

Pyrex Journal of Medicine and Medical Sciences. Vol 1(2) pp 013-022 December, 2014. http://www.pyrexjournals.org/pjmms Copyright © 2014 Pyrex Journals

Full Length Research Paper

### Perceived Causes and Impacts of Buruli Ulcer and Societal Measures to Reduce Human Suffering from the Disease in the Nsawam-Adoagyiri Municipality of Ghana

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Accepted 22nd November, 2014.

We analyzed the perceived causes of Buruli ulcer disease, impacts of the disease and measures that the government could undertake to reduce the impacts based on a random sampling survey of 200 respondents from the Nsawam-Adoagyiri Municipality in Ghana. The study involved sufferers of the disease, non-sufferers of the disease living in the communities of the sufferers, and health personnel offering care to patients at two government health centres. The results indicated that the most important cause of the disease, from the perspective of its sufferers, was the use of contaminated water for domestic household activities. On the other hand, non-sufferers living in the community indicated that the most important cause of the disease was from the natural environment due to the swampy nature of the area and worms or insects being the mode of spread of the disease from this swampy environment. However, health personnel considered the most important cause of the disease was poor personal hygienic practices. The majority of sufferers indicated that the disease had limited their ability to perform tasks in their community and imposed considerable costs on them. Respondents requested the government to undertake societal interventions to reduce the prevalence and impacts of the disease in the Municipality. These included the provision of free medical treatment for the disease, the provision of more information about the disease and its prevention to the public, improvement of the quality of environmental sanitation and research to identify the causes of the disease and its cure.

**Keywords:** Buruli ulcer, disease perceptions, Ghana, health economics, health education, neglected tropical diseases, prevention.

#### INTRODUCTION

#### 1.1 Background

Mycobacterial diseases such as leprosy and tuberculosis plagued the world for thousands of years until major scientific advances in the 20th Century led to their cure and freedom for millions of people afflicted with these diseases. Another mycobacterial disease, Buruli ulcer thought to be caused by the parasite, Mycobacterium ulcerans, is a major disease based on its morbidity and mortality effects (Aujoulat et al., 2003). The disease is considered to be the most important among the 17 Neglected Tropical Diseases (NTD). These NTDs occur mainly in poverty-stricken tropical and sub-tropical areas, and according to the World Health Organization (WHO), there are no known cures (WHO, 2000; WHO, 2012).

Buruli ulcer affects mostly the limbs and the trunk, starting as a painless swelling (called nodule) in the skin and causing severe deforming and debilitating ulcers if it is not detected and treated on time (WHO, 2000; WHO, 2012). The mode of its transmission is still unknown. Infection leads to extensive destruction of skin and soft tissues with the formation of large ulcers usually on body extremities. Patients who are not treated early suffer long-term functional disabilities such as restriction of joint movement as well as the obvious cosmetic problem of ugly scarring that may need extensive skin grafting to bring the body even a little bit closer to normal. Skin grafting is expensive for many patients of the disease such as the scar developed from the ulcers become permanent for life. Early

diagnosis and treatment are is vital in preventing such disabilities and/or death (WHO, 2000; WHO, 2001; WHO, 2012).

#### 1.2 The Problem Statement

The incidence of buruli ulcer in Ghana is relatively high (Asiedu et al., 2000). Ghana is ranked as one of the most endemic countries of the disease. It is the perception of most people in the endemic areas that, the disease is as a result of poor hygiene, drinking contaminated water from the rivers, contact with other sufferers, sexually transmitted or a general disease from the environment where they are in contact with the swamps and other insects or worms from the rivers or marshes. Others have linked the disease to magical and religious factors like witchcraft (Stientra et al., 2002). Scientific studies have shown that mycobacterium ulcerans which is a suspect for the cause the disease is found living free in the environment and so therefore, the disease is believed to be contracted from the environment.

According to the Ghana national case search for Buruli ulcer conducted by Amofah et al. (2002), the overall crude national prevalence rate of active lesions was 20.7 per 100,000 persons, but the rate was 150.8 per 100,000 in the most disease-endemic districts. According to the WHO fact sheet 119 on Buruli Ulcer, more than half of the infected persons in Africa such as Ghana are children (WHO, 2001). Children may have to spend long hours getting treatment in the hospital for the disease and may lose valuable learning and playing time which is more important in their transformative years. In some cases, children had discontinued their education all together. Children disfigured by this disease fall short of a normal life not being able to get decent jobs and work in the fields to support themselves in the future.

The effects on children are similar to those of men and women. The disease limits the movement of the sufferer and incapacitates him/her in its advanced stage. The ulcer has a terrible smell which causes the sufferer to shy away from the public to avoid being ostracized or being accused as being cursed. For women especially those in rural and impoverished communities, the effects are much greater. Women generally undertake many household activities, like cooking, cleaning and fetching of water from communal sources, and also pursue income-generating activities, like farming and trading. Women sufferers who develop disabilities from the disease are limited by their ability to perform household tasks and undertake income-generating activities.

Our study area is the Nsawam-Adoagyiri Municipality (district), one of the major endemic areas of the disease in Ghana. The campaign against buruli ulcer in this area is geared towards the treatment of reported cases which almost too frequently are reported a bit too late into the lifespan of the disease, where the disease may have already passed the pre-ulcerative stage (the stage at which antibiotics can be used to suppress the ulcer from occurring). Not much work has been done on education and sensitization about the disease. The disease also does not follow a particular trend and so may not be easily detected in its early stages. Many people end up with the severest of ulcers due to their ignorance and the perception they hold about the disease and show up too late at the health centre for treatment.

