

# SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA

“COMMUNITY PERCEPTION AND KNOWLEDGE OF BURULI ULCER  
IN THE GA WEST MUNICIPALITY AREA”



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## DECLARATION

I Ibrahim J. Kargbo-Labour, declare that except for other people's investigations which have been duly acknowledged, this work is the result of my own original research, and that this dissertation, either in whole or in part has not been presented elsewhere for another degree.

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## DEDICATION

This dissertation is dedicated to my father the late Mr. Bai Kargbo and also to my college mate and friend at the Moscow Medical Academy in Russia - the Late Mr. John Lule of Buruli County (now called Nakasongola District) in Uganda.

May their souls rest in perfect peace (R.I.P).



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## **ABSTRACT.**

Buruli Ulcer is becoming a Public health problem in tropical Countries prompting the establishment of a Global Buruli Ulcer Initiative by the WHO in 1998.

The objectives of the study are to assess the community perception and knowledge of BU and the health-seeking behaviour of Patients.

Quantitative and qualitative data were obtained by interviewing patients with this disease and control subjects in the Ga West Municipality Area.

Common perceived causes were attributed to drinking from pond/river, swimming in rivers, wading in swampy areas, witchcraft and curses. Other reported causes were poor personal hygiene and sanitation.

The common mode of transmission is by drinking contaminated water followed by body contact and through the wound of an infected person.

Financial difficulties, fear of the mutilating aspects of treatment, and social stigma were the main reasons found for delay in obtaining treatment. Patients are reluctant to seek treatment outside their own community.

In conclusion, suffice it to say that community perception and knowledge are major factors contributing to the health-seeking behaviour of Buruli ulcer Patients.

## Table of Contents

DECLARATION .....	ii
DEDICATION .....	iii
ACKNOWLEDGEMENTS .....	iv
ABSTRACT .....	v
LIST OF TABLES .....	ix
LIST OF FIGURES .....	x
LIST OF ABBREVIATIONS.....	xii
CHAPTER ONE .....	1
1. INTRODUCTION .....	1
1.1BACKGROUND.....	1
1.1 STATEMENT OF THE PROBLEM .....	6
1.2CONCEPTUAL FRAMEWORK .....	8
1.3 JUSTIFICATION.....	9
1.4 LIMITATIONS OF THE STUDY .....	10
1.5.....	11
OBJECTIVES OF THE STUDY .....	11
CHAPTER TWO .....	12
2.0 LITERATURE REVIEW .....	12
2.1 INTRODUCTION .....	12
2.2 VIEWS ON BURULI ULCER. ....	12
2.3 KNOWLEDGE .....	19
2.4 COMMUNITY PERCEPTION.....	20
2.5 STIGMATISATION AND SOCIAL ISOLATION .....	25

CHAPTER THREE.....	27
3.0 METHODS.....	27
3.1 Type of Study .....	27
3.2 Study Location/Area. ....	27
3.3 Variables: .....	36
3.4 Sampling .....	37
3.5 Data Collection Techniques/ Methods and Tools .....	39
3.6 Training of Research Assistants.....	41
3.7 Quality Control .....	42
3.8 Data Processing and Analysis .....	42
3.9 Ethical Consideration/Issues:.....	43
3.10 Pretest or Pilot Study .....	43
CHAPTER FOUR .....	44
4 RESULTS .....	44
4.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS. ....	44
4.2 ENVIRONMENTAL SANITATION ISSUES.....	50
4.4 LOCAL NAMES OF BURULI ULCER .....	51
4.5 BURULI ULCER BEING A MAJOR HEALTH PROBLEM IN THE AREA.....	51
4.6 LOCAL IDEAS OF HOW ONE CAN GET INFECTED .....	52
4.7 INFECTIOUSNESS OF BURULI ULCER .....	54
4.8 SPREAD FROM PERSON TO PERSON .....	54
4.9 CATEGORY OF PEOPLE AFFECTED BY BURULI ULCER.....	55
4.10 TREATMENT SEEKING BEHAVIOUR .....	56
4.11 COMMUNITY REACTION TOWARDS BURULI ULCER PATIENTS .....	58
CHAPTER FIVE .....	60
5. DISCUSSIONS.....	60
5.1 Introduction .....	60
5.2 Socio- demographic Characteristics of Respondents .....	61
5.3 Environmental sanitation issues of the communities .....	63
5.4 Local names for Buruli ulcer.....	64
5.5 Mode of transmission of Buruli ulcer .....	64

5.6 Community perception and knowledge of BU .....	65
5.7 Category of people affected by Buruli ulcer .....	65
Community reaction towards Buruli ulcer patients .....	66
5.8 Health seeking behaviour .....	66
CHAPTER SIX .....	68
6. CONCLUSIONS AND RECOMMENDATIONS.....	68
RECOMMENDATIONS.....	69
APPENDIX A .....	71
QUESTIONNAIRE .....	71
APPENDIX B.....	77
APPENDIX C.....	78
REFERENCES .....	80

<b>LIST OF TABLES</b>	<b>PAGE</b>
Table 1: Prevalence of Buruli ulcer cases by region in Ghana 1999	17
Table 2: Prevalence of Buruli ulcer cases in the 10 district with the highest case load  In Ghana, 1999	18
Table 4: Analysis of health indicators	35
Table 4.1.3: Distribution of Respondents by Marital status	48
Table 4.1.5: Distribution of Respondents by religion	49
Table 4.1.6: Distribution of Respondents by Occupation	50
Table 4.9: Distribution of Respondents by who the disease affects most	54
Table 4.11: Distribution of Respondents reaction towards Buruli ulcer patients  by community members.	57

<b>LIST OF FIGURES</b>	<b>PAGE</b>
Figure 1: conceptual framework	8
Figure 2: Map of Ghana showing Buruli ulcer prevalence	15
Figure 3: A map of the Ga West Municipality Area of Ghana	36
Figure 4.1.1 Distribution of Respondents by Age	45
Figure 4.1.2: Distribution of Respondents by sex	46
Figure 4.1.4: Bar graph showing distribution of Respondents by level of education	47
Figure 4.1.7 Pie graph showing ethnicity of Respondents	49
Figure 4.2 Distribution of Respondents source of water for their activities	50
Figure 4.5 A bar chart showing Respondents response on if Buruli ulcer was a Major health problem in the area	51
Figure 4.6: Distribution of Respondents by how one can get infected	52
Figure 4.7: Pie chart showing if Buruli ulcer is infectious	53
Figure 4.8: Distribution of Respondents by how Buruli ulcer is spread from person to person	54
Figure 4.10: Distribution of Respondents by where Buruli ulcer patients	

seek treatment 55

Figure 4.11: Distribution of Respondents by how Buruli ulcer could be

Prevented in their communities 56

## LIST OF ABBREVIATIONS

AIDS	-	Acquired Immune Deficiency Syndrome
BU	-	Buruli Ulcer
DCO	-	Disease Control Officer
DDHS	-	District Director of Health Services
DHMT	-	District Health Management Team
EPDC	-	Epidemiology and Disease Control
FGD	-	Focus Group Discussion
GHS	-	Ghana Health Service
GSS	-	Ghana Statistical Service
MDHS	-	Municipal Director of Health Services
MHMT	-	Municipal Health Management Team
MOH	-	Ministry Of Health
MPH	-	Master of Public Health
NGO	-	Non-Government Agency
SHMT	-	Sub-district Health Management Team

SPSS	-	Statistical Package for Social Science
SHS	-	Senior High School
SUNDS	-	Sudden explained Nocturnal Deaths
WHO	-	World Health Organization

## CHAPTER ONE

### 1. INTRODUCTION

#### 1.1 BACKGROUND

Buruli ulcer is a devastating infectious disease caused by *Mycobacterium ulcerans*. It is named after Buruli County (now called Nakasongola District) located near the Nile River in Uganda, where in 1961 the first large number of cases was reported (WHO, 2007).

The causative organism is from the family of bacteria which causes tuberculosis and leprosy but Buruli ulcer has received less attention than these diseases (WHO, 2009).

The exact mode of transmission is still under investigation. Some patients state that lesions develop at the site of antecedent trauma. Research suggests that in Africa, some aquatic insects of the order Hemiptera (Naucoridae and Belostomatidae) can harbour *M. ulcerans* in their salivary glands and transmit the disease to experimental animals. More recent data from Australia suggest that salt marsh mosquitoes test positive for *M. ulcerans* DNA, although transmission by this type of mosquito has not been established. Further research is in progress to establish the exact role of insects and other factors in the transmission of the disease to humans. If confirmed, BU will be the only known mycobacterial disease to be transmitted by insects (WHO, 2009). The natural reservoir and mode of transmission of the infection remain largely obscure and might differ between endemic foci around the world. However, skin injury and insect bites have been proposed as modes of transmission (Nienhuis et al, 2010).

Buruli ulcer frequently occurs near water bodies – slow flowing rivers, ponds, swamps and lakes; cases have also occurred following flooding. Activities that take place near water bodies, such as farming, are risk factors, and wearing protective clothing appears to reduce the risk of the disease (WHO, 2009).

All ages and sexes are affected, but most patients are among children under 15 years. In general, there is no difference in the infection rate among males and females. The disease can affect any part of the body, but in about 90% of cases the lesions are on the limbs, with nearly 60% of all lesions on the lower limbs. Unlike tuberculosis (TB), there is no evidence to suggest that infection with the human immunodeficiency virus (HIV) predisposes individuals to Buruli ulcer infection. There is also no evidence that the disease can be transmitted from person to person. There is little seasonal variation in the incidence of the disease (WHO, 2009).

Buruli ulcer has been reported from 30 countries in Africa, the Americas, Asia and the Western Pacific, mainly in tropical and subtropical regions. West Africa appears to be the most affected region. In Côte d'Ivoire, approximately 24,000 cases have been recorded between 1978 and 2006. In Benin, nearly 7000 cases have been recorded between 1989 and 2006. In Australia, more cases of BU are being reported recently – 25 in 2004, 47 in 2005 and 72 in 2006. Most of the recent cases have come from the State of Victoria and the town of Point Lonsdale. Increasing number of cases are being reported from Cameroon, Congo, Gabon, Sudan, Togo and Uganda. After 30 years of no official report, an assessment carried out in south-eastern Nigeria in November 2006 confirmed some BU cases.

Some patients have been reported from China, but the extent of the disease is not known. Recent reports suggest, for the first time, that Brazil may be endemic in the areas bordering French Guyana. These numbers may only be an indication of the presence of the disease but do not reveal the magnitude of the problem (WHO, 2009).

In Ghana more than 11,000 cases have been recorded since 1993. The first probable case of Buruli ulcer in Ghana was reported in the Greater Accra Region in 1971; the presence of additional cases along the tributaries of the Densu River in the area was considered likely. In 1989, Van der Werf et al. described 96 cases in the Asante Akim North District of Ashanti Region. This report was followed by the description of a major endemic focus in Amansie West District in the same region. Since then, isolated cases have been found in scattered communities in many parts of the country, generating much political and media concern and interest.

A study by Asiedu and Etuaful (1998) which examined the socioeconomic implications of Buruli ulcer in Ghana showed severe disabilities at high treatment costs. However it was found out that costs could be reduced by treatment in an earlier stage of the disease. The study also revealed that factors including geographic access, lack of funds, superstitious beliefs about the illness, and stigma were important determinants for health-seeking behaviour.

Buruli ulcer often starts as a painless, mobile swelling in the skin called a nodule. The disease can present as a large area of indurations or a diffuse swelling of the legs and arms.

Strains of *M. ulcerans* isolated from the different clinical forms of the disease in a particular geographical region appear identical, suggesting that host factors may play an important role in determining the different clinical presentations. Because of the local immunosuppressive properties of mycolactone, or perhaps as a result of other unknown mechanisms, the disease progresses with no pain and fever, which may partly explain why those affected often do not seek prompt treatment. However, without treatment, massive ulcers result, with the classical, undermined borders. Sometimes, bone is affected causing gross deformities. When lesions heal, scarring may cause restricted movement of limbs and other permanent disabilities in about a quarter of patients. Other conditions that may mimic BU include: tropical phagedenic ulcers, often referred to as tropical ulcers; leishmaniasis, particularly in South America; onchocerciasis nodules; and fungal skin infections (WHO, 2009).

*M. ulcerans* infection usually starts as a nodule, papule, plaque, or oedema. When left alone, the lesion breaks open and a typical painless ulcer with undermined edges appears which can progress to a large necrotic lesion. WHO has defined lesions with a cross-sectional diameter of less than 5 cm as category I, 5–15 cm as category II, and more than 15 cm, lesions on important sites (eye, breast, and genitalia), or multiple lesions as category III. *M. ulcerans* infection can be self-limiting, but scar tissue and contractures in joints leave patients with functional limitations and can result in social stigma (Nienhuis et al, 2010).

The first stage of Buruli ulcer starts as a firm, non tender nodule. Other possible pre-ulcerative lesions in the first stage are plaques or edema.

In the second stage, ulceration of the skin with an undermined edge can be seen. Occasionally, osteomyelitis complicates the course of illness. In stage three, a granulomatous healing response occurs. In stage four, fibrosis, scarring, calcification and contractures with permanent disabilities may result. Surgery is the present standard treatment. The average hospital admission time for Buruli ulcer in Ghana is approximately three months. Patients often come to the hospital in an advanced stage of the disease, leading to more extensive disfiguring and costly treatment (Stienstra et al, 2002).

In 1998, the World Health Organization (WHO) established the Global Buruli Ulcer Initiative (GBUI) with financial support from the Nippon Foundation in response to the growing spread and impact of the disease. That same year, WHO established an 18-member Advisory Group to guide its activities on Buruli ulcer. Members meet every March in Geneva and represent some of the world's experts on the disease in the areas of control, management and research. During the past few years, the scope of this meeting has broadened to allow some field health workers from endemic countries, researchers and nongovernmental organizations (NGOs) currently involved in Buruli ulcer control activities to attend and present their work. The meeting is an important part of global advocacy and a necessary component of efforts to raise awareness and interest about this poorly known disease, to share and disseminate new information and to coordinate efforts among endemic countries, researchers and NGOs. Thanks to continued support from the Nippon Foundation, Acción Sanitaria y Desarrollo Social (ANESVAD) and other NGOs, from dedicated researchers and field health workers and commitment from an increasing

number of countries dealing with Buruli ulcer, much progress has been made during the past five years in advocacy, control and research. However, much work remains to be done and many challenges await in finding better ways of diagnosing, treating and preventing this debilitating disease (WHO, 2003).

