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Rapid community identification, pain and distress associated with lymphoedema and adenolymphangitis due to lymphatic filariasis in resource-limited communities of North-eastern Nigeria

O.B. Akogun[a,*], M.K. Akogun[b], E. Apake[c], O.O. Kale[d]

[a] The Elephantiasis Project, Common Heritage Foundation, No. 27 Shelter Road, Federal Housing Estate Phase 2, Bajabure, Box 5124, Yola, Nigeria
[b] Clinical Psychology Unit, Department of Psychiatry, Jos University Teaching Hospital, Jos, Nigeria
[c] Department of Primary Health Care and Diseases Control, Taraba State Ministry of Health, Jalingo, Nigeria
[d] Department of Social and Preventive Medicine, University of Ibadan, Ibadan, Nigeria

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ABSTRACT

Identification of communities with people that could benefit from adenolymphangitis (ADL) and lymphoedema morbidity management within Lymphatic Filariasis Elimination Programmes (NLFEP) in many African countries is a major challenge to programme managers. Another challenge is advocating for proportionate allocation of funds to alleviating the suffering that afflicted people bear. In this study we developed a rapid qualitative technique of identifying communities where morbidity management programme could be situated and documenting the pain and distress that afflicted persons endure. Estimates given by health personnel and by community resource persons were compared with systematic household surveys for the number of persons with lymphoedema of the lower limb. Communities in Northeastern Nigeria, with the largest number of lymphoedema cases were selected and a study of local knowledge, physical, psychosocial burden and intervention-seeking activities associated with the disease documented using an array of techniques (including household surveys, key informant interviews, group discussions and informal conversations). Health personnel gave a more accurate estimate of the number of lymphoedema patients in their communities than either the community leader or the community directed ivermectin distributor (CDD). Community members with lymphoedema preferred to confide in health personnel from other communities. The people had a well developed local vocabulary for lymphoedema and are well aware of the indigenous transmission theories. Although the people associated the episodic ADL attacks with the rains which were more frequent at that period they did not associate the episodes with gross lymphoedema. There were diverse theories about lymphoedema causation with heredity, accidental stepping on charmed objects and organisms, breaking taboos. The most popular belief about causation, however, is witchcraft (60.9%). The episodic attacks are dreaded by the afflicted, since they are accompanied by severe pain (18%). The emotional trauma included rejection (27.5%) by family, friends and other community members to the extent that divorce and isolation are common. Holistic approach to lymphoedema morbidity management should necessarily be an integral component of the ongoing transmission elimination programme. Any transmission prevention effort that ignores the physical and psychological pain and distress that those already afflicted suffer is unethical and should not be promoted.

1. Introduction

Sub-Saharan Africa alone is reputed to harbour about 28 million filarial-parasite-disabled people (Micheal et al., 1996), a probable gross underestimation of the extent of the problem. Fortunately however, there is enough evidence and tools for the elimination of the disease (Ottesen et al., 1997; Haddix and Kestler, 2000).

In Nigeria which is atop the list of the infection table in Africa, for example, more than 22 million people are estimated to be infected with the worm (Lindsay and Thomas, 2000) and despite several years' experience in large scale community intervention programmes only two of its 36 States had been receiving mass drug administration (Akogun, 1991; Akogun and Badaki, 2011). It is now generally accepted that integrating filariasis intervention activities into other drug delivery programmes such as worm and

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* Corresponding author. Tel.: +234 8037220460.
E-mail address: akoguno@yahoo.com (O.B. Akogun).

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malaria control will create the required synergy for accelerating programme action (Njepuome et al., 2009).

The community directed approach has been used for the distribution of drugs in the intervention against lymphatic filariasis in Ghana (Gyapong et al., 2001). With the commencement of mass drug administration in many parts of the world, the need to identify those who require clinical care for morbidity due to the disease becomes more urgent. Perhaps a study of the psychosocial aspects of the disease will be an advocacy material for promoting morbidity management (Wijesinghe et al., 2007).

Although the global elimination plan entails transmission interruption in endemic areas and morbidity alleviation, steps towards the latter has been slow and uncertain. There is a lot of understanding from the ongoing elimination programmes that could be applied into morbidity alleviation (Kyelem et al., 2008). It remains to be seen how advantage may be taken of the global interest to alleviate suffering of those already disabled by the disease even when MDA is fully implemented, yet participation in the ongoing mass drug administration is influenced by the experiences of community members that benefit from its disability alleviation component. In preparation for developing a lymphatic filariasis (LF) morbidity management approach in resource poor communities of North-eastern Nigeria, a rapid qualitative technique for identifying communities with lymphoedema was developed and the physical, social and psychological burden of morbidity documented.

