East African Medical Journal Vol. 92 No. 11 November 2015
KNOWLEDGE AND ATTITUDE TOWARDS BURULI ULCER DISEASE IN ADJUMANI DISTRICT, NORTHWESTERN UGANDA

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ABSTRACT

Background: Buruli ulcer is a devastating skin disease caused by Mycobacterium ulcerans. It produces a necrotissing toxin, which destroys the skin, subcutaneous tissue and bone, often leaving the patients with debilitating deformities. The mode of transmission of the disease is unclear, but water borne vectors may transmit _M. ulcerans_. Treatment is difficult and often involves extensive surgery, which is the current standard treatment, but it may result in scarring and subsequent physical limitations due to scar retraction. These physical limitations may result in psychosocial and economic problems. It was hypothesised that superstitious beliefs about the illness, and stigma were important determinants for health seeking behaviour. The consequences of the disease include social isolation and economic problems in family life.
Objective: To explore the knowledge and attitude of the people affected by Buruli ulcer disease in Adjumani district, in northwestern Uganda.
Design: A semi-structured questionnaire was administered to all the selected patients.
Setting: Selected Health centres in Adjumani district, which included Adjumani hospital, Pakele HCIII, Dzaipi HCIII, Mungula HCIII and Opinjinji HCIII.
Subjects: A total of Nineteen (19) clinically diagnosed patients with Buruli ulcer were consented and interviewed for this study.
Results: A total of nineteen (19) patients were interviewed for this study. Of these, 10 (52.6%) were female and nine (47.4%) were male. Majority of the respondents were peasant farmers (N=9, 47.4%), mainly undertaking subsistence farming for home consumption. Most of the patients (N=16, 84.2%) had their lesions on either the upper or lower limbs. The majority (N=13, 68.4%) said they know the disease affecting them and only 6 (31.6%) patients did not know. Majority of patients 17 (89.5%) sought for medical and/or traditional therapy, while only two (10.5%) did not do anything about it. Of those who sought for help, nine (52.9%) opted for traditional herbal treatment, while 8 (47.1%) went for conventional medical treatment at a health unit. Most patients reported a wide range of stigma labeled against them, and these included; fear that they may infect others (N=2, 10.5%), fear that they have been bewitched or cursed (N=2, 10.5%), discrimination at school to the extent that he dropped out of school, and avoidance by others.
Conclusion: This study has shown that patients with Buruli ulcer are still stigmatised as members of the community. It is important that educational programme on Buruli ulcer be developed which increases awareness of the disease and may also lower the level of stigma. These programme will also help in disease detection and hopefully improve the health seeking behaviour of patients.

INTRODUCTION

Buruli ulcer occurs in atleast twenty-seven countries in Africa, Asia, South America and the Western Pacific, mainly in tropical and sub-tropical regions (1, 2). The disease was first documented in Australia in 1948 (3), and given the name Bairnsdale ulcer because of their focal distribution.The majority of reported cases are from west and central Africa: Cameroon (4), Benin (5), Ivory Coast (6), Gabon (7), Ghana (8, 9), Liberia (10), Nigeria (11), Togo (12), Uganda (13) and the Democratic Republic of Congo (14). In Uganda, Cook first described the disease in 1897 (15), and the disease got its name from the Buruli County in central Uganda, where several cases were reported. Buruli ulcer is a devastating skin disease caused by Mycobacterium ulcerans. It is the third most common mycobacterial disease of humans in the world (16). The bacteria are peculiar among pathogenic mycobacteria because it produces a potent necrotising exotoxin called mycolactone. This necrotising toxin destroys the skin, subcutaneous tissue, and bone (17), often leaving the patients with debilitating deformities. In severe cases, the disease may involve 20% or more of a person's skin surface (18). Cases of bone involvement are rare, but up to 15% of patients have been observed to have bone involvement (19). The mode of transmission of the disease is unclear, but water borne vectors may transmit *M. ulcerans* (20). The disease usually starts as a painless nodule or papule, most commonly on the extremities, that may go unnoticed and may then expand into a plague or widespread indurated oedema and subsequently ulcerate (21). The pre-ulcerative stage of the disease is treated by excision, which can be performed relatively easily. However, most patients do not come to hospital until the ulcerative stage of the disease (22). Treatment is difficult and often involves extensive surgery, which is the current standard treatment, but it may result in scarring and subsequent physical limitations due to scar retraction. These physical limitations may result in psychosocial and economic problems (23, 24, 25). In Ghana, the socio-economic implications of Buruli ulcer showed severe disabilities and high treatment costs (23). Early treatment could reduce treatment costs. It was hypothesised that delay in early treatment is influenced by factors like distance from the health facilities, lack of funds, superstitious beliefs about the illness, and stigma were important determinants for health seeking behaviour. The consequences of the disease include social isolation and economic problems in family life (23). Data of an assessment of the impact of Buruli ulcer disease on the lives of the affected people may be a necessary tool in developing disease control programs appropriate for the community and compatible with traditional perceptions of etiology, prevention and control. Education on the disease, usually propagated for early detection, might be useful in reducing stigma (24). This study was undertaken to explore the knowledge and attitude of the people affected by Buruli ulcer disease in Adjumani district, in northwestern Uganda. Specifically, the study focused on two areas: knowledge of the disease among the patients and,their health seeking behaviour and views on treatment.

