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COMMUNITY MANAGEMENT OF BURULI ULCER WOUNDS AND SCARS IN THE AKUAPEM SOUTH MUNICIPALITY

BY

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DECLARATION

I, Robert Mensah Kwaku Gbley, hereby declare that, with the exception of other people's work which have been duly acknowledged, this dissertation is my own work under the supervision of Rev. Dr. Mercy M. Ackumey, and that this work, either in whole or in part, have not been presented elsewhere for another degree.

…….. ……

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(Student)

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Rev. Dr. Mercy M. Ackumey Date

(Academic Supervisor)

DEDICATION

I dedicate this work to my Parents, Norviegbor Nyadzi and John Kofi Gbley, and my siblings who have been my source of encouragement and support throughout this program.

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I am highly indebted to the Almighty God for His grace and mercy, and constant supply, both material and immaterial that made it possible for me to complete this Program.

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ABSTRACT

Introduction: Buruli Ulcer (BU) is an environmental pathogen found in poor rural communities of tropical and sub-tropical regions. BU, caused by *Mycobacterium ulcerans* infection, is a debilitating disease of the skin and underlying tissues which starts as a painless nodule, oedema or plaque and could develop into painful and massive ulcers that might result in severe and permanent functional disabilities, if not treated well.

Methods: This cross-sectional exploratory study examined local perceptions and practices of wounds/sores and scars management, as well as community perceptions of health facility management of wounds/sores and scars. An in-depth interview, a qualitative data collection method was used. In all, twenty-six (26) respondents were interviewed which included the clinician of the Parkro Health Facility (Key Informant), and BU patients in the Akuapem South Municipality. Data was transcribed and analyzed thematically.

Results: The study revealed that most sufferers of BU disease sought help from herbalists, traditional healers and pastors because they believed the disease is caused by supernatural forces. However, they go to the health facility for management of their wounds/sores and scars when these alternative sources failed, a situation which usually leads to recurrence of wounds/sores and leaves patients with permanent deformities. The majority of patients considered the health facilities as most effective but geographically inaccessible.

Conclusion: There is the need for a community awareness on BU disease through health education. More community-based BU surveillance volunteers should be recruited,

trained and motivated to facilitate early detection and management of the disease. Health workers should also be reoriented and motivated to be willing to manage BU patients. Finally, halfway homes (temporary accommodation) closer to the facilities should be established by government and other relevant stakeholders for highly infected patients and their caregivers to lodge in while receiving treatment.

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LIST OF ABBREVIATIONS

BU –	Buruli Ulcer
BUPaT –	Prevention and Treatment of Buruli Ulcer
CDC –	Center for Disease Control
PHC -	Parkro Health Center
TRA –	Theory of Reasoned Action
WHO –	World Health Organization

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND

Buruli Ulcer (BU) is a one of the seventeen (17) neglected tropical diseases which bedeviled tropical and subtropical regions, particularly, sub-Saharan Africa (WHO, 2014). BU, caused by *Mycobacterium ulcerans* infection is a debilitating disease of the skin and underlying tissue which starts as a painless nodule, oedema or plaque and could develop into painful and massive ulcers if left untreated (Ackumey, Kwakye-Maclean, Ampadu, de Savigny, & Weiss, 2011). Globally, BU is presently the third most common mycobacterial pathogen of humans, after *M. tuberculosis (tuberculosis) and M. leprae (leprosy)*, but most poorly understood among the three (Ackumey, Kwakye-Maclean, et al., 2011a). In Ghana, BU is currently the second *mycobacterial* infection after tuberculosis (Agbenorku, 2014).

Before the 1980s, a number of *M. ulcerian* infections were reported in several countries in sub-Saharan Africa, including Congo, Uganda, Nigeria, Cameroon, Gabon, and Ghana. The name "Buruli ulcer" was first coined by The Ugandan Buruli Group, because the cases they described were first identified in patients in the Buruli County (Johnson, Stinear, Small et al., 2005). Depending on the geographical location where it was historically reported, it was also referred to as Bairnsdale, Searles, Kunusi ulcer and "The Mysterious Disease" (WHO, 2014).

1.1.1 Epidemiology and Global Distribution

Buruli ulcer has been reported in 33 countries in Africa, the Americas, Asia and the West Pacific. According to WHO, 5,000 – 6,000 cases are reported annually from 15 of the 33 countries. Most of the cases reported are found in tropical and subtropical regions, except in Australia, China and Japan. In Africa, the majority of cases were reported from the West and Central African countries such as Benin, Cameroon, Cotê D'Ivoire, Democratic Republic of Congo, and Ghana. Whereas Australia and Japan recorded 10% and 19% respectively of those affected to be under 15 years, for the same population, Africa reported 48% (WHO, 2014). While Africa tops the list of the most affected region, Ghana was reported currently as the second most affected country after Cote D'Ivoire (Agbenorku, 2014).

Gender distribution according to WHO Fact Sheet N. 199 (2013), varies. Australia recorded 55% males and 45% female, Japan has 34% males and 66% females, and Africa reported 52% males and 48% females. Ghana reports approximately 1,000 cases of BU a year, and has a national prevalence of 20.7 cases/1,000 population (Ackumey, Gyapong, Pappoe, & Weiss, 2011a; Ahorlu, Koka, Yeboah-Manu, Lamptey, & Ampadu, 2013).

1.1.2 Help Seeking Practices for Buruli Ulcer Wounds

In their study, Ackumey et al., (2011a) noted that most persons with the Buruli ulcer infection do not seek early treatment. Among the factors believed to have accounted for this situation are cultural beliefs, financial capacity, access to treatment facilities,

prolonged hospitalization, and fear of surgical outcomes (Ackumey, Gyapong, Pappoe, & Weiss, 2011b).

1.2 PROBLEM STATEMENT

BU affects people of all ages, but the most affected are children under the age of 17 years who live in deprived rural communities (Ackumey, 2013). The pre-ulcer stage of infection is characterized by nodules, plaques and oedemas (Ackumey, Gyapong, Pappoe, Kwakye-Maclean, Weiss, 2012.). The mean incubation period of the pre-ulcer stage could vary from a few weeks to several months. An earlier study put the average time at 1-3 months (Ackumey, Gyapong, Pappoe, Kwakye-Maclean, Weiss, 2014.). WHO Fact Sheet report (2014), indicated that 35% of lesions occur on the upper limbs, 55% on the lower limbs and just about 10% on the body.

The belief that BU is caused by supernatural forces influences the use of herbal medicine and other local practices to manage wounds with adverse consequences - physical, social, economic, and psychological (Ackumey, Kwakye-Maclean, et al., 2011; Ackumey, Gyapong, Pappoe, Maclean, & Weiss, 2012; Bigelow, Welling, Sinnott, Torres, & Evanson, 2002). BU manifests itself in the form of extensive ulcers, especially on the arms and legs. (Ackumey, 2013).

However, the ability to prevent its recurrence or long-term functional disabilities in the treatment of BU lies in effective management of wounds/sores and scar. This is because the BU illness is mostly ulcers.

Anecdotal evidence suggests that there are local wound and scar management practices that impede healing of BU wounds and influence recurrence (personal observation). Research has shown that more than a quarter of BU patients suffer severe and permanent disabilities (Chukwuekezie et al., 2007).

Additionally, though studies have been done involving local practices with regards to the treatment of BU wounds, there has not been any study done exclusively on wounds/sores and scar management.

1.3 CONCEPTUAL FRAMEWORK

This study adopted the Theory of Reasoned Action Model (developed by Martin Fishbein and Icek Azjen, 1975), as its Conceptual Framework. The theory is based on three basic assumptions as follows:

- Human behavior is under the voluntary control of the individual.
- People think about the consequences and implications of their actions or behavior before they decide whether or not to do something.
- Therefore, the intention must be highly correlated with behavior, i.e. whether or not a person intends to perform a health behavior should correlate with whether or not he actually does the behavior.

The theory sees behavior as a function of two things – Attitude and Subjective Norm. According to the proponents of the theory, an individual's attitude towards a specific behavior is made up of what the individual believes will happen when he engages in the behavior, and whether the outcome is desirable or undesirable. Subjective norms,

according to the theory, are made up of expectations of others regarding the behavior and whether or not the individual is motivated enough to do what is required they tell him. An individual's attitude about the behavior and his subjective norm determine his intention to carry out the behavior or not (Behavioral Intention), The researcher seeks to explain that the likelihood of a BU ulcer patient adopting the *behavior* (appropriate management of wounds and scars – i.e. management according to the health facility protocols) depends on a number of factors as illustrated by the Model below.

