses were related to the inability to move or stand for long. Some changed their jobs to exercise an activity that is physiologically less demanding, which often comes along with a lower income as it was the case of a 40-year-old woman who reported: "I was a seller and earned enough money to take care of my family. Now I cannot sell as I used to because I cannot stand for long periods and walk long distances." Furthermore, it was noted that the search for care took patients away from their earning activities, as reported by a car driver: "I was a driver when the disease started. I was told it was a curse. I then went to the village for care where I stayed for 6 months. When I returned, my car was given to another person. Today, I work as apprentice in order to survive." The majority of patients interviewed had no profession, which they directly linked to their health condition. The abandonment of the profession is not only caused by the search for care, but also by the depletion of financial resources preventing them from settling and starting new activities.

 Table 6. Occupation of patients before and after experiencing elephantiasis in Conakry

 in late 2012/early 2013

Occupation	Before elephantiasis		After elephantiasis	
	Males (%)	Females (%)	Males (%)	Females (%)
Without employment	0 (0)	0 (0)	10 (71.4)	7 (77.8)
Public service	3 (20.0)	0 (0)	1 (7.1)	1 (11.1)
Merchant	5 (33.3)	4 (50.0)	1 (7.1)	0 (0)
Private service	7 (46.6)	4 (50.0)	2 (14.3)	1 (11.1)
Total	15	8	14	9

This view is expressed by a 74-year-old man: "I was a trader at the Madinan market. I used to travel to other countries for wares. When the disease appeared, I visited healers in different places. I was told it was due to curse from an enemy. I started to sell my wares, but 6 months later, the pain reappeared and I could not move. I did everything to find a solution for my leg, I could not go to the market and my shops were sold to other people. Today, I have no resources and I live very unhappy at the charge of my wife and my children." A female bar owner gave up her job following the development of elephantiasis with acute attacks that not only prevented her from moving, but also depleted her resources in search for treatments. A patient who was a carpenter by training presented an advanced stage of the disease with chronic hyper-infection exacerbated by mental depression. During the interview, the investigators noted that he referred to subjects not related to the discussion. On further inquiry by relatives, the investigators were informed that the patient became mentally unstable following the degrading conditions imposed by the disease.

4. Discussion

Our study revealed that lymphatic filariasis does occur in Conakry, including cases of elephantiasis. Interestingly though, hydrocele, which is a common clinical manifestation of lymphatic filariasis (Thomas and Nutman, 2013), was not observed in the current study. Most of the patients with elephantiasis were above 30 years, which is in agreement with a previous study conducted in Ghana (Gbakima et al., 2005).

In the present study, most of the patients originally came from or grew up in the inland regions of the Republic of Guinea. Most home regions of these patients are considered endemic for lymphatic filariasis (Anonymous, 2013), and hence, it is conceivable that these people have contracted the disease before they moved to Conakry. However, our investigation revealed that some of the patients are native to the study area although there is a low risk of lymphatic filariasis transmission in Conakry, as demonstrated in concomitant entomological and serological surveys done by Kouassi et al. (2015). Approaches involving the living itinerary of these patients revealed that 73.9% of them spent at least 10 years in Conakry before the onset of the disease and 82.6% of them reported that the disease onset indeed occurred while they lived in Conakry. These observations warrant confirmation, by drawing inference from recent entomological and serological surveys conducted in the study area (Kouassi et al., 2015). The results presented here support a need to focus on the study sites where infections are suspected to detect pockets of disease transmission. The peak of elephantiasis onset has been observed in patients aged between 30 and 50 years, which might be considered the most productive age, during which people are usually involved in intense professional activities. These results are aligned with previous studies reporting that lymphatic filariasis in the majority of cases, begins at an age where individuals are economically most active (Babu et al., 2006).