### **1.1 STATEMENT OF THE PROBLEM**

In developing countries, sociocultural beliefs and practices strongly influence the health-seeking behaviours of people affected by BU. The first recourse is often traditional treatment. In addition to the high cost of surgical treatment, fear of surgery and concerns about the resulting scars and possible amputations may also prevail. Due to the disfigurement, stigma is a problem that also prevents people from seeking treatment. As a consequence, most patients seek treatment too late, and both the direct and indirect costs are considerable (WHO, 2009). Factors such as geographic access, lack of funds, superstitious beliefs about the illness, and stigma were important determinants for health-seeking behavior (Stienstra et al, 2002).

In Ghana, traditional therapy is the preferred choice in the management of the disease. Majority of cases reported to Health Facilities after traditional medicine has failed them woefully and complications may have set in (Mensah-Quainoo, 2004). Even though a lot of epidemiological studies on the disease have been undertaken in endemic countries, Ghana inclusive, very little has been done on the knowledge and local perception of the disease although it is believed that the disease can have untold implications for the welfare of the individual, the family and the nation as a whole (Asiedu, 1998).

In Ghana majority of Buruli Ulcer patients do not report early for treatment. This could

be due to the inaccessibility of health facilities (WHO, op.cit). Traditional therapy is often resorted to in the management of the disease. Therefore the majority of cases are reported to hospitals during the late part of the disease by which time complications may have set in and therefore Patients would require surgery and long periods of hospitalization (Mensah-Quainoo, Unpublished).

Community perception of the cause and consequently the appropriate measure to remedy an ailment determine to whom people turn to for advice, help, information and treatment when bogged down with a disease. This Individual could be a general practitioner, priest, Traditional Healer or Family Member (Helman, 1989).The role that cultural factors play in the etiology, explanation, prognosis and treatment seeking behaviour cannot be underscored (Fumham, 1994), because it provides in-depth information on the burden of the disease, the local understanding of the causes of the disease and therefore its management.

The improper management of a disease could contribute immensely to its spread. Disease Control Programs in developing countries are often unsuccessful or inappropriate because they failed to take into consideration local etiology, perceptions and beliefs which are interwoven into the socio-cultural milieu of people. These factors aid in the local prognosis, treatment seeking behaviour and any taboo or stigma associated with the disease. For Public Health to make a sustainable inroad into disease control and to design meaningful health programmes, a conscious effort should be made to understand the social, economic and cultural aspect of disease.

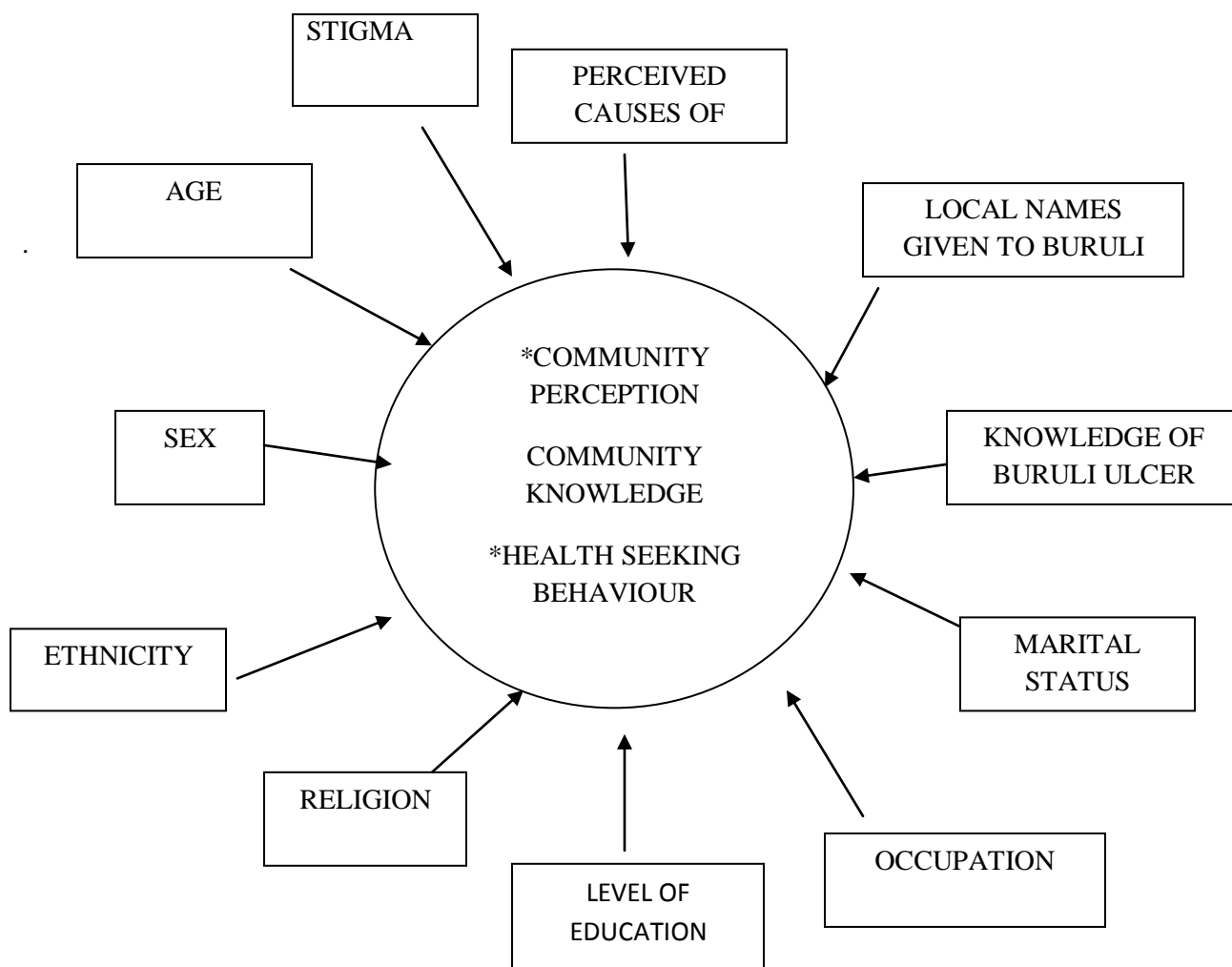
Ga West municipality area ranks fifth in terms of the disease prevalence among the ten selected

most endemic districts in Ghana (Amofah et al, 2000).

## 1.2 CONCEPTUAL FRAMEWORK

Figure 1 below, described the relationship between background variables, independent variable and the main dependent variables- Community perception of Buruli Ulcer and Health- seeking behaviour of cases.

Figure 1. CONCEPTUAL FRAMEWORK



### 1.3 JUSTIFICATION

Even though lots of studies on the disease have been undertaken in various endemic countries, Ghana inclusive, very little has been done on the local perception and knowledge of the disease (Asiedu, 2006). Hopefully, this study will help to understand why people do not seek treatment from Health Facilities early and also provide a critical and analytical perspective for understanding the local perception and knowledge of Buruli ulcer in the area of study.

Studies have shown that, the community perception and knowledge about the disease has a negative impact on the health-seeking behavior of cases. For this reason, all information on the perception and knowledge about the disease are highly relevant for a better understanding of the disease as a whole and again serve as a useful material for future research and reference material for policy makers, government and non-governmental institutions, world bodies such as the World Health Organisation (WHO) and the Center for Disease Control (CDC), who are interested in the living standards and health of humanity.

The improper management of a disease could contribute immensely to its spread. Disease control programmes in developing countries are often unsuccessful or inappropriate because they fail to take into consideration the local perception of the disease. For public health to really make an inroad into the control of diseases and also to design meaningful health programmes to the betterment of disease burdened persons, a conscious effort should be made to understand the socioeconomic and cultural aspects of diseases.

Ga West Municipality Area ranks 5<sup>th</sup> among the top ten districts that are severely affected

by the disease. The research will benefit the people of the district immensely.

#### **1.4 LIMITATIONS OF THE STUDY**

Time was a constraining factor for the researcher. This was because, combining the semester's academic work to this research made it very time consuming and very demanding. The researcher however managed to solve this by scheduling his time very well and making sure that timelines were strictly adhered to.

Illiteracy was also a problem that the researcher encountered. This was also solved that by resorting to interview and observation as alternative and additional forms of collecting information which did not call for any writings from some of the respondents.

Another constraint to the study encountered by the researcher was that a few respondents were not willing to give out information about the subject matter of the research. This was because they felt several investigations have been carried out on Buruli ulcer in the community yet there has not been any dramatic improvement in the eradication of the disease. The researcher therefore explained the purpose of the research to them after which they readily gave out information.

## 1.5

### **OBJECTIVES OF THE STUDY**

#### **1.5.1 GENERAL OBJECTIVE**

To assess the community perception and knowledge of Buruli Ulcer (BU) and how these affect the management of the disease

#### **1.5.2 SPECIFIC OBJECTIVES:**

1. To assess the community perception of BU
2. To assess the knowledge of the community about BU.
3. To determine the various health-seeking behavior of BU cases

## **CHAPTER TWO**

### **2.0 LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

The burden caused by Buruli Ulcer is seen as serious skin destruction, disability, amputation, and poor living conditions and in some cases, death. At present, there is limited understanding of the impact of Buruli Ulcer on infected individuals, households, and communities. This chapter therefore presents a review of various literatures on the following topics; a general view of Buruli ulcer incidence worldwide with emphasis on Ghana (a developing country with high number of Buruli ulcer cases) and particularly the Ga West Municipality Area, the local perception and knowledge towards Buruli ulcer disease.

#### **2.2 VIEWS ON BURULI ULCER.**

##### **2.2.1 GLOBAL VIEW ON BURULI ULCER**

Buruli ulcer disease is assuming public health importance in many countries, prompting the establishment of a Global Buruli Ulcer initiative by the World Health Organisation (WHO, 2001) in early 1998. Ever since *Mycobacterium ulcerans* infection was first described in Australia in 1948 and later named Buruli ulcer in Uganda, cases have been reported throughout the tropical and subtropical world. In the African WHO region, at least 16 of 46 member countries have reported cases, especially in West Africa and parts of Eastern and Central Africa.

One characteristic of the disease is its apparent association with water bodies worldwide. Buruli ulcer commonly affects the young, even though cases are reported in all age groups. Oluwasanmi et al. and Van der Werf (1976) in their research did not find any sex difference, but Barker (2006) reported prevalence to be higher among women than men and among boys than girls. Age is important to note, since 70% of all cases occur in children under 15 (WHO, 2005). The youngest reported case to date is a 6-week old baby; the oldest is 70 years of age (Curtis James Denton, 2007). Population structure is important in Buruli ulcer because in many countries where it is endemic, 50% or more of the population is under the age of 18 (Asiedu et al., 2000). Gender plays a part in Buruli ulcer, not necessarily because of a specific difference of genetics, but more than likely because of occupational roles such as farming for men, bathing of children, and the method in which women do laundry (Debacker et al., 2005). Most studies have shown slightly higher incidences among males than females. A case control study by Debacker, Aguiar, Steunou, Zinsou, Meyers, Scott, Dramaix and Portaels also found that males and people of the ages above 59 had a higher risk of Buruli ulcer infection than the average person (Debacker et al., 2004).

### 2.2.2 BURULI ULCER IN AFRICA

Recently, Buruli ulcer is emerging from the West and Central African countries. The disease comes up with necrotizing and immuno-suppressive type ulcer in the skin, subcutaneous tissue and bone, and shows indolent chronic course as mycobacterial infection like tuberculosis and Hansen's disease. After the transmission to human, the lesion is usually single and begins as firm, painless, subcutaneous nodule and on any area

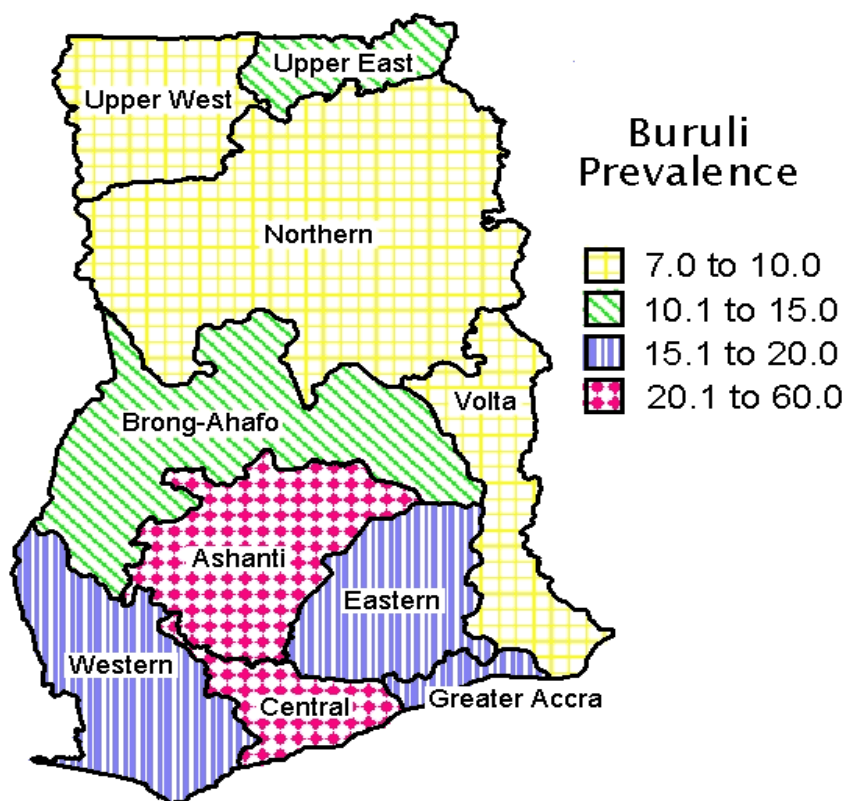
of human body skin, though most frequently on lower limbs. Buruli ulcer incidence is highest among developing West African nations (WHO 2001), with cases in some countries exceeding those of tuberculosis and leprosy (Amofah et al. 2002). Up to 16% of villages are affected in La Cote de' Voir (Marston et al. 1995; WHO 2001), and Benin has recorded 4000 cases since 1989 (Lagarrigue et al. 2000). A 1999 national survey in Ghana identified over 6,000 cases, making Buruli Ulcer the second most prevalent mycobacterial disease (after TB) in that country (Amofah et al. 2002). In West Africa, nearly 25% of people infected are left permanently disabled (Johnson et al. 2005). There is also evidence of vast under-reporting of the disease. (ibid)

The incidence of infection has increased dramatically over the past decade, even after considering improved reporting rates, largely as a consequence of environmental changes. Approximately 31 countries in the sub-tropical and tropical regions have reported cases of Buruli ulcer. These countries include: Angola, Australia, Bolivia, Burkina, Faso, Cameroon, China, Congo, Democratic Republic of Congo, Equatorial Guinea, French Guyana, Gabon, Ghana, Guinea, French Guyana and Gabon. The rest are India, Indonesia, Japan, Liberia, Malaysia, Mexico, Papua New Guinea, Peru, Sierra Leone, Sri Lanka, Sudan, Suriname, Togo and Uganda. A few isolated cases have also been reported in non-endemic areas in North America and Europe, but these cases have been linked to international travel. (ibid)

### 2.2.3 BURULI ULCER IN GHANA

In Ghana, the number of reported cases has been increasing since 1993 and these cases have come from 5 of the 10 regions of this country. The disease is found predominantly in the Ashanti region as seen in the map provided below.