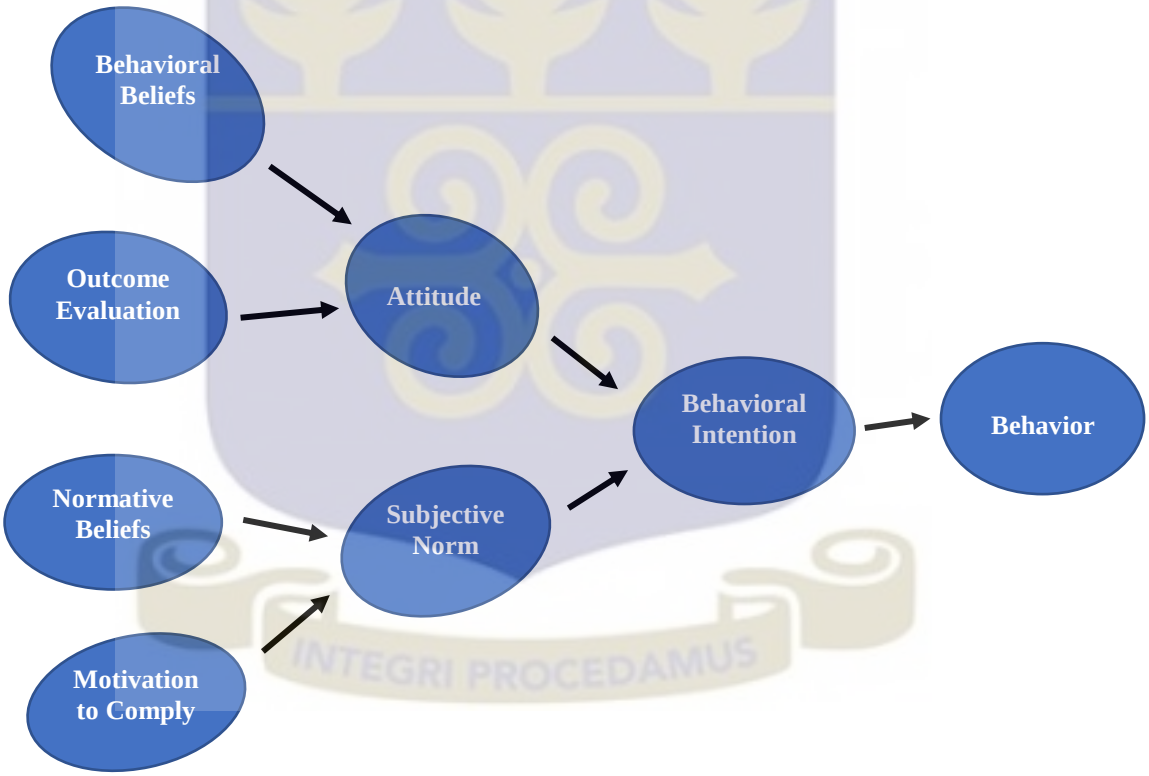

Figure 1:1 A Framework showing various factors that are likely to influence a BU patient's decision to adopt appropriate management of wounds and scars.

As illustrated by the Model, the BU patient's *beliefs* about appropriate management of his/her wounds and scars, and his/her assessment about whether or not the practice will lead to a desirable outcome (*outcome evaluation),* forms his/her positive or negative feelings about the behavior (*attitude)* concerning the practice. The patient's perception about whether the significant others approve or disapprove of the behavior (*normative beliefs),* and whether his/her intention and behavior are affected by the opinions of these people (*motivation to comply),* forms the patient's belief about the expected behavior *(Subjective Norm).*

The BU patient's *Attitude* about the expected behavior and *Subjective norm* lead to the perceived likelihood of the patient adopting the appropriate management of BU wounds and scars *(Behavioral Intention)* which consequently results in the *Behavior.*

1.4 JUSTIFICATION

The debilitating nature of the BU disease requires careful treatment which includes wounds and scar management in order to improve treatment outcomes, minimize suffering and disabilities. BU has become a growing Public health concern and this necessitated the establishment of a Global Buruli Ulcer Initiative by the WHO in 1998 (Kargbo-Labour, 2010), and consequently, the Ghana National Buruli Ulcer Control Program.

BU is one of the least studied neglected tropical diseases, despite the progress made in the area of diagnosis and treatment (O'Brien et al., 2014). There is no research done in Ghana exclusively on BU wounds/sores and scar management. This study, therefore,

seeks to investigate BU wounds/sores and scar management among patients. To succeed in the fight against the disease, there is the need for more research in the area of prevention and management of the disease (van der Werf, van der Graaf, Groothuis, & Knell, 1989)

Knowledge in the Community management of wounds/sores and scars, therefore, will empower Public health workers in the fight against the disease.

1.5 OBJECTIVES

1.5.1 General Objective

To investigate BU wounds and scars management in the community.

1.5.2 Specific Objectives

1. To examine local perceptions of BU wounds and scars management in the community
2. To examine local practices of wounds and scars management in the community.
3. To examine community perceptions regarding BU wounds and scars management at the health facility.

1.6 RESEARCH QUESTIONS

1. What are the local perceptions regarding wounds and scars management within the community?

2. What are the local practices regarding wounds and scars management in the community?

CHAPTER TWO

2.0 LITERRATURE REVIEW

2.1 INTRODUCTION

BU, caused is caused by *Mycobacterium ulceran* infection, is a debilitating disease of the skin and underlying tissues which starts as painless nodule, oedema or plaque and could develop in painful and massive ulcers if left untreated.(Ackumey, Kwakye-Maclean, Ampadu, de Savigny, & Weiss, 2011b). BU is a one of the 17 neglected tropical diseases which bedeviled tropical and subtropical regions, particularly, sub-Saharan Africa (WHO, 2014).

2.2 NEGLECTED TROPICAL DISEASE

According to WHO, Neglected Tropical Diseases are "Chronically endemic and epidemic-prone tropical diseases, which have a very significant negative impact on the lives of the poor populations and remains critically neglected in the global public health agenda (Liese, Rosenberg, & Schratz, 2010). Also defined by the Public Library of Sciences, Neglected Tropical Diseases are a group of poverty-promoting chronic infectious disease, which primarily occur in rural areas and poor urban of low-income and middle-income countries. They are poverty-promoting because of their impact on child health and development, pregnancy, and worker productivity, as well as their stigmatizing features (Liese et al., 2010). More than one billion of the World's population suffer from one or more Neglected Tropical Disease ("CDC - Global Health - Neglected Tropical Diseases," 2011.)

2.3 HISTORY OF BURULI ULCER

In Africa, Sir Albert Cook in 1897, and Kleinschmidt in 1920s had described large ulcers most certainly caused by *M. ulcerans.* A comprehensive description of *M. ulcerans* was published in 1948, when McCallum and others in Australia reported of an unusual skin infection caused by *mycobacterium* (Johnson et al., 2005).

Prior to 1980s, a number of *M. ulceran* infections were reported in several sub-Saharan countries including Ghana; and since 1980, there has been a report of increased incidences of Buruli ulcer cases in the West African countries of Cotê D' Iviore, Benin and Ghana (Johnson et al., 2005). The initial phase of efforts towards the prevention and treatment of BU (BUPaT) was from 2005–2008, in Ga West and Ga South Municipalities of Ghana (Ackumey, Kwakye-Maclean, Ampadu, de Savigny, & Weiss, 2011c).

2.4 LOCAL PERCEPTIONS OF MANAGEMENT OF BU WOUNDS AND SCARS IN THE COMMUNITY

Peoples' perceived cause of BU influences their choice of the mode of treatment. To examine local perceptions about managing BU wounds and scars in the community, it important to identify their perceived cause of the disease (Bigelow, Welling, Sinnott, Torres, & Evanson, 2002).

Studies in Central Cameroon and Ghana found out that the local people ascribed the disease to a supernatural or mystical origin, among others (Ackumey, 2013; Grietens et al., 2012; Bigelow et al., 2002), and in Benin, BU is seen as of a natural cause (environment or behavioral factors), or 'sent by God' or induced by another person through sorcery, (Aujoulat, Johnson, Zinsou, Guedenon, & Portaels, 2003). It was

reported by Ackumey et al. (2011), in a study titled, "Help-seeking pre-ulcer and ulcer conditions of Mycobacterium ulcerans disease (Buruli Ulcer) in Ghana", that some respondents sought two types of help for their conditions, thus, home and outside helps. With regards to home treatment, they commonly used herbs from their backyards or asked neighbors for assistance in that regard. And with the outside help-seeking, patients sought herbalists, traditional healers, faith healers, and private or government health facilities.

Villagers mentioned supernatural forces such as witchcraft as the cause of BU and as a result, sought treatment from the traditional healers as the most authentic source (Bigelow et al., 2002).

2.5 LOCAL PRACTICES OF WOUNDS AND SCARS MANAGEMENT

A research conducted in the rural communities of the in Ga District in 2001 reported more than 80% of the locals sought traditional treatment and would only turn to clinical treatment when traditional medicines failed (Bigelow et al., 2002). Some of the local practices identified in literature include "local excision of nodules to expose infected tissues, after which herbs are placed on the sores. Analgesics, balms, blood tonics and antibiotics were purchased from local chemists and itinerant drug peddlers" (Ackumey, 2013). Some locals in Benin use herbalists to treat and manage the BU wounds as a result of the belief that the disease is sent by God or induced by sorcery (Aujoulat et al., 2003). Other forms of local practices with regards to wounds/sores and scar management included drinking of herbal concoctions, herbal dressing of both pre-ulcer/ulcers, use of

pills and other drugs at home, offer of prayers at home, hot compress, massage, and slitting nodules (Ackumey, Gyapong, et al., 2011b).

2.6 COMMUNITY PERCEPTIONS OF HEALTH FACILITY MANAGEMENT OF BU WOUNDS AND SCARS

Some studies indicated community perception of health facility management of BU wounds/sores and scar as too costly in terms of money (because the free treatment advertised by these facilities were mostly not available), and time due to the distance and multiple visits to the facility (Bigelow et al., 2002; Ackumey, Gyapong, Pappoe, Maclean, & Weiss, 2012).