MATERIALS AND METHODS

The study was conducted in selected health centres in Adjumani district, which is reported to be endemic for the Buruli ulcer disease in Uganda (New Vision, March 30, 2012). These health units were Adjumani hospital, Pakele HCIII, Dzaipi HCIII, Mungula HCIII and Opinjinji HCIII. Patients, who reported to these health units with suspected Buruli ulcer disease, were clinically diagnosed and their consent to participate in the study was sought before the questionnaire was administered. For minors, consent of their parents or guardians was sought and they were administered the questionnaire. Signed informed consent was obtained from adult participants and from caretakers of the minors. A semi-structured questionnaire was administered to all the selected patients. Open interviews were also conducted. The ideas about knowledge of the disease was assessed by open questions, and later followed by more specific semi-structured questions. Ideas about treatment was assessed by questions on help seeking behaviour of patients with Buruli ulcer and expectations, and ideas on perception of others towards those affected with Buruli ulcer was assessed by open interviews of the patients.

RESULTS

Characteristics of respondents: A total of nineteen (19) patients were interviewed for this study. Of these, ten (52.6%) were female and 9 (47.4%) were male (Table 1). The youngest was 12 years old, and the oldest was 72 years old. Majority of the respondents were peasant farmers (N=9, 47.4%), mainly undertaking subsistence farming for home consumption. Two were housewives (10.5%), while one was doing charcoal burning, another was a cleaner and two of the minors were school going pupils and the other two were children who stayed at home.

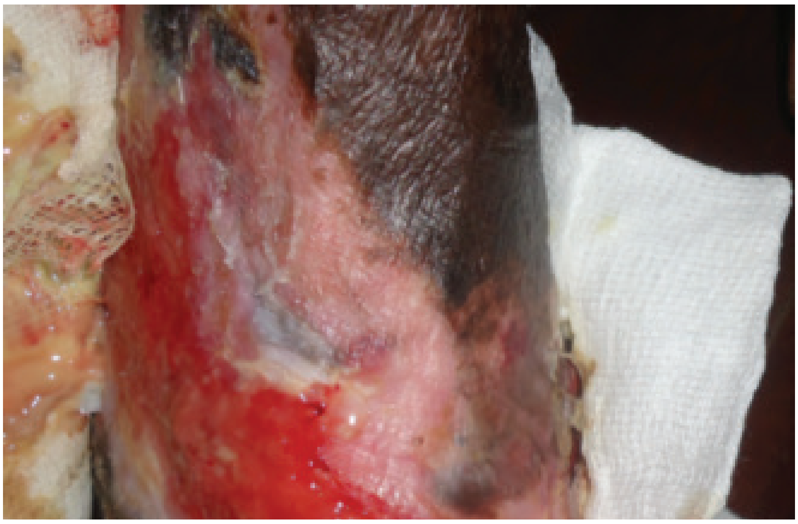
Table 1
Respondents' age and knowledge of Buruli ulcer disease

	Number of respondents	Mean age in years (range)	Knowledge of disease %(No)	
			Yes	No
Male	9	30.4 (12 – 61)	6 (66.7%)	3 (33.3%)
Female	10	50.2 (16 – 75)	7 (70.0%)	3 (30.0%)
Total	19	41.0 (12 – 75)	13 (68.4%)	6 (31.6%)

Most of the patients (N=16, 84.2%) had their lesions on either the upper or lower limbs, while the others had it on the left side of the neck, the left cheek and on the lower abdomen.