#### A MAP OF GHANA SHOWING BURULI ULCER PREVALENCE.



*Fig 2.0* Buruli ulcer prevalence rates among the regions of Ghana, Africa. Figure from Amofah et al. (2002).

From fig.2.0 it is realized that Ashanti region has the highest Buruli Ulcer prevalence of 20.1% to 60.0%. The Greater Accra, Eastern and Western regions follow with a prevalence of 15.1% to 20.0%. Brong-Ahafo, Upper East, Upper West, Northern and Volta regions follow respectively.

The management of Buruli Ulcer is difficult, treatment costs are high, and complications of the disease are frequently severe. Buruli Ulcer creates an enormous long term demand on resources for health care and rehabilitation. The disease has a very low mortality rate, but the associated morbidity and treatment costs poses a serious challenge to a struggling rural economy and its health system giving the growing number of cases and current control strategies.

According to Van der werf et al (2003), the first probable case of Buruli ulcer case in Ghana was reported in the Greater Accra region in 1971; the presence of additional cases along the tributaries of Densu River in the area was considered likely. In 1989, Van der Werf et al, described 96 cases in the Asante Akim North District of Ashanti region. This report was followed by the description of a major endemic focus in the Amansie West District in the same region. Since then isolated cases have been found in scattered communities in many parts of the country, generating much political and media concern and interest.

In 1993 a passive surveillance system for reporting Buruli ulcer was initiated in Ghana. By the end of 1998 approximately 1200 cases had been reported from 4 regions. Gross underreporting was suspected, however, the media continue to report cases in remote

rural communities. Because most cases were known to be in relatively deprived, inaccessible areas, the routine reporting system was judged inadequate to provide a true picture of the extent of the disease and the geographic distribution of cases for design of a national control program. In addition a case search would provide base line data against which intervention measures could be assessed.

The main objective of the national case search was to establish the extent of the disease in Ghana to facilitate development of a national program for its control. Cases of Buruli Ulcer were identified in all 10 regions. Table 2.1 shows the prevalence rates for a region based on estimated 1999 population figures from the 2000 census.

Table 1: **PREVALENCE OF ACTIVE BURULI ULCER CASES BY REGION IN GHANA, 1999.**

Name of Region	Rate per Region (100,000)	No. of Males	No. of Females	Total No. of active cases
Ashanti	30.8	482	475	957
Brong Ahafo	12.5	113	110	223
Central	59.2	519	395	914
Eastern	16.9	202	150	352
Greater Accra	18.5	259	255	514
Northern	7.4	65	68	133
Upper East	10.7	34	63	97
Upper West	7.4	21	21	42
Volta	9.6	78	74	152
Western	17.9	181	140	321

Source: Buruli Ulcer in Ghana: Results of a National Case Search, 2000

The Central region has the overall prevalence rate of active cases, followed by the Ashanti; the Northern and Upper West regions had the lowest prevalence rates.

Cases of the disease were identified in 90(81) % of Ghana's 110 districts. Table 2.2 also shows the prevalence rates of the disease in the 10 districts with the highest caseloads. Amansie West had the highest rate of (prevalence 150.8 per 100,000), followed by Asante Akim North (prevalence 131.5 per 100,000) and Upper Denkyira (prevalence 114.7 per 100,000)

**Table 2 PREVALENCE OF BURULI ULCER IN THE 10 DISTRICTS WITH THE HIGHEST CASELOADS IN GHANA, 1999**

District	Prevalence(rate per cases,100,000)	Region	No. of active cases	No. of active and healed lesions
Ga	87.7	Greater Accra	467	1,113
Amansie West	150.8	Ashanti	159	474
Assin	83.7	Central	159	173
Gomoa	81.9	Central	158	161
Asante Akim N.	131.5	Ashanti	138	265
Wassa Amenfi	61.1	Western	136	167
Kwahu South	57.0	Eastern	122	132
Upper Denkyira	114.7	Central	121	306
Afigya Sekyere	107.1	Ashanti	118	149
North Tongu	85.7	Volta	107	129

Source: Buruli Ulcer in Ghana: Results of a National Case Search, 2000

The study has shown that Buruli ulcer disease in Ghana is much more widespread than previously thought. In all areas where Buruli ulcer cases have been identified, the extent of the disease is likely to be much greater than currently recognized through the routine reporting system.

### 2.3 KNOWLEDGE

The Ghanaian media published that “a strange and terrible disease” has bedeviled Agroyesum area of Amansie west district of Ashanti Region in 1993 (Daily graphic, 1993). This publication caused much political and public concern until a seasoned clinician in the person of Professor J. H. Addy of Korle- Bu Teaching Hospital appeared on National TV to allay the fears of Ghanaians by diagnosing the “ strange and terrible disease “ as Buruli Ulcer which had been with mankind, Ghana inclusive for ages (GNT New Time, 1993).

The role that cultural factors play in the etiology, explanation, prognosis and treatment seeking behaviour cannot be underscored (Furuham, 1994), because they provided in-depth information on the burden of the disease, the local understanding of the causes of the disease and therefore its management. It has been asserted that socio-cultural beliefs and practices strongly influence the health-seeking behaviours of people affected by BU. The first recourse is often traditional treatment. In addition to the high cost of surgical treatment, fear of surgery and concerns about the resulting scars and possible amputations may also prevail. Due to the disfiguration, stigma is a problem that also prevents people from seeking treatment. As a consequence, most patients seek treatment too late, and both the direct and indirect costs are considerable. The impact of the disease on the few health facilities in the affected areas is enormous. The long hospital stay, often more than three months per patient, represents a huge loss in productivity for adult patients and family caregivers, and loss of educational opportunities for children. The long-term care of those disabled, most of whom are children aged 15 years, places an additional costly burden on affected families.

## 2.4 COMMUNITY PERCEPTION

According to Ymkje Stienstra et al (2002), the causes of Buruli Ulcer disease in his research indicated that the respondents were divided into both biomedical and magico-religious thinking. An answer in the biomedical domain does not exclude an answer in the magico-religious domain. Thirty-nine respondents (59% of the total number of respondents) mentioned personal hygiene, but some patients denied this possibility. “Hygiene cannot be of influence because I have good hygiene and I have the disease and other people without good hygiene don’t have it.”

The environment was mentioned as a risk factor by 32 respondents (48% of the total number of respondents). These thoughts are illustrated by the following statements.

“When walking in swampy areas and if wearing sandals, insects or worms can bite you and cause the disease.” “Some of the rivers will have swampy areas, walking or bathing here could cause the disease.” “When walking with open toe shoes in swampy areas, you’ll scratch yourself and an organism or insect can get in and it can develop in a big ulcer.”

In the research, four persons mentioned drinking water and three mentioned food as the bacteria-containing source of the disease. Four respondents referred to an insect bite or snakebite. One person thought Buruli ulcer is a relapse of the disease known as a tropical ulcer. During the interview, 15 respondents (23% of the total number of respondents) mentioned the fear of becoming infected by close contact with patients with Buruli ulcer. “If a friend is infected and you continue to play with him you might be infected also. Wearing dressing is not protecting, if a fly comes from this wound and then to you, you

can get it.” “The disease can be transferred via breathing.” “Family and friends can spread this disease through clothing, housing and feeding.” Forty respondents were asked if they thought the disease was sexually transmitted. Five (13%) said it can be sexually transmitted, 14 (35%) did not know, and 21 (53%) said it is not. “More women have the disease because they usually engage in prostitution.”

Different magico-religious factors were given, of which witchcraft was most common. This was mentioned by 39 respondents (59% of the total number of respondents). Witchcraft sometimes seems to be mentioned as the only explanation as long as no other explanation can be found for the disease. “Witches are known mainly for spreading mysterious diseases in Ghanaian societies, like tuberculosis, Buruli ulcer and leprosy.” “In my case, I think it’s caused by witchcraft because I have good hygiene.” “I hope it is only a witch who can bring such a strange sickness or disease to someone because God the almighty love us and will not bring us such a sickness.” Other reasons to be bewitched are conflicts in the family, and the witch is usually someone from your own family. “When I got the disease, my sister asked me to give her 5,000 cedis (75 cents, US) and a cock and then it would heal. She’s a witch. We went to my sister to tell her she gave me the disease and she told me I’ll be dead before I’ll be free of Buruli.” “I had only a small injury before the Buruli ulcer developed. Usually such a small wound does not become this big, so it must be witchcraft that caused this severe disease.” I think it’s because I had a fight with my mother’s sister’s daughter, she might have given the disease to me. I’m afraid people in the village think I’m bewitched. People in my village will think witchcraft is probably involved if I’m admitted for a longer period because witches usually cause diseases that are difficult to cure. I’m also afraid the witchcraft will

cause my leg to be amputated.”

In addition to a long admission as proof of witchcraft, the clinical presentation and lack of effective drug treatment was another reason to think of witchcraft, as illustrated by the following quote. “If I see the patient, I think it’s a disease, but if a patient says she’s surprised by its size and if medical treatment fails, I think it’s caused by witchcraft.” A witch can also develop the disease. “Witches can develop the disease because they eat women’s flesh and if that flesh has Buruli ulcer, she can get it.” Thirty-one respondents mentioned a curse as a cause of the disease (47%, 16 were patients with Buruli ulcer), six respondents said they did not know whether a curse has an influence. Patients with Buruli ulcer who said a curse could cause the disease denied that a curse was the cause of their own disease. “It is possible that a curse causes this disease, but not in my case, I did not do anything wrong to get a curse.” “If you continue doing something that someone else does not want, you can get cursed. A person can do that by performing rituals, like talking to an egg and breaking it. I’ve never been cursed. I would have known if I were cursed, outside I would have heard and otherwise the person who cursed you would have told you.”

Five patients regarded the disease as God’s will. “God protects us all. Someone who gets the disease might have done something wrong and therefore not get protected by God. I do have Buruli ulcer myself, but I don’t know why God did not protect me.”

The evil eye was mentioned as an influence factor. “If a lot of people see my wound, it might not heal. If all people start to talk about it, stare at it and are surprised by it, it would not heal either.” “I always want the door closed during changing of dressings, to

protect it from evil eyes.”

Even though ancestors play an important role in the daily life of Ghanaians, no one attributed the disease to problems in the relationship with ancestors. (Stienstra et al, 2002)

Outbreak of unexplained new diseases with some resulting in deaths to which no logical explanation has been arrived at by both medical research and the local people culminate in consultation with folk-practitioners of all types. In the face of such situations, to rural communities, westernized medicine does not seem to have the answer anymore (Lyttleton, 1996).

Other studies conducted in Ghana have also revealed that disease without an immediate known cause are given supernatural explanations such as offense against one's Spirit, the Gods, the Ancestors or curses, Witchcraft and casting of Juju Spells (Twumasi, 1992). Among the Amba of East Africa, major catastrophes which culminate in illness and death are attributed to witchcraft (Lieban).

Chronic conditions with low rate of success of treatment are often attributed to supernatural causes and for such conditions, Hospital treatment is often avoided and regarded as irrelevant (Hunter, op. cit).

Studies have indicated that diseases that are associated with skin lesions tend to be attributed to “bad blood”. In a study in north-western Botswana to determine some socio-cultural factors influencing knowledge and attitudes of the Community towards Leprosy,

were cases of Leprosy have existed over years, Leprosy was attributed to “bad blood” (Kumaresan & Maganu, 1994). This “bad blood” phenomenon holds true in similar studies on Leprosy in other countries such as Trinidad and Tobago, India, Ethiopia, Congo and Tanzania. Association of “bad blood” in other studies on Syphilis and boils is also known (ibid & Senah, 1997).

In a study conducted in northern Ghana on lymphatic Filariasis, almost all the respondents interviewed attributed super natural causes to the disease. Among the explanation given for the spiritual etiology of Filariasis was Juju. However, there were other non spiritual causes such as diet, hereditary and fever which were in the minority (Gyapong et al, 1996).

In a study by (Gyapong et al,1996) also conducted in Northern Ghana, it was observed that since the victims of Filariasis were not responsible for its occurrence, the community accepted them and therefore these Victims went about their normal duties in a congenial atmosphere void of stigmatization.

Outbreak of unexplained new diseases with some resulting in deaths to which no logical explanation has been arrived at by both medical research and the local people culminate in consultation with folk-practitioners of all types. In the face of such situations, to rural communities, westernized medicine does not seem to have the answer anymore (Lyttleton, 1996).

If the diseases cycle is not properly understood, home base care is the first line of action, followed by traditional healers. The health facility is the last resort when everything else

has failed (Mull et al, 1989)

In cases where a disease has been with the people for several years, they tend to resign themselves to their fate and no longer use up their meager resources to combat it. However, if a choice is to be made as to the line of treatment to follow, the Herbalist or the soothsayer is the most preferred (Gyapong et al, 1996).

Buruli ulcer Patients often resorted to traditional therapy in the management of the disease. Therefore majority of Cases are reported at Hospitals during the late part of the disease by which time complications may have set in (Mensah-Quainoo, op. cit).