Other literature reported community perceptions in terms **of** intimidation experience from the staff of the health facilities, the patients not sure of what to expect from the health facilities and unfavorable outcomes of the treatment often caused by witchcraft (Ackumey et al., 2012; Bigelow et al., 2002).

A study in Ga West and Ga South Municipalities of Ghana on Help-seeking for Pre-ulcer and Ulcer Conditions of BU recorded that respondents opted first for herbalist treatment, both for pre-ulcer (42.5%) and ulcers (47.5%), probably because it was less expensive and convenient. However, it was noted that respondents would more likely seek medical help from government health facilities for ulcers (66.9%) and for pre-ulcers (17.1%). In addition, they perceived government health facilities to be the helpful provider type (Ackumey, Gyapong, et al., 2011b).

2.7 SUMMARY OF LITERATURE

Though community members perceived government health facilities to be a helpful provider type for the management of BU wounds and scars, factors such as cost (money and time), superstition and negative attitude of the health facility staff resulted in negative community perceptions.

CHAPTER THREE

3.0 METHODS

3.1 STUDY DESIGN

The study adopted a cross-sectional exploratory design. This was a qualitative study that made use of nonprobability sampling techniques, such as purposive and snowball sampling techniques, to collected data. Purposive Sampling, also known as subjective sampling, is a type of nonprobability sampling technique used in qualitative study where the units of the study are based on the judgement of the researcher. Snowball sampling also known as chain-referral sampling is also a nonprobability sampling technique that is used by researchers to identify potential subjects in a studies where subjects are hard to locate. Here respondents give referral to other potential respondents.

3.2 STUDY AREA

Akuapem South Municipality occupies about 403 square kilometers of land area. The Municipality cultivates a total land area of about 20,000 hectares, and an additional 6,000 hectares under cultivation along the Densu River. Akuapem South Municipality shares boundaries with the Ga West Municipality and the Tema Metropolis to the south, Suhum-Kraboa-Coaltar, Akwapim North and West Akim Municipal to the north-west respectively ("Akuapem South Municipal – Ministry of Food & Agriculture," 2013).

A number of water bodies in the form of rivers, dams and dugouts are located in the Municipality. The major rivers among them include the Densu River, Ponpon, Dobro and Nsakyi. The rainfall pattern is bimodal, and records 1700mm per annum with an average annual rainfall of 1250mm.

The Municipality has an estimated population of 133,698. The people of Akuapem South Municipality are mostly farmers and therefore 69.6% were estimated to be resident in rural communities, while 30.4% live in urban communities ("Ghana Districts - A repository of all districts in the republic of Ghana," 2006.)

Since 1999, BU continues to be a major cause of morbidity in the Akuapem South Municipality, with increasing numbers graduating from the pre-ulcer stage to severe ulcers; 187 cases were recorded (Kenu et al., 2014).

Pakro Health Center is the only health facility that treats BU cases in the municipality.

3.3 THEMES OF THE STUDY

This study focus on the following themes:

1. Local perceptions of Management of BU Wounds/Sores and Scars in the Community.
2. Local Practices of Wounds/Sores and Scars Management.
3. Community Perceptions of Health Facility Management of BU Wounds/Sores and Scars.

3.4 STUDY POPULATION

The population of the study included the Clinician at the Parkro Health Center (Key Informant) and BU patients in the Akuapem South Municipality of the Eastern Region of Ghana.

3.5 SAMPLING

BU patients receiving treatment at the Parkro Health facility beginning from January 2013 were selected. With this, the researcher was able to sample those who still had wounds/sores and those with scars. Purposive Sampling Technique, a non-probability sampling technique was used. Using the register of BU patients from the health facility the researcher purposively identified and interviewed them. A key informant (clinician at the Parkro Health Center) was also interviewed to understand the wounds/sores management protocols. In addition, Snowball sampling was used to select other BU patients in the community and interviewed.

3.6 DATA COLLECTION TECHNIQUES/ METHODS AND TOOLS

In-depth Interviews

In-depth interviews were carried out with BU patients receiving treatment from the Parkro Health Center, BU patients in the community who were not registered with the Health Center as well as the key informant. The investigator used an in-depth interview guide which included questions on demographic characteristics of respondents, local wounds and scars management practices, local perceptions about community management and community perceptions about health facility management. Each interview session lasted between twenty (20) to forty-five (45) minutes. In all, twenty-six (26) in-depth interviews were conducted.

3.7 QUALITY CONTROL

Data for the study was collected by the researcher, assisted by a research assistant who also recorded alongside to ensure consistency and accuracy. The necessary triangulation methods such as the use of voice recorder alongside hand-recording were employed to eliminate possible errors. Triangulation is an approach in research that combines more than one research strategy in a single investigation in order to assure completeness and to confirm findings.

3.8 DATA PROCESSING AND ANALYSIS

Data analysis was done manually. Data collected was transcribed and categorized using thematic analysis, concepts and themes were examined, and relationships between and among the themes defined. Direct quotes from participants were used to support findings.

3.9 PRE-TESTING OF STUDY GUIDE

Pre-testing was done at Obom Government Hospital in the Eastern Region. Two (2) wound/sore patients and two (2) scar patients were interviewed to test the validity of the study guide. The interview guide was edited based on the pre-test. For instance, question one which read "What causes BU disease?" was edited after the pretest to read, "In your opinion, what causes BU disease?" Also, the question "What is the difference between BU wound and scar?" was deleted and, "In your opinion, what influences your management of sore", and "In your opinion, what influences your management of scar?" were included.

3.10 ETHICAL CONSIDERATION/ISSUES

Ethical Approval was sought from the Ghana Health Service Ethical Review Board before the study was carried out.

Subjects of the Study: Participants of this study included BU patients resident in the communities who were receiving care at the Parkro Health Center (PHC), and those who were receiving care from other places apart from the PHC. The Clinician of the PHC was also interviewed as a key informant.

Privacy and Confidentiality: The setting of the interviews guaranteed the respondents' privacy and confidentiality. Respondents were interviewed in their homes in a quiet space away from other members of the family. Their opinions were valued and respected, therefore, they were not judged or intimidated. They were allowed to freely express themselves and their own views, and permission was sought before audio recording the interview sessions which lasted between twenty (20) to forty-five (45) minutes. Questions asked were relevant to the study and clear, and non-repetitive. These measures were to prevent negative feeling during participation. All these were done to ensure that respondents did not leave the interview sessions with negative feelings about participation. The investigator also avoided the use of respondents' real names and rather utilized pseudonyms.

Voluntary Participation: Participation in the study therefore was purely voluntary. Respondents were given the opportunity to discontinue with the interview if they so desired. No respondent was pressurized to answer questions against his/her will. At any point in the interview process respondents were free to stop answering questions if they so wish.

Risks/Benefits: The research did not pose any risk to the respondents. The benefits of this study were: (1) the elucidation of practices employed in the management of wounds/sores and scars that can guide Buruli ulcer public health programmes. (2) The publication of research findings in academic journals for the benefit of a wider public health community.

Informed Consent Process: A Parental Consent Form designed by the Principal Investigator (PI) was signed by parents/care-givers on behalf of their children or wards after the purpose, risks and benefits of the study have been explained. The PI ensured that the consent form was read and explained to the parents in a language that they understood before they decided whether or not to sign.

Data Storage and Usage: Information gathered for this study have been treated as confidential and used only for the purpose of this research. Responses of respondents were not to be shared with other study participants or members of the respondent's household. Finally, data collected and all materials related to the study including audio-recording have been stored in locked cabinet by the Principal Investigator for a period of one year.

Compensation: Apart from snacks for participants after interview sessions, there were no other forms **of** compensations.

Conflict of Interest: The researcher's only interest in conducting and reporting the research findings was to fulfill his academic requirement for MSc. in Applied Health Social Science.

Proposal and Funding Information: This research proposal was the result of the Principal Investigator's efforts under the supervision of Dr. Mercy Ackumey, his Supervisor. The researcher had no funding support but he funded the whole process all by himself.

CHAPTER FOUR

4.0 RESULTS

4.1 INTRODUCTION

The chapter features the results from the field data. It begins with the socio-demographic characteristics of the respondents and continues with findings on the local perceptions of BU wounds and scars management in the community, local practices of BU wounds and scars management in the community and concludes with the community perceptions regarding BU wounds and scars management at the health facility.

4.2 SOCIO-DEMOGRAPHIC INFORMATION OF STUDY RESPONDENTS

A total of twenty-six (26) respondents made up of twenty-five (25) patients (56% male and 44% female) and the clinician at the Parkro Health Facility were interviewed. The ages of the respondents therefore ranged from ten (10) to sixty-six (66) years. With the exception of 4% of respondents (patients) who had no education, 44% had Primary Education, 48% had either Basic School, Secondary or Vocational School Education, while 4% had a Diploma. Respondents (patients) have varied occupational backgrounds; while 8% were pupils, 44% were engaged in unskilled labor such as family and petty trading, 28% were unemployed, and 24% were involved in trades such as carpentry and dressmaking. With regards to their marital status, 48% were single 48% married and 4% widowed. The illness status of respondents was categorized into four, namely, wound/sore 32%, scar 48%, scar/new infection 8%, and recurrent wound/sore 12%. The Clinician was a qualified medical doctor and had a PhD in Public Health. She was

working with the National Yaws Eradication Program, National Buruli Ulcer Control Program and the Parkro Health Center. The clinician, according to her, had been working on BU cases since 2007, and her personal and direct management of patients dated back to 2010.