Although lymphatic filariasis was well recognized by the communities, the main causes remain unknown by many and their perceptions are strongly influenced by socio-cultural norms and superstitious beliefs. In fact, the majority of subjects – both patients and healthy counterparts – do not know the exact causes of the disease, which may confuse patients in seeking appropriate care. Furthermore, 8.7% of patients relate the disease to supernatural reasons and trust in traditional practitioners that reassure having the remedy to relieve them. Similar perceptions of lymphatic filariasis, where the true cause and the mode of disease transmission are replaced by superstitious reasoning, were reported in Nigeria (Braide et al., 2003; Omudu and Okafor, 2011), Ghana (Gyapong et al. 1996; Ahorlu et al. 1999); the Philippines (Lu et al., 1988) and India (Kumar et al., 2005; Jayakumary et al., 2006). However, the real causes are known to some health workers that state the involvement of infected mosquitoes as vectors. Surprisingly, aggressive curative options involving scarification were recorded. As people link elephantiasis to heredity, they may not feel exposed to infection where there is no parent affected by the disease nor realize that their children may be exposed to the disease. In West Africa and in Thailand, there is a general perception that children born to women with lymphatic filariasis will be similarly affected (Amazigo and Obikeze, 1992; Ahorlu et al., 1999).

In the current study, few people associate elephantiasis to mosquito bites. Moreover, the role of mosquitoes in transmission of filarial parasites is poorly appreciated in the community, which could be an obstacle to raising awareness of the importance to minimize or reduce mosquito contact in order to prevent infection (Omudu and Okafor, 2011). However, preventive measures are being used; although, primarily to avoid mosquito bites and to improve sleep quality. As a result, the population uses mainly mosquito insecticide sheets and, to a lesser extent, fans in order to prevent mosquito bites. ITNs that effectively reduce human-vector contact are used by few people. Krentel et al. (2013) reported that knowledge

of the causes of lymphatic filariasis and its prevention methods are important determinant of people's compliance to the proposed methods of control. It is therefore necessary to develop health education programmes demonstrating the involvement of parasite and mosquito bites in the infection process of the disease. This should encourage the population to adopt objectively protective measures against mosquito bites and sustain campaigns against mosquito bites at the community level (Ramaiah et al., 1996).

As first signs of the disease occur, patients use different methods to treat their lymphedema; however, few of them continue to get treatment for advanced elephantiasis of the leg and only visit medical services when they experience acute inflammatory attacks. Abandonment of care over time by these patients might be justified as they suffered from the disease for some time, but they are disappointed of having tried various treatment options without relief. The surgical removal of tissue or so called 'scarification' worsens the condition of the disease and exposes the patient to secondary infections. Subsequently, the increasing limitation of a patient's resources in face of progressing disease renders the person incapable to care for the family. Similar observations have been reported from a study exploring disability management related to lymphatic filariasis in Togo (Richard et al., 2007). Regarding the treatment and management of the disease, as recommended by WHO, none of the patients had an adequate knowledge of hygiene measures, such as washing and cleaning of infected feet two to three times a day, exercising and elevation of legs that can help improving their condition. Hence, programmes in which patients are taught practices recommended to slow the progression of lymphedema and to reduce the pain of these people are warranted (Nanda and Ramaiah, 2003).

Patients are seen by parents, relatives and friends as weak and powerless victims to whom they express compassion. However, considering that they perceive elephantiasis as a disease of "*bad people*" who did "*wrong things*" to which a punishment has been imposed –

either by God or an enemy – might expose victims to reluctance and sometimes acts of abandonment and stigmatization. Some respondents considered elephantiasis as a contagious disease, and hence, they avoided patients' vicinity. These issues need to be addressed, should the control of lymphatic filariasis be improved and sustained.

Our study revealed that most patients lost their profession due to advanced ill-health condition of lymphatic filariasis. Most of the patients have difficulty performing activities that require travelling and are therefore limited in their ability to meet basic family needs. These illustrations show how lymphatic filariasis is likely to perpetuate the vicious cycle of poverty in affected communities. Previous studies have demonstrated that patients with chronic filariasis could not participate in activities of higher wages (Babu et al., 2002, 2006). Thus, the income of patients is lower than that of their healthy counterparts. Again, our results confirm previous observations, where patients with sequelae presented a considerable economic burden for their families and communities. As the disease progresses, the patient severely disabled can no longer contribute to the household work and becomes a burden for the household economy (Suma et al., 2003). This negative impact of lymphatic filariasis was demonstrated in India where 66% of all patients reported impaired ability to perform daily activities (Ramaiah et al., 1997). Loss of authority of parents due not only to their physical impairment but also to the permanent financial dependence on the family could have adverse social implication on family stability and child education.