Efforts to control the disease have been promoted by local authorities in the municipality, but they lack the logistics to reach out to every individual. The disease itself is unsightly and also the fact that there is no known cure makes it also difficult

to attract donors to support the cause of eradication of the disease. Scientists and medical experts in this field have not been able to come up with a significant mode of spread or diagnosis of the disease and in effect have been unable to develop any form of vaccine or counter drug to solve the problems of this disease. The perception of people about the disease has influenced the health seeking behavior of sufferers and also affected the rate of prevalence of the disease.

The objectives of the study are threefold: (1) to identify the perceived causes of Buruli ulcer disease from both sufferers and non-suffers; (2) to determine the effects of the disease on human welfare; and (3) to establish the social intervention measures required to reduce suffering from the disease in the Nsawam-Adoagyiri Municipality. The rest of the paper is organized as follows: the next section expands on the literature review of the disease partly discussed earlier and provides a theoretical framework that guides the study. This is followed by the methods used to elicit data from respondents to tackle the objectives. The results are reported in the fourth part of the paper. The conclusions and recommendations follow.

#### 2. LITERATURE REVIEW

# 2.1. The Prevalence Rate and Morbidity of the Buruli Ulcer Disease

Buruli ulcer is a skin disease, which usually begins as a painless nodule or papule and may progress to massive skin ulceration. If untreated buruli ulcer may lead to extensive soft tissue destruction, with inflammation extending to deep fascia. Subsequent complications may include contractures and deformities (Duker et al., 2004). The disease gradually eats up the skin and rots the flesh away in a distasteful manner and gradually affects the bone of the sufferer leaving a behind necrotic aftermath (Ofori-Adjei, 2011).

Buruli ulcer is prevalent all over the world with major appearances of the disease reported in Southeastern Australia, Japan, in Asia, and several countries in Africa. McCallum first discovered the disease in a child from Bairnsdale in Australia in 1940, and gave the name Bairnsdale as the name of the disease in reference to where he first recorded it. In 1948, MacCallum published the first clinical description of the disease. Previously in 1897, Sir Robert Cook had observed the disease characterized by some large ulcers in a region near the Nile River in Uganda. The area where he discovered the disease most prevalent was called Buruli near Lake Kyoga and therefore named the disease after that region (WHO, 2000).

According to WHO, Buruli ulcer has been reported in over 30 countries all over the world. Limited knowledge of the disease, its focal distribution and the fact that it affects mainly poor rural communities contribute to low reporting of cases. The disease is said to occur in the swamps of subtropical and tropical climates. The common feature of the disease is that it is prevalent in areas located close to swamps with green and damp vegetation or aquatic areas. Progress is being made now to develop tools for early diagnosis, to understand how the infection is transmitted and to improve treatment even though there are several speculations stating that the disease is caused by a vector or insect in the environment (WHO, 2000).

WHO reports that the total buruli ulcer cases recorded globally in 2012 including that of Ghana was 5,076 with Africa

being the worst affected region. Ghana is the second most endemic country after La Cote D'Ivoire globally (WHO, 2012). The overall prevalence in Ghana is 22.7 cases per every 100,000 inhabitants. Amofah et al. (2002) indicate that the disease has been reported in all the ten regions of the country with the Ashanti Region accounting for over 60% of all cases. In Ghana, the disease has been reported in several communities with occurrences now seen in urban and periurban areas instead of only rural areas that was observed in the past. The first possible case of Buruli Ulcer in Ghana was reported in 1971 in the Greater Accra Region (Bayley, 1971). Local Ghanaian names exist for the disease such as 'Mpompo bone' (dangerous boil) (Adoma, 2003).

#### 2.2. Theoretical Framework

Buruli ulcer has major impacts on those afflicted generating impacts across the community where the afflicted people live. Sufferers of buruli ulcer are largely incapable of reaching their economic potential due to the restrictions the disease imposes on their movements and participation in labor and commodity markets. This inability to fully participate in markets is a clear example of what economists call market failure, reflecting the basic failure of the individual, regardless of how talented he or she is, from participating fully in social and economic activities due to the disease.

This market failure is not only due to the disease afflicting the person but can also be due to inadequate information about the causes of the disease and its prevention for those afflicted and the general public. This information failure problem means that preventable cases of the disease persist because individuals and the general public do not have the basic information about the disease. Market failure, means that free market economic system, where everyone is left to himself or herself to manage their own affairs, in the production, consumption and distribution of goods and services, is largely dysfunctional in the case of the buruli ulcer disease where the cause of the disease has not been established and many people potentially at risk do not have adequate information about the disease and its prevention.

Anaman (2014) summarizes the ten major sources of market failure inherent in the actual performance of the free market-based systems which then require some interventions to correct the failure to allow for better functioning of the market system. These failures are (1) the good produced is non-homogeneous in quality; (2) there is the absence of many buyers and sellers in the market for the good; (3) there are significant barriers to entry into the market and exit out of the market; (4) producers and consumers of the good (market participants) have imperfect information; (5) there is the presence of negative third party effects, beyond those accruing to the producer and consumer of the good or product, from the production or consumption of the good, (6) there is presence of decreasing returns to scale; (7) the good can be consumed by many people at the same time or indivisible in nature; (8) participants in the market are not capable of working and are not able to produce goods and services for themselves or for exchange in the market place; (9) the natural environment is not conducive for the production of any good and (10) peace and basic functioning of basic law do not exist.