## **2.5 STIGMATISATION AND SOCIAL ISOLATION**

According to (WHO CPEGBUL/2001), stigma is the reaction of society towards people with certain characteristics (for example, a deformity or an ulcer) which are perceived as abnormal and undesirable; the result is that such people are deprived of the same social inclusion and human rights as are enjoyed by others. Fears and misunderstanding about the disease can cause a person affected by Buruli ulcer (and the family) to be isolated or neglected by communities and health workers. Such discrimination can result in persons with the disease hiding or denying the problem, delaying early diagnosis and treatment. Fearful health workers may neglect to give the care needed to prevent or minimize disability.

Fear, devaluation, and social inequality can also be a response to the physical deformities and scars that remain after medical and surgical treatment of Buruli ulcer. These physical signs visually mark the individual and depart from societal standards of beauty. The disease may be viewed as a sign of a curse, or a punishment for some sin committed.

Deformities may also lead many to believe that the person is unable to participate in activities and normal family, educational, and community life. These people may be viewed as a burden to themselves, their families, and their community. This stigma creates social and economic difficulties.

In the African tradition, disability is reportedly viewed as a curse, a punishment from the ancestral spirits or God, for wrongs committed by one's parents. The family is usually isolated by the community, in the same way that the family isolates their disabled family member. Negative stereotypes are common, resulting in low expectations of people with impairments, which can prevent them achieving their full potential (UN, 2002b). In Cambodia, disabled people are often excluded from society because they are thought incapable of contributing to family or community life (Hanko, 1998 as cited by DFID document 2002). As a result, disabled children tend not to be sent to school, to play or mix with other children. 'In adulthood they become victims of ignorance, poverty, disease, discrimination and a whole range of negative attitudes - they become isolated from the general social systems' (ibid).

In Bangladesh, because many community members believe that impairments are contagious or a punishment, disabled people may for example be prevented from sharing latrine facilities, which forces families to use unhygienic sanitation practices (CRP, 2002). Cultural perceptions of water and purification rites also create problems for disabled people and disabled women in particular (Van der Kroft, 2002).

## CHAPTER THREE

### 3.0 METHODS

#### 3.1 Type of Study

The Study was a cross-sectional descriptive study that employed the use of both quantitative and qualitative data collection tools.

#### 3.2 Study Location/Area.

The Ga West Municipality Area is the second largest of the six districts that make up the Greater Accra Region in the south of Ghana.

The Ga west district was in the year 2004 carved out of the erstwhile Ga district which was created in 1988 in pursuance of the government decentralization and local government reform policy. The Ga West district was further divided into Ga West and South Municipalities in June 2008. Amasaman the former district capital of the Ga West district remains the capital for the newly created Ga West Municipality. The Municipality is sub-divided into 3 health catchment areas, referred to as Health Sub-municipals or institutions namely:

1. Amasaman
2. Pokuase
3. Ofankor

Data was collected from different areas in Ga West Municipality of the Greater Accra Region.

Health Service delivery in the Ga West district poses many challenges at all levels of service delivery. Many of the communities are more than 8 kilometers from the existing government and NGO/quasi-government health facilities and thus have limited access geographically to any service delivery point.

Although there are a number of private clinics in the urban and periurban areas, they are beyond the physical and financial reach of most rural dwellers. The population's access to health care and health information is inadequate.

The major health facility which is the Municipal Hospital is located in Amasaman, the Municipal Capital. There are five (5) other Community Clinics located in Oduman, Samsam, Kojo Ashong, Amamorley and Mayera-Faase communities. Three other CHPS Zones located in Pokuase, Nsakina and Dom sampaman serves a considerable portion of the rural population of the Municipality. Some of these areas are highly endemic for Buruli ulcer.

A significant number of the population live in scattered rural settlements covering about 70% of the land area of about 568.2 sq km. In order to make up for the inadequate coverage of health facilities, outreach services are organized in selected communities monthly.

### 3.2.1 Population Growth

According to the 2000 National Population and Housing Census, the population of the Ga West Municipal is 214, 996, with growth rate of 4.4%. The growth rate is as a result of the Municipals closeness to the capital city Accra where there is a lot of inflow of migrant workers. The population distribution by sub municipals is shown in the table below.

**Table 3: Population Distribution of Sub-Municipals**

TARGET POPULATION	% OF TOTAL POPULATION	POPULATION FIGURES BY SUB-DISTRICT			
		Amasaman	Pokuase	Ofankor	MUNICIPAL TOTAL
% of Municipal Population	Pop.	24	20	56	100
0-11 months	4	2072	1727	4834	8633
12-23 months	2.21	1145	954	2671	4770
24-59 months	6.63	3434	2862	8013	14309
5-14 years	22.09	11442	9535	26698	47676
15-49 years (WIFA)	27.9	14452	12043	33720	60215
15-49 years (Men)	27	13985	11654	32633	58272
50-60(Men & Women)	5.17	2678	2232	6249	11158
60+ (Men & Women)	5	2590	2158	6043	10791

Total Population (App.)	<b>100</b>	<b>51798</b>	<b>43165</b>	<b>120861</b>	<b>215824</b>
Expected pregnancies	4	2072	1727	4834	8600
0-59 months	12.84	6651	5542	15519	27712

### 3.2.2 Boundaries

The district shares boundaries with the Ga South Municipality in the West, the Ga East Municipality to the east, the Akwapim South district to the north and the Accra Metropolis in the south east.

### 3.2.3 Topography

The land consists of gentle hills to the East, interspersed with plains in the central parts. There are number of small lagoons in the coastal areas. The River Densu, the largest water body, runs from North to South through the district, dividing it into two thirds and one third on the East and West of the river respectively. The damming of this river at Weija for water supply to the West of Accra has led to the submergence of the surrounding lowlands to form a large lake, this serves as a fishing resource.

Other water bodies mostly tributaries of the Densu, are the Adaiso, Dobro, Insaki, Ntafrara, Opintin, Honi and Ponpon rivers. There are many other natural small ponds, and seasonal streams. In addition, numerous surface water bodies have sprung up in the wake of extensive sand-winning to supply the building industry in the neighboring Accra Metropolis. Others have been created as a result of dams built across water courses.

These water bodies are significant for economic activities (Fishing and farming), and disease causation. Several water related diseases are endemic in the district. The hydrological characteristics encourage the breeding of mosquitoes, and hence Malaria is the most common health problem there also several Buruli Ulcer endemic communities in the district, Other important diseases commonly seen , are skin diseases such as scabies, acute respiratory infection, and diarrhea, yaws and schistomiasis.

#### 3.2.4 Vegetation

The vegetation is coastal Savannah and shrub-land in the most parts of the Densu River basin. Towards the northern section there are thin remnants of forests. The coastal lands are mainly covered with mangrove swamps and brackish water lagoons.

#### 3.2.5 Rainfall

There are two main seasons, wet and dry. The major rains come from April/May to July. There is a short break in August, followed by the minor rains from September to October or November. The period from November to March constitutes the main dry seasons, characterized by dusty Harmattan winds. The dry seasons are characterized by severe water shortages in most of the rural and some urban areas. Families are forced to spend relatively large sums to purchase water. Those who cannot afford to buy water drink from contaminated sources with adverse health consequences.

#### 3.2.6 Infrastructure

The District Administrative capital, Amasaman is located nearly centrally, some 25 km from Accra and is deceptively accessibly off the Accra Nsawam trunk road. It is in reality not easily accessible to sub-districts and the majority of the communities. About 30% of

the district land area is urban or peri-urban. Seventy percent of the land is rural with over 300 small rural settlements. About 70% of the population is in the urban communities.

### 3.2.7 Basic Amenities

The rural communities comprising some 70% of the district lack basic amenities like pipe borne water and electricity. Most rural settlements can only boast of basic schools. There are number of markets in the district which helps in revenue generation.

### 3.2.8 Roads and Transportation

The Accra - Kumasi trunk road crosses the district from South to North. Other roads are unpaved or in bad conditions hence, public transportation is scarce and expensive. The Adeiso-Nsawam paved road in the Akwapim South district is in fairly good condition travels along the northern boundary of the district. It serves as a de-tour access to reach the North-Western part of the district from the capital. All other roads in the district are feeder roads in various stages of disrepair.

Many communities become inaccessible during the rainy season, when the dirt roads go from bad to worse and are barely motorable. Public road transport to most parts of the district is consequently scarce and expensive. The cost of transport assumes even more inflated values when hired to convey sick persons, especially at night.

Train transport is used by the villages along the rail lines that cross the district. Other important means of transportation within the district include the motorcycle, bicycle, and canoe. Most of the rural populations, especially the women, walk long distances often carrying heavy loads of water.

### 3.2.9 Ethnicity

The indigenous inhabitants are mainly of the Ga tribe. However, many other ethnic groups have settled in the urban as well as rural communities, giving a mix of Akans, Dangmes and Ewes. In areas such as Alhaji Tabora, almost all the northern tribes such as Dagombas, Frafras, Dagatis etc. can be found.

### 3.2.10 Economic activities

These include fishing in the river belts, and farming in the inland areas. Cattle rearing is fairly widespread. The majority of rural dwellers in the district are peasant farmers who grow maize, cassava, peppers okra (okro) etc. There are large commercial industries and farms which produce bottled water, alcoholic beverages, fruit drinks and pineapple, water melon, pawpaw, mango, pepper and coconut respectively for export. The urban and sub-urban dwellers engage in varied activities and comprise artisans, distributive traders, handcrafters, civil servants and industrial workers. Cassava dough production and Gari making are processing activities in some areas. There are local gin distillation plants in a number of communities.

### 3.2.11 Health facilities in the municipality

Government Hospital	-	1
Private Hospitals/Clinics	-	9
Government Polyclinic	-	0
Private Maternity Homes	-	7
Health Centres	-	0

Community Clinics	-	5
Operational CHPS Zone	-	3
<b>Total</b>		<b><u>25</u></b>

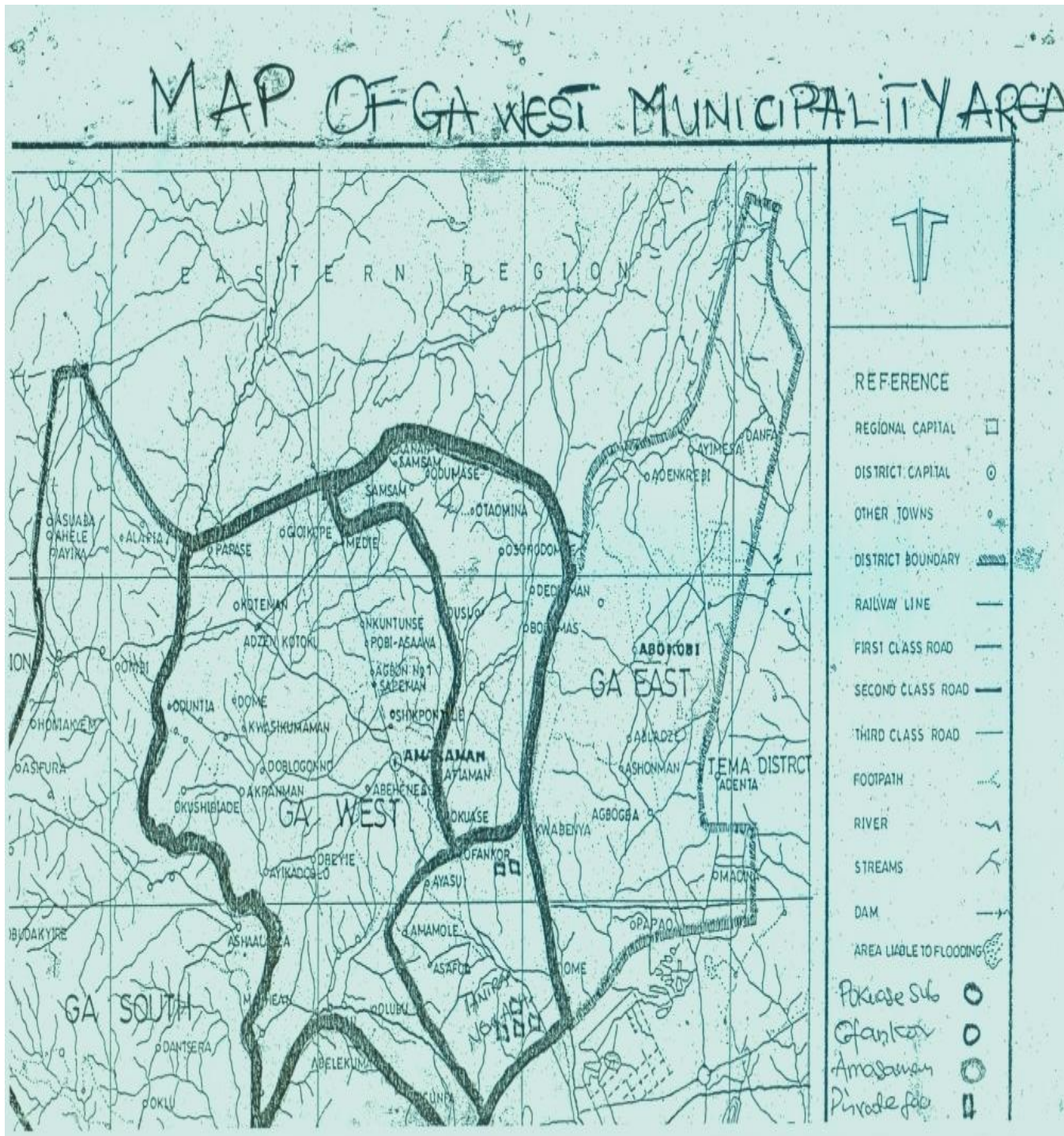
**Table 4: Analysis of Health Indicators**

INDICATOR	2007	2008	2009
IMR	N/A	N/A	N/A
<5 Mortality rate	N/A	N/A	N/A
MMR	N/A	N/A	N/A
%<5 who are malnourished			
<5 malaria case fatality	0	0	0
EPI measles coverage	89.6	85.0	77.0
Supervised del rate	30.2	35.4	35.8

\* MMR and IMR rates are unavailable because over the year's government facilities were providing services on outpatient basis.