Our study has some limitations, which are offered for discussion. First, we conducted a cross-section study, and hence, the quality of the evidence is lower compared to other epidemiological designs. Second, we cannot exclude recall and reporting biases. Indeed, our study population was not randomly selected and the findings are only valid for the observation period in late 2012/early 2013. Third, due to limited financial and human resources, we were not able to tape-record and transcript the in-depth interviews; instead,

quotes were taken directly in the field, as good as we could. Yet, a mixed-methods approach mitigates some of these inherent study limitations.

5. Conclusions

This study revealed that elephantiasis of the legs was present in the capital of the Republic of Guinea at the time of the study in late 2012/early 2013. Although afflicted individuals were generally accepted and cared for, there was an important element of stigmatization not only due to the displeasing features of elephantiasis, but also due to the threat of contamination and misunderstanding of the origin of the disease. Hence, there is a need for a better explanation of how the disease is transmitted, and how it can be prevented and managed. Involvement of CHWs should be considered, as they evoke the crucial role of infected mosquitoes as disease vectors. Traditional healers ascribe the causes of the disease to supernatural sources. Thus, in a context marked by a strong dominance of spiritual beliefs, it is difficult to orient people to adopt appropriate measures against a specific disease. It appears important to insure patients about the necessity of MDA as long as transmission occurs and to engage in innovative and intensified disease management. There is a need to initiate a lymphatic filariasis management programme to reduce the physical and emotional burden of this disease in Conakry.

Competing interests

The authors declare that they have no competing interests.

Acknowledgements

We would like to address our thanks to the National Programme for Onchocerciasis, Blindness and Neglected Tropical Diseases. We are grateful to health authorities for their support in identifying lymphatic filariasis patients and sensitizing the population. We thank the communities for their cooperation and active participation in our questionnaire survey and

the interviews. We are grateful to Dr. Jasmina Saric for carefully reading our manuscript. This study was supported by the Filarial Programme Support Unit from Liverpool School of Tropical Medicine, through funds from the Department for International Development (DFID).

Authors' contributions

BGK, MJB and AG conceived and designed the experiments. AG and BGK supervised the implementation of field work. BLK, OB, AB, MLN and MSB performed the experiments. BLK and AB analyzed the data. BLK, AB, SJK Wrote the first draft of the manuscript. MJB, BGK, KHT and JU revised the manuscript. JU, MJB and BGK provided conceptual advices and final editorial feedback prior to manuscript submission and resubmission. All authors read and approved the final version of the manuscript.

References

- Ahorlu, C.K., Dunyo, S.K., Koram, K.A., Nkrumah, F.K., Aagaard-Hansen, J., Simonsen,P.E., 1999. Lymphatic filariasis related perceptions and practices on the coast of Ghana: implications for prevention and control. Acta Trop 73:251-264.
- Amazigo, U.O., Obikeze, D.S., 1992. Social consequences of onchocercal skin lesions on adolescent girls in rural Nigeria. WHO/TDR Discussion Paper. Geneva: World Health Organization.
- Anonymous, 2013. Plan directeur (master plan) incluant le rapport sur la cartographie de la filariose lymphatique en Guinée. Programme National de Lutte contre l'Ochocercose et les Maladies Tropicales Négligées. Ministère de la Santé et de l'Hygiène Publique, 77.
- Babu, B., Swain, B., Rath, K., 2006. Impact of chronic lymphatic filariasis on quantity and quality of productive work among weavers in an endemic village from India. Trop Med Int Health 5:712–717.