Factors 3, 4 and 8 exist for people afflicted with buruli ulcer disease, even in a society that is peaceful and have good natural environment for the production of goods such as Ghana. When markets clearly fail as is the case with buruli ulcer disease, interventions may come from the Community and/or the State to ameliorate the situation of helpless and

impoverished people who are simply incapable of helping themselves (Hayami, 1989; Hayami, 2009; Buadi et al., 2013; Anaman and Nyadzi, 2014). The Community is composed of non-State actors such as non-governmental organizations, religious groups and semi-voluntary structures linked through blood ties such as extended families.

The State can also intervene in the case of market failure; it raises taxes as part of its functions for the development of the country and some of these taxes can be used to undertake research work for the treatment and cures of diseases such as buruli ulcer. The State can also provide subsidized medical treatment for people afflicted with diseases who are poor. An important role of the State is also to provide proper and timely information to the citizenry so that people can take measures to prevent them from getting diseases such as buruli ulcer.

#### 3. METHODOLOGY

#### 3.1. Survey Sampling and Administration Procedures

The survey area was in the Nsawam-Adoagyiri Municipality, a peri-urban area, which is one of the 216 local government districts in Ghana. It is situated about 30 kilometers from Accra, the capital town of Ghana, and serves a major commuting centre for many people working in Accra. The municipality is considered an endemic area for the disease. Data were collected from two health centres namely Djankrom Health Centre and Nsawam Health Centre with the aid of the structured questionnaire over a period of six months from April to September 2013. A pilot survey was undertaken at the Pakro Health Centre in January 2013. Pakro Town used to be part of the municipality, but was joined to a newly-created district during the national government decentralization rezoning in 2012. Before 2012, Pakro Health Centre used to be the major clinic that treated buruli ulcer patients in the old municipality.

Given that the disease was a rare situation, many sufferers were quite difficult to reach. Weekly visits over a period of six months were made to the two health centres to have access to sufferers who had come in for treatment. Most sufferers visited the health centres only on the days when the epidemiologist was due to visit. Others who were still on the medical treatment of the antibiotics visited their health centres daily for injection and receive antibiotics to treat the ulcer. These informed the choice of random sampling of sufferers. All patients who were present at the two health centres during each weekly visit were interviewed. Caution was taken so as not to interview the same respondent twice.

Non-sufferers of the disease were also interviewed using a random sampling method. First, all available health personnel at the health centres were interviewed using the same structured questionnaire during the weekly visit to the two health centres. Non-sufferers living in the communities resided by the sufferers were also interviewed based on the use of multi-stage cluster random sampling method. Non-sufferers were interviewed in each town that sufferers indicated they came from. For interviewing non-sufferers, the number of houses in each village was ascertained and numbered sequentially. Then one-sixth of the houses were chosen randomly using a scientific calculator with a random number generator. The interviewer (the second author of the report) visited each house that was randomly selected by the calculator and interviewed house heads and/or relevant people

who were non-sufferers of the disease using the questionnaire. This sampling method was applied to all the 16 communities where the sufferers had reported they came from. In all, 107 houses were randomly selected.

The number of people interviewed was 200 but due to incomplete questionnaires only 193 were used for analysis. This was made of 43 sufferers, 128 non-sufferers and 22 medical personnel. Overall, it could be argued that the study was based on a scientific sampling approach, allowing us to generalize the results to the larger population in the Municipality.

#### 3.2. Ethical Considerations

During this research, however, a conscious effort was made to base all conclusions and recommendation on the results gathered and processed from the field. Voluntary participation and informed consent were sought and the proper protocol was observed during the data collection process and throughout the study. Respondents were made aware of the purpose of the study and assured of confidentiality and anonymity during and after the survey. All the interviews were held in the most confidential manner and the information gathered was categorized to be personal considering the nature of the disease. Each respondent was taken to a private area and a face-to-face interview was conducted using the prepared questionnaire.

#### 4. RESULTS

### 4.1. Socioeconomic Characteristics of Respondents

Table 1 provides a summary of the socioeconomic characteristics based on frequency analysis for the 193 respondents of the survey consisting of a total of 43 sufferers, 128 non-sufferers living in the community and 22 government health personnel. Thus 22.3% of the respondents were sufferers of the Buruli Ulcer disease, 65.3% were non sufferers of the disease who lived in the communities where the sufferers also lived and the remaining 12.4% were the health personnel based at government clinics and health centres in the municipality.

About 51.2% of the total sufferers of the disease, 45.2% of non-sufferers living in the municipality and 75.0% of the government health personnel were female. With regards to the marital status of respondents, 41.9% of sufferers of the disease were married, about 9.3% were divorced, 14% were widowed while 34.9% were single. For non-sufferers, 46.8% of them were single as compared to the 37.5% of health personnel. About 38.9% and 45.9% of the non-sufferers and health personnel, respectively, were married. About 3.2% of the non-sufferers were divorced in comparison to 8.3% of the medical health personnel.