Table 4.1 Background Characteristics of Respondents

Characteristics	Value (%)
Sex (Patients)	
Male	14 (56)
Female	11 (44)
Age (Patients), years	
Minimum	10 years
Maximum	66 years
Education (Patients)	
None	1 (4)
Primary	11(44)
Middle School/ Secondary/Vocational	12 (48)
Diploma	1 (4)
Occupation (Patients)	
Pupil/Student	2 (8)
Unskilled Labor	11 (44)
Unemployed	7 (28)
Other	6 (24)
Marital Status (Patients)	
Single	12 (48)
Married	12 (48)
Widowed	1 (4)
Illness Status	
Wound/Sore	8 (32)
Scar	12 (48)
Scar and New infection	2 (8)
Recurrent Wound/Sore	3 (12)

4.3 COMMUNITY PERCEPTIONS OF THE CAUSES OF THE BURULI ULCER (BU) DISEASE

While some respondents are completely ignorant of what causes BU, others enumerated a number of causes; some respondents were of the view that BU is caused by environmental and behavioral factors, such as contaminated river or stagnant water, bathing or drinking contaminated water, and therefore, a *natural disease*. Some also said it is caused by supernatural forces such as curses, witchcraft, sorcery, while others attributed its cause to both factors. The following are some of the statements of respondents on the perceived causes of BU:

> *I don't know what causes BU disease. However, I heard that there are some people who can curse one with the BU disease.*
>
> **(IDI- 49 year old female patient).**

> *I don't know. But I heard people say that drinking contaminated stagnant water or well cause the disease.*
>
> **(IDI- 30 year old male patient).**

> *In my opinion, contaminated drinking water causes it, but mainly, it is as a result of Spiritual forces. I think it is Spiritual because I stay in Accra, undergoing an apprenticeship where I was drinking only pipe borne water. I came back only to be affected by BU. So the issue about contaminated drinking water is not realistic. I believe it's spiritual.*
>
> **(IDI- 31 year old patient).**

These narratives clearly express strong community perceptions of the causes of the BU disease as supernatural forces. Some respondents, however, mentioned that BU disease is waterborne.

However, from the perspective of the Clinician, the disease is caused by *Mycobacterium ulcerans* infection. She also said when people are traumatized, or their personal hygiene is compromised they are likely to have the infection and the disease.

4.4 RESPONDENTS' EXPERIENCES OF HOW THEY ACQUIRED THE BU DISEASE

Respondents' experiences of how they acquired the BU disease varied. While some said they got infected in a contaminated [river] or stagnant water, and contaminated drinking or bathing water, majority said their condition started like a boil (the initial stage of the disease known as nodules). As they started the treatment for a boil, the affected part of their body progressed to a swelling, burst out and then became a big sore. Other respondents said they had injury or cuts on their limbs which they either took to the hospital for treatment, or decided to manage at home. The affected limbs became swollen and the small cuts progressed to extensive sores, local remedies proved ineffective. Later, they discovered their condition was BU disease. According to other respondents, [Some also, according to them,] they did not have any boil or cut but suddenly they began to experience unusual heat or pains at the affected part. Later, those places developed bruises and within a short space of time, became sores which were later diagnosed as BU disease. Some of the participants shared the following experiences about how they got affected by the BU disease:

> *It started like a boil and I rubbed my hand on it. The following day my foot became as large as football* (indicating how big the foot has become). *A*

friend of mine said he knows someone who treats boils. The person came and after he looked at my foot, he said I was bitten by a snake. Another person came and said someone has cursed me with that condition. So I took it to Roman Clinic (Missionary Clinic) *for treatment. I spent two months there but there was no improvement, so I came back home. Later, I was told about Parkro Health Center … it was when I went there that my condition was diagnosed as BU infection.*

(**IDI – 60 year old male respondent**).

I fell into a gutter and had cuts on my leg. As a result the leg became swollen; so I went to the Nsawam Government Hospital and had it stitched. When I came back home the legs became more swollen so I decided not to go back to the hospital again but take care of it myself. Later, one of the volunteers (Emmanuel) *from the Parkro Health Center who going round met me. He recommended the Parkro Health Center and when I went there it was confirmed that I had BU.*

(IDI- 37 year old female patient).

I was involved in a motor accident and was severely injured on the leg. Because of its serious nature, when I went to the hospital the doctor proposed to carry out a surgery to do skin graft. However, the nurses dressing the sore said that if skin graft is done the sore may not heal, which could end up in amputation of my leg. I therefore didn't allow the skin graft but hoped that the sore would heal eventually. … I stayed at the hospital for many days before I was discharged. ….At the time I was discharged the sore was not healed. Fortunately, we heard about Mr. Seidu so we contacted him. He came and led us to the Parkro Health Center. There I was diagnose as having BU.

(IDI- 40year old female patient).

I was holding a knife and it fell from my hands and pierced my foot. I went to the hospital for tetanus injection and suddenly, the leg became swollen and developed into sore. It was when I went to the hospital that I was told that I had BU. However, some neighbors says that someone juju me.

(IDI- 46 year old female patient).

It began with a swelling like a boil, and very painful. I went to the hospital for treatment and I was told by the doctor that the swollenness was an indication of the extent of damage caused to the underlying tissues, and that there was the need for a surgical procedure. It was the surgery that made me realized that I had a sore there.

(IDI- 30 year old female patient).

I went to the farm. When I returned, I noticed that there was a swelling on my hand like a boil which, few days later burst and became a sore with some sort of smelling water coming out of it. My hand became swollen. Thankfully to God, a volunteer with Parkro Health Center who was going around identifying people ***who*** *might be affected with the BU disease saw me and took me to Parkro Health Center where the disease was confirmed.*

(IDI- 30 year old male patient).

The place was itching me and I scratched it. As a result, I had bruises at the place. The bruises later developed into a sore which was later diagnosed to be BU.

(IDI- 25 year old female patient).

I was going to draw water from the river and I stumbled over a stem of plantain. So I told my mother that I fell and my leg hurts. So I was taken to one herbalist who massaged it, after which my leg became swollen and developed bruises. It was then someone advised us to come to Parkro

Health Center for medical treatment. A medical examination was carried out and it was confirmed as BU.

(IDI- 10 year old male patience).

The various accounts of patients' experiences on how they contracted the BU disease did not explain how they got infected, but rather the circumstances or the symptoms that led to the diagnosis of the disease. The most outstanding among them included appearance of a swelling that looked like a boil (nodule), swellings that burst to become sores (oedema), and cuts or injuries that resulted into sores.

4.5 MANAGEMENT OF BU WOUNDS/SORES AND SCARS

Field data revealed that respondents adopted various management practices in managing their wounds/sores and scars. These practices were informed by their perception about the disease, and what they believed was responsible for their predicament. As a result, various management practices were adopted.

4.5.1 Management of Wounds/Sores

Sufferers of BU disease who believed the conditions were caused by supernatural forces sought help from herbalists, traditional healers, churches or prayer camps to manage their condition. These alternative wounds/sores management practitioners were seen as authentic and were expected to unravel the mystery surrounding their ailment and provide the needed solution. They are readily available in the community making accessibility very easy. Some of these herbalists and traditional healers are relatives of the patients and therefore influential in the patients' decision regarding how to manage the wounds/sores.

Those patients whose conditions began with injuries and cuts first visited the hospital for medical attention. Later, when their conditions worsened with symptoms they could not understand, they decided to seek help from either herbalists or traditional healers or prayer camps who confirmed that supernatural forces are responsible for their conditions. Some respondents chose facility management of their wounds/sores over all other forms of management practices. Some of these patients also believed that God has a hand in their recovery, no matter the kind of treatment they adopted. Therefore despite the fact that they sought help from health facilities, they also sought for prayer intervention simultaneously. Some respondents who did not know what caused their condition (the BU disease) were influenced by significant others to adopt any of the above practice(s).

Most respondents who perceived the onset of the disease *(nodule)* as a boil or believed supernatural forces were responsible for their condition, or others who did not know what exactly was wrong with them either sought help from herbalists, traditional healers or went to pastors for prayers. They later visited the hospital with the hope that the health facility may provide them with a solution to their predicament, if they failed to get the needed help from alternative treatment sources and their conditions became worse. Others also, while managing their wounds/sore at the facility still believed that God had a role to play in their recovery. They therefore visited prayer camps or churches and the health facility simultaneously.

> *At the initial stage of the problem I sought help from a traditionalist/ herbalist because I thought the swollenness of the leg was as a result of a boil. I also went for prayers. Later when I sent the condition to Parkro Hospital they gave about 60 injections and drugs in addition to the dressing of the sore. I have completed the 60 injections. Now am no longer*

doing anything about the sore. This is because am tired; since 1998, all my money is finished. I have sold all my cars and other possessions. Recently, I nearly sold my house to use the proceeds to take care of myself.

(IDI- 60 year old patient).

When it started we taught it was a boil so we began to use local medicine such as herbs. We sought a spiritual help from a Pastor who said someone cast a spell on me and that he could remove the spell. He collected goat and other things from us, made incisions on the leg amidst incantations but there was no improvement. When it got worse, I was sent to government hospital to for treatment. It was after that we got to know that it was a BU. Because the leg bones were badly affected I went to Sunyani Orthopedic Hospital for surgery to correct the bones. At Parkro Health Center, I was given injections, my sores were dressed and drugs were given to me to take. Then I was thought how to manage the sore after which I was given some medications to use at home and then come back to the hospital for review every eight days. While attending the hospital for treatment, I also go to church to pray for the sore to heal faster.