- Babu, B.V., Nayak AN, Dhal K, Acharya AS, Jangid PK, Mallick G, 2002. The economic loss due to treatment costs and work loss to individuals with chronic lymphatic filariasis in rural communities of Orissa India. Acta Trop. 82:31–38.
- Braide, E., Ikpeme, B., Atting, I., Kale, O., 2003. Preliminary observations on the occurrence of lymphatic filariasis in Cross Rivers State, Nigeria. Nig J Parasitol. 24:9-16.
- Calvertoń Maryland USA, 2000. Enquête démographique et de santé Guinée. Direction Nationale de la Statistique, Ministère du Plan et la Coopération, Conakry. Guinée Macro International Inc. 370 p. http://dhsprogram.com/pubs/pdf/FR109/FR109.pdf. Accessed 8 Feb 2016.
- Coreil, J., Mayard, G., Louis-Charles, J., Addiss, D., 1998. Filarial elephantiasis among Haitian women: social context and behavioral factors in treatment. Trop Med Int Health, 3:467-473.
- Diallo, N.K., Sanogo, M., Barry, O.B., Barry, M.L., Bandush, J., Dabiré, A., and Sergio, Y.,
 2005. Rapport sur la cartographie de la filariose lymphatique en Guinée, Ministère de la
 Santé et de l'Hygiène Publique & Programme National de Lutte contre l'Ochocercose et
 les Maladies Tropicales Négligées 18 p.
- Dreyer, G., Addiss, D., Bettinger, J., Dreyer, P., Norões, J., Rio, F., 2001. WHO Lymphoedema Staff Manual Treatment and Prevention of Problems Associated with Lymphatic Filariasis. Geneva: World Health Organization, 87 p. http://apps.who.int/iris/bitstream/10665/67224/1/WHO_CDS_CPE_CEE_2001.26a.pdf.
- El-Nahas, H., El-Shazly, A., Abulhassan, M., Nabih, N., Mousa, N., 2011. Impact of basic lymphedema management and antifilarial treatment on acute dermatolymphangioadenitis episodes and filarial antigenaemia. J Glob Infect Dis. 3:227-232.

- Gbakima, A., Appawu, M., Dadzie, S., Karikari, C., Sackey, S., Wilmot, A., Gypong, J., Scott, L., 2005. Lymphatic filariasis in Ghana: establishing the potential for an urban cycle of transmission. Trop Med Int Health.;4:387-392.
- Gyapong, M., Gyapong, J.O., Adjei, S., Vlassoff, C., Weiss, M., 1996. Filariasis in Northern Ghana: some cultural beliefs and practices and their implication for disease control. Soc Sci Med. 43:235-242.
- Haddix, A.C., Kestler, A., 2000. Lymphatic filariasis: economic aspects of the disease and programmes for its elimination. Trans R Soc Trop Med Hyg.;94:592–593.
- Ichimori, K., King, J., Engels, D., Yajima, A., Mikhailov, A., Lammie, P. et al., 2014. Global Programme to Eliminate Lymphatic Filariasis: the processes underlying programme success. PLoS Negl Trop Dis. 8:e3328.
- Jayakumary, M., Jayadevan, S., Divakaran, B., Jeesha, S., Dass, L., 2006. Awareness and practices regarding factors associated with lymphatic filariasis in a municipal area of North Erala. Ind J Com Med. 31:11-15.

http://www.indmedica.com/journals.php?journalid=7&issueid=73&articleid=936&action =article.

- Kouassi, B., de Souza, D., Goepogui, A., Narh, C., King, S., Mamadou, B. et al., 2015.
 Assessing the presence of *Wuchereria bancrofti* in vector and human populations from urban communities in Conakry, Guinea. Parasit Vectors. 8:492. doi 10.1186/s13071-015-1077-x
- Krentel, A., Fischer, P., Weil, G., 2013. A review of factors that influence individual compliance with mass drug administration for elimination of lymphatic filariasis. PLoS Negl Trop Dis. 7:e2447.

- Kumar, S., Das, D., Babu, B.V., Dash, A.P., 2005. Knowledge of lymphatic filariasis among the population of an endemic area in rural Madhya Pradesh, India. Ann Trop Med Parasitol. 99:101-104.
- Lu, A., Valencia, L., Llagas, L., Abala, L., 1988. Postrado L. Filariasis: a study of knowledge, attitude and practice of the people of Sorsogon. Social and economic Research Project No 1. (TDR/SES/PRS/1). Geneva: World Health Organization. 1988.
 http://apps.who.int/iris/bitstream/10665/61220/1/TDR_SER_PRS_1.pdf.
- Nanda, B., Ramaiah, K.D., 2003. Lymphoedema-management measures practised by cases of chronic lymphatic filariasis. Ann Trop Med Parasitol. 97:427-431.
- Omudu, E., Okafor, F., 2011. Gender dimensions of knowledge, physical and psycho-social burden due to lymphatic filariasis in Benue State, Nigeria; Department of Biological Sciences, Benue State University, Makurdi, Nigeria. Department of Zoology, University of Nigeria, Nsukka,Nigeria. J Parasitol Vect Biol. 3:22-28.

http://www.academicjournals.org/journal/JPVB/article-full-text-pdf/C84DBF31521.

- Ottesen, E., Duke, B.O., Karam, M., Behbehani, K., 1997. Strategies and tools for the control/elimination of lymphatic filariasis. Bull World Health Org. 75:491-503.
- Ramaiah, K.D., Kumar, K., Ramu, K., Pani, S., Das, P., 1997. Functional impairment caused by lymphatic filariasis in rural areas of south India. Trop Med Int Health. 2:832-838.
- Ramaiah, K.D., Kumar, K.N., Ramu, K., 1996. Knowledge and beliefs about transmission, prevention and control of lymphatic filariasis in rural areas of south India. Trop Med Int Health. 1:433-438.
- Rath, K., Nath, N., Mishra, S., Swain, B.K., Mishra, S., Babu, B.V., 2006. Knowledge and perceptions about lymphatic filariasis: a study during the programme to eliminate lymphatic filariasis in an urban community of Orissa, India. Trop Biomed. 23:156–162.

- Rauyajin, O., Kamthornwachara, B., Yablo, P., 1995. Socio-cultural and behavioural aspects of mosquito-borne lymphatic filariasis in Thailand: a qualitative analysis. Soc Sci Med. 41:1705–1713.
- Rebollo, M.P., Bockarie, M.J., 2014. Shrinking the lymphatic filariasis map: update on diagnostic tools for mapping and transmission monitoring. Parasitol Res; 16:11-16.
- Richard, S., Els, M., David, G., Addiss, Y., Sodahlon, K., 2007. A survey of treatment practices and burden of lymphoedema in Togo. Trans R Soc Trop Med Hyg. 101:391-397.
- Suma, T., Shenoy, R., Kumaraswami, V., 2003. A qualitative study of the perceptions, practices and socio-pyschological suffering related to chronic brugian filariasis in Kerala, southern India. Ann Trop Med Parasitol. 97:839-845.
- Nutman, T. B., 2013. Insights into the pathogenesis of disease in human lymphatic filariasis. Lymphat Res Biol:11:144–148.
- Upadhyayula, S., Mutheneni, S., Kadiri, M.R., Kumaraswamy, S., Nagalla, B., 2012. A Cohort Study of Lymphatic Filariasis on Socio Economic Conditions in Andhra Pradesh, India. PLoS ONE, 7(3):e33779.
- WHO, 2000. Preparing and Implementing a National Plan to Eliminate Lymphatic Filariasis.
 WHO/CDS/CPE/CEEE/ ;15. World Health Organization, Geneva. 2000.
 http://apps.who.int/iris/bitstream/10665/66899/1/WHO_CDS_CPE_CEE_2000.16.pdf
- WHO, 2010. World Health Organisation. GPELF Progress Report 2000–2009 and Strategic Plan 2010–2020. WHO/HTM/NTD/PCT/2010, 6. 2010.
- WHO, 2013. Lymphatic filariasis: managing morbidity and preventing disability. http://apps.who.int/iris/bitstream/10665/85347/1/9789241505291_eng.pdf. 2013.

- WHO, 2016. Lymphatic filariasis. Global Health Observatory (GHO) data. http://www.who.int/gho/neglected_diseases/lymphatic_filariasis/en/. Accessed July, 2016.
- Wynd, S., Melrose, W.D., Durrheim, D.N., Carron, J., Gyapong, M., 2007. Understanding the community impact of lymphatic filariasis: a review of the sociocultural literature. Bull World Health Org. 85:493–498.