Below is a Map of the Ga West Municipality Area

**Fig. 3 A MAP OF THE GA WEST MUNICIPALITY AREA OF GHANA**



### 3.3 Variables:

#### 3.3.1 Background Variables

- Age of respondent
- Sex of respondent
- Ethnicity of respondents
- Religion of respondents
- Educational status of respondents
- Occupation of respondent
- Marital status of respondent

#### 3.3.2 Dependent Variable:

- Community perception of Buruli Ulcer
- Community Knowledge of Buruli Ulcer
- Health- seeking behaviour of BU Patients

#### 3.3.3 Independent Variables:

- Socio- demographic characteristics: Age, Sex, Ethnicity, Religion, Education, Occupation, Marital Status.
- Perceived causes of BU: Witchcraft, Curse, Environments (swampy areas, ponds, drinking water, insects, snakes), Personal hygiene, Close contact, Prostitution, Promiscuity etc.
- Period of manifestation of the disease
- Local names given to BU
- Category of people most at risk: Young Boys

- Stigma

### 3.4 Sampling

#### 3.4.1 Study Population

The study population included all community members who are above 10 years of age and could express him/herself well.

#### 3.4.2 Sample Size

The appropriate sample size for the population-based survey was determined largely by three factors: (i) the estimated prevalence rate of the variable of interest – Buruli ulcer in this instance, (ii) the desired level of confidence and (iii) the acceptable margin of error. The survey design was based on a simple random sample; the sample size required was calculated according to the following formula.

*Formula:*

$$n = \frac{z^2 \times p(1-p)}{m^2}$$

*Description:*

**n** = required sample size

**Z** = confidence level at 95% (standard value of 1.96)

**p** = estimated prevalence rate of the perception of Buruli Ulcer in the project area = 0.5

**m** = margin of error at 5% (standard value of 0.05)

The estimated prevalence rate of the perception of Buruli Ulcer in the project area was then estimated as 150.8 per 100,000 and therefore the perception rate for Ga West

Municipality was 0.5 %

$$N = \frac{1.96^2 \times 0.5 (1-0.5)}{0.05^2} = 384$$

**Because of time constraint the sample size was limited to 200 respondents.**

### **3.4.3 Sampling methods:**

Multiple stage sampling techniques was used. Two Sub-Municipals were selected out of the existing three Sub-Municipals for the study due to their endemicity. Communities with high prevalence of the disease in the sub-Municipals were carefully selected with the assistance of the Disease Control and Health Information officers of the Municipality. Names of these communities were written on pieces of papers and folded into a bowl, 8 communities were then picked for the study.

The following are the list of selected communities:

- Amasaman
- Pokuase
- Kotoku
- Mayera
- Ayikai Doblo
- Adusa

- Kojo Ashong
- Otuaplem

After this stage, a systematic sampling process was used to include every other house after an initial randomly selected house.

A non- probability sampling technique was used to interview household members who are within the study population.

For every community selected, key- informants such as assembly men, head teachers, Unit Committees chairpersons and others were contacted for in-depth interviews.

Focus Group Discussions (FGDs) were formed. Groups consisted of either males or females or both. This produced spontaneous results that were used to increase information sort. The different grouping was to ensure partly that answers may not be influenced by the presence of opposite sexes as groups have been proven to produce induced answers or no realistic answers at all especially from females.

In each group, participants were not being limited to any characteristic once the person is an eligible participant.

### **3.5 Data Collection Techniques/ Methods and Tools**

Three main data collection techniques were employed in this study:

- Structured questionnaire
- Focus Group Discussions with members of the community some of which were caretakers and relatives of Buruli ulcer patients

- Case studies of Buruli ulcer patients on admission at the Amasaman Hospital and in Kojo Ashong Community.

The idea on the cause of the disease was assessed by open interviews combined with semi-structured questions about the influence of 10 items on Buruli ulcer.

These items were work/school, hygiene, environment, family/friends, behavior, mood, religion, curse, witchcraft, and ancestors. The answers were in relation to biomedical explanations and magico-religious influences.

Ideas about treatment was assessed by questions on help seeking behavior of patients with Buruli ulcer, the reasons and expectations of this help seeking, and experiences with health-seeking behavior of friends/family.

Questions were asked about their help-seeking behavior for a skin lesion in three stages of disease. Answers were categorized by reasons for patients' delay, patients' experiences with health-seeking behavior of friends and family, help-seeking behavior of the patients, and patients' expectations of treatment in the hospital.

The stigma of Buruli ulcer was studied by open questions and quantitatively by a stigma query adapted from Vlassoff and others, who studied stigma of onchocercal skin disease in Africa, including Ghana.

Verbal consent was obtained from all adult participants and from the parents of minors. The study protocol was reviewed and approved by the local hospitals and district health authorities in Ghana.

A stigma score per individual was computed by adding the responses to each question. Each question contributed equally. Items will be evaluated for internal consistency. Comparison of stigmatizing scores of affected and unaffected subjects were done by responses to questions asked to both affected and unaffected respondents, and considering internal consistency. Stigma scores were analyzed for the influence of gender, education, and the difference in scores between affected and unaffected subjects. The influence of perceived cause on stigma and help-seeking behavior was studied. The scores of the respondents in Amasaman Sub-Municipal were compared with the scores of respondents in Pokuase Sub-Municipal.

This distinction was made because hospital records might indicate that Buruli ulcer is less endemic in one Municipality or the other. The open questions complimented the quantitative part of the study, providing explanations for stigmatizing aspects. The combination of quantitative and qualitative methods enabled looking for a consistent pattern among socially desired answers.

### **3.6 Training of Research Assistants**

There was a four day intensive training of the research assistants by the researcher, assisted by the field supervisor. Four research assistants with some considerable amount of knowledge in data collection who could speak and understand the local languages were used for the study. The content of the training included the purpose and objectives of the study, data collection techniques and tools to be used, translation of questionnaires into their local language (Ga), actual data collection and ethical issues or consideration.

### 3.7 Quality Control

The following measures were put in place to ensure the quality and validity of the data and findings of the study;

- Questionnaire was designed with systematic checks to avoid errors at the stage of data collection and data entry. All research assistants were trained. Questionnaire was pre-tested
- A Field Supervisor facilitated the filling of the forms. Forms filled in correctly were rectified within a day.
- Data which was clearly inconsistent were excluded from processing and analysis since it could affect the consistency and validity of the results.
- All data collected were entered twice by two different qualified personnel to ensure validity.
- Questions were marked after entry to prevent double entry.

### 3.8 Data Processing and Analysis.

The data after collection was edited in order to address the objectives. After editing, there was the coding of responses which were open-ended questions. The assignment of coding makes the responses machine readable. After editing and coding, the data was entered into the computer using the spreadsheet package to create Epi info file. This was imported into a Statistical Package for Social Scientist file using SPSS software to

perform the desired data transformation. Descriptive statistics in the form of frequency distribution, graphs and means were conducted.

### **3.9 Ethical Consideration/Issues:**

Before onset of the study, ethical clearance was sought from the Ethical Review Board of the Ghana Health Services and the Municipal Director of Health Services (Ga West), the MHMT members, chiefs and other stakeholders. Verbal Informed Consent was sought from participants and from the Parents of Minors. Respondents were assured of confidentiality.

### **3.10 Pretest or Pilot Study**

The structured questionnaire was pre-tested at Onyansana, an endemic community which was not among the communities selected for the survey. The results helped to improve the questionnaire so that the appropriate responses are generated.

## CHAPTER FOUR

### 4 RESULTS

This chapter presents data from the field:

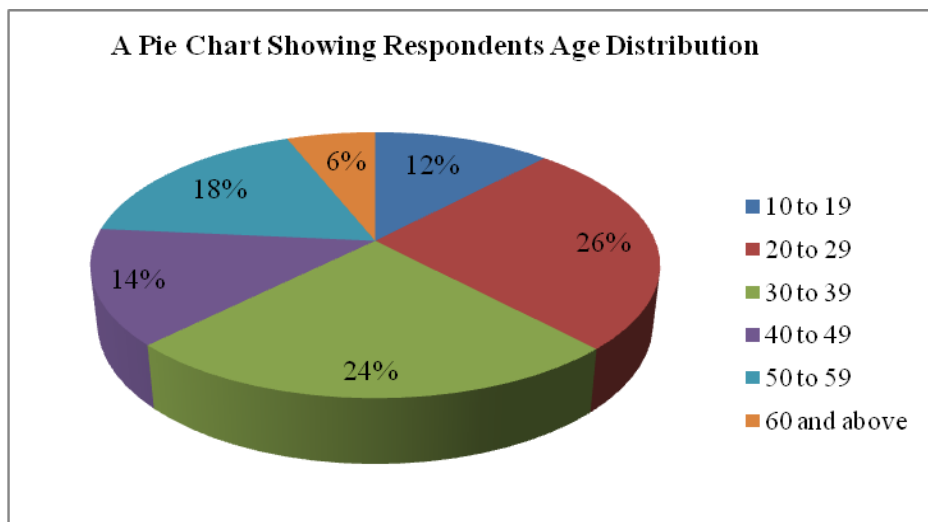
#### 4.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS.

The demographic data collected from respondents covered: age, gender, marital status, educational background, occupation, religious affiliation, and ethnicity.

##### 4.1.1 AGE OF RESPONDENTS.

Figure 4.1.1 shows the age distribution of respondents whose information and perception about Buruli ulcer in the community was solicited from. Out of the total number of 200 respondents 12% indicated they were children between the ages of 10 and 19 years, 26% between the ages of 20 and 29 with 24% also indicating they were between 30 and 39 years. Overall, it is evidently clear that the area, like most parts of Ghana has a youthful population, since majority of the respondents (50%) fell between the ages 20 to 39

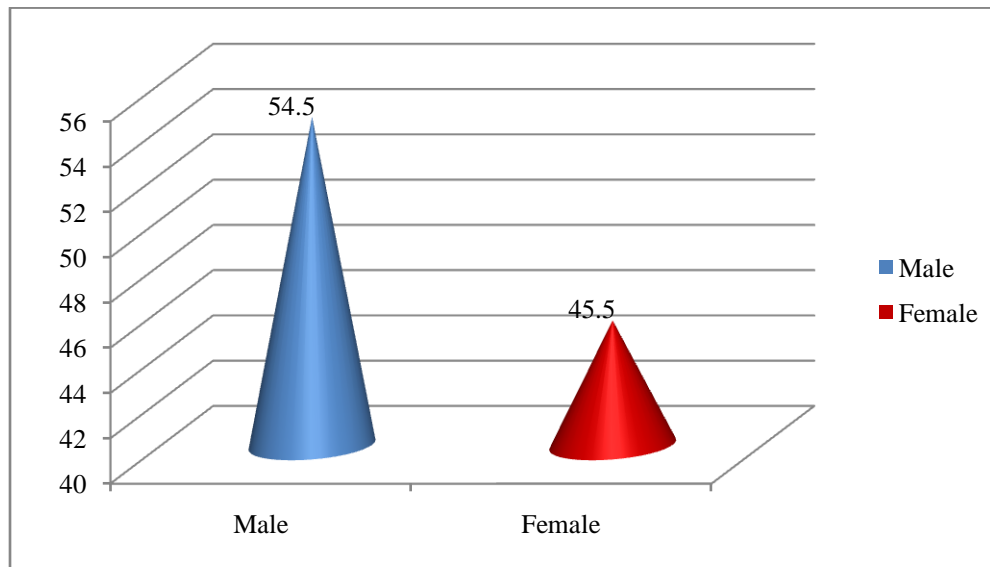
**Figure 4.1.1: Distribution of Respondents Age**



Source: Field study, June 2010.

#### 4.1.2 SEX DISTRIBUTION

**Figure 4.1.2: Distribution of Respondents by Sex**



**Source: Field study, June 2010.**

Fig.4.1.2 above shows the sex distribution of respondents in the 8 communities in the Ga West municipality used for the research. 54.5% of the total respondents were males while the remaining 45.5% were females.

#### 4.1.3 MARITAL STATUS

Out of the 200 respondents engaged in the research, 59.5% indicated they were married which constituted the highest percentage. This was followed by singles 35.5%, with those whose status was identified as divorced or widowed forming 4.5% and 0.5% respectively. Table 4.1.3 below shows the marital status of respondents.

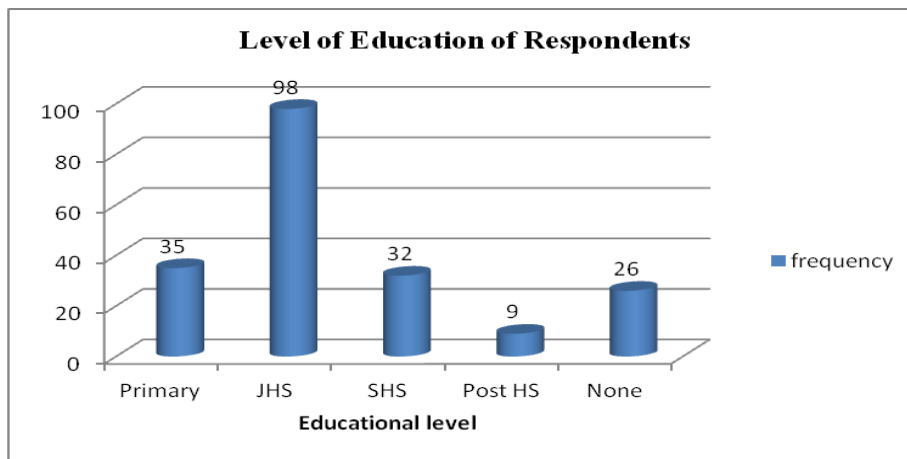
**Table 4.1.3: Distribution of Respondents by Marital Status**

STATUS	NO. OF RESPONDENTS	PERCENTAGE (%)
Single	71	35.5
Married	119	59.5
Divorced	9	4.5
Widowed	1	0.5
<b>TOTAL</b>	<b>200</b>	<b>100</b>

**Source: Field study, June 2010.**

#### 4.1.4 LEVEL OF EDUCATION

Fig.4.1.4 below indicates the levels of education of respondents. From the diagram it was evidently clear that majority of the respondents interviewed had had some form of basic education even though 26 respondents representing 13 % had no form of formal education . Figures from the diagram also indicates that 17.5 % of the respondents had just primary education, 49.0 % JHS whiles 16.0 % and 4.5% attended SSS and Post Secondary institutions respectively.