(IDI- 38 year old male patient).

I began with herbal management and then went to Roman Hospital and you see over there, especially the private ones they only want money. So even if they never seen the disease before or they can't manage it or they can't do anything they will still take money from you. I came into contact with Emmanuel and he sent me to the Hospital (Parkro) and we started seeing signs of healing.

(IDI- 45 year old male patient).

My husband took me to one Banaman's clinic in Nsawam. Banaman carried out a surgery. At that time I was carrying my first child. He put bandage around the wound and we came back home. Later, the wound

spread and became a big sore on the arm which I could not manage on my own. Consequently, I became incapacitated. We therefore sought the help of a herbalist in our area who is renowned in curing this kind of disease. First he used hot water to clean the sore, put the herb preparation on it and then bandaged it.

He used the same procedure every day for 3 years, because the sore did not heal early. My arm became stiff and doesn't bend. I could not use it to do any work; I could not bath myself, someone has to do that for me. We went from one herbalist to another seeking for solution. We spent lots of money, my husband spent so much. Everywhere we went they either requested goat and cock. We paid all that but there was no improvement. I went back to Nsawam hospital and they managed to remove the tread used by Banaman to stitch the wound before the local healers were able to cure it eventually after 3 years.

(IDI- 65 year old female patient).

Some respondents said their wounds/sores were managed by the herbalists. They did not visit any health facility for treatment. The herbalists used hot water to press the wounds/sores to allow any offensive water to come out. This made the sore drier. The herbalist then prepared some herbs and put on the wounds/sores after which he used a piece of cloth to tie the herbs onto the wounds/sores to prevent it from falling off. This was repeated until the wounds/sores became healed. In some of the cases, according to respondents, the limbs became stiffened due to continual tying or bandaging in particular positions. The herbalists would use herbs to massage it until it becomes flexible and normal.

Herbalist treated my sore. They used herbal medicine to massage my stiffed arm and that is why I can bend it now. At that time I cannot tell why my parents chose herbal treatment for me. But I think because herbalists treated my mother's condition that is the reason.

(IDI- 27 year old male patient).

These alternative forms of managing the wounds/sores and scars resulted in the recurrence of the sores and permanent deformities in some patients due to improper management.

Health facility management of BU wounds/sores among respondents was influenced by environmental and behavioral factors, what they referred to as "natural cause" (contaminated river or stagnant water, and contaminated drinking and bathing water). They said BU can therefore be treated in the hospital like any other disease. Some also said that they had [have] seen or heard about other BU patients whose wounds/sores were successfully managed at these facilities. The following are some of the narratives of respondents who managed their conditions at the health facility.

> *I chose to go to the hospital because I don't trust the herbalists' treatment. I know the hospital is where I can get the proper treatment.*
>
> **(IDI- 30 year old male patient).**

> *I decided to come to Parkro Health Center for treatment because I learned that those whose wounds/sores are managed at the Center recover and are able to walk again. I know someone from Adabraka who told me her aunt came there and she was cured.*
>
> **(IDI- 40 year old female patient).**

> *I know this disease can't be treated at home, and I don't want this to keep me at home for too long. This is why I went to hospital. I know that is where it can be treated.*
>
> **(IDI- 60 year old male patient).**

I fell into the gutter and got injured and that is how I got infected. Therefore I believe that hospital is the best place to manage it.

(IDI- 37 year old female patient).

First I went to the traditionalist because I thought it was a boil. When there was no improvement I went to consult a pastor because I am a Christian, and he told me my condition was the result of a spell. Finally, I decided to go to the hospital because all these treatments didn't help.

(IDI- 60 year old male patient).

In addition, the work of the Community-based BU surveillance volunteers contributed immensely to the facility management of wounds/sores among patients. Most respondents have testified to their timely intervention by introducing them to the Parkro Health Center. Apart from referring them to the facility, they also followed on the patients and in some cases dressed their wounds/sores in the community.

First, I went to hospital and the sore was stitched for me. Subsequently, a community-based BU Surveillance volunteer came to see me and so he advised me to go to Parkro Health Center. After that he comes to dress it for me at home. Anything that is needed to dress the sore, he brings them from the hospital. No, I have never been to any spiritualist for assistance. This is not a spiritual issue, I fell into the gutter and hurt myself.

(IDI- 37 year old female patient).

One of the Center's volunteers was a patient and we taught him how to dress the wound. He did well for his own wound and he got healed. So he follows up patients and also dresses their wounds/sores for the people at home. The patient would only report and I wound look at the wound and they are healed. He has a lot of successes with patients. As a result, people call him in the area (community) to come and dress wound for them. For

BU lesion, it does not matter the size of the wound, what matters is how you dress it.

(IDI- Clinician at Parkro Health Center).

... We were told about the Parkro health Center by a volunteer who works there. When we went I was diagnosed to be having BU, the doctor at the Parkro Health Center asked me to come daily for wound dressing. They also gave me drugs to swallow daily and injections for two months. When my condition was improved greatly, the doctor gave me some medications to be using at home and then come for review every eight days.

(IDI- 40 year old female patient).

4.5.2 Management of Scars

Inadequate knowledge regarding scar management among some respondents consequently resulted in the recurrence of sores. Scar management practice observed among patients included the use of Vaseline gauze on the scar, application of Nivea Cream on the dry surface and bandaging to prevent injury to the scarred surface. These are practices taught them at the health facility. However, field information revealed that while only a few of the patients who have scars adhere to these protocol, the majority do not. The few who observe these practices are respondents who sought help from the health facility at Parkro. According to some of them, they use clean hot water to clean the scared surface, then either put a Vaseline gauze on or smear the Nivea Cream on it before putting bandage around it to prevent injury. Some patients also said the Clinician at the Parkro Health Facility taught them how to manage their scars, but after the Nivea Cream

she gave them got finished, they did not have money to buy the prescribed cream to continue using on the scars. As a result, they suffer recurrence.

On the contrary, majority of those who have scars do not observe any of the above management protocol. Instead, they mentioned that once the wound/sore is healed, they do not visit the health facility. They also do not have any idea about what medication to use on the scar. Some said they were told by their relatives and neighbors that if they continue to bandage the affected limbs, the underlying tissues would not heal properly. In addition, their limbs would become smaller than the unaffected one.

> *When I get up every day, I use hot water to clean the surface and then use the medicine on it. The way the hospital does it for me, I saw it and therefore am able to do it the same way. Now, I don't go to the hospital. I have some ointment which I smear around it before putting a bandage around it.*
>
> **(IDI- 60 year old male patient).**

> *The Hospital gave me a Vaseline gauze which I put on it before I bandaged it. The pain comes and goes. Most often I use the bandage on it. Because I am used to the bandage close to a year now, when I remove I feel my leg becomes very light. So that is the reason why I have to put it on. The day I got the scratch I didn't put on the bandage. I remember I used to exercise the leg in order to do away with the lightness so that I can bounce back to normal walking.*
>
> **(IDI- 45 year old male patient).**

> *I have been given an ointment by Dr. Kotey that I smear on it and then tie a bandage around it so that I would not injure the surface. It is only today that I removed the bandage. Apart from that ointment I bought the white cheer butter to smear on it. It also helps.*

(IDI- 38 year male patient).

I did not do anything beyond the hospital treatment for the wounds/ sore. However, I have been advised to wear dresses that would cover the scar, otherwise injury to that place would result in a more serious sore.

(IDI- 31 year old female patient).

After the sore was healed I did not do anything to the scar.

(IDI- 65 year old female patient).

I don't have any medicine that is used to treat the scar, however I learned there is a medicine that is used for scar management. A doctor came from Accra who prescribed a medication for me to buy. ... However, I didn't have money to buy that medication.

(IDI- 30 year old female patient).

4.6 Local Practices of Wounds/Sores and Scars Management in the Community

The cause of BU disease was perceived differently among respondents as noted earlier, thus, environmental and behavioral factors referred to as contaminated river or stagnant water, contaminated bathing and drinking water, and supernatural causes such as curses, witchcraft and sorcery. As a result, they sought help from many local practitioners such as herbalists, traditional healers, and pastors.

Some of the practices of wounds/ sores management in the community included slitting the nodules or the affected area and putting herbs on it, dipping the sore in a warm herbal preparation, doing hot press, use of herbs on the sores, use of a piece of white cloth to tie the herb on the sore, drinking of herbal concoctions, consultation with the spirit world, performance of certain rituals, and prayers by pastors.

I used herbal treatment. The herbalist uses hot water to do hot-press and then put herbal preparation on it before using piece of cloth to tie the medicine on the leg. While doing this the herbalist will forbid you from eating certain food items.

(IDI- 30 year old female patient).

I used herbal medicines to manage the wound/sore. I do not know any treatment for the scars.

(IDI- 27 year old male patient).

At the early stages of the disease, I went to a spiritualist who used a combination of herbs and rituals, herbalist who used herbs to treat the disease, and pastors who was praying for God to cure the disease.

(IDI- 38 year old male patient).

Associated with these practices of wounds/sores and scars management were certain taboos (mainly food) prescribed for patients. They were forbidden to eat certain food items including, okro, meat, sugar, groundnut, coconut, cooking oil, palm oil, maize, and rice. A respondent also mentioned that, in addition to the food taboos, he was also forbidden to walk across roads or foot paths. Violation of these taboos, according to them, would lead to serious adverse consequences, for instance, the sore may recur or never get healed.