Figure 1
Lesion on left leg with extensive tissue and bone involvement

Figure 2
Lesion on the right ankle joint



Knowledge of Buruli ulcer: The majority(N=13, 68.4%) said they know it, and that it's called "lupilupi" in Madi, the local dialect. Only six (31.6%) patients did not know the disease affecting them. However, only one patient had another local name for the disease, calling it "aci-ci" in Madi, meaning Cellulitis. Most patients reported that their lesions started as small blisters with itching, later developing into ulcers. Majority of patients have had the disease for long periods of time, ranging from one month to forty years. For those who have had the disease for long (three years or more), reported having re-occurrences of the ulcers even after seeking medical and/or traditional herbal treatment. There was no reported case of a new infection site on other parts of the body. Majority of patients 17(89.5%) sought for medical and/or traditional therapy, while only two (10.5%) didn't do anything about it (Table 2). Of those who sought for help, 9 (52.9%)opted for traditional herbal treatment, while 8 (47.1%) went for conventional medical treatment at a health unit.Two patients later reverted to traditional herbal treatment after initially seeking medical help, and three patients also went to a medical unit after first seeking traditional herbal treatment.

Table 2

Respondents' health seeking pattern

	Health seeking pattern			
	Yes	No	Medical	Herbal
Male	9 (100%)	0 (0%)	6 (66.7%)	3 (33.3%)
Female	8 (80%)	2 (20%)	2 (25%)	6 (75%)
Total	17 (89.5%)	2 (10.5%)	8 (47.1%)	9 (52.9%)

Several respondents 11 (57.9%) reported having received support from family members. This ranged from moral to financial support especially towards facilitating their transport to seek treatment, payment of medical bills, provision of care during their hospital stay and house chores. Only one respondent said she got no help at all from family members. When asked about their perceived attitude from other members of the community, most patients reported a wide range of stigma labeled against them. These include; fear that they may infect others (N=2, 10.5%), fear that they have been bewitched or cursed (N=2, 10.5%), discrimination at school to the extent that he dropped out of school, and avoidance by others.

DISCUSSION

This study was to examine the level of knowledge and the perceived attitude of community members towards those suffering from Buruli ulcer disease in an area where the disease is emerging. Buruli ulcer disease was first reported in 1961 in Buruli County in Nakasongola district, central Uganda. It has since emerged in other regions outside Buruli County, especially further along the River Nile in the districts of Adjumani and Moyo, in northwestern Uganda. This study is a measure of the impact of Buruli ulcer on people apart from the physical and socioeconomic aspects.

The majority of respondents affected were adults above 18 years of age, contrary to previous studies that reported children less than 15 years of age being predominantly affected compared to adults in Ghana (25, 26) and in Ivory Coast (6). This is because most of the respondents reported having suffered the disease for long periods, and the fact that the disease is re-emerging in this area supports the high level of knowledge that the people in this region have about the disease. But the hope to fill the knowledge gap surrounding its etiology and transmission is still very remote, hence being difficult to cure. This perception is consistent with a study in Ghana that pointed out that perception on etiology of the disease changed if the situation worsened (27). The mystery surrounding its transmission and not having proper treatment is a major factor determining the stigma of this disease. This is evidenced by what patients confessed in this study that they were being labeled as being infectious to others, being bewitched and cursed. Similar findings were also observed in a study that was done in Ghana that concluded that social stigma for patients with Buruli ulcer are huge (24). Our respondents were mainly peasant farmers and fishermen who frequently went out to gardens in swampy areas along water bodies, thus strengthening the notion of these activities being risk factors for acquiring the disease.

In this study, 17 (89.5%) of the 19 patients went to seek help for the disease, of which 52.9% first tried to solve their problem by visiting the traditional healers for treatment with herbs. Majority of those who sought for help reported doing so after seeing the ulcerative form of the disease. Only two patients did not seek any help at all. With the reported high level of stigma among our patients, it did not show any influence on health seeking pattern of our patients. Some of our patients sought help from both the traditional herbalist and the health units. Other studies done on tuberculosis patients found that stigma significantly influenced the neglecting of a disease (28, 29).

This study has shown that patients with Buruli ulcer are still stigmatised as members of the community. Much as this is a community where the disease is reported to be emerging, the community's perception of the disease is of fear and resentment. This could be explained by its unknown mode of transmission. However some patients reported having received support from family members. This could be a result of tolerance to the disease and hence they adjust their attitude towards it. It is important that educational programs on Buruli ulcer be developed which increases awareness of the disease and may also lower the level of stigma. These programs will also help in disease detection and hopefully improve the health seeking behaviour of patients. Educational programs should emphasize treatment at early stages of the disease, explanation on the possible cause of disease and the best treatment and prevention strategies available (24). This will help reduce the cultural beliefs and feeling about the disease in the community.

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