The majority of the respondents were Christians making up 79.1% of sufferers, 71.4% of non-sufferers and 75.0% of health personnel. About 9.3% of sufferers, 27.0% of non-sufferers and 25.0% health personnel were Muslims. About 7.0% of sufferers and 0.8% of non-sufferers practice traditional religions, while the remaining 4.7% and 0.8% of sufferers and non-sufferers, respectively, practiced both traditional and Christian religions. About 11.6% and 2.4% of sufferers and non-sufferers, respectively had no formal education. A total of 39.5% and 8.7% of the sufferers and non-sufferers had attended primary school and 18.6% sufferers and 16.7% non-

sufferers had acquired junior secondary school level of education.

The largest group of respondents from the sufferers (20.9%) and non-sufferers (27.8%) were engaged in traderelated occupations while students and self employed individuals made up 16.3% each of the sufferers alone. The largest group of the medical respondents were nurses (83.3%). About 8.3% of the health personnel, physician assistants and doctors and epidemiologists constituted 4.2% of the health personnel each. Non-sufferers had various mixed occupations; farmers (12.7%), artisans (17.5%), and civil servants (11.1%). About 7.0% of the sufferers were unemployed as compared to 4.0% of the non-sufferers.

The average figures of selected socioeconomic characteristics of the respondents are reported in Table 2. The mean age for the sufferers was 35.4 years with the youngest respondent aged 15 and the oldest aged 83. This showed that the disease affected a wide range of individuals across age groups. The average age of the non-sufferers was 40.1 years (18 to 76 years range) and 38.5 (24 to 59 years range) for the medical health personnel. Sufferers were engaged in low incomegenerating economic activities like farming and petty trading. Their average monthly income of the sufferers as a group was the lowest, 71.8 Ghana cedis (GHS) (between 0 to 950 GHS). Non-sufferers had an average monthly income of GHS297.3 (50 to 1050 GHS) while health personnel had an average income of GHS366.7 (50 to 1350 GHS). One GHS was worth 0.4 U.S. dollar in September 2013 when the survey was completed.

Overall, sufferers had considerably lower incomes. This factor could the result of their inability to work continuously because of the infection of the disease and the large amounts of time that they spent receiving treatment at clinics. The average lower income of sufferers also reflected their lower educational attainment levels; these levels were also apparently related to the severity of the disease and when sufferers were afflicted with the disease. Table 2 also indicates that the average household size of household for sufferers was 7.9, the lowest of the three groups. The non-sufferers of the disease from the community had an average household size of 9.7 and non-sufferers who were health personnel had an average household size of 9.1.

Table 1: Summary socioeconomic characteristics of respondents based on their Buruli Ulcer suffering status using frequency analysis based on

percentages.			
Item/group	Sufferers of	Non-	Non-
- '	Buruli Ulcer	sufferers of	sufferers of
	disease	Buruli Ulcer	Buruli Ulcer
		from the	who are
		general	Health
		community	Personnel
Proportion of sub-group	22.3	65.3	12.4
in the whole group			
Gender			
Female	51.2	45.2	75.0
Male	48.8	54.8	25.0
Marital Status			
Single	34.9	46.8	37.5
Married	41.9	38.9	45.8
Divorced	9.3	3.2	8.3
Widowed	14.0	4.0	0.0
Informal	0.0	7.1	8.3
Religious Affiliation			
Christian	79.1	71.4	75.0
Muslim	9.3	27.0	25.0
Traditionalist	7.0	0.8	0.0
Christian//Traditionalist	4.7	0.8	0.0
Educational Level			
No formal education	11.6	2.4	-
Primary school	39.5	8.7	-
Junior secondary	18.6	16.7	-
School		11.9	
Middle school	9.3	19.8	8.3
Senior secondary	20.9	7.9	4.2
school			8.3
Secondary  Taskeisel	-	45.4	
Vocational Technical Commercial	-	15.1	41.7
		4.8	41.7
	-	4.6	4.2
secondary certificate  Post secondary		7.1	4.∠
diploma	-	/.1	25.0
► Bachelor degree		3.2	25.0
Postgraduate degree		2.4	8.3
, i osigraduate degree	_	∠.+	0.0

Table 2: Summary of selected socioeconomic characteristics of respondents based on averages.

respondents based on averages.				
Item	Sufferers of Buruli Ulcer (Percentage)	Non-sufferers of Buruli Ulcer from the general community	Non-sufferers of Buruli Ulcer who are Health Personnel	
Age (years)	35.4 40.1 (15 to 83) (18 to 76)		38.5 (24 to 59)	
Personal monthly income in Ghana cedis (GHS)	71.8 (0 to 950)	297.3 (50 to 1050)	366.7 (50 to 1350)	
Total number of people in the household	number of people (2 to 20)		9.1 (4 to 26)	
Number of children in the household	3.4 (1 to 15)	3.6 (0 to 11)	3.5 (1 to 8)	

#### Notes

The figures in the parentheses are the ranges.

#### 4.2. Assessment of the Causes of Buruli Ulcer

Tables 3, 4 and 5 provide information on the perceived causes of Buruli ulcer as ascertained from the various groups of respondents for (a) Buruli ulcer sufferers, (b) non-sufferers living in the community and (c) health personnel in the community who worked closely with patients. Since scientists have not clearly and fully established the causes of Buruli ulcer conclusively, this study attempted to ascertain the perceived causes of the disease directly from respondents as a way of

guiding scientific researchers in finding cures for the disease. The respondents were required to rate their responses using scores based on 5 denoting that item is extremely important, 4 very important, 3 moderately important, 2 of low importance and 1 not important.