There is nothing like taboos at the health facility. However, herbalists would prescribe taboos especially about food. My first BU infection was treated at the Hospital. Later, my arm was also infected. At that time they sent me to herbalist to treat me. When I went there he asked me not to eat red oil, meat, and okro. I tried to adhere to those taboos prescribed for me but it was not long when I noticed I was worrying myself so I stopped. For instance, the doctor told me to eat red oil because it is healthy, but the

herbalist said I should stop eating it. That is why I told myself this herbalist would not help me. I simply stopped going to him.

(IDI- 30 year old female patient).

The doctor who is managing my condition did not prescribe any taboo for me, but some neighbors advised me not to eat maize, rice, and okro. This is because, according to them, when one continues to eat those food items when treating BU, the sores may come back or will never get healed. However, I didn't go by those advices.

(IDI- 46 year old female patient).

I was told never to carry or touch a lantern until my parents performed certain rituals prescribed by the herbalist who cured me.

(IDI- 27 year old male patient).

When I went to the pastor he prescribed the following food taboos for me: forbade me to eat okro, groundnut, coconut, cooking oil, and meat.

(IDI- 38 year old male patient).

Some of my people asked me not to eat okro and sugar; that is all. This they said is because if you have a sore other sickness can enter if you are not careful.

(IDI- 60 year old male patient).

4.7 HEALTH FACILITY MANAGEMENT OF WOUNDS (SORES) AND SCARS

Health facilities use medical diagnosis and treatment to manage BU wounds/sores and scars. Information gathered from respondents revealed that most patients would visit the facility when other management methods such as herbalists, traditionalists, pastors or spiritualists have failed and their condition worsened. Some also would only visit the

hospital based on the testimonies and recommendations of others such as former patients. Few of them, however, did not go to the herbalists or traditional healers because according to them BU disease is like any other disease which they believed can be cured at the hospitals. Majority of respondents attested to the effectiveness of the health facility management of BU wounds/sores and scars at the Parkro Health Center. Though the treatment was free, it still cost them (time and money) to access treatment. This they said is because the facility is far from where they live and as a result, they have to walk very long distances or board vehicles on daily or bi-weekly basis for their wounds/sores to be dressed, and the scars to be managed. Nevertheless, some respondents noted they would not mind traveling the distance to the facility for treatment because they were seeing great improvements in the facility management of their wounds/sores and scars.

> *The facility management is good and am happy about the care I receive there. The only challenge is that because I could not walk on the leg my mother had to back me all the way from where we stay to the facility.*
>
> **(IDI- 10 year old male patient).**

> *The facility is very far from where I stay. As a result, I have to take transport from my place to the hospital. The days I don't have money, I have to trek the distance from my house to the facility. At the moment, I visit the hospital every 8 days because they taught me how to dress the* ***sore*** *on my own and I do. So I only go for review every eighth day.*
>
> **(IDI- 30 year old patient).**

> *The health facility management is good because they take care of you well and monitor the way you take your medication and the entire treatment so that you can be cured. However, trekking to the health center is not easy. This is because I don't have money for transport.*
>
> **(IDI- 14 year old patient).**

Other respondents who live in the Parkro township spoke about how easily accessible the facility or the Parkro Health Center is to them, and as such they do not have to spend any money to access treatment. They highly commended the treatment they receive at the facility at Parkro.

I live in the Parkro Township, so the facility is not far from where I live. The treatment is entirely free, and so as for me, it does not put any financial burden on me. I am happy about the way things are done at the facility. Now I see great improvement in my condition. I didn't know my sore can heal. So I keep asking "will this sore be healed?" But the keep assuring me that I will be healed. Those who have seen some before also assure me that it will be well. Now with the extent of improvement, I think the treatment is good.

(IDI- 46 year old patient).

The facility management is very good. Am very happy with it. They do not collect any money from me. It is totally free. Any cost incurred is borne by the health facility. However the distance from my house to the hospital is far and cost me lots of money, which was GhC30.00 when I hire a taxi. That is why I made a conscious effort and learned how to dress the sore so that I would be able to dress the sore by myself.

(IDI- 38 year old male patient).

Respondents who have experienced remarkable healing of their wounds/sores said they no longer go to the facility on daily basis but only for review every eighth day. This is because the facility taught them how to dress their own wounds/sores in-between visits to the Center. However, new patients and those with serious infections visit the Center daily for dressing.

On the part of the Clinician, how the sore is managed depends on the nature of the lesion. If the sore has sloughs, then those sloughs need to be removed first before you dress it. According to her, the facility uses the normal saline dressing solution made of povidone-iodine and metronidazole to dress the wounds/sores. If sore is emitting bad odour, the use of Metronidazole will stop the bad smell within a maximum of three days. If the sore is highly infested, then some of the slough is removed and then triple antibiotic ointment made up of neomycin, bacitracin and polymyxin is applied on it. By the following day, the slough will start sticking on to the gauze little by little, and by the end of two weeks, the slough is totally removed. Then the normal saline can be used to clean it. If the slough is not removed the sore will never heal.

With regards to scar management, the Clinician said she uses Nivea Cream which causes the scar to disappear with time. According to her, the wounds/sores of those who were treated with tropical antibiotics heals without scars.

The WHO Protocol for managing the BU wounds/sores, spoke about the use of the normal saline and drawtex. But this method, she noted, would not be helpful since her facility uses ordinary gauze which are not sterilized and the nature of lesions of sufferers in Ghana differs from that of advanced countries. This is why the facility uses the procedure described above.

4.8 CHALLENGES AND RECOMMENDATIONS

The facility, in its quest to deliver services to BU patients is faced with some critical challenges. These include inadequate supply of non-drug consumables (wound/sore dressing materials), unwillingness of nurses to manage patients, distances patients have to walk to access treatment at the facility and lack of money to transport themselves, and

lack of accommodation in the Parkro township to enable them come for their daily wounds/sore dressing. She recommended the provision of resources, especially, financial resources by relevant stakeholders to make the delivery of effective services to patients possible. The following is what she has to say:

> *...Relevant stakeholders should make available funds to motivate those who are helping to manage this disease. Because of the education in the Parkro area, we don't have any new case coming from the Parkro town. Those who come to the Center are from far places. We need money to build a half-way-home center for them to enable them to come for daily wounds/sores dressing. We also need to reorient staff to accept the patients, and other stakeholders such as the District Assemblies if we are going to be successful.*
>
> **(IDI- Clinician, Parkro Health Center).**

The main challenges of respondents have to do with the long distances they have to trek in order to access treatment; and unemployment as a result of their present conditions leading to difficult living conditions and financial problems. Consequently, they recommended that the government should support them financially or with a form of employment that they would be capable to do.

> *The government should try and help us financially since we are not able to work to feed ourselves due to the sickness.*
>
> **(IDI- 25 year old female patient).**

> *When you have this disease you cannot work. Therefore even food to eat is a problem. I am appealing to the government to support us financially to help better our living condition.*
>
> **(IDI- 30 year old male patient).**

We don't have any help from anywhere. We are told not to go to farm, maybe because if we go we may have bruises or cuts at the affected places that would create more serious problems for us. We also need medications that will cause the disease to heal well. Some of us, we are very shy and we find it difficult to expose the affected parts, contrary to the doctor's advice to allow air to pass on it. Any time I expose the legs it attracts people in the neighborhood to gaze at me. I become confused and cannot even walk properly. The government should supply the facility with the needed medications to facilitate their work.

(IDI- 30 year old female patient).

CHAPTER FIVE

5.0 DISCUSSION

The main objective of this study is to investigate community management of BU Wounds and Scars in the Akuapem South Municipality. Theory of Reasoned Behavior Model put forward by Martin Fishbein and Icek Azjen was adopted as the framework of the study (Vallerand, Deshaies, Cuerrier, Pelletier, & et al, 1992). The Model explains that an individual's (BU patient) decision to adopt a specific behavior is dependent on his attitude about the behavior and subjective norm. In other words, he would carry out the behavior or not depending on the individual's belief about the outcome of the behavior, whether desirable or undesirable, and whether the opinions of referent others motivate him enough to do what they expect him to do.

The study findings suggest that the low level of awareness BU disease makes society to attribute its cause to supernatural forces. This community and for that matter societal perception, influences the choice of wounds/ sores and scars management practices. Secondly, the type of community management practice adopted determines the local practices used in managing the BU wounds/sores and scars. Finally, the study revealed that the health facility management of BU wounds/ sores and scars becomes the final resort after patients have tried all other methods. This is so because of the community's perceptions about the causes of the disease, and as such, it is not the kind of disease to be managed at the health facility.

The central themes and concepts that emerged from the data analysis and interpretation process are discussed and evaluated as they relate to and contribute to the existing literature.

5.1 LOCAL PERCEPTIONS OF MANAGEMENT OF BU WOUNDS/SORES AND SCARS

The findings of the study indicate the association of BU disease with both supernatural causes (curses or induced by another person through charm, witchcraft, sorcery) and natural causes (environmental and behavioral factors such as poor hygiene, drinking and or bathing contaminated water). These findings are consistent with similar findings in the available literature on studies done in both Central Cameroon and Ghana, where the local people ascribed the disease to supernatural or mystical causes (M. Ackumey, 2013; Peeters Grietens et al., 2012; Bigelow et al., 2002; Renzaho, Woods, Ackumey, Harvey, & Kotin, 2007) and in Benin where BU is seen as a natural cause (Aujoulat et al., 2003). The supernatural explanations of the cause of the disease by respondents were probably because they were related to the strange manifestations of the disease and their illness experiences. This is indicative of the low levels of awareness of the causes of the BU disease among the local people. However, one can question responses about the natural cause since they could either be the patients' own opinion and as a result of the influence of health educational programs.