**Figure 4.1.4: Percentage Bar Graph showing Respondents Level of Education**

Source: Field study, June 2010.

#### 4.1.5 RELIGIOUS AFFILIATION

Christianity formed the majority of the respondents with 75.0 % followed by Islam with 18.0 % and Traditional and Pagans with 1.5 % and 5.5 % respectively as seen in Table 4.1.5 below.

**Table 4.1.5: Distribution of Respondents by Religion**

		Religion	
		Frequency	Percent
Valid	Christianity	150	75.0
	Muslim	36	18.0
	Traditional religion	3	1.5
	pagan	11	5.5
	Total	200	100.0

Source: Field study, June 2010

## 4.1.6 OCCUPATION OF RESPONDENTS

**Table 4.1.6: Distribution of Respondents by Occupation**

occupation		
	Frequency	Percent
Farmer	46	23.0
trader	66	33.0
student	40	20.0
unemployed	34	17.0
teacher	1	.5
driver	5	2.5
seamstress	2	1.0
plumber	3	1.5
mason	1	.5
electrician	2	1.0
Total	200	100.0

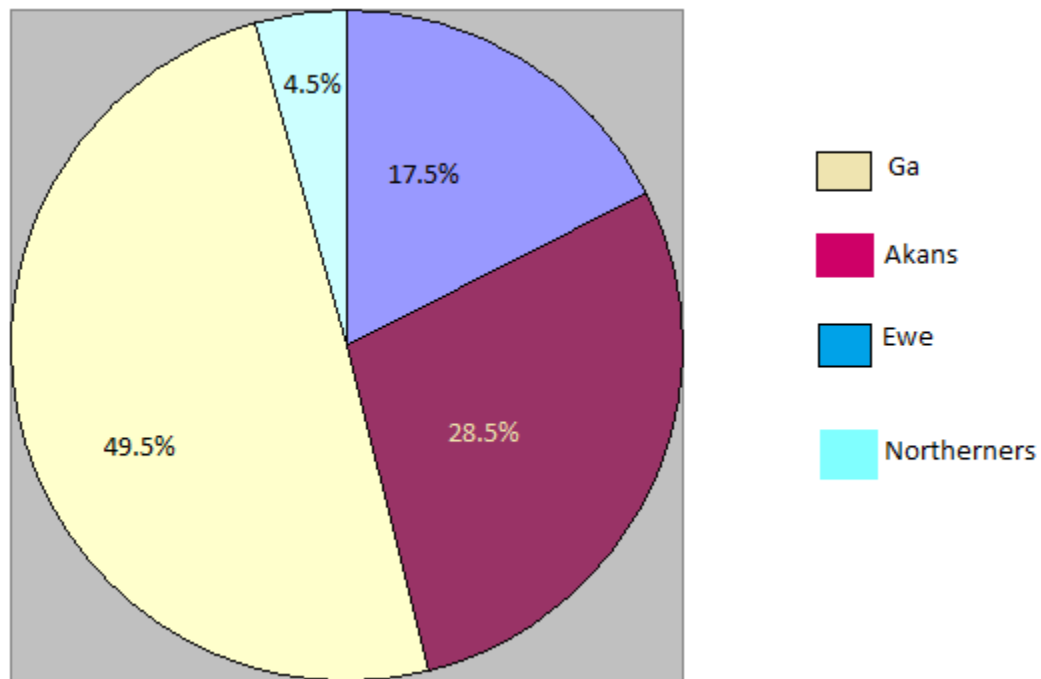
Source: Field study, June 2010.

Further analysis from the demographic data revealed that 17.0% of the respondents were unemployed. 23.0 % of the respondents were farmers, 33.0% traders, 20.0% of respondents were students, and 2.5%, 0.5 % and 1.5 % were Drivers, Teachers and Plumbers respondent respectively as seen in Table 4.1.2 above.

## 4.1.7 ETHNICITY

Ethnicity wise, quantitative data collected from the Municipality again showed that Ga's were in the majority (49.5%) followed by the Akans (28.5%), the Ewes (17.5%) and Northerners (4.5%). Fig. 4.1.7 shows the various ethnic groups of respondents.

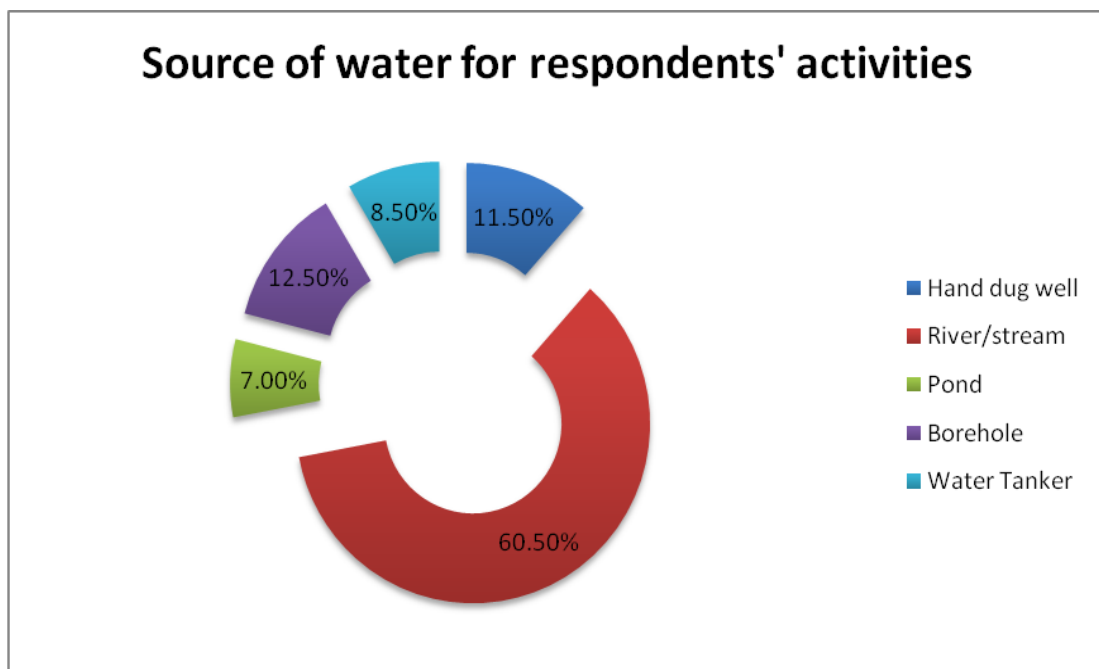
**Figure 4.1.7: Pie Graph showing Ethnicity of Respondents**



Source: Field study, June 2010.

#### 4.2 ENVIRONMENTAL SANITATION ISSUES

**Figure 4.2: Distribution of Respondent's Source of Water for their Activities**



**Source: Field study, June 2010.**

Figure 4.2 shows respondents sources of water for their daily activities of washing, bathing, cooking and drinking. The responses showed that 25 out of the 200 respondents representing 12.5% get their water from boreholes. 60.5% of the populace had their water

from rivers/stream. From this it can be deduced that should it be proven that the source of water accounts for the mode of spread of BU then this issue must be readily resolved. 11.5 % get their water from hand dug wells. From observation the researcher also found out that the community had some boreholes but only a few were functioning. This resulted in tremendous pressure on the functioning ones making it difficult for people to get access to water. Also due to the high cost of maintenance of the facility any fault developed would mean no water for users.

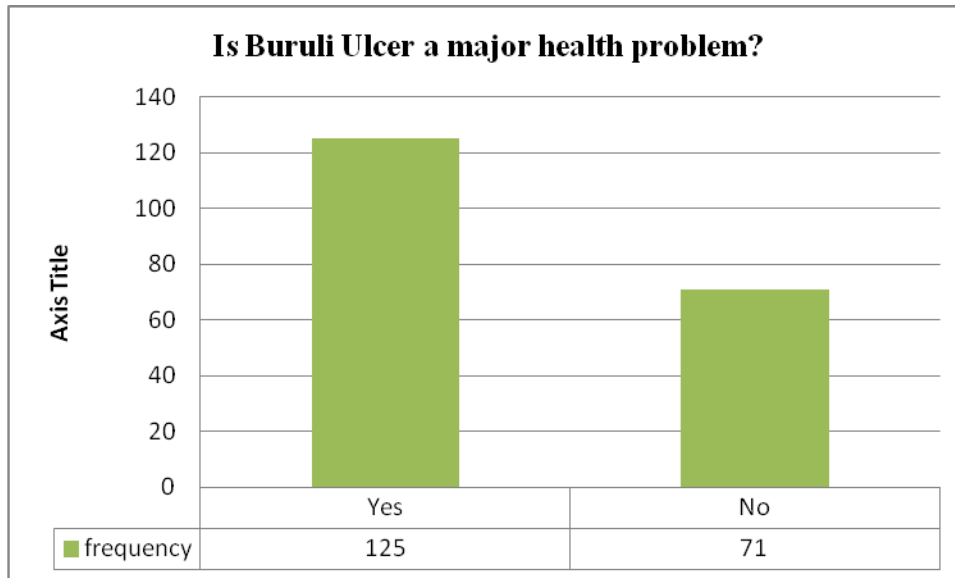
#### 4.4 LOCAL NAMES OF BURULI ULCER

Local names of the disease vary by the local languages of the respondents. Data from the study revealed that the Ga names for the disease are ‘helagbonyo’ ‘abuagbnyo’ and ‘odontihele’. The Ewe names are ‘datsifudor’ and ‘abimakumaku’ and the Akans call it ‘abuaboni’.

#### 4.5 BURULI ULCER BEING A MAJOR HEALTH PROBLEM IN THE AREA

Fig. 4.1.5: Frequency Distribution of Respondents on if Buruli Ulcer was a Major Health Problem of the Area

**Figure 4.5: A Bar Chart showing Respondents response on if Buruli Ulcer was a Major Health Problem in the Area**



Source: Field study, June 2010.

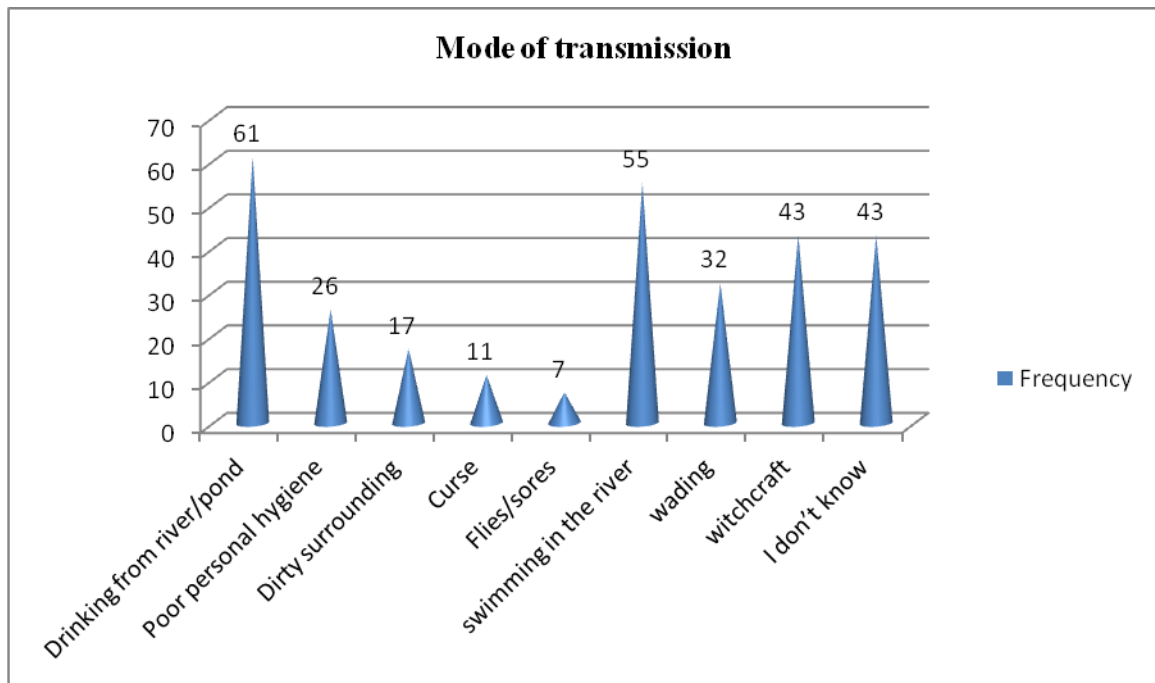
Out of the 200 responses 71 respondents (35.5%) said Buruli ulcer was not a major health problem in their area with reasons that the disease is not common these days or have either not seen any these days as education about the disease is going down well with the people. The other 125 (62.5%) still think Buruli ulcers is a major health problem since the mode of transmission is not known, there are no definite preventive measures and it is affecting most children in their communities.

#### 4.6 LOCAL IDEAS OF HOW ONE CAN GET INFECTED

From the data gathered, respondents attributed causes of BU to three main factors: wading in swampy areas (16%), drinking from river/pond (30.5%) and swimming in rivers (27.5%). Other reasons given aside this was: poor personal hygiene (13%), dirty surroundings (8.5%) and casting of spell through witchcraft and curses (27%). 21.5% however indicated they had no idea about how one gets infected with the disease as

shown in the figure below.

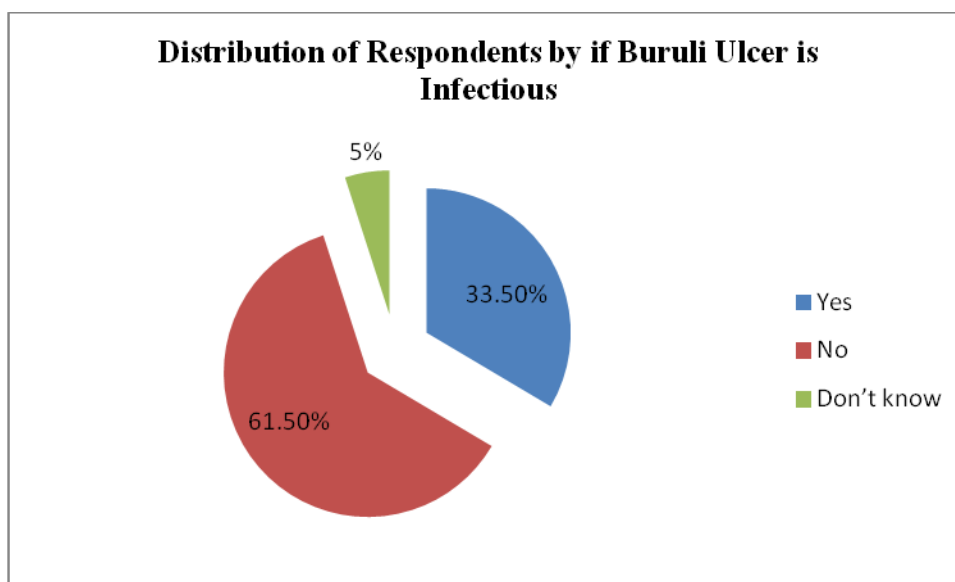
**Figure 4.6: Percentage distribution of Respondents by how one can get infected**



Source: Field study, June 2010.