Table 3 provides a summary of the assessment by Buruli Ulcer sufferers of the importance of their perception of the cause of the disease. The most important perceived cause of the Buruli Ulcer disease was drinking and using contaminated water for domestic and household activities, based on an average score of importance of 3.23 (out of a maximum score of 5.0). The second most important perceived cause of the disease with an average score of 3.19 was the nature of the environment due to the swampy nature of the area and the possibility of worms or insects being the carrier or the mode of spread of the disease. The sufferers indicated that there was a possibility of getting infected due to the contact they had with the swampy areas probably through farming activities or the dense forest region that surrounded them.

The sufferers also rated, by with an average score of 3.0, poor hygiene as the next most important cause of the Buruli ulcer disease. They felt that perhaps the disease could be contracted through maintaining improper hygienic practices. Ranked as the fourth most important cause of the disease, where witchcraft and black magic with an average score of 2.28. This observation led to the indication that even though this disease is clearly a medical condition, due to the ignorance about the causes of the disease, some of the sufferers blamed sorcery and magic-religious sources as the cause of the disease. Other relatively unimportant reasons (with lower average scores of 2.23 and under) were swimming in the River Densu or other water bodies, generational curses, having physical contact with the infected person, eating some peculiar foods or through sexual contact.

Table 4 provides summary results of respondents's assessment of the importance of their perceived causes of the disease for non-sufferers of the Buruli Ulcer disease who lived in the community. From the table, the highest average score of 3.85 was attributed to the contraction of the disease from the environment due to the swampy nature of the area and the possibility of worms or insects being the carrier or the mode of spread of the disease. Closely ranked with an average score of 3.69 was poor personal hygiene followed by drinking and using contaminated water for domestic and household activities with an average score of 3.25. This group of respondents ranked witchcraft and black magic as the fourth most important cause of the disease with an average score of 2.70. Sufferers of the disease ranked this cause at the same position as the nonsufferers even though the average score differed. There were other perceived causes with a score that were modestly important (with scores of 2.54 and under) like, swimming in the River Densu or other water bodies, contact with an infected person, giving care to sufferers or through sexual contact.

Table 5 provides a summary of the respondents' assessment of the importance of their perception of the cause of Buruli Ulcer by health personnel. This group of respondents ranked poor personal hygiene the most important perceived cause of the Buruli Ulcer Disease with an average score of 4.13. With an average score of 4.08, the contraction of the disease from the environment due to the swamps in the area was ranked as the second most important perceived cause of the disease. The third most important perceived cause of the disease ranked by this group of respondents with an average score of 3.50, was drinking and using contaminated water for domestic and household activities. Other perceived causes with lower average scores of importance, (from 3.24 or lower),

included swimming in the river and witchcraft or black magic which scored relatively higher averages than generational curses physical contact with an infected person, sexual transmission, caring for sufferers or from eating specific foods which were of less importance to the respondent.

Table 3: Buruli ulcer sufferers' assessment of the perceived importance of causes of the disease

causes of the disease.				
	Cause	Average	Standard	Coefficient
No.		score of	deviation of	of variation
		importance	score	of score
1	Drinking and using	3.23	-1.49	0.46
	contaminated water for			
	domestic and household			
	activities			
2	Contraction of the	3.19	1.50	0.47
	disease is from the			
	environment due to the			
	swampy nature of the			
	area and the possibility			
	of worms or insects			
	being the carrier or the			
	mode of spread of the			
3	disease	3.00	1.77	0.59
3	Poor personal hygiene practices	3.00	1.77	0.59
	practices			
4	Witchcraft and black	2.28	1.59	0.70
7	magic	2.20	1.00	0.70
	ag.c			
5	From swimming in the	2.23	1.62	0.73
_	River Densu or other			
	water bodies			
6	Generational curses	1.53	1.32	0.86
7	Having physical contact	1.44	0.80	0.56
	with an infected person			
8	From eating specific	1.29	0.77	0.60
	foods			
9	Sexually transmitted	1.02	0.15	0.15
	disease			
10	The disease is	1.00	0.00	0.00
	contracted from giving			
	care to persons			
	suffering from the			
	disease			

The scoring is based on 5 denoting that the item is extremely important, 4 very important, 3 moderately important, 2 of low importance and 1 not important.

Table 4: Assessment of the perceived causes of the disease by non-

sufferers who live in the community of the sufferers				
No.	Cause	Average score of importance	Standard deviation of score	Coefficient of variation of score
1	Contraction of the disease is from the environment due to the swampy nature of the area and the possibility of worms or insects being the carrier or the mode of spread of the disease	3.85	1.13	0.29
2	Poor personal hygiene practices	3.69	0.99	0.27
3	Drinking and using contaminated water for domestic and household activities	3.25	1.34	0.41
4	Witchcraft and black magic	2.70	1.31	0.49
5	From swimming in the River Densu or other water bodies	2.54	1.60	0.63
6	Having physical contact with an infected person	1.96	1.13	0.58
7	The disease is contracted from giving care to persons suffering from the disease	1.51	0.75	0.50
8	Generational curses	1.50	0.86	0.57
9	Sexually transmitted disease	1.34	0.60	0.45
10	From eating specific foods	1.19	0.39	0.33

#### Notes:

The scoring is based on 5 denoting that the item is extremely important, 4 very important, 3 moderately important, 2 of low importance and 1 not important.

Table 5: Assessment of the causes of the disease by non-sufferers who are health personnel

	Cause	Average	Standard	Coefficient
No.		score of	deviation of	of variation
		importance	score	of score
1	Poor personal hygiene practices	4.13	1.26	0.31
2	Contraction of the disease is from the environment due to the swampy nature of the area and the possibility of worms or insects being the carrier or the mode of spread of the disease	4.08	0.83	0.20
3	Drinking and using contaminated water for domestic and household activities	3.50	1.38	0.39
4	From swimming in the River Densu or other water bodies	3.42	1.53	0.45
5	Witchcraft and black magic	2.58	1.56	0.60
6	Generational curse	1.79	1.38	0.77
7	Having physical contact with an infected person	1.75	1.11	0.63
8	Sexually transmitted disease	1.38	0.88	0.64
9	The disease is contracted from giving care to persons suffering from the disease	1.29	0.69	0.45
10	From eating specific foods	1.25	0.44	0.35

#### Notes:

The scoring is based on 5 denoting that the item is extremely important, 4 very important, 3 moderately important, 2 of low importance and 1 not important.

# 4.3. Health Effects of Buruli Ulcer Ascertained from Sufferers of the Disease

Tables 6 and 7 provide some information on the health effects of the disease as reported by sufferers of the disease. About 72.1% of the sufferers indicated that the disease had affected their performance of their usual duties. Of all the respondents, 39.9% of them expressed the extent of the limitation as very severe, 16.3% said it was severe, 20.9% moderate, 14.0% very little and 14.0% said they were not limited at all. Those who felt that they were not limited in their movement were those who had reported the disease early to the health centre (refer to Table 6 for the identical figure of 27.9% for those who were not limited by the disease in rows 2 and 3 and also for those who sought treatment for the first time at the health centre in row 5).

About 97.7% of sufferers had sought treatment at the health centre over the previous 12 months. Only 27.9% of the sufferers sought treatment for the first time at a health centre. The largest proportion of sufferers, 34.9%, initially used self-medicated products. Another 25.6% of the sufferers initially consulted the traditional herbalist for treatment with local herbs while the remaining 11.6% went to the traditional shrine/religious priest for divine consultation. There were several reasons for the delay in reporting to the health centre. Over 50% of the sufferers blamed the delay on being ignorant about the disease.

A total of 19.5% blamed the delay on both financial constraints and ignorance about the disease while 17.1% blamed the delay on financial constraint alone. The remaining 7.3% of the sufferers delayed in reporting to the hospitals for fear of being stigmatized. Due to delays in reporting on time and first to the health centres, 56.1% of the sufferers arrived at the health centre when the disease had progressed to the ulcerative stage, 24.4% at the oedema stage and 19.5% at the nodal stage. A total of about 93% of the total sufferers reported that they had no prior education on detecting the early symptoms of the disease indicating a major information failure or problem.

The average number of times that sufferers visited a health centre for treatment during the previous 12 months was 44.4. This indicated that out of the 52 weeks in the year, the sufferer was in the clinic almost once every week, spending an average of GHS7.00 per visit. The average cost per treatment at the health centre over the previous 12 months was GHS310.7. Considering the average monthly income of the sufferer, which was GHS71, it was clear that the sufferer was financially burdened with the treatment for the disease. Transportation to the health centre was also an additional cost item that took a toll on the sufferer's income.

Table 6: Summary of health effects of Buruli ulcer identified by sufferers of the disease during the survey and places that they sought treatment.

Item	Percentage of
	sufferers
Has the disease limited the ability of the sufferer to perform	
tasks in the community	
> Yes	72.1
➤ No	27.9
Extent of limitation of ability caused by the disease	
Very severe	34.9
Severe	16.3
Moderate	20.9
Very little	13.95
Not at all	13.95
Where the sufferer sought treatment over the previous 12	
months	
Health centre	97.7
Traditional shrine/religious priest	4.7
Traditional herbalist	9.3
Self medication	14.0
Where the sufferer sought treatment for the first time	
Health centre	27.9
Traditional shrine/religious priest	11.6
Traditional herbalist	25.6
Nursed at home/self medication	34.9
Reason for the delay in reporting the disease at the health	
centre	
Ignorance of the disease	56.1
Financial constraint and ignorance of the disease	19.5
Financial constraint	17.1
Fear of stigmatization	7.3
The stage that the disease was reported to the health centre	
Ulcerative stage	56.1
Oedema stage	24.4
Nodal stage	19.5
Any prior education on detecting the early signs of the	
disease	
➤ Yes	7.0
➢ No	93.0

Table 7: Summary of some effects of Buruli ulcer on human welfare as ascertained from sufferers of the disease during the survey based on averages.

No.	Item	Outcome
1	Proportion of sufferers who indicated that the disease has limited their ability to perform in the community expressed as a percentage	72.1
2	Number of times that the sufferer has received treatment at a government health centre during the previous 12 months	44.4
3	Average cost of treatment per visit to the health centre over the previous 12 months in Ghana cedis	7.0
4	The total average cost for treatment at the health centre over the previous 12 months in Ghana cedis	310.7

#### 4.4 Perceived Quality of Treatment Services Received by **Buruli Ulcer Sufferers**

The perceived quality of the treatment received by sufferers of the disease at various centres is reported in Table 8 based on a Likert-type scoring system with 5 denoting an excellent quality, 4 good quality, 3 moderate quality, 2 unsatisfactory qualities and 1 low quality. Though only 27.9% of sufferers sought medical care for their ulcers from health centres when they were initially infected, however the quality of service in the health centre was rated of generally good quality with an average quality score of 3.86 out of the maximum of 5.0.

The perceived quality of treatment rendered by the traditional herbalist, was given a very low average score of 1.0 even though a total of 25.6% first reported their infection to traditional herbalist. About one third of infected patients first nursed themselves at home before visiting the health centre. However the perceived quality of self-medication averaged only 2.0. This indicated that even though the majority of sufferers initially resulted to self-medication, they perceived the treatment at the health centres to be of much better quality.

Table 8: Perceived quality of services rendered by various treatment centres as ascertained by Ruruli ulcer sufferers

	centres as ascertained by buruit dicer sufferers.				
No.	Treatment centre	Average score of	Standard deviation of	Coefficient of variation of	
		importance	score	score	
1	Government-owned health centre	3.86	1.00	0.26	
2	Traditional herbalist	1.00	-	-	
3	Self medication	2.00	-	-	

#### Notes:

The scoring is based on 5 denoting that the item is excellent quality, 4 good quality, 3 moderate quality, 2 unsatisfactory quality and 1 very low quality.

#### 4.5. National Government Societal Interventions **Requested by Survey Respondents**

Table 9 presents various suggestions to the national government by various groups of respondents to reduce the prevalence and impacts of the disease in Ghana. About 40.5% of the sufferers of the disease suggested that the government should provide medication to treat the disease for sufferers including counselling advice related to treatment. About 29.7% of sufferers suggested the government should undertake more research into the causes and possible treatment and cure for the disease. Another 10.8% of sufferers suggested an increase

in awareness information about the disease and an equal proportion also requested a special treatment centre to be built for sufferers to award them some privacy of treatment without fear of stigmatization. The other suggestions made by sufferers included the government should undertake ventures like improving the quality of sanitation and water in the community, provide assistance to sufferers for transportation to clinics and hospitals, ensure that more medical personnel and experts are trained to reduce the long queues at the health centres and also to ensure that funds directed towards the disease are not misused.

Non-sufferers also expected the national government to undertake efforts to curb the disease. Most importantly, 48.3%, based on frequency analysis, suggested that the national government should provide medication to treat the disease for sufferers including counselling advice related to treatment. This was also the most important suggestion made by the sufferers. The second most important suggestion made by 22.4% of nonsufferers were the improvement of environmental sanitation by the government. About 10.8% of them suggested that more research be done into the causes and to find a treatment and a possible cure for the disease while 8.0% wanted more medical personnel trained in providing treatment for the disease.

For the health personnel the most important suggestion to the national government to reduce the impacts of the disease made by about 26.0% of the group was for the government to provide medication to treat the disease for sufferers including counselling, advice related to the treatment; this was a similar suggestion by sufferers and non-sufferers living in the community. About 21.7% of them felt that more research should be done into the causes and possible treatment and cure of the disease. Improvement in the quality of environmental sanitation and water supply, and increase in the awareness and information about the disease were two other important strategies suggested by health personnel.

Table 9: Respondents' suggested national government intervention measures to reduce the prevalence of Buruli ulcer in Ghana in terms of importance based on frequency analysis of reported suggestions for the

three different groups of people Nο Suggestion Percentage Percentage Percentage health of suffers of nonof indicating sufferers personnel this response indicating indicating this response this response The National 40.5 48.3 Government should provide free medication to treat disease the for sufferers including counselling advice related to treatment 10.8 2 The National 29.7 21.7 Government should undertake more research into the causes and possible treatment and cure for the disease 3 The National 10.8 7 1 13.0 Government should increase awareness information about the disease 4 The National 10.8 Government should build special hospital for sufferers of the disease 5 The National 22.4 13.0 Government should improve the quality environmental sanitation and water in the community 6 The National 8.7 Government should provide assistance for the transportation of sufferers to clinics and hospitals National The 8.0 8.7 Government should train more medical personnel and experts the treatment of buruli ulcer National 8 The Government funds for treatment of the disease should not be misappropriated

# 4.6. Local Government Societal Interventions Requested by Survey Respondents

Concerning the role of local government in reducing the prevalence and impacts of the disease in the community, almost half (48.6%) of sufferers suggested that the District Assembly should engage in awareness and sensitization drive within the community to inform the public about the disease including setting up zonal and area awareness committees. Other important suggestions by sufferers included the provision of mobile treatment centres that could reach the villages where sufferers lived and the improvement of the environmental sanitation and water supply situation in the community by the District Assembly.

About 50.9% of the non-sufferers said that the District Assembly should engage in awareness and sensitization drive within the community to inform the public about the disease including setting up zonal and area awareness committees.

Another 19.6% suggested the District Assembly should be active in the efforts against reducing the prevalence of the disease; 13.7% said an improved environmental sanitation in the community, including a halt in the use of polluted water sources by from the public. About 11.8% of the respondents suggested that the District Assembly should provide mobile treatment centres and vehicles for sufferers.

Suggestions by the health personnel for direct interventions by local government included the engagement of awareness drives by the District Assembly and this was the most important suggestion indicated by 28.5% of these personnel. Other suggestions were the improvement of the quality of environmental sanitation and water in the community, including halting the use of polluted water by the public and also proper education related to hygiene.

#### 5. CONCLUSIONS AND RECOMMENDATIONS

#### 5.1. Conclusions

The study involved a survey of 200 respondents dealing with Buruli ulcer disease in the Nsawam-Adoagyiri Municipality of Ghana. The respondents consisted of sufferers and nonsufferers of the disease as well as some medical health personnel offering care to patients at government health centres. Our study relied largely on randomly-selected respondents using highly-confidential interviews rather than the focus-group approach used by other researchers to gather data on the disease in West Africa, for example, refer to the works of Aujoulat et al. (2003) and Renzaho et al. (2007). Thus, we believe that our approach allowed the respondents to give a more valid assessment of their conditions compared to situations of focus groups where sufferers might be less inclined to provide fuller information.

The first objective of the study was to determine the perceived causes of the buruli ulcer disease from both sufferers and non-sufferers. The sufferers felt that drinking and using contaminated water for domestic household activities, was the most important cause of the buruli ulcer disease. Nonsufferers awarded an average score of 3.85 to the contraction of the disease from the environment due to the swampy nature of the area and the possibility of worms or insects being the carrier or the mode of spread of the disease. Health experts were of the view that the most important cause of the disease was poor personal hygiene practices.

The second objective was to determine the view of sufferers and non-sufferers on the effects of the disease on human welfare. About 72.1% of the total sufferers agreed that the disease had limited their ability to perform tasks in their community while 27.9% of them felt that the disease had not inconvenienced them. However, 34.9% of them felt that the extent of their limitation and inability to perform their tasks in the community was very severe.

The third objective was to determine the social intervention strategies, if any, which could be adopted to help reduce the degree of human suffering from the disease. It is clear from the findings of the study of the existence of extensive and pervasive market (individual) failure related to the debilitating nature of the disease for which sufferers and their communities are largely incapable of dealing with this disease alone and hence require assistance and support from State institutions in cooperation with Community-based organizations.

Several suggestions were provided for the three groups of respondents to both the national government and local government as intervention measures to reduce the prevalence and impacts of the disease. The most important suggestion to the national government coming from 40.5%, 48.3% and 26% of the sufferers, non-sufferers and health personnel respectively, was for the government was to provide free medication to treat the disease including counselling advice related to the treatment. About 48.6%, 48.3% and 28.5% of the sufferers, non-sufferers and medical health experts respectively agreed that the most important intervention needed from the local government was for in the District Assembly to engage in awareness and sensitization drive within the community to inform the public about the disease including setting up area awareness committees in cooperation with community organizations.

#### 5.2. Recommendations

Our study clearly shows the effects of Buruli ulcer are largely related to the individual or market failure related to information about the disease. As reported in the results section, those people who were afflicted with the disease and reported to the government health centre for their first treatment were exactly those who did not have any permanent damage and had not been limited by the disease. A total of 93% of the sufferers reported that they had no prior education on detecting early signs of the disease. Further, the 7% of sufferers who had prior education on the disease reported first to the government health centre for treatment and did not suffer any permanent damage or limitation to their movement. So while Buruli ulcer in its advanced stage does not have a cure, it is clear that proper information reaching the right people at the right time can effectively eliminate the permanent body damage and scars resulting from the diseases. Hence own recommendations that are noted below are linked to the correction of the individual and market failure related to information on the disease.

Since proper information about the disease is a major key to the early detection and reporting of the disease, the various gaps in the efforts on education on the symptoms of the disease should be abridged through various means. First, the local government (District Assembly) should encourage the formation of groups of sufferers and volunteers who will spend time going round the community to educate people of the symptoms and early signs of the disease and also the benefits of reporting to the right treatment centres on time. Second, educational efforts should be strengthened and also carried out frequently in various languages in which the respondents can make proper sense of, including other local dialects other than what is spoken locally in the area. Film shows can be organized with help from the local or national government to express the plight of other people who have experienced the disease in a bid to convince the people to attend the clinics and report the earliest signs and symptoms.

Third, the traditional herbalist and traditional religious priest are among the key sources of first contacts by with people suffering from the disease by almost half (47.6%) of the sufferers in our study indicating that these traditional sources were their first contacts for treatment. Hence it is important that traditional herbalists and traditional religious priests are trained in detecting the early symptoms of the disease and be encouraged to direct patients with such cases to the relevant health clinics and also to collaborate with health centres to ensure that the right treatment is carried out at these centres. A major learning point for them will also be on how to manage

common boils which are usually the primary symptom of the disease.

Given that traditional African religions encourage their devotees and patients to seek other sources of divine inspiration simultaneously if they desire, the training of traditional herbalists and religious priests by the Ministry of Health, District Assembly and the parent organization of traditional healers and practitioners, the Ghana Psychic and Traditional Healers Association (GPTHA) can be done effectively and efficiently with modest resources. GPTHA was very active as a major source of collaborative governmentcommunity health interventions during the period of rule of Dr. Kwame Nkrumah and the Convention People's Party (CPP) over the 15-year period from February 1951 to February 1966 when the modernization and the use of traditional healing and medical services were a cornerstone of the CPP health policy. This approach can be replicated for the effective control of buruli ulcer in current times.

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