It was clear from the study that people's perceived cause of the BU disease determined their help-seeking behavior. Patients who believed supernatural forces were responsible for their condition sought treatment from herbalists, traditional healers, and pastors or prayer camps. They only returned to health facility for treatment when they could not find solution from these places. This supports a finding in available literature of a study done in the Ga District of Ghana (Bigelow et al., 2002). However, this position is not

consistent with what was ascertained by Peeters Gratins et al; (2012) in a study done in Cameroon on "*What Role Traditional Beliefs Play in Treatment Seeking and Delay for Buruli Ulcer Disease".* They found out that people's beliefs about the etiology of BU did not determine the treatment choice of the people. Very few among the respondents were treated successfully where the sores healed without scars.

Community-based BU surveillance volunteers are doing a great job in surveillance, case detection and referral of these patients to the Parkro Health Center where their wounds/sores and scars are being managed with lots of success. This finding agrees with a current literature on a study done in the Ga-West and Ga-South Municipalities of Ghana (M. M. Ackumey, Kwakye-Maclean, et al., 2011c). Others who said the BU infection was as a result of environmental and behavioral factors such as poor personal hygiene, drinking or bathing contaminated water sought help from health facilities. However, some of them have tried other health facilities which could not diagnose their condition, and therefore could not manage it before they were later referred by these volunteers.

5.2 LOCAL PRACTICES OF WOUNDS AND SCARS MANAGEMENT

The study identified a number of local practices that are engaged in the management of wounds/sores. They include the use of herbalists, traditionalists, and pastors or prayer camp. Some local practices identified included dipping the sore in a warm herbal preparation, slitting of the nodules (considered to evil boil), hot press, use of herbs on the sores (ulcers), drinking of herbal concoctions, prayers by pastors, which are consistent with similar findings reported by Ackumey et al, (2011); charms, consultation with the spirit world and rituals.

In Ghana, it is common knowledge that herbalists are used to treat various ailments (M. Ackumey, 2013). They therefore become the first point of call from the onset of the disease. According to some respondents, the herbalists' process of treatment involves dipping the affected limb in a warm herbal preparation, or using hot water to press on the affected part, then the herbal preparation is applied on the wounds/sores before bandaging. The process is repeated until the sore is healed. However, the traditional healers use a similar procedure, but also impose certain taboos, violation of which may lead to the sore not getting healed and recurring. Clients are required to perform certain rites which are associated with the healing process. After the sores are totally healed, patients are expected to perform another rite in order to be free from taboos imposed on him. Similar findings were recorded in a study done in Southern Benin on "Psychosocial aspects of health seeking behaviors of patients" (Aujoulat et al., 2003). Witchdoctors use sacrifices to the gods and charms to be smeared on the affected part(s) and proscribes taboos to be observed during the period a patient is undergoing treatment. Due to the improper alternative wounds/sores and scars management procedures of some of these local practitioners, some patients suffer the recurrence of the wounds/sores and in some cases, permanent deformities.

5.3 COMMUNITY PERCEPTIONS OF HEATH FACILITY MANAGEMENT OF WOUNDS AND SCARS

Health facilities use medical diagnosis and treatment to manage BU wounds/sores and scars.

Medical research as well as local knowledge have been unable to satisfactorily explain the strange nature of this disease. Hence, many local people believe that the health facility does not have a cure for this ailment which has been known to result in the death and permanent disabilities of its sufferers. Most of these local people attribute the cause of BU disease to supernatural forces such as curses, charms, witchcrafts, sorcery and therefore saw the herbalists and traditional healers as the appropriate place to seek help. Most of the respondents said they sought help from the Parkro Health Center because the herbalists and the traditional healers could not cure them. This finding is in agreement with what was ascertained in two separate studies conducted in the Ga West Municipalities of Ghana (Renzaho et al., 2007); (Kargbo-Labour, 2010).

The majority of respondents attested to the effectiveness of the health facility management of BU wounds/sores and scars. It was noted, however, that though the treatment is free it still cost them (time and money) to access treatment. According to them, the facility is far from where they live and therefore poses a challenge to them with respect to the distances they have to walk on daily or bi-weekly basis for their wounds/sores to be dressed, and the scars to be managed. This reason also accounted for some defaulting on their treatment plans. Majority wished the facility were closer to them, preferably in their communities so that they would not have to travel for such distances to receive medical treatment. Others said they wasted their time and money seeking help from herbalists and traditional healers who could not help them, therefore, they do not care about the distance they have to travel to the Parkro Health Center because they are getting the solution they desired. Two of the respondents said they were

totally cured by herbalists who are no longer living. Their sores were healed, leaving no scars.

5.4 DISCUSSION IN RELATION TO CONCEPTUAL FRAMEWORK

The findings of the study suggested that BU patients' decision to seek help from what they perceived as appropriate for the management of their wounds/sores and scars was based on their beliefs that they would get a desirable solution which were reinforced by the approval of their significant others. It was also noted that the opinions of these significant others are the reflection of their normative beliefs about the disease and its management and these were very influential in the final decision about which help to seek for the management of the condition.

CHAPTER SIX

6.0 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 SUMMARY

This study looked at community management of BU wounds/sores and scars in the Akuapen South Municipality. It was found that sufferers of the disease adopted various practices in managing their wounds/sores and scars. These practices included herbalist care, traditional healers, churches or prayer camps, and health facility management. The management practice adopted by any individual patient was influenced by what he/she believed was responsible for the disease and the opinion of his/her significant others (community perceptions).

Two main categories of causes were identified, thus, supernatural forces, and natural causes (environmental and behavioral causes). Majority of patients who sought help from herbalists, traditional healers, and churches and prayer camps believed that BU disease is caused by spiritual or supernatural forces such as curses, witchcraft or sorcery. Those who believed that the disease is caused by environmental and behavioral factors like drinking or bathing contaminated water, and contaminated river or stagnant water, went to the health facility for management of the wounds/sores and scars. Some patients, though began with the herbalists or traditional healers' treatment or prayer camps, later sought for facility management based on the recommendations of others, or because either they failed to get the desired solution from the above or were referred by the community-based BU surveillance volunteers.

Various local practices engaged in the management BU wounds/sores and scars included slitting of nodules, dipping of affected limbs into warm herbal preparations, hot press,

putting herbs on the wounds/sores, use of piece of cloths to tie the herbs on the sore, prescription of taboos, and performance of rites.

Health facility management of the BU wounds/sores and scars management was considered by most respondents as very effective, however, time and distance are the major factors affecting its use. As a result, majority patients find alternative forms of treatment as most convenient, but some of which eventually result in recurrence of the sores and permanent deformities due to improper management of the wounds/sores and scars.

6.2 CONCLUSION

Beliefs in the supernatural or spiritual forces as the causes of BU disease lead patients to adopt alternative forms of wounds/sores and scars management in their communities before seeking for health facility management, which sometimes result in recurrence of wounds/sores and leaves patients with permanent deformities. Health facility management, though the most effective, remains geographically inaccessible to most patients, and therefore making the herbalists, the traditional healers and prayer camps the easily accessible and the obvious choice.

6.3 RECOMMENDATIONS

Further research is suggested with a larger sample size and in other BU endemic Districts or Municipalities of Ghana.

Health Education to increase community awareness on BU disease and the need for early detection and management is recommended to reduce recurrence of wounds/sores and permanent deformities. Ignorance about the disease make community members see the disease as caused by spiritual or supernatural forces, and therefore to alternative treatments and end up at the health facilities rather too late. More community-based BU surveillance volunteers should be recruited, trained and motivated to facilitate the early detection and management of the disease. Health workers such as nurses should be reoriented and motivated to be willing to manage BU patients. Municipal and District Assemblies should be encouraged to support these facilities to enable them deliver effective services to their communities.

It is also recommended that government and other interested parties should establish halfway homes (a temporary accommodation) near the facilities for highly infected patients and their caregivers to lodge in while receiving treatment. This will facilitate daily wounds/sores dressing and will solve the problem of distance and financial cost to patients and their caregivers.

Finally, government should supply the health facilities managing the BU wounds/sores and scars with the relevant medications and the non-drug consumables to enable them provide adequate care to patients.

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APPENDICES

APPENDIX I

INFORMED CONSENT FORM FOR ADULTS

TOPIC: Community Management of Buruli Ulcer (BU) Wounds and Scars in the Akuapem South Municipality.

Name of Principal Investigator: Robert Mensah Kwaku Gbley (AHSS Student)

Tel. 0244 438315 **Email:** bobbygbley@yahoo.com

Institution: School of Public Health, College of Health Sciences, University of Ghana, Legon.

Purpose: To investigate BU wounds and scars management in the community.

Procedure: The study is to explore local perceptions regarding wounds and scars management as well as local practices of wounds and scars management in the community. This will be done with the aid of in-depth interview. Permission will be sought to audio-record interview sessions, as well as take notes. Each interview session will last 45 minutes. I will very much appreciate your participation in this study. This is purely academic work which forms part of my work for a master's degree.