#### 4.7 INFECTIOUSNESS OF BURULI ULCER

Figure 4.7: Pie Chart showing if BU is Infectious



Source: Field study, June 2010.

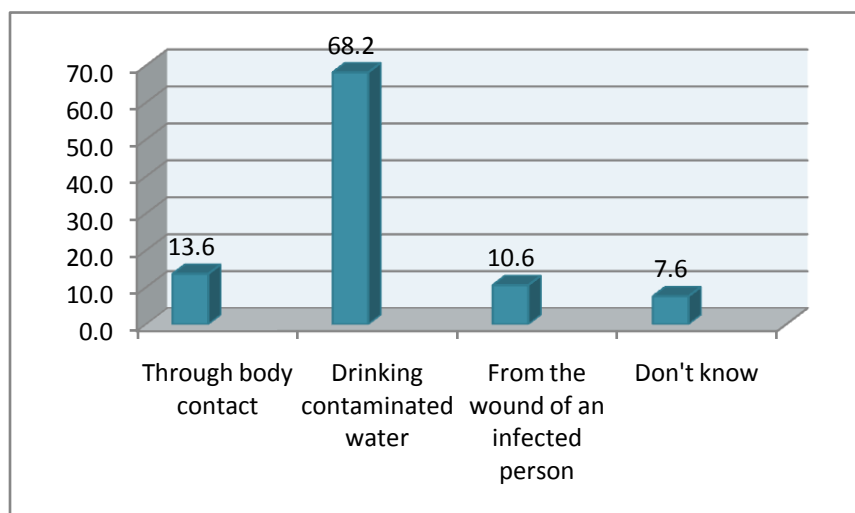
From fig. 4.7 it is seen that 33.5% of the respondents said Yes BU was infectious, 61.5% said No and the remaining 5% had no idea.

#### 4.8 SPREAD FROM PERSON TO PERSON

Out of the 33.5% who said BU was infectious, 13.6% of the respondents said Buruli ulcer was transmitted through body contact, 68.2% said it was through drinking contaminated

water, 10.6% said from the wound of an infected person and the remaining 7.6% said they do not know the mode of transmission.

**Figure 4.8: Distribution of Respondents by how Buruli ulcer is spread from person to person**



Source: Field study, June 2010.

#### 4.9 CATEGORY OF PEOPLE AFFECTED BY BURULI ULCER

**Table 4.9: Percentage distribution of Respondents on who the disease affects most**

INDICATOR	COUNT (%)
Infants	0 (0)
Males (1-17yrs)	28 (14)
Females (1-17yrs)	24 (12)
Women	1 (0.5)

Men	2 (1)
Everybody	132 (66)
Don't know	13 (6.5)
<b>TOTAL</b>	<b>200 (100)</b>

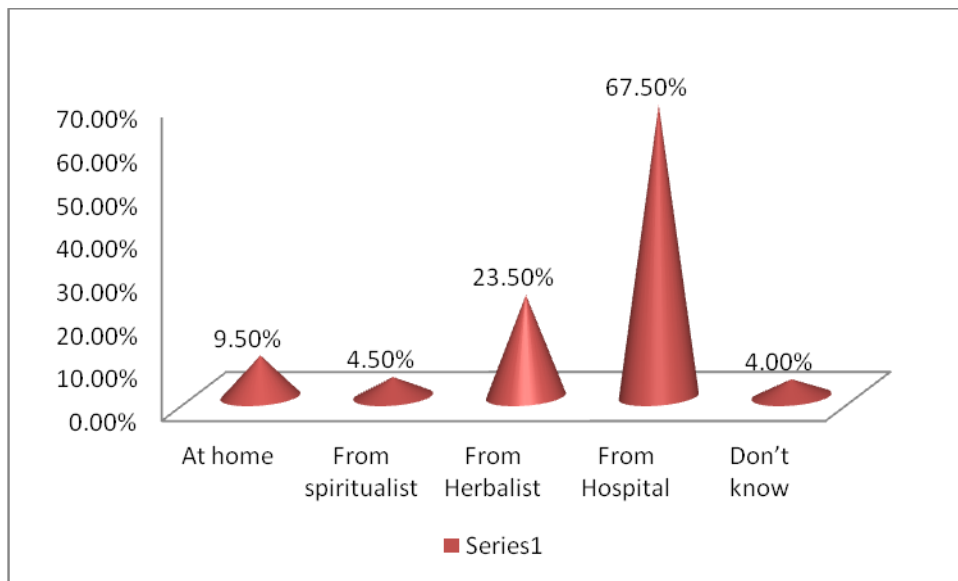
**Source: Field study, June 2010.**

Table 4.9 above clearly shows that even though children are mostly affected, males (14%) are most prone than females (12%). Further probing as to the disease affecting everybody revealed that within the “everybody” classification, children emerge the victims.

This means that there are more children affected by Buruli ulcer than adults. A study conducted by MacCallum et al in Australia, French Guinea and Papua New Guinea showed that more than 50% of those affected were children under the age of 15 years who live in remote rural areas. The above findings reaffirm the fact that children are mostly prone to be affected with BU.

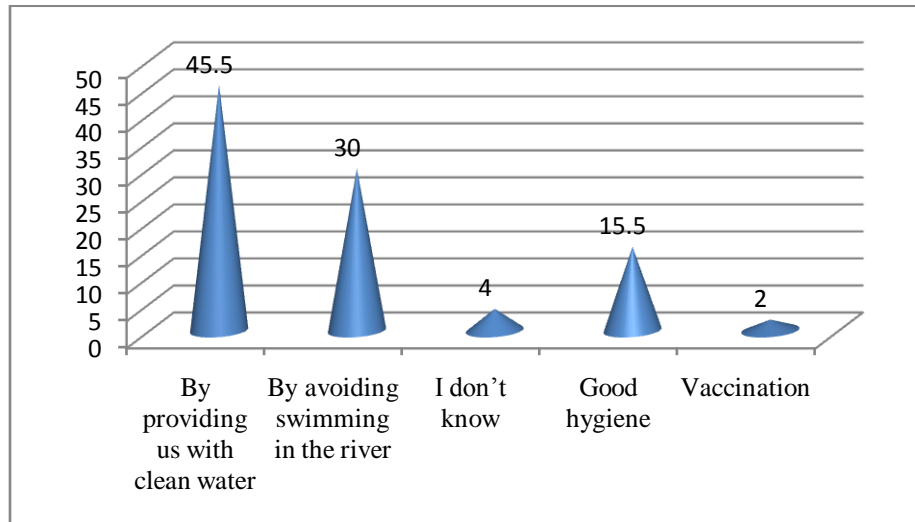
#### **4.10 TREATMENT SEEKING BEHAVIOUR**

From the data, (as seen in fig. 4.10 below), the hospital is the most preferred choice of seeking treatment (67.5%). It must however be stated that although majority seek medical treatment an appreciable number of people (23.5%) still resort to the herbalist for treatment.

**Figure 4.10: Percentage distribution of Respondents by where BU Patients seek treatment**

Source: Field study, June 2010.

**Figure 4.11: Distribution of Respondents by how BU could be prevented in their Communities**



**Source: Field study, June 2010.**

#### **4.11 COMMUNITY REACTION TOWARDS BURULI ULCER PATIENTS**

Table 4.11 below summarizes the various reactions of the people of the Ga West community towards Buruli ulcer patients. The condition of the disease evokes a lot of sympathy from members of the community (40.5%), this is so because the disease is seen as no fault of the patients. Some school children were avoided by their colleagues at school. During the field visits, there were quite a number of patients in the community going about their daily lives normally. However as the disease advanced, which was characterized by extreme pain, discomfort and offensive smell of the ulcer they were not allowed to take part in activities such as not being allowed to perform household chores, take on leadership roles, not allowed to go to school, stripped of social responsibilities and not welcomed at social/community gatherings

**Table 4.11: Distribution of Respondents reaction towards BU Patients by Community Members**

<b>INDICATOR</b>	<b>RESPONSES</b>	<b>PERCENTAGE (%)</b>
Recorded as people plaque with evil forces	3	1.5
Not allowed to perform household chores	37	18.5
Not allowed to go to school	11	5.5
Stripped of community/ social responsibilities	19	9.5
Locked in a room	0	0
Not suitable for marriage	5	2.5
Sympathized with	81	40.5
Not allowed to play leadership roles	31	15.5
Not welcome at social/community functions	13	6.5
<b>TOTAL</b>	<b>200</b>	<b>100</b>

**Source: Field study, June 2010.**

## CHAPTER FIVE

### 5. DISCUSSIONS

#### 5.1 Introduction

This chapter analyses, discusses and interpret data as it was obtained from the field in order to address the main and specific objectives of the study. The following are the outline of this chapter:

- Socio-demographic characteristics of respondents
- Environmental/sanitation issues of the communities
- Local names for Buruli ulcer
- Mode of transmission of Buruli ulcer
- Category of people affected by Buruli ulcer
- Community perception of Buruli ulcer
- Community knowledge about Buruli ulcer
- Community reaction towards Buruli ulcer patients
- Health seeking behaviours

The socio-demographic characteristics of the respondents begin this analysis.

## 5.2 Socio-demographic Characteristics of Respondents

Demographic background of respondents is an important piece of information and was therefore captured in the study against which other variables such as community perception of Buruli ulcer, health seeking behaviours could be analyzed. It was important to capture this information about the respondents because; studies have shown how people's social environments play a crucial role in how they perceive the world. Socio-demographic characteristics discussed under this section are, age, sex, ethnicity, religion, education and occupation.

### 5.2.1 Age

From the data obtained from the communities it was revealed that the 26% of the respondents were in the age group 20-29 and 24.5% 30-39 all falling under the youthful population (refer to fig. 4.1.0). It could be said that the youthful population of these communities which is not common of a rural community where young people would migrate to urban centers, could be due to activities such as sand winning in these communities that fetches them more money.

### 5.2.2 Sex

In the study, more males (54.5%) were interviewed than females (45.5%). Explanation for this phenomenon are that generally there are more females than males in any given

community, since most of the communities are occupied by settlers farmers, it is assumed that their wives are living with them. Moreover the period of the survey coincided with the rains and therefore the planting season for some and harvesting of certain crops such as cassava, pineapples and mangoes for others. For this reason men in certain households visited were away at their farms leaving behind their wives to take care of the home.

### 5.2.3 Ethnicity

Data collected from communities indicated that majority of the respondents were Gas (49.5%) followed by the Akan 28.5% and Ewe 17.5% and few Northerners (4.5%). It must be emphasized that all the ethnic groups in the respondents apart from the Ga are migrants.

### 5.2.4 Religion

Religion and Health are synonymous to one another. The religious and health institutions are the most fundamental to society as they are regarded as the bedrock of society. In the study it was therefore important to find out about the religious background of the respondents. It came out that Christianity represented 51.5% of the respondents, 29.5% were Moslems, 13% traditionalist and 6% Pagans as in table 4.1.1. This shows that Christianity is high in the Ga West Municipality and if education on Buruli ulcer is channeled through the churches and even the Mosques it will go a long way to help curtail the disease.

### 5.2.5 Education

The data on education showed that majority of the respondents 36.5% either had their education to the primary level or could even not complete this level, 18% completed

secondary/ form four and 17% JSS . Education is responsible to stimulate one's sense of reason to bring about a desired change and from the study, the findings the level of education of the respondents was the reason why they were aware of Buruli ulcer but could also be said that since majority could not go up the educational ladder it limits their exposure to modern concepts of health and disease.

#### 5.2.6 Occupation

One's source of livelihood is largely determined by the income one generates from the work he or she does. These occupations as given by respondents can be said not to generate enough income to support them and their families. According to the study, the vast majority of respondents are Traders (33%) followed by Farmers (23%). About 15.5% were unemployed.

In conclusion analysis of the socio-demographic characteristics of respondents has provide foreknowledge of the background to which their social environment and actions to adaptation could be better understood.

### **5.3 Environmental sanitation issues of the communities**

Cleanliness as the saying goes is next to Godliness. For any society to be free from the adverse effects of disease which might later result in deaths there is the need to maintain good sanitary conditions. The productivity of every country, every community and every town is dependent on the health of its people. The Ga West Municipality has relatively good number of private and public latrines. Garbage or refuse collection is effectively managed by the Zoom Lion. A few households have no toilet facilities and therefore attend nature's call (defecate) in bushes which tend to make some parts of the community

not habitable to live. The drainage facilities are well managed in the municipal capital (Amasaman). This cannot be said of the rural areas where the drainage systems are poorly managed.

#### **5.4 Local names for Buruli ulcer**

Local names given to the disease by the local language of the respondents as in page 50 (4.4.1) reveals that the Ga names for the disease are ‘helagbonyo’ ‘abuagbnyo’ and ‘odontihele’.

The Ewes refer to it as ‘datsifudor’ and ‘abimakumaku’ and the Akans call it ‘abuaboni’. According to (Marx 1989) in epidemiological research social factors remain largely understudied and poorly understood. He postulates that in order to diagnose, treat and control a disease effectively, a wide range of factors such as culture, behaviour, environment and economics should be taken into consideration.

#### **5.5 Mode of transmission of Buruli ulcer**

Though many factors concerning the mode of transmission about Buruli ulcer remain unknown, current research suggests several factors associated with the prevalence of the disease. For example, living in close proximity to slow moving water such as swamps, man-made lakes, dams, and creeks, or living in lower elevation areas appear to have a higher risk for Buruli ulcer (Duker et al., 2004). Similarly, living in areas with marshland vegetation or areas that have a high degree of human impact on the landscape such as construction of small scale mining, roads, hydropower dams, and new settlements appears to carry a higher risk of disease. Gender wise, males appear to have a slightly higher risk than females because they are vigorously involved in these activities. Curtis James Denton (2007). When the question “is Buruli ulcer an infectious disease?” was

posed to the respondents, out of the 33% who said BU was infectious, 13.6% of the respondents said Buruli ulcer was transmitted through body contact, 68.2% said it was through drinking contaminated water, 10.6% said from the wound of an infected person and the remaining 7.6% said they do not know the mode of transmission.

This goes down to prove the point that the mode of transmission of the disease still remains a mystery that needs further epidemiological investigation.

### **5.6 Community perception and knowledge of BU**

A combination of various occurrences and experiences whether natural or spiritual aids in shaping the perception of each individual and also defining its cultural milieu. Cultural, therefore, is the lens through which individuals perceive, relate and react to various phenomena including health. Various concepts of explanations are given by people in different cultures, to describe or explain illness. These explanatory models are congruent with the way people perceive illness and are derived from concepts, symbols, beliefs and practices that have deep roots in their culture. (Portaels et al, 2001). Responses from the focus group discussions revealed that BU is still a public health problem even though the number of affected persons continues to gradually decline.

### **5.7 Category of people affected by Buruli ulcer**

Children both males and females are known to be the most affected by Buruli ulcer, Oluwasanmi et al. (1976). Data from the study revealed that indeed children are mostly affected by the disease. Table 4.9 reaffirms this by indicating that children between the ages of 1 and 17 representing a total of 26% are mostly affected. The data also showed that even though children are mostly affected, males (14%) tend to be more susceptible than females (12%).

### **Community reaction towards Buruli ulcer patients.**

Teachers were reported as having told children with the disease to stop schooling for fear of passing it on and also because of the stench of the ulcer. Because of the pain experience by children, parents also do not have the moral courage to allow them to go to school. It could be possible that a large number proportion of children drop out of school as a result of the disease. This could be due to the long period of infection and treatment, several hours of tuition missed and the possibility of having to repeat a class or lag behind his/her peers by two or three classes.

### **5.8 Health seeking behaviour.**

It was gathered from the FGDs that the efficacy of any herbal treatment is subject to the body constitution of the patient. There are some patients who react negatively to herbal medicine whilst others do not. (Bang & Bang, 1994) agreed that some patients delay in seeking medical advice and treatment after seeking herbal treatment without any success for fear of amputation. Lack of time and money, as well as poor health care facilities play an important role in delays in seeking healthcare.

The belief that one could die or harmed if one receives injection when the cotton wool like substance has not been removed is responsible for preventing patients from seeking early treatment at the Amasaman Hospital. This propaganda is being disseminated by herbalist and traditional healers and must be stopped through appropriate health education strategies and sensitization.

Environmental and socio-economic factors like place of residence and education play an important role in the first line of action to take when illness strikes and also in making informed choices about treatment seeking. In a study in Nigeria on the response of patients to the five killer diseases among children, in a Yoruba community (Adetuni, 1991), discovered that mothers would not directly seek medical care immediately a child became sick. Local home remedies in all cases were the first line of treatment. It is only when this fails after repeated trials that another alternative would be tried. The choice of treatment would be determined by where the parents were at the time of sickness- the farm or the home.

Access is an important factor to seeking appropriate healthcare. Factors accounting for poor access to health facilities are: the unavailability of trained and qualified staff, long distance, poor road network leading to high transportation cost and poverty (Tanahashi, 1978). Unless all these bottlenecks are removed, in order to make health delivery effective, efficient and beneficial to the majority who incidentally happen to be the poor, mortality rates will continue to be high. Education plays a very important role in treatment seeking behaviour of people and the provision of accurate information on mechanisms of disease, disease patterns and inherent dangers, if only the right messages or appeal is communicated (Elisa, 1991).

The most serious cases of BU at Amasaman Hospital are those who have repeatedly consulted herbalists without any success.

## CHAPTER SIX

### 6. CONCLUSIONS AND RECOMMENDATIONS

The overall objective of this study is to assess the community perception and knowledge of Buruli ulcer (BU) and how these affect the management of the disease. This study is of significant importance for the reason being that socio-cultural factors play quite a significant role in the aetiology, mode of transmission and management of the disease.

1. All of the respondents do not know the cause of the disease as indicated by the fact that 30.5% of respondents attributed causes of BU to drinking from pond/river, swimming in rivers (27.5%) and wading in swampy areas (16%). Other causes: Poor personal hygiene (13%), dirty surroundings (8.5%), witchcraft and curses (27%). 21.5% said that they had no idea of how one gets infected with the disease.
2. All the respondents do not know the mode of transmission of the disease. This is illustrated by the finding that 68.2% of the respondents said BU is transmitted by drinking contaminated water and 13.6% said BU is transmitted through body contact. 10.6% said from the wound of an infected person and the remaining 7.6% said they do not know the mode of transmission.
3. Majority (67.5%) of the respondents preferred hospital as the first choice of seeking treatment whiles 23.5% of respondents said BU cases preferred herbalist treatment.

## RECOMMENDATIONS

Against the background of these conclusions the following recommendations are being made:

### Municipal Health Management Team (MHMT)

- It is recommended that knowledge and understanding about the disease should be improved. This could be achieved by the MHMT including key health workers, community leaders and persons affected by Buruli Ulcer in campaigns to inform the communities about the disease; education can decrease ignorance and prejudice, and the community's participation will help facilitate rehabilitation.

### Municipal Assembly

- The Municipal Assembly should provide the people with portable drinking water for not only drinking, but bathing and washing as well. This is against the backdrop that majority of the respondents indicated that the disease is contracted through drinking contaminated water and swimming in rivers. To what extent this assertion may be true also calls for further epidemiological and micro-biological studies.

### Ministry of Health/Ghana Health Service

- In order to encourage BU Patients to seek medical care well enough before complications set in, the Ministry of Health/Ghana Health Service should established well equipped health facilities closer to the people.

The researcher is highly optimistic that if these recommendations and those of other BU related studies already provided are taken into consideration the Ghanaian government, the World Health Organization (WHO) and Non Governmental Organizations (NGO's) who have dedicated their resources to the eradication of BU in all its entirety, that is in terms of its causes, effects and treatment of Buruli ulcer would be improved.

## APPENDIX A

### QUESTIONNAIRE

#### THE COMMUNITY PERCEPTION AND KNOWLEDGE OF BURULI ULCER IN THE GA WEST MUNICIPALITY AREA.

#### INTRODUCTION

The purpose of this questionnaire is to solicit information on the community perception and knowledge of Buruli Ulcer in your Community. This exercise is to help throw light on the causes of Buruli Ulcer and also to explain the health seeking behaviour of Patients. Your candid response will therefore be most appreciated and we wish to assure you of confidentiality of response.

#### THANK YOU

NAME OF COMMUNITY-----

NAME OF INTERVIEWER-----

#### SECTION ONE: BACKGROUND OF RESPONDENTS:

1. Age .....
2. Sex:  Male  Female
3. Marital status:  Single  Married  Divorced  Widowed
4. Level of education:  Primary  Secondary  JSS  SSS  
 Post secondary
5. Ethnicity:  Akan  Ga  Adangbe  Ewe  Northerner
6. Religion:  Christianity  Muslim  Traditional religion  Pagan
7. Occupation: .....

#### SECTION TWO (11): ENVIRONMENTAL/SANITATION ISSUES

8) Where do you obtain water for the following activities? Washing (Kindly tick the appropriate box (es))

- From a hand dug well  Rivers/stream  Pond
- Borehole  Water Tanker
- Others, please specify .....

9) Where do you obtain water for bathing? (Kindly tick the appropriate box (es))

From a hand dug well     Rivers/stream     Pond

Borehole     Water tanker     Others, please specify

.....

10) Where do you obtain water for Drinking? (Kindly tick the appropriate box (es))

From a hand dug well     Rivers/stream     Pond

Borehole     Water tanker

Others , please specify .....

11) Where do you obtain water for Cooking? (Kindly tick the appropriate box (es))

From a hand dug well     Rivers/stream     Pond

Borehole     Water tanker     Others, please specify .....

12) How is refuse disposed off in this community? (Please tick the appropriate box (es)).

Dumped on the community refuse collection site

Dumped in pit in the compound

Dumped at the back of the house

Dumped indiscriminately in the community

Dumped in the district assembly refuse containers

Other, please specify-----

13) How do you attend nature's call (visit the toilet)?

Household toilet

Pit latrines in the house

Pit latrines in the Community

Free range/ in the bush

Community's KVIPs

Others, please specify.....

14) Kindly indicate the kinds of animals that graze/feed in this community?

Goat

Pigs

Sheep Poultry Cattle No animals

15) Where do these animals drink from?

 Pond River/Stream Others specify-----**SECTION THREE: CAUSES/MODE OF TRANSMISSION OF BURULI ULCER**

16) What local names are given to Buruli Ulcer? -----

17) Is Buruli Ulcer a major health problem in this area?  Yes  No

17a). Please give reasons for your answer-----

-

18) How does one get infected with Buruli Ulcer? (Please tick the appropriate box (es) )

 By drinking from river/pond  
the skin Transmitted by flies into open sores/cuts on  
the skin Poor personal hygiene By swimming in the river Dirty surrounding By wading in swampy areas Curse By casting of a spell through witchcraft I do not know Others-----

19) At what times of the year is one likely to get infected?

TIME OF THE YEAR	REASON
During the dry season	

During planting/seed time	
During harvest	
Any time of the year	
Other specify	

20) Is Buruli Ulcer infectious?  Yes  No

20a). If yes how do you think the disease is spread from person to person? (Please tick the appropriate box (es)):

- Through body contact  From the wound of an infected person
- drinking contaminated water  I do not know
- Others, please specify-----

21) Who does the disease affect most? (Please tick the appropriate box (es))

- Infants (0-1year)  Children (1-17years)(female)
- Children (1-17yrs)(male)  Men
- Women  Everybody

21a). Why do you think these people suffer most? -----

-

#### **SECTION FOUR (IV): TREATMENT SEEKING BEHAVIOUR**

22). Have you ever contracted the disease before?  Yes  NO

22a). if yes to the above question, kindly describe how you sought treatment? -----

-

23). If No to question 22, where do Buruli Ulcer Patients often seek treatment in this

community? (Please tick the appropriate box (es)):

- At home  From the herbalist
- From the spiritualist  From the Hospital
- I do not know
- Other specify-----

### SECTION FIVE (V): COMMUNITY PERCEPTION/COMMUNITY ACTION

24). How are Buruli Ulcer Patients treated by the Community? (Please tick the appropriate box (es))

- Recorded as people plagued with evil forces  Not suitable for marriage
- Not allowed to performs household chores  Sympathized with
- Not allowed to go to school  Not allowed to play leadership roles
- Stripped of community/social responsibilities
- Locked up in a room  not welcome at social/community functions
- Other specify-----

25). What measures has the community put in place to curtail (stop) the spread of the disease?

-----

26). How do you think Buruli could be prevented in the community? (Pleas tick the appropriate box (es) ):

- By providing us with clean water  By avoiding swimming in the river
- I do not know
- Others specify-----

### SECTION SIX (VI): COMMUNITY KNOWLEDGE:

27).What do you think can cause Buruli Ulcer?

- 1.....
- 2.....
- 3.....
- 4. ....

28). How do you know that a disease is Buruli Ulcer?

.....

29). How can you be infected?.....

30). What do you think are the effects of Buruli Ulcer on the individual?

.....

31). Do you consider Buruli Ulcer as a dangerous disease

- 1. Yes
- 2. No

32). Please give reasons for your answer

.....  
.....

33). How can you prevent yourself from being infected with Buruli Ulcer?.....

.....  
.....

**APPENDIX B****FOCUS GROUP DISCUSSION GUIDE**

1. Name any three major health problems that affect men, women and children in this community?
2. What are the local names of Buruli Ulcer?.....
3. Is it a major health problem in this community?.....
- 3a. If yes why do you say so?.....
4. How does one get infected with the disease?.....
5. Is Buruli Ulcer infectious?.....
6. What times of the year (months, seasons) is one likely to get infected?.....
- 6a. what kind of explanation would you give to this anomaly?.....
7. How does the disease spread from person to person?.....
8. Who does the disease affect most?.....
9. Where/who does the Buruli Ulcer patient go to for treatment?.....
- 9a. In this place/ at these places, what kind of treatment is given to the patient? .....
  
10. Who is affected most by this disease?.....
11. How are Buruli Ulcer Patients treated in the community?
  - a. Are they stigmatized?  Yes  No
  - b. Are they allowed to carry out their normal/ social responsibilities e.g. (education, leadership roles, political roles, are mothers allowed to breast milk, are they eligible for marriage etc)?

**APPENDIX C****CASE STUDY GUIDE (FOR BURULI ULCER PATIENTS)**

1. How old are you?.....
2. What tribe are you?.....
3. Do you attend school? Yes/No .....
4. If yes what class are you in?.....
5. Do you still attend school? .....
6. Where do you work?.....
7. Do you still work? .....
8. Who do you stay with? .....
9. What is Buruli Ulcer?  
.....  
.....  
.....
10. How did you get infected with BU for the first time?.....  
.....  
.....
11. What chores/work were you doing when you first got infected (eg. Fetching water from a stream, collecting firewood etc)?
12. What year was that?.....
13. Did you have a cut on you before you got infected? Yes/No.....
14. How many times have you been re-infected?.....
15. For all the times you got infected, kindly describe your treatment seeking behaviour, beginning with the first  
.....  
.....  
.....  
.....

16. For each of this treatments, give reasons for your choice

1.....

2.....

17. Kindly evaluate each line of treatment (which one has helped you most)?

.....

18. How has this disease affected your life/social, economical, educational, marriage, political etc?

.....

.....

19. Are you stigmatized because of the disease? Yes/No.....

20. When you had BU or know that you have it, how were you treated by community members?

.....

.

21. In your opinion how is BU transmitted from person to person?

.....

22. What measure(s) do you think can be put in place to curtail (stop) the spread of BU?

.....

.....

.....

23. Where do you obtain water for the following in your community?

a. Drinking.....

b. Washing.....

c. Cooking .....

d. Bathing .....

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