2. Material and methods

The study employed a mix approach to document local knowledge, perception, physical, social and psychological burden and LF morbidity management practices. First, indepth and open ended semi structured interviews were used for obtaining the subjective but informed opinion of health professionals and community consultants for the rapid identification of the State, LGA, district and community in North-eastern Nigeria with highest magnitude of ADL and lymphoedema. Group discussions and indepth interviews were then used to document local knowledge about disease causation, community perception, attitude towards affected people and relief-seeking behaviours. Standard quantitative tools were then used for assessing the physical and psychosocial burden of illness on the affected persons. Post-analysis informal conversations with key informants helped in contextual data interpretation.

The study was carried out in two phases. First, a subjective estimation by health personnel and community resource persons was compared with household examination of the extent of lymphoedema problem in each Local Government Area (LGA) in both Adamawa and Taraba States. Three LGAs with highest perceived prevalence were subsequently selected from the list for further study of the social, psychological and economic burden of the disease at the community level.

2.1. Description of the study area and population

Taraba and Adamawa States of Northeastern Nigeria described in Akogun and Badaki (2011) are probably the least served by non-government development organizations involved in filariasis control. Besides the large scale ivermectin distribution that the African Programme for Onchocerciasis Control (APOC) supports in both States, there has not been any systematic intervention against filarial diseases in the area. Both States are rural, have a subsistent agriculture-based economy and a widely dispersed settlement pattern. The local governments (LGs) have responsibility for primary health care (PHC) service. Although there may be a public hospital in an LGA the front line health facilities are the main sources of health care delivery. In each LGA there are about 10 health districts, each under a senior health personnel referred to as the District Health Supervisor (or DHS). The DHS receives referrals from frontline health facilities within the health district and refers cases to the nearest hospital. The PHC Coordinator appointed by the Local Government Service is the administrative and professional head of the local government health department. PHC Coordinators meet quarterly at the instance of the commission to review activities. A similar review meeting is held monthly at the LGA level for the DHS at the instance of the PHC Coordinator. The study design took advantage of these arrangements.

2.2. Rapid community identification process

First, a list of LGAs in the State was compiled in alphabetical order. The Directors of Primary Health Care and Disease control were then requested to rank the LGAs according to their lymphoedema magnitude. The three highest ranking LGAs were thus selected. In each of the three LGAs, a list of health districts was compiled and the PHC Coordinator in the LGA was requested to rank the health districts according to the lymphoedema burden. The health district that was perceived as having the highest burden of lymphoedema was then selected in each LGA. At the health district level, the process was repeated. A list of communities was made and the DHS was required to rank them according to perceived burden of lymphoedema. The 2-step ranking (of health districts and communities within them) provided a list of communities with the highest lymphoedema in each LGA. A visit was made to each of the villages that were ranked highest. The health personnel in charge of the frontline health facility that serves the selected village was shown a photocard containing pictures of lymphoedema of the lower limbs at various degrees of deformity (swelling only, swelling with folds but not warts, swelling with folds and warts), and allowed to study it for 5 min (Akogun and Badaki, 2011). The health personnel were then asked if they knew anyone within the community with any of the manifestations, and to estimate how many there were in the community. The estimate was computed as a proportion of the village population obtained from the local government office. The same process was repeated with the estimation obtained from community directed distributor of ivermectin (CDD) and the village leader. A household survey was carried out in each of the communities. Beginning with the village head, one in every five households was visited and individuals within the household from age five years were examined for lymphoedema of the limb and then interviewed for history of acute filarial episodes (with or without oedema) and attitude towards it.

Evidence of lymphoedema was obtained by first asking for the individual's history of ADL episodes and the circumstances surrounding them. Information was obtained on the nature of acute attacks and extent of incapacitation. Type and grade of lymphoedema, location, perceived cause as well as the health-seeking habits were also collated. All those with suspected cases of ADL and lymphoedema in the community were advised to register with the nearest health facility for the planned LF morbidity management programme.

The initial plan was to use health facility records for evidence of diagnosed cases of lymphatic filarial worms but this was discarded since many of the health facilities lacked such records. The qualitative assessment was then compared with the household survey.

2.3. Social, psychological and economic burden of lymphoedema

Indepth interviews with community leader, CDDs, the health personnel, health provider (traditional doctor, PHC worker), spouses, co-wives (in polygamous homes) and children of affected individuals, group discussions were held with affected and