Possible risks/ benefits: The research will not post any risk to the participants as there will not be any invasive procedure. There will not be any direct benefit of this work to the participants. However, the result of the study may be beneficial to society as a whole in terms of better management of BU wounds and Scars.

Right to refuse: Participation in this study is voluntary and you can choose not to answer any individual question or all the questions. You are however encouraged to fully participate since your opinions are important in investigating local perceptions and local practices with regards to BU wounds and scars management.

Anonymity and confidentiality: You are assured that whatever information you provide will be taken with strict confidentiality and will be purely for research purpose. Your responses will not be shared with anybody who is not part of the study team. Data analysis will be done on aggregated level to ensure and anonymity. Data collected and all materials related to the study including the audio-recording will be stored in locked cabinet in the Principal Investigator's office for a period of one year. The person responsible for the data storage will be Robert Mensah Kwaku Gbley of School of Public Health, University of Ghana, Legon.

Contacts for additional information

Please call the person responsible for this study, Robert Mensah Kwaku Gbley at 0244438315 or 0206238001 if you have any question about this study.

If you have any question about your rights as research participants or feel you have not been treated fairly you can call the institution review board of the Ghana Health Service,

Hannah Frimpong 0243235225

Consent

I, ----------, declare that the purpose, procedure including risks and benefits of this study have been thoroughly explained to me / I have read the purpose, procedure including risks and benefits of this study thoroughly.

I hereby agree to take part in this study.

Signature/thumbprint of the participant_____ date ____/___/____

Signature of interview _____ date_____/____/____

INFORMED CONSENT FORM FOR PARENTS/ GUARDIANS

(ON BEHALF OF CHILDREN)

TOPIC: Community Management of Buruli Ulcer (BU) Wounds and Scarss in the Akuapem South Municipality.

Name of Principal Investigator: Robert Mensah Kwaku Gbley (AHSS Student)

Tel. 0244 438315 **Email:** bobbygbley@yahoo.com

Institution: School of Public Health, College of Health Sciences, University of Ghana, Legon.

Purpose: To investigate BU wounds and scars management in the community.

Procedure: The study is to explore local perceptions regarding wounds and scars management as well as local practices of wounds and scars management in the community. This will be done with the aid of in-depth interview. Permission will be sought to audio-record interview sessions, as well as take notes. Each interview session will last 45 minutes. I will very much appreciate your participation in this study. This is purely academic work which forms part of my work for a master's degree.

Possible risks/ benefits: The research will not post any risk to the participants as there will not be any invasive procedure. There will not be any direct benefit of this work to the participants. However, the result of the study may be beneficial to society as a whole in terms of better management of BU wounds and Scars.

Right to refuse: Participation in this study is voluntary, therefore participant can choose not to answer any individual question or all the questions. You are however encouraged to consent to the full participation of your ward since his/ her opinions are important in

investigating local perceptions and local practices with regards to BU wounds and scars management.

Anonymity and confidentiality: You are assured that whatever information he/she provides will be taken with strict confidentiality and will be purely for research purpose. His/ her responses will not be shared with anybody who is not part of the study team. Data analysis will be done on aggregated level to ensure and anonymity. Data collected and all materials related to the study including the audio-recording will be stored in locked cabinet in the Principal Investigator's office for a period of one year. The person responsible for the data storage will be Robert Mensah Kwaku Gbley of School of Public Health, University of Ghana, Legon.

Contacts for additional information

Please call the person responsible for this study, Robert Mensah Kwaku Gbley at 0244438315 or 0206238001 if you have any question about this study.

If you have any question about your rights as research participants or feel you have not been treated fairly you can call the institution review board of the Ghana Health Service,

Hannah Frimpong 0243235225.

Consent

I, ----------(on behalf of my ward, ----------), declare that the purpose, procedure including risks and benefits of this study have been thoroughly explained to me and my ward / I have read

and understand the purpose, procedure including risks and benefits of this study thoroughly.

I hereby agree that my ward takes part in this study.

Signature/thumbprint of the participant_____ date ____/___/____

Signature of interview _____ date_____/____/____

APPENDIX II

IN-DEPTH INTERVIEW GUIDE FOR BURULI ULCER PATIENTS

TITLE: COMMUNITY MANAGEMENT OF BURULI ULCER WOUNDS AND SCARS IN THE AKUAPEM SOUTH MUNICIPALITY

Name: ……

Sex: Male ⬭ **Female** ⬭

Age: ……..

Marital Status: ……....

Highest Level of Education Attained: ……

Occupation: ……...

Illness Status: …… (Sore or Scar)

1. In your opinion, what causes BU? (Probe for: natural, spiritual, psychological causes).
2. How did you get the BU disease?
3. How long have you had this sickness?
4. Describe your condition
5. Please tell me how your sore is managed (probe for medical treatment, spiritual treatment, herbal treatment and others and reasons for these treatments).
6. In your opinion, what influences your management of the sore? (Probe for local perceptions, cultural or religious beliefs).
7. Please tell me how the scar is managed (probe for medical treatment, spiritual treatment, herbal treatment and others and reasons for these treatments).

8. In your opinion, what influences your management of the scar? (Probe for local perceptions, cultural or religious beliefs).
9. Are there any local taboos practices when managing wounds and scars? (Probe for food taboos, social taboos, application of medicine, dressing and bandaging).
10. What local practices do you use to manage your BU wounds and scars in the community and reasons for your choice?
11. How are wounds managed at the health facility?
12. How are scars managed at the health facility?
13. What do you think about the health facility management of wounds and scars? (Probe for geographical, financial, sociocultural accessibility; satisfactory facility care).
    a. Are you familiar with the wounds and scars management protocols?
    b. How do you manage your wounds and scars in-between visits to the hospital?
14. What recommendations or suggestions would you make with regards to BU wounds and scars management?
15. Is there anything else you will like to say?

IN-DEPTH INTERVIEW GUIDE FOR BURULI ULCER PATIENTS WHO ARE NOT ON PAKRO HEALTH CENTER REGISTER

TITLE: COMMUNITY MANAGEMENT OF BURULI ULCER WOUNDS AND SCARS IN THE AKUAPEM SOUTH MUNICIPALITY

Name: ……

Sex: Male ◯ **Female** ◯

Age: ……

Marital Status: ……..

Highest Level Educational Attained: ……

Occupational: ……..

Illness Status: …… (Sore or Scar)

1. In your opinion, what causes BU? (Probe for: natural, spiritual, psychological causes).
2. How did you get the BU disease?
3. How long have you had this sickness?
4. Describe your condition
5. Please tell me how the sore is managed (probe for medical treatment, spiritual treatment, herbal treatment and others and reasons for these treatments).
6. In your opinion, what influences your management of the sore? (Probe for local perceptions, cultural or religious beliefs).
7. Please tell me how the scar is managed (probe for medical treatment, spiritual treatment, herbal treatment and others and reasons for these treatments).

8. In your opinion, what influences your management of the scar? (Probe for local perceptions, cultural or religious beliefs).
9. What do you think about community management of BU wounds and scars?
10. Are there any local taboos practices when managing wounds and scars (probe for food taboos, social taboos, application of medicine, dressing and bandaging).
11. What local practices do you use to manage your BU wounds and scars in the community and reasons for your choice?
12. How are wounds managed at the health facility?
13. How are scars managed at the health facility?
14. What do you think about the health facility management of wounds and scars? (Probe for geographical, financial, sociocultural accessibility; satisfactory facility care).
15. Do you go for medical treatment for your wounds and scars? (Probe which health facility, and how often?)
16. Are there wounds and scars management protocols where you go for treatment?
17. What recommendations or suggestions would you make with regards to BU wounds and scars management?
18. Is there anything else you will like to say?

INTERVIEW GUIDE FOR CLINICIAN

TITLE: COMMUNITY MANAGEMENT OF BURULI ULCER WOUNDS AND SCARS IN THE AKUAPEM SOUTH MUNICIPALITY

Name: ……

Sex: Male ⬭ **Female** ⬭

Age: ……..

Marital Status: ……

Highest Level of Education Attained: ……..

Occupational Status: ……

1. In your opinion, what causes BU? (Probe for: natural, spiritual, psychological causes).
2. How long have you been caring for BU patients?
3. Please tell me how the sore is managed at your facility.
4. Please tell me how the scar is managed at your facility.
5. What are the BU wounds and scars management protocols?
6. What would you say about BU patients' adherence to these protocols?
7. What challenges do you (health facility) face with regards to service delivery to these patients? (Probe for challenges faced by the facility and challenges faced with patients).
8. What recommendations or suggestions would you make with regards to BU wounds and scars management?
9. Is there anything else you will like to say?

APPENDIX III

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.

My Ref. :GHS-ERC: 3
Your Ref. No.

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Tel: +233-302-681109
Fax + 233-302-685424
Email: *Hannah.*
Frimpong@ghsmail.org

15th May, 2015

Robert Mensah Kwaku Gbley
School of Public Health
University of Ghana
Legon, Accra

ETHICS APPROVAL - ID NO: GHS-ERC: 04/02/15

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

"Community Management of Buruli Ulcer Wounds and Scars in the Akuapem South Municipality"

This approval requires that you inform the Ethics Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethics Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within seven days verbally and fourteen days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please note that this approval is given for a period of 12 months, beginning May 15th 2015 to 14th May 2016.

However, you are required to request for renewal of your study if it lasts for more than 12 months.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....

DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra