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EXPERIENCES OF BURULI ULCER PATIENTS WITH THE ANESVAD INTERVENTION IN ENDEMIC DISTRICTS IN GHANA

BY

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DECLARATION

I Dorcas Mmoaden Nawiene hereby do declare that this dissertation is a self-composed work. It is the result of an independent study. Apart from references to other research works indebted which have been duly credited, I declare that this work has not been submitted or accepted for any other degree in any institution.

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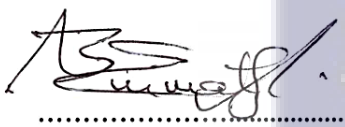

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DEDICATION

This dissertation is dedicated to the Almighty God, my family and loved ones.

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LIST OF ABBREVIATIONS

AIDS	-	Acquired immunodeficiency syndrome
BCG	-	Bacille Chalmette-Guerin
BU	-	Buruli Ulcer
CHA	-	Community Health Assistant
CHV	-	Community Health Volunteer
DMDI	-	Disease Management, Disability and Inclusion
DNA	-	Deoxyribonucleic Acid
ERC	-	Ethics Review Committee
FDG	-	Focus Group Discussion
GBUI	-	Global Buruli Ulcer Initiative
GES	-	Ghana Education Service
GHS	-	Ghana Health Service
HIV	-	Human Immunodeficiency Virus
IDI	-	In-depth Interview
KII	-	Key Informant Interview
KCCR	-	Kumasi Center for Collaborative Research
LAMP	-	Loop-mediated isothermal Amplification
MPH	-	Master of Public Health
NBUCP	-	National Buruli Ulcer Control Program
MDA	-	Mass Drug Administration
NGO	-	Non-Governmental Organization
NTD	-	Neglected Tropical Disease
SDG	-	Sustainable Development Goal
WASH	-	Water, Sanitation and Hygiene
WHO	-	World Health Organization

ABSTRACT

INTRODUCTION: Buruli ulcer (BU) is a neglected tropical disease that affects mainly the skin, tissues and, in some instances, the bones. The disease is caused by *Mycobacterium ulcerans*, an environmental pathogen in the same family as the bacteria that causes leprosy and tuberculosis. After tuberculosis and leprosy, BU is the third most common *Mycobacterium* infection. In Ghana, the ANESVAD Intervention is one of the key health interventions that have been implemented to control the morbidity of BU and reduce the risk of disability associated with it. Though the intervention also took care of Leprosy and Yaws patients, this study only explored the experiences of buruli ulcer patients with the ANESVAD Intervention in three ANESVAD sponsored district. The experiences of implementers of the intervention were also explored to get broader understanding of the intervention and the experiences buruli ulcer patients had with it.

METHODOLOGY: This was a qualitative study that used in-depth interviews to explore the experiences of nine buruli ulcer patients and nine key informant interviews of program implementers in addition to get a broader understanding of the ANESVAD Intervention. Purposive and convenience sampling were used to select participants and Thematic content analysis was used to analyze data with the aid of NVivo 10 software.

RESULTS: Buruli ulcer patients before the ANESVAD Intervention resorted to herbs to treat their wounds due to their limited knowledge on the cause and treatment of the disease. For some patients, financial difficulties hindered their ability to seek for treatment at the hospital. During the implementation of the intervention, patients were educated to understand the cause of the disease and its treatment. The intervention provided free antibiotics for patients, transportation to the health facilities and provided logistics for health workers to dress the wounds of the patients. The implementers gained in-depth knowledge on the disease and were provided with financial support and logistics to take care of the needs of the patients. The implementers partnered with agencies such as the media, NGOs, GES, KCCR among others during implementation of the intervention. The commitment of patients, implementers and other stakeholders made the implementation a success. Delayed funds, relapse of patients and drug wastage due to expiration were some challenges of the ANESVAD Intervention.

CONCLUSION: From this study, buruli ulcer patients had a positive experience with the ANESVAD Intervention. Patients were enlightened on buruli ulcer and other NTDs, had treatment, changed their health seeking behavior and also reduced stigmatization against them.

CHAPTER ONE

INTRODUCTION

1.1 Background

Buruli ulcer (BU) is a neglected tropical disease that affects mainly the skin, tissues and, in some instances, the bones. The disease is caused by *Mycobacterium ulcerans*, an environmental pathogen in the same family as the bacteria that causes leprosy and tuberculosis. After tuberculosis and leprosy, BU is the third most common *Mycobacterium* infection (Akoachere et al., 2016). The disease occurs in three stages: the first stage is characterized by nodules that are firm and non-tender which may result in edema and plaques, and the second stage, which results in the ulceration of the skin resulting in a complication called osteomyelitis. The final stage involves healing immune response, which may result in scarring, fibrosis, calcification and, in extreme cases, permanent disabilities (Bratschi et al., 2013).

The virulent nature of the *Mycobacterium ulcerans* leads to the production of a toxin called mycolactone, which destroys adipose tissues in the skin's subcutaneous layer resulting in the development of large ulcers. BU mainly affects the extremities though it affects other parts of the body (Phillips et al., 2015). Though the causative organism of BU is an environmental pathogen, the exact mode of transmission of the disease is still elusive. Besides, some aquatic bugs are believed to be reservoirs for the *Mycobacterium ulcerans* and are instrumental in the disease's transmission (Bratschi et al., 2013). Some previous studies have demonstrated that the persistent presence of the *Mycobacterium ulcerans* in decaying organic matter found underwater in water sources for BU cases indicates this decaying organic matter might be a reservoir for the disease (Jacobsen & Padgett, 2010; Kenu et al., 2014).

Prompt diagnosis is necessary to prevent disease progression to severe forms. BU's differential diagnoses include chronic lower leg ulcers, diabetic ulcers, ulcerative yaws, and tropical phagedenic ulcers (WHO, 2022). Surgeries are the standard treatment of BU in the early stages of the disease, which requires incision though the use of antibiotics is also employed. In extreme cases where there are large lesions and necrosis of the affected area, surgical procedures involve the removal of necrotic tissues to prevent the spread of the infection. In such situations, skin grafting is also considered, and amputation in extreme cases (Akoachere et al., 2016). In general, WHO recommends the combination of antibiotics such as rifampicin and clarithromycin and complementary treatments such as wound dressing. In extreme cases, physiotherapy is also employed to prevent disability (WHO, 2015).

According to the World Health Organization (WHO), BU has been reported in 33 countries spanning Africa, Asia, the Americas and the Western Pacific. However, most of these cases are reported from tropical and subtropical areas. Until 2016, the yearly number of BU cases was approximately 5000 until there was a decline in cases from 5000 to 1961. These numbers steadily rose to 2713 in 2018, but there has been a decline in the number of BU cases in 2020, primarily linked to the impact of the COVID-19 pandemic on case detection activities (WHO, 2022). The West African sub-region has borne the brunt of BU, with over 24,000 cases of the disease recorded in the Ivory Coast from 1978 to 2006 (Anokye et al., 2018) and about 7000 cases also reported from 1989 to 2006 in Guinea as well as 51 cases confirmed in Nigeria (Ukwaja et al., 2016). Over 11,000 cases of BU have been reported in Ghana since 1993 (Owusu & Adamba, 2012). A recent retrospective PCR analysis of BU cases showed that the Greater Accra (668 confirmed cases), Eastern (163 confirmed cases), and Ashanti (74 confirmed cases) were the top three endemic regions (Yeboah-Manu et al., 2018).

Though BU is endemic in some countries, some people in these countries do not know about it, and some individuals perceive the disease to be an infliction from the gods, as a result of curses, due to witchcraft and drinking from ponds, wading in swampy areas and swimming in rivers (Owusu & Adamba, 2012). In Nigeria, it was reported that 35% of community members had good knowledge of BU and 66.7% considered it to be a severe disease (Nwafor et al., 2019). A recent study in Ghana reported that more than a third of community members perceived BU to be caused by witchcraft (38%), not pouring libation (16%) and enemies (15%). The same study also reported being overweight, having an increased appetite and swelling on the skin to be signs and symptoms of BU (Anokye et al., 2018). All these studies have shown the relevance of knowledge on BU. This is because some other studies reported that, most cases report to hospitals in the late stages of the disease, which complicates the conditions of these individuals (Akoachere et al., 2016; Nsai et al., 2018; Nwafor et al., 2019). In that regard, adequate knowledge of the disease is essential for early detection to lessen the burden of the disease concerning pain, trauma and the cost associated with late treatment.

The WHO regards BU as one of the Neglected Tropical Diseases (NTD) of public health importance and thus collaborates with NTDs control programs in endemic countries by providing technical guidance, coordinating prevention, control and research efforts, and developing policies. This collaboration brings together major stakeholders and actors involved in BU to share information, consolidate research efforts and coordinate disease prevention and control (WHO, 2022). Donors and NGOs such as ANESVAD (Spain), MAP international (USA), Deutsche lepra- und Tuberkulosehilfe -DAHW (Germany) and Foundation Raoul Follereau -FRF (France) are actively involved in BU control and research activities. These research activities are focused on priority areas, including understanding the mode of transmission of BU, developing rapid

diagnostic tests and instituting best-case antibiotic treatments. To ensure these priorities are met, the WHO recommends integrating BU control within skin NTD programs for diseases peculiar to endemic countries.

Additionally, the organization has also developed a Skin App to enable health workers to perform quick diagnoses of skin NTDs in the field (WHO, 2018). In Ghana, the Ghana Health Service established the National Buruli Ulcer Control Program in 2001. The program's main objective was to reduce the morbidity and disability associated with BU. The program also aimed at collaborating with research centers regarding diagnosis and standard case management (Rufai et al., 2019).

Velink et al. (2016) assessed the experiences of former buruli ulcer patients in focused group discussions. The researchers reported from their study that women were more affected from their experience than men, indicating that women experienced more social consequences than men (Velink et al., 2016). Social consequences translated into individuals refusing to seek medical care as a result of stigma. Consequently, Ahorlu et al. (2013) reported that instituting social interventions, including providing free transportation and breakfast meals served as incentives to encourage health-seeking behavior. Woolley et al. (2016) have indicated that patients usually experience pain during the dressing of the ulcer, or during treatment regimen. Others have also been reported to experience pain as they carry out their daily activities (Woolley et al., 2016). It is noteworthy, however, that patients of Buruli ulcer have been noted to have no experience of pain at the onset of the presentation of the ulcer. Velink et al. (2016) reported that whereas some individuals express their pain by crying out loud, others decide to be silent, especially during the times when their ulcers are being dressed at the health care facility.

The Ghana Health Service, in its master plan for the NTD Control Program for 2016-2020, highlighted that the main challenges for BU control in Ghana were the late reporting of cases, inaccessibility to patient care, insufficient information for decision making and lack of organized social involvement. That notwithstanding, the master plan also outlined six intervention areas that need strengthening, which include: early detection and screening activities in endemic areas, strengthening the BU surveillance system, enabling cases to complete daily injections and wound dressings with modern wound dressing materials, monitoring and evaluation, community-based rehabilitation and disability prevention and research interventions into the mode of transmission and effective treatment (Ghana Health Service, 2016).

All these intervention areas outlined by Ghana Health Service indicate that there is still much work to be done and challenges to be surmounted to find better ways to understand the disease, its treatment and prevention, and to reduce its associated disabilities. In that regard, this study sought to explore the experiences of buruli ulcer patients with the ANESVAD Intervention in endemic district in Ghana. The districts selected for the study included Asikuma Odoben Brakwa in the Central Region, Wassa Amenfi East Municipality in Western Region and Upper West Akim in the Eastern Region of Ghana.

The ANESVAD Intervention is an initiative of the ANESVAD Foundation. The ANESVAD Foundation is a Spanish NGO that is dedicated to bringing quality health to the vulnerable in societies across the world especially in the area of NTDs. The foundation in partnership with the Ghana Health Services has sponsored fifteen NTD endemic districts in Ghana. The foundation supported the selected districts with medication, that's is antibiotics (rifampicin and clarithromycin) for treatment of BU, logistics for wound dressing, vehicles, motorbikes, bicycles, laptops, desktops, mobile phones and funding for the intervention activities. This intervention was

implemented from 2018 to 2022 as a pilot for possible rollout of another phase that would support more districts. Although the intervention sponsors leprosy and yaws patients, the study only explored the experiences of buruli ulcer patients with the intervention.

1.2 Problem Statement

BU is a Neglected Tropical Disease (NTD) of public health concern whose transmission remains unknown. However, it continues to plague people from all walks of life, particularly those residing in tropical and sub-tropical areas (WHO, 2022). Currently, early detection and treatment are the optimum ways to prevent the disease from progressing to the ulceration stage, which could go a long way to affect bone formation negatively, disrupt limbs' movement, and even result in amputation in extreme cases. The WHO reported that 2713 cases were reported in 2018, although there is a high likelihood of underreporting due to limited surveillance systems of the disease (WHO, 2022).

In a developing country like Ghana, the perception of most people residing in endemic areas about the disease is that it is a result of witchcraft, curses, poor hygiene, drinking contaminated water and contact with sufferers (Anokye et al., 2018; Nsai et al., 2018; Nwafor et al., 2019). However, scientific research has shown that the *Mycobacterium ulcerans,* which causes the disease, is an environmental pathogen. These knowledge gaps reported have been demonstrated to influence late reporting of the disease for proper health care. This results in extensive destruction of the skin, tissues in some cases, bones and the formation of large ulcers on body extremities (Akoachere et al., 2016). The long-term effects of BU include functional disabilities and excessive skin scarring. The effect of BU on children and adults cannot be underestimated. Children plagued with severe forms of BU may have to spend extended hours away from school to seek treatment in the hospital. In some extreme cases, some might have to discontinue their education due to extreme deformities

from the disease. These children may become entirely dependent on their families for support hence exerting economic pressure on their immediate and distant families. For adults, the disease might restrict movement and hinder them.

The unpleasant smell associated with BU can also cause the sufferer to be ostracized. For women in rural areas where the disease is endemic, the disease could hinder social and economic activities such as household activities, farming and trading, which could adversely affect their social relationships (Ahorlu et al., 2013; Owusu & Adamba, 2012). Proper case management of BU also requires inter-sectorial collaboration between health care providers, donors and community members. It is thus vital for service providers to consider socio-cultural beliefs associated with the disease in the formulation, design and implementation of interventions for alleviating the disease. This is because these considerations could be instrumental in improving local case detection and health-seeking behavior of sufferers of BU (Koka, 2018). Therefore, it is imperative that, for BU public health interventions to succeed, relevant stakeholders need to make a conscious effort to understand the cultural, social and economic aspects of the disease and its management. Though strides have been made in the fight against BU in endemic districts, there are still impediments to the war on the disease. The implementation of the ANESVAD intervention was to address buruli ulcer in the districts. However, the implementation of every health intervention comes with experiences beneficiaries have with it, its stakeholder partnerships and its facilitators and barriers. It is to this effect that the experiences of BU patients need to be explored to identify its barriers and facilitators. Therefore, this study sought to explore the experiences of the Buruli Ulcer patients with the ANESVAD intervention endemic districts in Ghana.

1.3 Justification

BU is a dehumanizing disease with no known transmission mode but continues to be rampant in many regions in Ghana, particularly in forest regions. The study explored the experiences of BU patients, determine the stakeholder partnerships and their specific contribution to the implementation of the intervention and the barriers and facilitators of the intervention. The ANESVAD intervention has been in existence since 2018, and it will be appropriate to explore the experiences of buruli ulcer patients with this intervention targeted at controlling an NTD of public health importance. Exploring patients experiences with this intervention helped unearth aspects of the intervention that met set targets and areas that needed strengthening so that the overall objective of this intervention and subsequent interventions can be achieved. The findings from this study would also provide valuation information to donors on the performance of the intervention.

1.4 Research Questions

1. What are the experiences of Buruli Ulcer patients with the ANESVAD Intervention?
2. What are the existing partnerships among stakeholders of the ANESVAD Intervention?
3. What are the barriers and facilitators influencing the implementation of ANESVAD intervention in the endemic districts?

1.4.2 General Objective

This study aimed at exploring the experiences of Buruli Ulcer patients with the ANESVAD Intervention in endemic districts in Ghana.

1.4.3 Specific Objectives

1. To explore the experiences of Buruli Ulcer patients with the ANESVAD Intervention.
2. To explore partnerships of the ANESVAD intervention among stakeholders.
3. To identify barriers and facilitators influencing the implementation of ANESVAD intervention in the endemic districts.

1.5 Conceptual framework

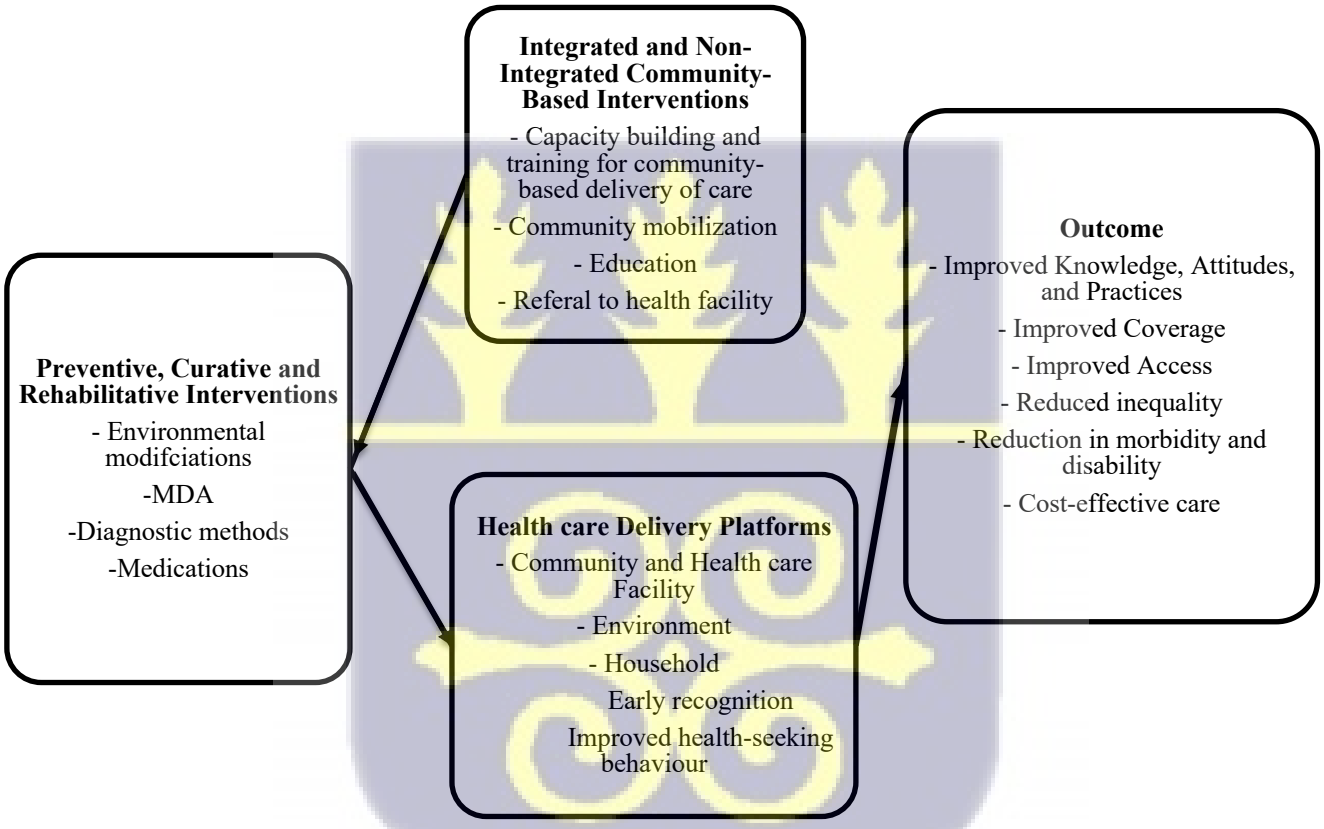

Figure 1: Conceptual Framework on Interventions for Buruli Ulcer (adapted from Lassi et al. (2014)

The conceptual framework was adapted from Lassi et al. (2014) in their study to assess community-based interventions for the prevention and control of infectious diseases of poverty.

Preventive, curative and rehabilitative interventions are required to achieve prevention and control of NTDs. Activities involved include establishing environmental factors such as providing potable drinking water, implementing WASH interventions, among others (Lassi et al., 2014). Further, mass drug administration efforts are required diagnostic tools are employed in case detection and disease confirmation procedures. Because health care professionals may not be residents of the communities, integrated and non-integrated community-based interventions are required, which focus on capacity building for community-based delivery of care, community mobilization and education on the disease condition. Consequently, community members are encouraged to refer suspected cases to health care facilities for medical and/or surgical attention. As a means of community integration, health care facilities are equipped with the required resources for early detection, diagnosis and treatment, while empowering households with knowledge on early detection, and encouraging health-seeking behavior. The impact of these interventions would lead to improve knowledge, attitudes and practices of community members towards the disease condition. Further, there will be improved coverage and access to health care interventions, reduced cost of care, reduced inequality and a general reduction in disease morbidity and mortality rates

Theoretical Underpinning

The social ecological model has been applied in many studies on disease prevention (Ohri-Vachaspati et al., 2015; Lee et al., 2017; Wold & Mittelmark, 2018). In the studies in health promotion, the model has been applied to comprehend and categorize targets for health behavior interventions. The model explains and depicts the dynamic relations that exist among individuals, institutions, communities and policies. The model is developed on the premise of human growth where individuals are meant to influence and susceptible to influence by, persons, and

organizations they have interactions with, accessible resources, institutions, norms and rules of the community (Bronfenbrenner, 1992). According to Espelage & Swearer (2009) and Kolff, Scott, & Stockwell (2018) highlights the multifaceted interaction between individual, relationship, community, and societal elements.

Variables such as preventive, curative and preventive intervention in the conceptual framework are important factors to consider when planning health promotion and public health interventions on buruli ulcer and other NTDs. Though the mode of transmission of BU is unknown, the capacity of individuals, households and communities built on BU equips them to seek for the right care when the need arises. Curative and rehabilitation of BU patients through diagnostic methods, wound dressing and medication ensures holistic treatment of patient and complete healing of their wounds, the collective efforts of the patient, household and community with an enabling environment would facilitate their recovery is which what the social ecological model seeks to achieve with its application to health interventions. Integrated and non-integrated community based intervention facilitate capacity building and training for community based delivery of care and community mobilization, when the capacity of the entire community is bult on BU and other NTDs, community members not only seek for the right care but also understands and support patients which addresses stigmatization against BU patients. Equipping health care facilities with both human and material resources together with the aforementioned variables of the conceptual framework leads to better health outcomes such as improved knowledge, attitudes, practices, improved health coverage, improved access, reduced inequality and stigmatization, reduction in morbidity and disability and cost-effective care for BU patients.

The model was applied to the study to understand the experiences of Buruli Ulcer patients with the ANESVAD Intervention in endemic districts in Ghana. The application of the theory to the

study was guided by the question of how, why and what to understand the experiences of Buruli Ulcer patients with the ANESVAD Intervention in endemic districts in Ghana. The theory was relevant to this topic in two ways: a) the theory helped analyses the experiences of Buruli Ulcer patients with the ANESVAD Intervention, b) explores partnerships of the ANESVAD intervention among relevant stakeholders, and c) identifies barriers and facilitators influencing the implementation of ANESVAD intervention in the endemic districts.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter gives a review of important literature in relation to the study and its objectives. The review also covers other important aspects of buruli ulcer such as case detection and case treatment.

2.2 Experiences of Buruli Ulcer Patients

In their study to assess the experiences of buruli ulcer patients following discharge in the Greater Accra region of Ghana, Menlah et al. (2020) reported that patients usually report feeling embarrassed, being financially handicapped, and others also experience marital conflicts. The issue of being financially handicapped was attributed to the fact that dressing and other treatment regimen required for treatment while on admission are financially inclusive (Menlah et al., 2020). This has been corroborated by Constantine et al. (2011), who reported on the economic burden of buruli ulcer on affected individuals. Constantine et al. (2011) reported that buruli ulcer consequently leads to poverty among individuals and affected communities altogether. In a study conducted in Ghana, the researchers indicated that poor households were most inflicted by buruli ulcer, compared to rich households, especially when there was more than one patient of buruli ulcer was identified in that household (Constantine et al., 2011).

Buruli ulcer has been noted to impact the mental health and quality of life of affected individuals. In a case-control study in 3 buruli ulcer endemic districts in Ghana, it was discovered that both active and previously affected individuals faced significant levels of distress and mental health deterioration (Amoako et al., 2021). In their study to determine the impact of neglected tropical

diseases on mental health, Bailey et al. (2019) reported that the socio-economic impacts of buruli ulcer leads to the developments of common mental health conditions, including depression and anxiety. Consequently, the WHO has indicated the need to incorporate mental health management in the total management provided to buruli ulcer patients. The Organization has been reported to have invested in researches to evaluate the psychological impact of the disease condition in a bid to provide evidence-based mental health care to improve the quality of life of both active and past patients of buruli ulcer (WHO, 2021).The experience of patients of buruli ulcer has been reported to be influenced by certain socio-cultural beliefs and practices. According to Constantine et al. (2011), people with buruli ulcer are thought to be victims of an evil eye, and are stigmatized because they are considered to have engaged in evil practices. Consequently, such individuals would be abandoned by friends and relatives, and are usually found to be isolated (Constantine et al., 2011).

According to Velink et al. (2016) former patients of buruli ulcer felt that lack of information on the disease condition, including its early diagnosis and treatment options would have gone a long way to improve their well-being. This is corroborated by the fact that taking rifampicin, one of the medications used for the treatment regimen, causes individuals' urine to change color. Consequently, providing information to patients to expect such changes in their physiology would position them to be ready to receive the treatment regimen to the full extent (Velink et al., 2016).

Buruli Ulcer is an infectious disease that is caused by the bacterium *Mycobacterium ulcerans*, and has been reported by the World Health Organization (WHO) as a skin-related neglected tropical disease (NTD) (Yotsu et al., 2018). It ranks among the WHO's list of 17 NTDs, and has been described as an "infectious disease of poverty" (Tschakert et al., 2016). According to the WHO, the disease was named after Buruli County, a place in Uganda near the Nile River where it was

first reported in large numbers (WHO, 2013). The infection is also known as Bairnsdale ulcer and Daintree ulcer in Australia, named after the Daintree River and Bairnsdale locations in Australia, where it is considered endemic (Nsai et al., 2018). It must be noted that *Mycobacterium ulcerans* belongs to the family of bacteria known to cause such diseases as tuberculosis and leprosy (Udujih et al., 2020), hence same attention given to these disease conditions must be given to Buruli ulcer. However, unlike tuberculosis, there has been no evidence to indicate infection with Human Immunodeficiency Virus (HIV) to be a risk factor to developing Buruli ulcer. Further, there has been no evidence of person-to-person transmission of the disease (Kargbour-Labour, 2010). Consequently, it has been reported that Buruli ulcer is the third most common mycobacterial infection (Nsai et al., 2018). It is reported to affect children typically under the age of 15 years living in rural areas in Africa. However, in the Australian regions, the age distribution is slightly higher, particularly due to the age differences in the populations affected (Pluschke & Roltgen, 2019). The specific mode of transmission of Buruli ulcer has not been clearly identified. However, insect bites and skin injuries have been propounded to be the commonest means of transmission (Nienhuis et al., 2010). Kenu et al. (2014) reported, other means of transmission of the disease, including poor hygiene and worms in marshy areas.

According to a report by the World Health Organization, up until 2010, about 5000 cases of Buruli ulcer were reported annually globally. Consequently, there was a gradual reduction in the number of cases of up to 1961 cases reported annually globally up until 2016. In 2018, 2019, and 2020, the Organization reported 2713, 2271, and 1258 cases respectively globally, with the drastic reduction in the number of cases in 2020 attributed to the COVID-19 pandemic outbreak (WHO, 2022). The WHO has indicated the possibility of underreporting of the disease condition, deduced from the fact that out of the over 33 countries have ever detected cases, only 14 countries provide

consistent update on disease incidence (WHO, 2022). According to Tschakert et al. (2016), the number of reported cases of Buruli ulcer in Ivory Coast, Ghana, and Benin, along the west coast of Africa were 1039, 550, and 378 respectively. Anokey et al. (2018) has reported that there have been more than 11,000 cases of Buruli ulcer in Ghana since 1993 when it was first identified. Buruli ulcer is said to typically develop from a painless swelling, which when left untreated develops into large ulcers, and is commonly seen on the arms, face and legs (Tschakert et al., 2016). Consequently, there is progression without any signs of pain or fever, eventually tissue damage results from a unique toxin that is produced by the *Mycobacterium ulcerans*. *Mycobacterium ulcerans,* the causative organism of Buruli ulcer, is said to grow in temperatures between 29 to 33 degrees Celsius, with low oxygen concentration of about 2.5% (WHO, 2022).

In a study that was conducted to evaluate the knowledge of Buruli ulcer among health care practitioners, Nsai et al. (2018) reported that although most health care workers had knowledge of the disease condition, there was poor knowledge on identifying the various stages of development of the ulcer. Further, few health care practitioners could outline the accurate treatment regimen for Buruli ulcer (Nsai et al., 2018). The WHO (2022) has classified Buruli ulcer into three categories: "Category I single small lesion (32%), Category II non-ulcerative and ulcerative plaque and edematous forms (35%), and Category III disseminated and mixed forms such as osteitis, osteomyelitis and joint involvement (33%)". In other studies, however, healthcare practitioners have been reported to have poor knowledge altogether. According to Akoachere, Nsai and Ndip (2016), some health care practitioners have no knowledge of Buruli ulcer, and its treatment. Hence, patients who report to their facilities are referred to other health care facilities for treatment. Consequently, such patients resort to visiting prayer camps, herbalists, witch doctors, or other alternative means of treatment (Akoachere, Nsai, and Ndip, 2016). In a study that was conducted

in Cameroon, the researchers indicated low level of knowledge among respondents (Kamga et al., 2013). The researchers argued that low level of knowledge could be attributed to selective inclusion of health care facilities, hence, the likelihood that selected health care facilities reported lower cases of Buruli ulcer (Kamga et al., 2013). This is supported by findings from a study a few years later in the same region in Cameroon conducted by Akoachere, Nsai and Ndip (2018). According to their findings, more than 80% of the respondents reported higher levels of knowledge of Buruli ulcer. This could be attributed to the respondents' description of the disease condition in the local languages. The researchers further argue that increased knowledge and awareness of the disease condition could be as a result of increased educational campaigns conducted nationwide in Cameroon, as part of a national Buruli Ulcer Control Program (NBUCP) instituted by the country's Ministry of Health. This finding indicates that increased educational campaigns would invariably increase awareness and knowledge of Buruli ulcer amongst the populace in general, and health care practitioners.

In Ghana, the coastal areas of the Ga West District, Amansie West District, and Asante-Akim North District have been reported to be the most endemic areas for Buruli ulcer (Anokye et al., 2018). The researchers argue that most people are ignorant of the disease and its causes, and have attributed its occurrence to being a punishment from God, witchcraft and curses. This could indicate why patients in Cameroon seek for help from prayer camps, witch doctors and herbalists (Akoachere, Nsai, and Ndip, 2018). In another study conducted in Ghana, the researchers indicated that indigenes attribute the causes of Buruli ulcer to drinking from ponds, wading in swampy areas, and swimming in rivers (Adobea & Adamba, 2012). Because the specific mode of transmission of the disease has not been scientifically established, most of these misconceptions are frequently

tolerated. It is imperative to appreciate that adequate knowledge of the disease condition will go a long way in aiding early detection and treatment. Further, such challenges as loss of productivity as a result of long hospital stays will be mitigated with adequate knowledge, which would invariably result in keeping from risk factors to the disease (Anokye et al., 2018).

The challenges to the incidence of Buruli ulcer faced among the Ghanaian populace has predominantly been attributed to poor knowledge. As indicated by Adobea and Adamba (2012), some perceptions held by Ghanaians are erroneous, including attributing it to be as a result of a curse. Anokye et al. (2018) reported that "tradition and superstition played significant role in explaining what causes Buruli ulcer". The researchers indicated most people as indicating the causes to be repercussions for offending the gods, being plagued by witches or your enemies, or by carrying out a taboo (Anokye et al., 2018). These misconceptions imply that individuals are likely to practice risk factors that predispose them to developing the disease without their knowledge. In Cameroon, training programs conducted for health care professionals have reportedly been the reason for increased knowledge and awareness among health care professionals, who in turn educate their patients on their hospital visits (Akoachere, Nsai, and Ndip, 2018). On the contrary, Nsai et al. (2018) reported low levels of knowledge among respondents, attributing their findings to limited population samples.

2.3 Case Detection of Buruli Ulcer

NTDs reportedly affect more than a billion people globally, and is typically recognized among populations of low socioeconomic status in Africa, the Americas and Asia (WHO, 2012). Typically, at the community level, NTDs are managed by mass drug administration (MDA) by

either volunteers or professional health care providers. In 2013, the Sustainable Development Goals (SDGs) included ending NTDs as a means of achieving equity, indicating, “to end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases by 2030” (WHO, 2017b). To achieve this goal, several policies have been implemented. Godwin-Akpan et al. (2022) has indicated the importance of an integrated approach, where there are joint planning involving personnel with the requisite skills, implementation of policies, and evaluation of implemented policies. Adequate resources are required for carrying out MDA activities, diagnostic, curative and morbidity management activities (Godwin-Akpan et al., 2022).

Because the mechanism of transmission of *Mycobacterium ulcerans* is not fully understood, the most effective means of control of Buruli ulcer is by active case detection and consequent treatment (Yeboah-Manu et al., 2013). Epidemiology of Buruli ulcer has not been firmly established, as a result of such factors as delayed reporting to health care facilities, lack of designated health care facilities for treating cases, and poor knowledge of the disease condition (Ahorlu, Okyere, & Ampadu, 2018). Between 1993 and 2013, more than 10,000 cases of Buruli ulcer were reported in Ghana due to passive surveillance systems that were implemented across the country (Yeboah-Manu et al., 2013). The National Buruli Ulcer Control Program (NBUCP) has designated specific health care facilities for clinical diagnosis and laboratory investigations of the disease condition. In Nigeria, it has been reported that data from case detection on Buruli ulcer is inadequate and largely underreported. According to Nwafor et al. (2019), only about 8 states, out of the 36 in Nigeria have reported cases of Buruli ulcer, although number of cases is believed to be increasing by the passing of years. According to the study, about 18.7 cases per 100,000

population were reported in 2012, which is not representative of the entire population (Nwafor et al., 2019).

Because case detection of Buruli ulcer has posed a challenge over the years, the WHO has recommended for community-level assessment prior to any intervention modules. According to the Organization, understanding the community context ensures "culturally-appropriate and behaviorally-feasible prevention and treatment interventions" (Nwafor et al., 2019). Because of the burden of disease, resources are being invested towards developing diagnostic tools for effective clinical management of Buruli ulcer (Ahorlu, Okyere, & Ampadu, 2018). However, these interventions will prove futile without active surveillance and case detection techniques. This implies that it is imperative that good health-seeking behavior is advocated among community members, to enhance early case detection, and consequent successful prognosis of the disease. Ahorlu, Okyere and Ampadu (2018), in agreement to the WHO recommendations, have indicated the importance of community-based interventions, which ensure community members are involved in case detection system, enforcing reduced late reporting of cases.

It is imperative to appreciate that case detection systems of Buruli ulcer have faced challenges as a result of stigmatization from the disease. According to Nwafor et al. (2019), people with Buruli ulcer are often stigmatized, especially because community members fear contracting the disease should they relate with infected individuals. This situation can be argued to be as a result of poor knowledge amongst most community members, who possess little to no knowledge about Buruli ulcer, and are often of the perception that the disease has spiritual roots. People with Buruli ulcer have been withheld from holding such job positions as teachers; families prevent their children

from playing with infected children; infected individuals are marginalized for fear of contracting the disease, among other actions of stigma in communities (Nwafor et al., 2019). Stigma from Buruli ulcer has also been documented to be as a result of the physical impairment the disease causes, as well as the possible disabilities it renders to those infected (Godwin-Akpan et al., 2022).

In recent years, case confirmation of Buruli ulcer is done through detection of *Mycobacterium ulcerans* DNA using PCR of IS2404, IS2606, and ER (Yotsu et al., 2018). Other recommended diagnostic confirmation methods include histopathology, cultures, and microscopic detection of acid-fast bacilli in wounds (WHO, 2018). These methods of case detection have proven more beneficial than the DNA PCR tests, particularly as a result of unavailability of PCR test kits in rural communities, where the disease is predominant. Thus, alternative means of case detection and diagnosis have become imperative (Yotsu et al., 2018). Further, diagnostic test kits must be applicable for use in field work as well. Beissner et al. (2015) have reported newer methods of diagnoses that enables for early detection of disease, and are effective for fieldwork, including the loop-mediated isothermal amplification (LAMP) test, antigen detection assays, and the thin-layer chromatography for the detection of mycolactone. Mycolactone is a toxin released by *Mycobacterium ulcerans* upon infection, which leads to tissue damage and subsequent ulcer. In the absence of diagnostic test kits, clinicians based on clinical presentations of patients often make diagnosis. Eddyani et al. (2018) in a study to evaluate clinical diagnosis of Buruli ulcer from other skin ulcers in an endemic area reported high sensitivity of 92% exhibited by clinicians. Thus, clinical diagnosis in the absence of diagnostic test kits is highly probable. It must be appreciated, however, that there are several differential diagnoses of Buruli ulcer, intimating the need for expert diagnosis. Consequently, Yotsu et al. (2018) advocates for clinicians to undertake a comprehensive

study of detected cases in order to be abreast with the latest clinical presentations of people infected with the disease.

Godwin-Akpan et al. (2022) discuss three models to improve early case detection. The first model, the Community Health Assistant Model (CHA Model) recruits semi-literate community members who would volunteer to identify and refer individuals with clinical manifestations of Buruli ulcer to the nearest health care facility. These volunteers typically work beyond a 5km radius from the nearest health care facility, in order to identify patients not identified by health care professionals (Godwin-Akpan et al., 2022). The second model is known as the Community Health Volunteer Motivation Model (CHV Model). This model, as is suggested in its name, serves as a means of motivating volunteer members of the community to identify and report disease management and disability inclusion (DMDI) cases within their communities. The third model, known as the Integrated Mass Drug Administration and DMDI Active Case Search Model (MDA-CM Model) involves training both community health volunteers (CHVs) and community health assistants (CHAs) as direct distributors, where they actively searched for DMDI cases and distribute medications for NTDs during their campaigns (Godwin-Akpan et al., 2022).

2.3 Treatment of Buruli Ulcer

Whereas the first case of Buruli ulcer in Africa was reported in 1897 (Nsai et al., 2018), the first case of Buruli ulcer in Ghana is reported to have been detected in 1971, in the Greater Accra Region (Kargbour-Labour, 2010). In the ensuing years following its detection, treatment regimen has been reported to be costly, with increasing cost found to be associated with later stage of the disease (Kargbour-Labour, 2010). Thus, early detection of Buruli ulcer among individuals resulted in lesser treatment cost, compared to delayed detection treatment costs. Vaccination has been found to be effective in treating BCG. According to Nsai et al. (2018), the Bacilli Calmette-Guerin

(BCG) vaccine offers some protection against Buruli ulcer in the short term. However, because the BCG was not developed for treating Buruli ulcer, a more permanent and lasting solution should be sought for in combating the disease condition. Presently, the most effective means of treating Buruli ulcer is by drug therapy, surgical procedures, or by both methods (Nsai et al., 2018). Overall, it must be noted that early reporting of the disease to a health care facility increases the possibility of good prognosis.

It is imperative to appreciate that perception of individuals on Buruli ulcer will ultimately influence their health-seeking behavior. Udujih et al. (2020) argue that there is dearth of information on Buruli ulcer in Nigeria, which has resulted in poor health-seeking behavior among individuals who develop the disease. As in Ghana, most individuals in rural communities in Nigeria perceive Buruli ulcer to have spiritual roots, and therefore resort to spiritualists, churches, and witch doctors, among others, for their healing (Udujih et al., 2020). In a study that was conducted in Obom sub-district, Ghana, the researchers established a significant association between age, education and occupation with knowledge of Buruli association, indicating that higher levels of education were associated with good knowledge (Ahorlu et al., 2013). These findings are consistent with findings from Udujih et al. (2020) who indicated that community perception of Buruli ulcer and its treatment options were significantly associated with levels of education and occupation.

Untreated and/or delayed reporting of Buruli ulcer could lead to debilitating complications, which have themselves being acknowledged to contribute to poor health-seeking behavior (Udujih et al., 2020). Among reported complications of poorly managed Buruli ulcer are such conditions as osteomyelitis, secondary infections, metastatic lesions, and squamous cell carcinomas (Udujih et al., 2020). In a study that was conducted in Ghana, it was reported that individuals who developed Buruli ulcer were predominantly co-infected with *Mansonella perstans* nematodes (Phillips et al.,

2014). People who have been previously infected with Buruli ulcer have been reported to develop lifestyle changes to avoid re-infection. According to Tschakert et al. (2016), behavioral changes were in two-fold, where individuals who had previously been infected reported "avoiding high-risk areas whenever possible, especially after contracting cuts or wounds, or by wearing protective clothing". This was documented to be as a result of long stays at health care facilities that kept them away from home and their workplaces (Tschakert et al., 2016). According to Anokye et al. (2018), poor knowledge of Buruli ulcer leads to poor health-seeking behavior, which results in late detection of the disease, posing the risk of poor prognosis. Further, inadequate knowledge indicates that the likelihood of treatment is low. In their study, Anokye et al. (2018) indicates most respondents as indicating a sign of Buruli ulcer to be increased appetite for food. Consequently, such individuals would not consider the disease condition as one that demands urgent medical and/or surgical attention.

According to the WHO, a combination of rifampicin (10mg/kg once daily) and clarithromycin (7.5mg/kg twice daily) is the recommended treatment regimen for Buruli ulcer in the sub-Saharan region (WHO, 2022). In Australia, however, the suggested drug regimen is the combination of rifampicin (10mg/kg once daily) and moxifloxacin (400mg once daily) (WHO, 2022). Another antimicrobial medication that has been recommended for use in treating Buruli ulcer is streptomycin (WHO, 2017). Typically, uses of these medications prove effective when the disease is detected at an early stage and treatment began promptly. According to Ekeke et al. (2017) use of chemotherapy at an early stage of development of Buruli ulcer not only halts the progression of the disease, but has also been proven to reduce the likelihood of re-occurrence. It has been reported that several factors contribute to patients early reporting to health facilities for treatment from Buruli ulcer. Such factors have been documented to include, but not limited to feelings of fear

about Buruli ulcer and the methods of treatment, poor knowledge of Buruli ulcer treatment options, ascribing Buruli ulcer to supernatural and mystical causes, cost associated with Buruli ulcer treatments, and fear of surgical procedures (Ekeke et al., 2017).

A study that was conducted in Nigeria has reported increasing number of cases of Buruli ulcer annually, after the first ever case reported in 1967 (Nwafor et al., 2019). According to the study, patients typically report during the late stage of the disease, which invariably requires extensive surgical procedures as the means of treatment, which tends to be associated with increased costs and severe pains (Nwafor et al., 2019). One of the strong predictors of timely treatment for Buruli ulcer has been documented to be education. Akoachere, Nsai and Ndip (2016) reported that educational status enhances understanding of the disease condition, its risk factors and options for treatment. Further, Nwafor et al. (2019) argues that attaining educational status at any level positions individuals to understand every information provided to them about Buruli ulcer disease, and allows for easy dissemination of information among the remaining members of the community.

2.4 Intersectional Collaboration and Stakeholder Partnerships

There are presently no primary preventive measures of Buruli ulcer, hence the objectives of controlling the disease are aimed at reducing the socioeconomic burden associated with it, as well as the pain and probable disability that could result from late reporting to health care facilities for appropriate interventions (WHO, 2022b). Consequently, organizations and donors come together to achieve this aim. According to the WHO (2022b), the core indicators of progress in achieving the aims of Buruli ulcer control include, proportion of cases in Category III at diagnosis, proportion of laboratory-confirmed cases in Category I, and the proportion of confirmed cases who have completed a full course of antibiotic treatment (WHO, 2022b). Qurient is a Korean company that

has joined the fight against Buruli ulcer. The company has developed Telacebec, a medication that was identified as potent in combating *Mycobacterium ulcerans* in animals, reducing the duration of treatment from 8 weeks to about 2 weeks (Almeida et al., 2020).

In an attempt to combat Buruli ulcer, the WHO established the Global Buruli Ulcer Initiative (GBUI) "is a partnership of Member States, academic and research institutions, donors, non-governmental organizations, WHO and others" with the objective to raise awareness of Buruli ulcer disease. By increasing awareness, the WHO envisions to encourage increased partnership from global organizations in strengthening health care systems with requisite resources, improve surveillance systems, and to sponsor research initiatives in developing better diagnostic tools, methods of treatment and prevention of Buruli ulcer (WHO, 2022a). Consequently, donors and non-governmental organizations (NGOs) across the globe have been named as partners with the WHO, including, but not limited to ANESVAD in Spain, American Leprosy Missions (ALM) in the United States of America, AIM Initiative in Canada, FAIRMED in Switzerland, and Deutche Lepra- und Tuberkulosehilfe (DAHW) in Germany (WHO, 2022a).

As part of its contribution, the WHO has developed a Skin App to aid health care providers in the field in diagnosing skin NTDs, including Buruli ulcer (WHO, 2020). The application provides information on clinical features of specific skin NTDs, geographical distribution, management regimen, and differential diagnoses (WHO, 2020). The WHO has recommended an integrated approach to tackling skin NTDs, which offers health care providers the opportunity to accurately diagnose diseases, organize school-based health education programs to increase awareness, as well as screening large sections of the population in a bid to ensure early detection of disease (WHO, 2022).

Through the literature review for this study, it can be concluded that, efforts have been made to address the challenges of case detection and identification of BU, several stakeholder engagements have been done to control the morbidity of the disease, efforts to create awareness about the disease and also support patients to cope with the disease better but more needs to be done in these areas to ensure these aspirations are achieved.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents a description of study design and area, study population, sample size determination, sampling, data collection, data analysis and ethical issues.

3.2 Study design

This study was a qualitative study that used an in-depth exploration of study objectives using qualitative data source through in-depth interviews (IDI) and key informant interviews (KII). The qualitative research approach provided an in-depth and comprehensive information as data was gathered through open-ended questions.

3.3 Study site

The study was conducted in three selected ANESVAD sponsored districts in Ghana. These districts include, Upper West Akim in the Eastern region of Ghana, Asikuma Odoben Brakwa District in the central region and Wassa Amenfi East Municipal District in the Western region of Ghana. These study sites were selected based their endemic rate at the beginning of the implementation of the intervention. Asikuma Odoben Brakwa in the central region for instance were not reporting BU cases to the districts until the implementation of the ANESVAD intervention. Just like other districts, Asikuma Odoben Brakwa did not report any case to the national office, districts underreported until they were trained as part of the intervention on how to detect cases. The district suspected thirty-five cases and confirmed six BU cases for the first time in 2018 and currently do not have any confirmed BU cases.

Upper West Akim in 2018 suspected twenty-two cases, and confirmed four BU cases and Wassa Amenfi East suspected fifty-one cases and confirmed seventeen BU cases. In 2022, Asikuma Odoben Brakwa and Upper West Akim did not record BU cases, however Wassa Amenfi East recorded three BU cases.

3.4 Study Population

The study population comprised of buruli ulcer patients (aged 18 years and above) and program implementers (disease control officers, field technicians and wound care nurses)

3.5 Inclusion and exclusion criteria

Inclusion

The study was participated by male and female buruli ulcer patients who were 18 years and above and also have capacity to give consent. Implementers who participated are 18 years and above and were available for the interview.

Exclusion

The study excluded patients who were unwilling and incapable of giving consent and implementers who were not available to be interviewed.

3.6 Sample size determination

Qualitative sample size determination was done based on data saturation (Goyal, 2013). Thus, at a point where no new themes from participants emerged. Five Buruli ulcer patients from Wassa Amenfi East and four from Osikuma Odoben Brakwa districts were interviewed, two program implementers Upper West Akim, four from Wassa Amenfi East and three from Osikuma Odoben Brakwa who were directly involved in the implementation of the ANESVAD intervention were

sampled for the interviewed. Patients from Upper West Akim were not included in the study due to unavailability of patients at time of data collection.

3.7 Sampling

Purposive sampling and convenience sampling were used in the study, purposive sampling was used to select the three districts and convenience sampling was used to select participants for interview.

3.8 Data collection methods and instruments

An interview guide was used to conduct in-depth interviews for patients and key informant interviews were conducted for program implementers to explore stakeholder partnerships and the barriers and facilitators associated with the implementation of the ANESVAD intervention. Each interview session was recorded with an audio recorder. Field notes were taken and non-verbal cues noted. Average duration of the interview was twenty-five minutes.

3.9 Data collection procedure

The in-depth interviews and key informant interviews were conducted at a time convenience for participants. All participants' interviews were audio-recorded after seeking verbal consent. At the start of the interview, basic sociodemographic information were gathered. Open-ended and probing questions were used to obtain detailed descriptions and enhance the depth of discussion respectively. The principal investigator conducted interviews of the implementers at the National Buruli Ulcer Control Office in Accra. The patients were interviewed at a place of convenience to them at the time of the interview which included, a health facility, place of work and their homes. Covid-19 safety protocols were observed during data collection.

3.10 Trustworthiness and credibility of qualitative survey

For quality control, interviews were conducted in an isolated and private location. Participants gave their consent for all IDIs to be taped. The data was transcribed and translated into English. Playing the recordings and reading transcripts at the same time checked accuracy of the transcripts. Moral standards, including confidentiality of the information was observed. Again, proportion of these transcriptions were checked to ensure the quality of the translation and transcripts was rechecked for data accuracy. A research folder was kept to provide full record of the process of data collection and analysis. PI was the main author of the transcripts. The PI developed themes and quotations during data analysis and analyzed the transcripts independently following the Colizzi's method.

3.11 Data analysis

Data generated from IDIs were digitally recorded and transcribed verbatim to English. Transcription was done immediately after the IDI. Observations and assessments during interviews were written in field notes to complement transcripts. All translated transcripts went through another round of consistency check to ensure data quality. Thematic content analysis was used to analyze data with the aid of NVivo 10 software. Guest, MacQueen & Namey (2012) process of thematic analysis as consisting of reading through textual data, identifying themes in the data coding those themes and then, interpreting the structure and content of the themes followed.

3.12 Ethical considerations

Ethical approval for the study was sought from the Ghana Health Service (GHS) Ethics Review Committee (ERC). Further, approval was again sought from the Programs Manager of the National Buruli Ulcer Control Program and the District Health Administrator in each district . Written consent was sort from all eligible participants after explaining the aims/objectives of the study,

benefits and risks and procedures involved in participation. Eligible participants were made to understand that, their participation in the study is purely voluntary and they can opt out at any time. However, withdrawal from the study will not affect service delivery. They were also made to understand that, there was no compensation for been part of the study. Data that was collected was kept under lock and key, with only the principal investigator and supervisor has access to it. In ensuring anonymity and confidentiality, participants were identified with codes and numbers instead of their actual names during and after data collection. The Ghana Health Service (GHS) Ethics Review Committee (ERC) should be contacted in case of any ethical issue.

- Voluntary Participation and Right to Leave the Research

Participants were made aware that, they can refuse to participate, withdraw their consent, and discontinue participation in the research at any time without any consequences or affect the services they are to receive.

- It did not cost the participant anything to be part of the study, participation in the study was free of charge and voluntary.

- Rights as a participant

Participants had the right to withdraw from the study at any time. They also had the liberty to decide which questions to answer. They were given a copy of the participant information sheet and the signed consent form.

- Informed consent

Two written informed consents were obtained from each participant before enrolling in the study. A copy was given to the participant, and the principal investigator kept the other copy under lock and key.

- Confidentiality

Information obtained from study participants has been kept confidential. Identifying and personal information was anonymized during transcription, analysis and dissemination of findings from the study. Codes were used during data management to avoid exposing the details of study participants. Any data and information generated from participants were stored in an encrypted file, which is only accessible by the principal investigator. However, the Ghana Health Service Ethics Review Committee can have access to the data and study files in the event of monitoring.

- Risks

There were no risks associated with this study. All information to be gathered from this study is purely for academic purposes. All information collected has been securely stored securely, and accessible only PI. If information from this study is published or presented at scientific meetings, study participants' name and other personal information will not be used. All participants' data will be kept for five years, after which time it will be destroyed.

- Benefits

There was no direct benefit of this research to the study participants. However, it is expected that, the findings from this study would inform policy decisions and planning health intervention by relevant stakeholders such as the World Health Organization, Ministry of Health, Ghana Health

Service, and ANESVAD among others on experiences of BU patients with health interventions implemented to alleviate the burden of the disease. Findings would also serve as a baseline study for researchers interested in experiences of patients of NTDs with implemented health interventions

- Compensation

There was no compensation for being a participant in the study. The study is for academic purposes, and participant contributions were solely voluntary with minimal vulnerability of participants.

- Conflict of Interest

The investigator had no conflict of interest to declare.

CHAPTER FOUR

RESULTS

4.1 Introduction

This section of the dissertation provides the study results in relation to study objectives.

4.2 Sociodemographic information of participants

Seven male and two female patients were interviewed, these participants were between the ages of 29 and 58. The implementers who participated in the study were five males and four females, between the ages of 32 and 46. All implementers have tertiary education and has at least four years working experience with GHS.

Table 4.2 Demographic of Participants (PATIENTS)

	PATIENTS	IMPLEMENTORS
	n(%)	n(%)
Sex		
Male	7 (78)	5 (56)
Female	2 (12)	4 (44)
Age		
20-30	1 (11)	0 (0)
30-40	3 (33)	6 (67)
>40	5 (56)	3 (33)
Marital status		
Single	1 (11)	2 (12)
Married	8 (89)	7 (78)
Widowed	0 (0)	0 (0)
Occupation		
Unemployed	1 (11)	0 (0)
Government	0 (0)	9 (100)
Private	8 (89)	0 (0)
Educational level		
No formal education	1 (11)	0 (0)
Primary	5 (56)	0 (0)
Secondary	3 (33)	0 (0)
Tertiary	0 (0)	9 (100)

4.3 Patients' experiences with the ANESVAD Intervention

This section of the study assessed patients experiences with Buruli ulcer before and after the implementation of the ANESVAD Intervention. The themes that emerged were; awareness of ANESVAD, experiences before intervention, experiences after intervention and benefits of ANESVAD intervention.

Awareness of ANESVAD

It was found that, the patients were aware of the ANESVAD intervention due to the changes in the services they received. Health workers sensitized and created awareness on Buruli ulcer and the ANESVAD intervention. They had an idea of what the intervention aimed to do for them so far as Buruli ulcer was concerned. They emphasized on how the intervention offered them free wound dressing at least twice a week, free medication and free transport.

"Ok, it was one of the nurses who told me about it. She told me some NGO,s have partnered with the District Health Administration and the hospital to help patients with my condition" ***(Patient 1, Asikuma Odoben Brakwa District)***

"I went to the hospital, and they told me they have medication that can help. I remember they emphasized that I have to come for regular wound dressing. At least twice in a week because only the medication cannot heal me" ***(Patient 3, Wassa Amenfi East District).***

"Yes, I was told it's an NGO that has come into the district to support patients with BU. They are really helping, as you can see, I am even at the hospital for my wound dressing" ***(Patient 4; Asikuma Odoben Brakwa District).***

"When I started going to the hospital and was receiving free treatment and wound dressing, I realized some NGO,s were probably assisting to do that" ***(Patient 2; Wassa Amenfi East District).***

"Yes, for me, they told me about BU. They said it's a bad disease and that I should be careful with it. They gave me medication free of charge and advised me to come for regular wound dressing. I took their advice, went for another batch of medication when the old one got finished. I did this plus the wound dressing until the wound got healed" ***(Patient 5; Wassa Amenfi East District).***

Experiences before ANESVAD

With respect to patients experiences before the intervention, it was realized that most of the patients resorted to the use of herbal medicine in treating their wounds. They didn't know the cause of their wounds and why they had that wound. To them herbs was the solution and they believed that it will get worse before it got better. Based on this belief they were not much bothered when the wounds were becoming bigger and bigger, they went to health facilities when it affected their mobility.

"I was using herbs, as in local medicine but I realized it won't help me so I went to the hospital when I couldn't walk. When I went to the hospital, they checked and said it was BU. I was using the herbs because I didn't know what it was. I used the herbs for one month" ***(Patient 1; Wassa Amenfi East District).***

"It wasn't easy for me. The ulcer has caused me a lot of money and due to financial difficulties; I am unable to go to the hospital regularly for treatment" ***(Patient 1; Asikuma Odoben Brakwa District).***

"Before they came, it wasn't good at all, it wasn't something to be proud of. I was using native herbs to dress the wound" ***(Patient 3; Asikuma Odoben Brakwa District)***

"*Before I went to the hospital, I had the disease before and I took care of it at home till the wound got healed. That was two years ago, somewhere September 2022, that was when this one came*

and I decided to take it to the hospital for treatment. It is almost healed" ***(Patient 1; Wassa Amenfi East District).***

Experiences after ANESVAD

After the implementation of the ANESVAD intervention, patients attested it relieved them of many financial burdens and the treatment actually healed their wounds compared to when they were using herbal medicines. They had these to say;

"They dress the wound for me, they give medicine to take which is free of charge. The also provide transportation for me, so I just have to wake up in the morning, take my bath and go to the facility for wound dressing. I have nothing to complain about" ***(Patient 3; Asikuma Odoben Brakwa District)***

"I go for medications every month and I also go to a CHIPS compound around for the nurses to dress the wound for me" ***(Patient 4; Wassa Amenfi East District).***

"They took me to theatre for skin grafting that's why it kept long for it to heal. No, we didn't pay. I did a previous surgery before the intervention, that was what I paid for but with the intervention, the skin grafting, I didn't pay anything. I would be lying if I say I paid a pesewa" ***(Patient 1; Wassa Amenfi East District).***

"*Ok, they told me that the list of things I need for the wound dressing has already been provided by the intervention. And they would also support me financially and give me medication"* ***(Patient 1; Asikuma Odoben Brakwa District)***

Benefits of intervention

According to the patients interviewed, the three main benefits received from the intervention were free medication, free wound dressing at least twice a week and free money to cover for transportation cost. Their views of these benefits are expressed below;

"Ok, for the benefit I got from it is the free wound dressing. I wake up early in the morning and walk to the hospital for the wound dressing. I mostly get to the hospital around 7 or 7:30 am in the morning" ***(Patient 4; Asikuma Odoben Brakwa District)***

"Of course, I have benefited. I go for medication free of charge, before I got introduced to the intervention, I used to bear the cost of the wound dressing when I started going to the hospital. But that is not the case anymore" ***(Patient 2; Wassa Amenfi East District).***

"The main activities are the free wound dressing, free treatment with medication and the money they provide for us for transportation" ***(Patient 2; Asikuma Odoben Brakwa District)***

"The nurses dress the wound for me without taking money, wound, they medication I go for monthly is also free of charge and they give me money for transportation" ***(Patient 5; Wassa Amenfi East District).***

4.4 Existing partnerships among stakeholders of the ANESVAD Intervention

Under this objective, before looking at the existing partnerships among stakeholders of the intervention, the experiences of implementers were explored to get a better understanding of the implementation of the ANESVAD Intervention. Benefits of the intervention and specific activities that was done during implementation was also explored.

The findings are from interviews of nine implementers in three ANESVAD sponsored districts which include implementers Wassa Amenfi East District, Upper West Akim, and Asikuma Odoben Brakwa. Each interview with a participant lasted for an average of 20-30 minutes. The objectives of this qualitative analysis were to explore the partnership of the ANESVAD

intervention among stakeholders. and identify barriers and facilitators influencing the implementation of the ANESVAD intervention in endemic districts.

The major themes that emerged were, knowledge of ANESVAD, experiences with Buruli Ulcer before ANESVAD, experiences after ANESVAD, benefits of ANESVAD from the perspective of implementers, agencies involved in implementation and challenges of ANESVAD intervention, and factors to effective implementation.

Knowledge on ANESVAD

The first theme that emerged from the partnership of ANESVAD intervention among stakeholders was to assess their general knowledge of the intervention. It was found that ANESVAD is a Spanish Non-governmental organization aimed at supporting the Ghana Health Service to implement programs for eradicating yaws, eliminating leprosy, and controlling Buruli Ulcers.

*"ANESVAD an NGO that has partnered with the Ghana Health Service in the area of Neglected Tropical Diseases with emphasis on Yaws, Buruli Ulcer, and Leprosy" (**Implementer; Asikuma Odoben Brakwa District).***

From the respondents, the intervention was initiated in 2018 as a pilot study in 15 selected districts to help control the incidence and prevalence of Buruli Ulcer. Some were fortunate to be part of the selected districts while others came in after a transfer from other districts.

"So, in my district, they started in 2018 as part of the district that is piloting and the district was chosen to be part of the fifteen ANESVAD-sponsored districts. That's what I know, but they do

other activities on child trafficking and so many things about health" ***(Implementer; Asikuma Odoben Brakwa District).***

"I came to meet the program ongoing; I wasn't in the district when it started, I have been on it since 2022. From my side, it has been very beneficial to the patients and I have benefited from it a lot" ***(Implementer; Wassa Amenfi East District).***

"Yes, ANESVAD is a Spanish NGO that came into the district to ease the district of financial stress and support them on how to identify Buruli ulcer cases and other Neglected Tropical Disease cases" ***(implementer; Upper West Akim District).***

Experiences before ANESVAD

The study further sought to explore the experiences of implementers in these three districts before the ANESVAD intervention. It was expressed that, most of these implementers who are Nurses, Disease Control Officers and field technicians had limited knowledge of Buruli Ulcer case identification and surveillance before the implementation of the AVESDAD intervention. According to some, they have read the condition in books and haven't seen it firsthand. Others also stated that they come in contact with big wounds but it all goes undetected because there was no effective system in place to monitor this condition efficiently.

"Oh, before I came to Wassa Amenfi, I was reading about Buruli Ulcer in books. In my previous district, they have been dressing big wounds but we didn't know anything about it, like taking a sample to test and confirm. I saw big wounds but I didn't know that its Buruli Ulcer until I came to Amenfi East and I realized that if we had known about this, we would have been able to help a lot of patients who came to the facility with big wounds" ***(Field Technician; Wassa Amenfi East District).***

"I started working in Wassa Amenfi in the year 2006. There were spotted cases of Buruli Ulcer, Yaws, and Leprosy but there was a challenge with management. I didn't know much about how to manage it. There were senior technical officers before I arrived but the staff knowledge about Buruli Ulcer and Leprosy was very limited. When we get the cases we report to region, and sometimes we do not get drugs to manage them, we leave them" ***(Implementer; Wassa Amenfi East District).***

Another contributing factor to undetected and increasing cases of Buruli Ulcer before the AVESDAD intervention was the spirituality attached to the condition. It was mostly attributed to spirituality or punishment meted out on an individual for wrongdoing. Given this, most affected individuals resorted to prayer camps and shrines for directions and intervention. According to implementers, this worsened and made identified cases too late to make any intervention to restore the health or functionality of the affected area in the case of big wounds.

"Initially, the patients thought it is a cursed disease and cannot be healed or there is no treatment and they resorted to alternative ways of using herbs on their ulcers" ***(Implementer; Upper West Akim District).***

"There was too much spirituality attached to the disease. Some of them end up at prayer camps, and herbal practitioners, and we don't even look for them again" ***(Implementer; Wassa Amenfi East District).***

"Yes, you see, Buruli Ulcer, in my area, in the system that we live in, there is a saying that "biibi nsi kwa" as they say in TWI, (translates, nothing happens without a reason) "obi koraa de abo nnwom ", (translates, someone has composed a song with it). So, most people who suffer Buruli

*Ulcer in my region or my district attribute it to a spiritual cause. So, it comes with that psychological trauma and psychological thinking" (**Implementer; Wassa Amenfi East District).***

It was also emphasized that, due to limited knowledge of case identification and management, when affected individuals with wounds come to the facility, they refer to the nearest hospital close to the facility. As a result of this, most of the affected persons with big wounds do not bother coming to the district but go straight to the nearest hospital. This according to the implementer led to a loss of confidence in the health system at the district level.

*"The wounds come to the facility but we refer them to other facilities because our district did not have a hospital. We refer them to facilities like Nsawam hospital or Asamankese. And because they know when they come, we would refer them, they automatically go to those facilities without passing through" **(Implementer; Upper West Akim District).***

Experiences after ANESVAD

After exploring the experiences before the implementation of the intervention, the study assessed implementers' experiences after the implementation of the intervention. One of the major setbacks to the effective management of Buruli Ulcer indicated was limited training in case identification and management. According to implementers, after the intervention was initiated, there was training on case detection or identification as well as effective management. Staff at the selected district were trained in case searching, wound care, drug administration, and sample taking. This training helped them to differentiate between wounds that are related to Buruli Ulcer and those that did not relate with Buruli Ulcer. One important attribute of the intervention which was emphasized by almost all respondents was the training of community volunteers to complement the activities of health workers as far as Buruli Ulcer is concerned. This paved the way to instill confidence and trust in the health system at the district level.

"I have benefited a lot from the project. Why am I saying that? I have received a lot of training personally, staff has been trained, and capacity has also been built for volunteers even at the community level. We received capacity building in case search, wound care, and even drug administration; they have been very supportive. They have given us drugs and logistics to work with, and I would say they have been very supportive in implementing our programs" ***(Implementer; Wassa Amenfi East District).***

"So, with my district, until ANESVAD came in, we never reported or detected Buruli Ulcer cases, following the training and active case search we did, we picked some samples and six of them came out positive. That was when we realized we have Buruli Ulcer cases in the district ***(Implementer; Asikuma Odoben Brakwa District).***

"Oh, the intervention has helped the district, we were not aware that we have Buruli Ulcer cases or wounds in the district but they came in and after training, we realized we have a lot of cases that we did not know. This is because most Buruli Ulcer Cases are in the houses and they are isolated because of stigma but with the help of ANESVAD we have been able to reach them in their communities and house" ***(Implementer; Upper West Akim District).***

"Staff was trained in a better way of dressing wounds. We used to manage wounds traditionally by using hot water and other thing but after the training, the staff now dress the wound in a better way" ***(Implementer; Asikuma Odoben Brakwa District).***

"Oh, I was part of the field workers, I quite remember, that was my first time seeing Buruli Ulcer and Yaws. I've been reading about them in books and I've not seen them before, the first time I

tested Yaws and it was positive, I was very happy" ***(Field Technician; Wassa Amenfi East District).***

"When ANESVAD came to support us, we conducted a series of case searches and training. So, clinicians, non-clinicians, clinical staff, volunteers, and even teachers could identify signs of leprosy and potential Buruli Ulcer and report to the health facility. In this case, when they come to us, we take a sample and they are managed well" ***(Implementer; Wassa Amenfi East District).***

"We can identify Buruli Ulcer cases and differentiate between the wounds that are Buruli Ulcer and what are not Buruli Ulcer. Although some of them may be negative when samples are taken and how to even take samples, the ANESVAD Intervention trained us on how to take Buruli Ulcer samples" ***(Implementer; Upper West Akim District).***

Another positive attribute of the intervention was training on how to counsel patients with Buruli Ulcers. Most of these patients go through a lot of stigmatizations from the community they reside as well as their very own families. Through the intervention, health staff knows who to counsel and get to those who are traumatized by the condition and offer any assistance that will ease their worries and speed up the healing process.

"So, most people who suffer Buruli Ulcer in my region or my district attribute Buruli Ulcer to a spiritual cause. This comes with that psychological trauma and psychological thinking, but ANESVAD has given us training so clients who are down with Buruli Ulcer, we counsel and psych before they are put on treatment. So that kind of capacity, knowledge, and skills they have built in us has also helped us to help the patients cope with it" ***(Implementer; Wassa Amenfi East District).***

Partnerships among Stakeholders

The implementation of the intervention would not have been successful without the action and support of several agencies, the primary partners of this intervention was the Ministry of Health and the Ghana Health Service. The intervention would not have been successful at the district level without the roles played by governmental, non-governmental, and faith-based institutions in its implementation. The Ghana Education Service, the media, the District Assembly, opinion leaders in the community, and KCCR. According to the implementers, the Ghana Education Service played a very critical role in awareness creation in schools among the selected districts. The District Assembly helped in mobilizing funds for many ANESVAD activities and interventions when where necessary. The opinion leaders also helped in mobilizing community members and ensuring sensitization on Buruli Ulcer was done to the benefit of all inhabitants.

"Yes, the education service is one; they mostly help us with Yaws cases especially when it comes to educational activities in the school" ***(Implementer; Asikuma Odoben Brakwa District).***

"One of them is the education service, NCCE, faith-based organizations, radio stations, community volunteers, and elders of the community. The district assembly also supports us. Last year, during the case search, the project car for the district was stolen so the district assembly had to provide a car for us to do the case search" ***(Implementer; Wassa Amenfi East District).***

"One is the community-based surveillance volunteers, health workers, district assembly, or local government, the DCE and the coordinating director were very happy to hear about the ANESVAD Intervention in the district. There was a time we did not have funds to perform specific ANESVAD activities, they came in to support us with funds and other things we needed" ***(Implementer; Upper West Akim District).***

"Through the media, we were able to create awareness to a larger audience to enable the community to have all the needed information to seek the right care. Traditional healers were part of the initial training, so they refer any ulcer that is been brought to them" ***(Implementer; Asikuma Odoben Brakwa District).***

"The district assembly also built a container and stocked it with provisions for a patient to sell to generate income for the family. The media as I mention plays a vital role in the implementation of the project" ***(Implementer; Asikuma Odoben Brakwa District).***

"One is KCCR, we pick samples and send them, they don't keep it there, and they work on it and send the results to us" ***(Implementer; Wassa Amenfi East District).***

"We have this NGO in our district called Obra Foundation, they also helped with the social mobilization activities most times, in case we have to go to a community for education, they come in to help. And also. The Ghana Education Service, there is no way you can go to a school to do an activity without passing through the GES for permission" ***(Implementer; Upper West Akim District).***

Benefits of ANESVAD from the perspective of implementers

The study again assessed the benefits of ANESVAD from the perspective of implementers. It was highly emphasized by all implementers that, the intervention paid for and supported patients in various ways. The cost of physiotherapy for patients with large ulcers in the district was catered for by the intervention. Additionally, the cost of wound dressing was made free through the

intervention and made patients more active in their health care needs as far as Buruli Ulcer is concerned. This according to clients eased the financial burden on patients and also prevented them from having life-altering disabilities.

"The project took up the cost of physiotherapy for patients who have large ulcers, which has helped to heal and also cope with the disease better. So actually, the project has helped a lot" ***(Implementer; Wassa Amenfi East District).***

"The project pays for the wound dressing cost and also the cost of treatment with medication. I hope the project would be extended so that those who have not benefited would the opportunity to because looking at the economic situation now, most patients would not be able to afford the cost of treatment, especially the cost of wound dressing" ***(Implementer; Wassa Amenfi East District).***

It also came to light that, aside from bearing the cost of wound dressing and physiotherapy, health workers travel to the homes of patients who cannot come to the district facility to dress their wounds and do so for them. The children of these patients are not left out of the benefits received from the intervention. Since most parents are inhibited from actively working due to these ulcers, the intervention has factored in children of patients below 17 years and has catered for their health care needs by paying for their national health insurance.

"There are children under 17 years who sometimes have parents with BU which inhibits them from making ends meet. This means they can't afford healthcare so the project it upon itself to register them on health insurance" ***(Implementer; Wassa Amenfi East District).***

Assisting children was not only reflected in paying for their health insurance levy but also in helping them to be mentally stable in the face of diseases not on their parents but on them. The intervention also bore the cost of surgery for marginalized children who had severe ulcers and were stigmatized by their families and loved ones. After benefiting from all these, the intervention also served as a good platform for soliciting funds and securing decent accommodation for patients who have been marginalized from their communities and families.

"I remember, in my district, there were three siblings that were affected with leprosy, they were ostracized because of the severity of their ulcers. Their family members did not take care of them but through the ANESVAD Intervention, they were taken to Ankaful Hospital to undergo surgery. The surgery was free and they are now healed and reintegrated back into their family and the community" ***(Implementer; Asikuma Odoben Brakwa District).***

The intervention offered health staff all the necessary materials for wound dressing and they established that wounds they treated took less time to heal compared to when they used the traditional ways of dressing wounds. They expressed their joy and how it has boosted their confidence in awareness creation and bringing reluctant patients on board to dress their wounds as the evidence says it all.

"It has helped the people in the districts, there hasn't been a time that we used the materials the project gave us and the wounds didn't heal, any wound that we touched got healed. Since I came, patients have healed without any deformities" ***(Field Technician; Wassa Amenfi East District).***

The study brought to bear that, the benefits such as training were not only for health staff and volunteers but also supporters and caregivers of these patients. It was emphasized that caregivers were trained in wound dressing and volunteers were scaled up to identify Buruli Ulcer cases as well as other skin diseases.

"Oh, a lot of health workers have been trained, community-based surveillance volunteers have also been trained and even some of the supporters or caregivers of the patients have been trained to dress the wound themselves" ***(Implementer; Upper West Akim District).***

"The volunteers were trained to identify Buruli Ulcer cases and other skin NTDs. The health workers are now able to properly dress the wounds which make the health workers happy. They were previously dressing wounds that were not healing even after a year, but with the ANESVED Intervention, within a few months or weeks, the wounds are completely healed without medications" ***(Implementer; Upper West Akim District).***

Specific interventions in managing Buruli Ulcer

After assessing the benefits and experiences, the study further assessed specific interventions for managing Buruli Ulcers in these districts. It was found that the major intervention was the training on case identification and management as well as community-based surveillance. Other specific interventions of importance included wound dressing for those with ulcers, financial support in terms of transportation to a health facility, payment of health insurance, payment of physiotherapy and surgery as well as funds for accommodation and food.

"The training in wound dressing is one, enablers package or financial support for patients, sometimes when the patients come to the districts, we give them transportation to go back to their communities" ***(Field Technician; Wassa Amenfi East District).***

"The training is one, financial support, social mobilization, educating the community members and logistics for wound dressing and also medication for the treatment of the disease. Some of the nurses also embarked on home visits to patients who could not come to the health facilities to treat them and also dress their wounds" ***(Implementer; Upper West Akim District).***

"The project provided funds for social mobilization activities and stakeholders meetings and at the community level, we were able to engage with the community to bring them on board for the implementation of the intervention. We had community-based surveillance volunteers who helped in the identification of Buruli Ulcer cases. We also printed stickers and distributed them to taxi drivers to help create awareness on the disease, also to some departments and offices" ***(implementer; Asikuma Odoben Brakwa District).***

"Training to identify cases, manage the case, for wound care and community treatment (MDA and total community treatment). They have given support for meetings; stakeholders meetings to share the progress of the project with stakeholders. Both at the district and regional level, there were regular meetings" ***(Implementer; Wassa Amenfi East District).***

Further, social mobilization and education on the condition were done in communities in the district to create awareness of the condition and the interventions available to the community. Night shows and jingles at the information centers and radio stations were added benefits to the intervention.

"One of them is the night video shows in selected communities helped the patients understand their condition which helped them manage it better. We also have a jingle that the information centers and radio stations play to educate them about the disease. Education also helped; the radio allowed us to have discussions on Buruli Ulcers. We also went into the communities to educate them on the disease" ***(Implementer; Wassa Amenfi East District).***

4.5 Barriers and facilitators to the implementation of the Intervention Barriers

Despite the remarkable progress achieved by the intervention, there are still some challenges that are worth noting to be discussed. One such challenge is traveling to hard-to-reach communities in the district due to transportation issues. Mostly, community volunteers are willing to also assist but there is no means of transportation either because the roads are bad during the rainy season or the means of transportation is not available.

"With challenges, it's impossible to implement an intervention without challenges, getting to hard-to-reach communities has been a challenge. Volunteers are ready to move into these communities but transportation to these places is difficult, especially during rainy seasons. Also, we don't have life jackets so going to island communities is a challenge" ***(Implementer; Wassa Amenfi East District).***

The second challenge has to do with delay in receiving funds to set some activities in motion. According to some implementers, bureaucracy is an issue when money has to be sent to the district for program implementation. This delays the process and gives stress to both health workers and beneficiaries.

"With finance, the challenge is that the money delays because of bureaucracies so sometimes if the district doesn't have money to support the activities before the money comes, it becomes a challenge" ***(Implementer; Wassa Amenfi East District).***

It was noted among implementers that staff attrition is an issue because staff gets trained on case identification and management of Buruli Ulcer and then they transfer out or travel out of the country without imparting that knowledge to those who didn't benefit from the training.

"I would say staff attrition. You build the capacity of staff to perform a specific activity and before you say "jack", the person has either gone to school or has asked to transfer either to join the family, husband, or whatever" ***(Implementer; Wassa Amenfi East District).***

Another challenge to the implementation of the intervention is the use or preference of traditional medicine. In Ghana, traditional medicine has been with us since time immemorial and it becomes very difficult for some individuals to embrace something new. Although the intervention has created so many platforms to help those affected to heal, others still prefer the services of traditional healers although they have vividly seen the progress and success stories of others. Also, some do not believe in the concept of free services offered by the intervention and see it as not genuine and rather frequent the service of these traditional healers who themselves do not understand Buruli Ulcers.

"The presence of traditional healers or practitioners in the district posed some kind of challenge because some people think that Buruli Ulcer is spiritual. They move to these people and they apply

*a whole lot of concoctions and herbs on the wound, so when you are even called to pick samples, you do not get a good sample for confirmation" (**Implementer; Wassa Amenfi East District).***

*"Yes, it is difficult to get everybody to buy into an idea, people still solicit the help of traditional healers to dress their wounds even after a lot of social mobilization and stakeholder engagements. This has posed as one of the main challenges of the intervention" **(Implementer; Asikuma Odoben Brakwa District).***

*"For us, we encountered one or two challenges, one of them is, when you go to our communities, we have some herbalists who treat some Buruli Ulcer patients who go to them, some even call themselves doctors in the community" **(Field Technician; Wassa Amenfi East District).***

*"You know this mentality that when someone takes money from you for treatment, that means the person is doing things to help you heal, but not the free treatment they would get at the health facility. So sometimes, before they come to the health facilities, the wound is enlarged and has been covered with herbs and concussions, and other things" **(Field Technician; Wassa Amenfi East District).***

The challenge expressed by implementers is the issue of theft in the communities. Some of the implementers indicated that it's been very difficult to move to some communities because vehicles and motorcycles given to them have been stolen. Everyone in these communities knows the importance of their work but that didn't stop these individuals from stealing.

*"Ok, so, on our level, it's not a challenge actually because, with transport, ANESVAD gave us a vehicle, motorbikes, and bicycles which along the line our motorbike got stolen" **(implementer; Upper West Akim District).***

"Another challenge is when the project car got missing; it was very difficult for us to go to the communities. With me, for instance, I got pregnant during the implementation years of the project and I have to be on the motor to the community and that was a big challenge" ***(Field Technician; Wassa Amenfi East District).***

A striking challenge an implementor mentioned was the issue expired drugs. Antibiotics sent from the national office to the districts are mostly near their expiry dates so they are unable to administer them to all in time before they expire. A significant amount of the drugs expires before there is an opportunity to treat the patients with it.

"One challenge we had at some point was so many drugs expiring before we are able to treat the patients with it. Some of the drugs that come from national have few months to expire so after using the amount we need, the remaining expires in about three or four months" ***(Implementer; Asikuma Odoben Brakwa).***

Facilitators

Use of volunteers

Volunteers played a critical role in the various communities in ensuring patients as well as those at risk were identified and brought to the health facility for immediate and proper treatment. Volunteers were trained on how to educate people in their communities, how to use educational materials on Buruli ulcer and how to get to hard-to-reach communities.

"The volunteers have pictures of the disease in the volunteer registers so when they show it to the community member, they get directed to houses of community members with suspected cases of BU and other skin NTDs" ***(Implementer; Wassa Amenfi East District).***

"Playing the video and the jingle to the community members helped, they are educated about the disease and they know where to get the right help for it" ***(Implementer; Asikuma Odoben Brakwa District).***

Support from national level

Some implementers and field technicians indicated that support from the national level has been a factor that has ensured the smooth running of the intervention. They emphasized that, the national level assisted with logistics and finances when the need arose and they were always willing to come down to the district level to offer any form of help and support within their means.

"With transport for instance, initially we didn't have motorbikes but we worked with the national level and now we have them and also have bicycles for the volunteers. We had a whole lot, funds came for us to purchase some items for the volunteers, we asked them what they want and some said they want t-shirts and booths. So, for ANESVAD, they've really done a lot for the district ***(Implementer; Upper west Akim District).***

Staff commitment

It was found that, staff commitment played a role in ensuring the successful implementation of the intervention. Staff indicated they were motivated in training and were adequately prepared to facilitate and help patients and their district so far as Buruli ulcer was concerned. They had this to say;

"I would say staff commitment, because without that we would have encountered a lot of challenges. Staff motivation and the opportunity that was given to staff to learn new things. The

*moment you learn something now, you want to apply it to make a change in the lives of peoples "(**Implementer; Asikuma Odoben Brakwa District).***

*"Someone like the regional focal person is a very committed person, he doesn't joke with the project at all. He tries to put everything in place, ANESVAD has never come to our district to find anything bad with the project activities or reporting. He ensured every activity of the intervention was executed effectively. In general, the commitment of the stakeholders is what made the project a success despite its challenges" **(Field Technician; Wassa Amenfi East District).***

CHAPTER FIVE

DISCUSSION

5.1 Introduction

This section of the dissertation provides a discussion of study results in relation to study objectives.

5.2 Experiences of Buruli Ulcer patients with the ANESVAD Intervention

The study explored the experiences of patients with Buruli ulcers and the ANESVAD intervention. It was found that some patients had knowledge of Buruli ulcers and were also aware of the ANESVAD intervention. This was due to the sensitization and awareness creation by health workers in these districts to enable patients to take increased control of their own health needs by assessing health services and taking advantage of the ANESVAD intervention such as free wound dressing and free medication. It should be emphasized that increased knowledge and awareness of disease conditions is only possible with education campaigns and this was done in these districts in creative ways by involving the community through the training of volunteers as well as the use of mass media. This confirms a study in Cameroon by Akoachere, Nsai, and Ndip (2018) which indicated that increased educational campaigns would invariably increase awareness and knowledge of Buruli ulcers among the populace in general and health care practitioners in particular.

The study further assessed the experiences of patients before and after the implementation of the intervention so far as Buruli ulcer is concerned. It came to light that, before the intervention, most people did not know why they had such wounds and mostly attributed their predicament to spirituality, and most resorted to the use of herbs regardless of the wounds becoming bigger and bigger overnight. To these patients, when it comes to spirituality, they believed it will get worse before it gets better so they didn't mind how big their wounds were becoming and how it was

affecting their mobility. This affirms Anokye *et al.* (2018) who reported that "tradition and superstition played a significant role in explaining what causes Buruli ulcer". The researchers indicated most people as indicating the causes to be repercussions for offending the gods, being plagued by witches or enemies, or carrying out a taboo. Additionally, Constantine *et al.* (2011) concluded that people with Buruli ulcers are thought to be victims of an evil eye, and are stigmatized because they are considered to have engaged in evil practices.

One predominant issue before the implementation of the intervention was the cost of receiving health care services. Most of these patients reported financial difficulties as one of the hindrances to assessing health care services in their districts. They indicated that it was expensive to visit healthcare facilities because their family lived on very little and they cannot use all for their health needs so most of them resorted to the use of herbs which were readily available and inexpensive. This finding supports other studies specifically Menlah *et al*. (2020) which reported that patients usually report feeling embarrassed, being financially handicapped, and others also experience marital conflicts. The issue of being financially handicapped was attributed to the fact that dressing and other treatment regimens required while on admission are financially inclusive (Menlah *et al*., 2020). This has been corroborated by Constantine *et al*. (2011), who reported on the economic burden of Buruli ulcers on affected individuals. Constantine *et al*. (2011) reported that Buruli ulcer consequently leads to poverty among individuals and affected communities altogether. In a study conducted in Ghana, the researchers indicated poor households were most inflicted by Buruli ulcers, compared to rich households, especially when there was more than one patient of Buruli ulcer identified in that household (Constantine *et al*., 2011).

On the experiences after the intervention, patients attested it relieved them of many financial burdens, and the treatment healed their wounds compared to when they were using herbal medicines. Due to intensive health education and promotional activities by health professionals, the health-seeking behavior of patients with Buruli ulcers changed for the better. It is imperative to appreciate that perception of individuals on Buruli ulcer will ultimately influence their health-seeking behavior. Udujih *et al*. (2020) argue that there is a dearth of information on Buruli ulcers in Nigeria, which has resulted in poor health-seeking behavior among individuals who develop the disease.

The Social Ecological Model broadly conceptualized health by understanding individual, interpersonal, institutional, community and public policy on the health of BU patients. From the findings of this study, a majority of patients resorted to herbal treatment for their ulcers based on their understanding and community understanding of the cause of the BU, but during the implementation of the intervention, institutions and stakeholders such as GHS, GES, NCCE among others worked together on different stages of the implementation to change the beliefs of patients and the community on buruli ulcer which influence the health seeking behavior of patients and reduce stigmatization. It can be attested that when patients, institutions, communities work together with an effective implementation of health interventions and public policies positively affect the health outcomes of individual, communities and the country at large.

From this study, the three main benefits received from the intervention were free medication, free wound dressing at least twice a week, and free money to cover transportation costs. Patients were not just assisted to get free wound dressing and medication but the intervention went ahead and paid the cost involved in surgery, the renewal of health insurance for the children of those affected as well as enabling them with resources to get back on their feet after the treatment.

5.3 Partnerships of the ANESVAD intervention among stakeholders

The study explored the stakeholders of the intervention and the partnership that existed among these stakeholders, it was attested that the primary partners of the ANESVAD Intervention was the Ministry of Health and the Ghana Health service at the national level. The national agencies received funds from the ANESVAD Foundation and distributes to regions of the sponsored districts, before it's been transferred to the districts. At the district level, governmental organizations such as GES and NCCE played a significant role in the implementation of the intervention. These agencies educated the community members on buruli ulcer and other NTDs. The GES authorized health workers and volunteers to go to the schools in the district to educate them on the disease and also do case search when necessary. This was an effective way to detect and treat cases at the early stages. Community education and sensitization by the NCCE increased awareness on buruli ulcer and other NTDs, it significantly reduced stigmatization and affected the health seeking behavior community members so far as buruli ulcer and other skin NTDs are concerned. The district assemblies/ district health administrations directly implemented the intervention, they stepped in to assist with logistics and finance the intervention's activities when funds delay. NGOs such as Obra Foundation in the Upper West Akim District assisted with social mobilization and sensitization of the community. KCCR run some of the tests on buruli ulcer samples and sends results to the district which determines the kind of treatment the patient receives. Ulcers that test positive for buruli ulcer are treated with oral antibiotics(rifampicin and clarithromycin) and wound dressing while ulcers that test negative only get their wounds treated. As the Social Ecological Model emphasizes on the role institutions play in the implementation of health intervention, it can be attested that several government and non-governmental institutions, BU patients and the communities played their required roles and worked together at various levels

of implementation of the ANESVAD Intervention to ensure BU patients get the right information and healthcare which led to successful implementation despite its challenges.

The study further sought to explore the experiences of implementers in these three districts before the ANESVAD intervention. It was expressed that, most of these implementers who are Nurses, Disease Control Officers and field technicians had limited knowledge of Buruli Ulcer case identification and surveillance before the implementation of the AVESDAD intervention. According to some, they have read the condition in books and haven't seen it firsthand. Others also stated that they come in contact with big wounds but it all goes undetected because there was no effective system in place to monitor this condition effectively. This finding goes on to buttress a study conducted to evaluate the knowledge of Buruli ulcers among healthcare practitioners which reported that although most healthcare workers knew about the disease condition, there was poor knowledge on identifying the various stages of development of the ulcer. Further, few healthcare practitioners could outline the accurate treatment regimen for Buruli ulcers (Nsai *et al.,* 2018).

Another contributing factor to undetected and increasing cases of Buruli Ulcer before the AVESDAD intervention was the spirituality attached to the condition. It was mostly attributed to spirituality or punishment meted out on an individual for wrongdoing. Given this, most affected individuals resorted to prayer camps and shrines for directions and intervention. According to implementers, this worsened and made identified cases too late to make any intervention to restore the health or functionality of the affected area in the cases of category III ulcers. In Ghana, the coastal areas of the Ga West District, Amansie West District, and Asante-Akim North District have been reported to be the most endemic areas for Buruli ulcers (Anokye *et al*., 2018). The researchers argue that most people are ignorant of the disease and its causes, and have attributed

its occurrence to a punishment from God, witchcraft, and curses. This is in line with the findings of the study and was further buttressed by Anokye *et al*. (2018) who reported that "tradition and superstition played a significant role in explaining what causes Buruli ulcer". The researchers indicated most people as indicating the causes to be repercussions for offending the gods, being plagued by witches or enemies, or carrying out a taboo (Anokye *et al.,* 2018).

Again, it was also emphasized that, due to limited knowledge of case identification and management, when affected individuals with wounds come to the facility, they were referred to the nearest hospital close to the facility. As a result of this, most of the affected persons with big wounds do not bother coming to the district but go straight to the nearest hospital. This according to the implementer led to a loss of confidence in the health system at the district level. This was confirmed by Akoachere, Nsai, and Ndip (2016), which indicated that some healthcare practitioners do not know about Buruli ulcers, and their treatment. Hence, patients who report to their facilities are referred to other healthcare facilities for treatment. Consequently, such patients resort to visiting prayer camps, herbalists, witch doctors, or other alternative means of treatment (Akoachere, Nsai, and Ndip, 2016).

After exploring the experiences before the implementation of the policy, the study assessed implementers' experiences after the implementation of the intervention. One of the major setbacks to the effective management of Buruli Ulcer indicated was limited training in case identification and management. According to implementers, after the intervention was initiated, there was training on case detection or identification as well as effective management. Staff at the selected district were trained in case searching, wound care, drug administration, and sample taking. This

training helped them to differentiate between wounds that are related to Buruli Ulcer and those that had nothing to do with Buruli Ulcer. One important attribute of the intervention which was emphasized by almost all respondents was the training of community volunteers to complement the activities of health workers so far as Buruli Ulcer is concerned. This paved the way to instill confidence and trust in the health system at the district level. Given this, it was documented by Akoachere, Nsai, and Ndip (2016) that one of the strong predictors of timely treatment for Buruli ulcers is education. Akoachere, Nsai, and Ndip (2016) reported that educational status enhances understanding of the disease condition, its risk factors, and options for treatment. Further, Nwafor *et al*. (2019) argues that attaining educational status at any level positions individuals to understand every piece of information provided to them about Buruli ulcer disease, and allows for easy dissemination of information among the remaining members of the community. In the current study, education was given in the form of in-service training, workshops, and seminars. Experiences from Cameroon indicate that training programs conducted for healthcare professionals have reportedly been the reason for increased knowledge and awareness among healthcare professionals, who in turn educate their patients on their hospital visits (Akoachere, Nsai, and Ndip, 2018).

Another positive attribute of the intervention was training on how to counsel patients with Buruli Ulcers. Most of these patients go through a lot of stigmatization from the community they reside as well as their very own families. Through the intervention, health staff knows who to counsel and get to those who are traumatized by the condition and offer any assistance that will ease their worries and speed up the healing process. By this, it is imperative to appreciate that case detection systems of Buruli ulcers have faced challenges as a result of stigmatization from the disease. This

goes on to buttress the findings of Nwafor *et al.* (2019), which stressed that, people with Buruli ulcers are often stigmatized, especially because community members fear contracting the disease should they relate with infected individuals. This situation can be argued to be a result of poor knowledge amongst most community members, who possess little to no knowledge about Buruli ulcer, and are often of the perception that the disease has spiritual roots. Again, Godwin-Akpan *et al*. (2022) affirmed this when they concluded that stigma from Buruli ulcer has also been documented to be a result of the physical impairment the disease causes, as well as the possible disabilities it renders to those infected.

The study again assessed the benefits of ANESVAD from the perspective of implementers. It was highly emphasized by all implementers that, the intervention paid for and supported patients in various ways. It has been pinned by Kargbour-Labour, (2010) that in the ensuing years following the detection of Buruli ulcers, treatment regimens have been reported to be costly, with increasing costs found to be associated with the later stage of the disease. It should be noted that in this current study, the cost of physiotherapy for patients with large ulcers in the district was catered for by the intervention. Additionally, the cost of wound dressing was made free through the intervention and made patients more active in their health care needs so far as Buruli Ulcer is concerned. This according to clients eased the financial burden on patients and also prevented them from having life-altering disabilities.

It also came to light that, aside from bearing the cost of wound dressing and physiotherapy, health workers travel to the homes of patients who cannot come to the district facility to dress their wounds and do so for them. The children of these patients were not left out of the benefits received from the intervention. Since most parents are inhibited from actively working due to these ulcers, the intervention has factored in children below 17 years and has catered for their health care needs

by paying for their national health insurance. Assisting children was not only reflected in paying for their health insurance levy but also in helping them to be mentally stable in the face of diseases not on their parents but on them. This goes on to affirm the study of Bailey *et al*. (2019) in determining the impact of neglected tropical diseases on mental health. They reported that the socioeconomic impacts of Buruli ulcers lead to the development of common mental health conditions, including depression and anxiety.

It should be noted that the ANESVAD intervention also bore the cost of surgery for marginalized children who had severe ulcers and were stigmatized by their families and loved ones. After benefiting from all these, the intervention also served as a good platform for soliciting funds and securing decent accommodation for patients who have been marginalized from their communities and families.

Finally, the intervention offered health staff all the necessary materials for wound dressing and they established that the wounds they treated took less time to heal compared to when they used the traditional ways of dressing wounds. They expressed their joy and how it has boosted their confidence in awareness creation and bringing reluctant patients on board to dress their wounds as the evidence says it all.

5.4 Barriers and facilitators influencing the implementation of the ANESVAD Intervention

Despite the remarkable progress achieved by the intervention, there are still some challenges that are worth noting to be discussed. One such challenge is traveling to hard-to-reach communities in the district due to transportation issues despite the provision of various means of transport such as pick-up track, motorbikes and bicycles by the intervention. In Wassa Amenfi East for instance, the vehicle provided by the intervention was stollen, in other district the motor bikes are equally be

used by other projects so it may not be available when its needed. Mostly, community volunteers are willing to also assist but there are no means of transportation either because the roads are bad during the rainy season or the means of transportation are not available. Again, financial resources are still the issue on the side of health workers despite the numerous mechanism put in place to ease the burden on patients. This also has to do with financial problems in setting some activities in motion. According to some implementers, bureaucracy is an issue when money has to be sent to the district for program implementation. This delays the process and gives stress to both health workers and beneficiaries. In this situation, when health workers are not able to travel to hard-to-reach areas, it indirectly affects a community when those at risk are the head or providers of the family and their inability to work will impact their ability to even provide basic needs for their family.

A limitation of the Social Ecological Model is that, changing lifestyle can be extremely difficult for patients and the community due to the denial that they are at risk, BU patients for instance may not believe they are at risk of disability if they do not seek the right treatment. Despite the efforts of stakeholders such as GHS, GES and NCCE, it was difficult for some BU patients to change their preference for traditional medicine to the treatment with antibiotics and wound dressing provided for free at health facilities by the ANESVAD Intervention, some patients who changed their preference at some point relapsed, which was another striking challenge to the implementation of the intervention. In Ghana, traditional medicine has been with us since time immemorial and it becomes very difficult for some individuals to embrace something new. Although the intervention has created so many platforms to help those affected to heal, others still prefer the services of traditional healers although they have vividly seen the progress and success

stories of others. Also, some do not believe in the concept of free services offered by the intervention and see it as not genuine and rather frequent the service of these traditional healers who themselves do not understand Buruli Ulcers. This goes on to buttress a study conducted in Nigeria where it was found that most individuals in rural communities in Nigeria perceive Buruli ulcers to have spiritual (Udujih et al., 2020).

Also, a challenge expressed by implementers is the issue of theft in the communities. Some of the implementers indicated that it's been very difficult to move to some communities because vehicles and motorcycles given to them have been stolen. Everyone in these communities knows the importance of their work but that didn't stop these individuals from stealing.

The last challenge is an issue of expired drugs. Antibiotics sent from the national office to the districts are mostly near their expiry dates so they are unable to administer them to all in time before they expire. A significant amount of the drugs expires before there is an opportunity to treat the patients with it, some of the antibiotics that are shipped GHS the national office by WHO have less than a year to expiration. The district request for the drugs from the national office when they have news cases to be treated, so in some cases some of the drugs they receive are near its expiry, they treat the patients with the it and the remaining antibiotics in the stores gets expired

The study went on to identify factors that enhanced the implementation of the intervention and one such was the involvement of volunteers. They played a critical role in the various communities in ensuring patients as well as those at risk were identified and brought to the health facility for immediate and proper treatment. Volunteers were trained on how to educate people in their communities, how to use educational materials on Buruli ulcers, and how to get to hard-to-reach communities. This goes on to affirm the recommendation by the World Health Organization which

reported that because case detection of Buruli ulcers has posed a challenge over the years, a community-level assessment before any intervention modules. According to the World Health Organization, understanding the community context ensures "culturally-appropriate and behaviorally-feasible prevention and treatment intervention" (Nwafor et al., 2019). In this current study, volunteers were used for both case detection and education as they know and fit well in the cultural dynamic of the community and they captured cases to the attention of health workers.

To sum up, on the factors that enhanced the implementation of the ANESVAD intervention, some implementers and field technicians indicated that support from the national level has been a factor that has ensured the smooth running of the intervention. They emphasized that the national level assisted with logistics and finances when the need arose and they were always willing to come down to the district level to offer any form of help and support within their means. Staff commitment also played a role in ensuring the successful implementation of the intervention. Staff indicated they were motivated in training and were adequately prepared to facilitate and help patients in their district so far as Buruli ulcers were concerned.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Introduction

This section of the dissertation provides a summary of the study, findings, recommendations and directions for future studies.

6.2 Summary

The study found that buruli ulcer patients had positive experiences with the ANESVAD Intervention. The intervention has played a significant role in controlling buruli ulcer in the sponsored districts. Patients got the treatment required to heal their ulcers, they also received financial assistance from the intervention which relieved them from the financial burden as a result of the disease.

Another important aspect is the partnerships that existed among the stakeholder, the stakeholders of the ANESVAD Intervention played the individual roles to make the implementation a success. Stakeholders of the intervention sometimes played a collectively role by stepping in to assist when it became necessary to do that, an instance is the district assembly in Upper West Akim stepping in to provide funds for implementers to carry out activities of the intervention while they were waiting for the intervention funds to be available. It is the collective efforts and commitment of these stakeholders that made the intervention a success despite its challenges.

Finally, some challenges were encounter during the implementation of the ANESVAD Intervention as well as some facilitators that made the implementation of the intervention a

success. An outstanding challenge implementers inability to go to hard-to-reach communities in the district due to unavailability of means of transport or bad roads. Staff commitment was the outstanding facilitator of the intervention as well as community sensitization, strong partnership among stakeholder and the use of community-based surveillance volunteers.

6.3 Conclusion

Buruli ulcer continues to be an NTD of public health concern that requires significant investment from both government and private stakeholders. Studies have shown the impact of the disease on all aspects of the patients' life, but significantly their socio-economic life. The ANESVAD Intervention significantly reduced the morbidity of buruli ulcer in Ghana. Patients as well as implementers benefited from the intervention. Patients in sponsored district had positive experiences with the intervention, they were alleviated of the financial difficulties associated with the disease by getting antibiotics and treatment free of charge. Implementers gained knowledge and expertise in case detection and treatment of buruli ulcer and other NTDs. Despite the efforts of the ANESVAD Foundation to make logistics, drugs, transportation and funds available to ensure successful implementation of the intervention, it had some barriers that made implementation difficult for implementers. Facilitators such as staff commitment and community sensitization and awareness ensured the intervention achieved some level of success. The ANESVAD Intervention has contributed significantly to the control of buruli ulcer in endemic districts in Ghana, subsequent interventions on the control, elimination and eradication NTDs should adopt the implementing strategies of the ANESVAD Intervention and learn from the barriers of its implementation to enable an effective and efficient implementation of these interventions.

6.4 Recommendation

- The National Buruli Ulcer Control Program should invest more resources into sensitization and awareness creation to encourage patients to continue treatment until their ulcer heals.
- The Ghana Health Service should ensure that processes for funds transfer to the districts starts ahead of time so it can go through all the bureaucracies in time to avoid delayed transfer to the districts.
- District Health Administration of the ANESVAD sponsored districts should ensure vehicles, motorbikes and bicycles are packed at a designated place when there are not been use for official purposes. Alarm systems and trackers should be installed in all means of transportation to prevent theft.
- The Ministry of Health and Ghana Health Service should ensure that medication procured have at least three years before its expiration to prevent drug wastage due to its expiry.
- Students and researcher can conduct further studies into the barriers to the implementation of NTDs interventions.

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APPENDIX A: PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET FOR PATIENTS

Study Tittle: Experiences of Buruli Ulcer Patients with the ANESVAD Intervention in Endemic Districts in Ghana

Study Population: Buruli Ulcer Patients Program Implementers (disease control officers, field technicians and wound care nurses)

Introduction: My name is Dorcas Mmoaden Nawiene. I am an MPH student at the University of Ghana seeking to explore the experiences of Buruli Ulcer patients with the ANESVAD intervention, which has been implemented in your district. I am a research assistant at the University of Ghana Medical School Research Unit, stationed at Korle Bu Teaching Hospital.

Address: C/O Professor Justice Nyigmah Bawole.

P.O Box LG 78 Legon-Accra, Ghana

Telephone: 0248875562/ 0204021825

Email: nawienedorcas@gmail.com

Background and Purpose of research: The purpose of the study is to explore the experiences of Buruli Ulcer patients with the ANESVAD intervention, which has been implemented in your district. The study is primarily aimed to well understand the barriers/challenges to implementing the ANESVAD intervention, practical operation and major lessons learned. We will be asking about the project implementation approaches, barriers and drivers of project implementation and lessons learned during implementation to deepen the understanding of the effectiveness of the project implementation in bringing impacts on service quality and utilization.

Nature of research: The study is about exploring the experiences buruli ulcer patients has with the ANESVAD Intervention during its implementation in their districts. The study is primarily aimed

to well understand the barriers/challenges to implementing the ANESVAD intervention, practical operation and major lessons learned. We will be asking about the project implementation approaches, barriers and drivers of project implementation and lessons learned during implementation. The study participants include buruli ulcer patients and program implementers (disease control officer, wound care nurses and community-based surveillance volunteers). The study would be conducted in three of the ANESVAD sponsored districts, which include Upper West Akim, Wassa Amenfi East and Asikuma Odoben Brakwa. The study would be conduct among twenty-four participants across the three selected districts.

Participants involvement

- Duration: Participants would be engaged in an interview and a focused group discussion. These activities are expected to last between 45 minutes to an hour.

- Risk: There are relatively low anticipated risks associated with this study. Some questions may be uncomfortable to some participants. Additional verbal consent would be sort from participants who are not comfortable with the questions to determine if they want to continue or exit from the study. All information to be gathered from this study is purely for academic purposes. All information we collect will be stored securely, and accessible only by study staff. If information from this study is published or presented at scientific meetings, study participants' name and other personal information will not be used. All participants' data will be kept for five years, after which time it will be destroyed.

- Benefits: There is no direct benefit of this research to the study participants. However, it is expected that, the findings from this study would inform policy decisions and planning health intervention by relevant stakeholders such as the World Health Organization,

Ministry of Health, Ghana Health Service, and ANESVAD among others on experiences of BU patients with health interventions implemented to alleviate the burden of the disease. Findings would also serve as a baseline study for researchers interested experiences of patients of NTDs with implemented health intervention.

- Compensation: There will be no compensation for being a participant in this study. The study is for academic purposes, and participant contributions are solely voluntary with minimal vulnerability of participants.

- Confidentiality: Information obtained from study participants will be kept confidential. Identifying and personal information will be anonymized during transcription, analysis and dissemination of findings from the study. Codes will be used during data management to avoid exposing the details of study participants. Any data and information generated from participants will be stored in an encrypted file, which will only be accessible by the principal investigator. However, the Ghana Health Service Ethics Review Committee can have access to the data and study files in the event of monitoring.

- Voluntary Participation: Participants may refuse to participate, withdraw their consent, and discontinue participation in the research at any time without any negative consequences or affect the services they are to receive.

- Would it cost anything to be part of the study?

  It would not cost you anything to be part of the study.

- Expected Outcome and feedback: At the end of this study, it is expected that, the experiences of Buruli Ulcer patients with the ANESVAD Intervention would be explored. Also, the

findings from this study would inform policy decisions and planning health intervention by relevant stakeholders such as the World Health Organization, Ministry of Health, Ghana Health Service, and ANESVAD among others on experiences of BU patients with health interventions implemented to alleviate the burden of the disease. Findings would also serve as a baseline study for researchers interested experiences of patients of NTDs with implemented health interventions. Findings of the study would be disseminated to participants of the study and other stakeholders. Making the finding available to the districts health administration of each district would do this. Also, a meeting would be held at the National Buruli Ulcer Control Program office in Accra to disseminate findings to the Disease Control Department of the Ghana Health, ANESVAD Foundation and other stakeholders

- Funding information: The National Buruli Ulcer Control/ Yaws Eradication Program, under the Public Health Division of the Ghana Health Service, funds the study.

- Sharing of participants Information/Data: The data generated from the study would be owned by the principal investigator and would be shared with the funding agency.

- Provision of Information and Consent for participants: Participants would sign two copies of the consent form. The principal investigator would keep one and a copy would be given to the participant. Permission would be sort from participants before the commencement of the interview and focused group discussion

- Who to Contact for Further Clarification/Questions:

Principal Investigator Name: Dorcas Mmoaden Nawiene,

Department: Department of Social and Behavioral Sciences, School of Public Health. University of Ghana.

Telephone: 0248875562/ 0204021825

Email: nawienedorcas@gmail.com

The Ghana Health Service (GHS) Ethics Review Committee (ERC) should be contacted in case of any ethical issue

Ghana Health Service Ethics Review Committee

Name: Nana Abena Apatu

Telephone: 0503539896

Email: ethic.research@ghs.gov.gh

APPENDIX B: CONSENT FORM FOR PATIENTS

STUDY TITLE: Experiences of Buruli Ulcer Patients with the ANESVAD Intervention in Endemic Districts in Ghana

Study Population: Buruli Ulcer Patients and Program Implementers (disease control officers, field technicians and wound care nurses)

PARTICIPANTS' STATEMENT

I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and all questions satisfactorily explained to me in a language I understand (English/ Twi). I fully understand the contents and any potential implications as well as my right to change my mind (i.e., withdraw from the research) even after I have signed this form.

I voluntarily agree to be part of this research.

Name of Participant.....

Participants' Signature .....OR Thumb Print.....

Date:.....

INTERPRETERS' STATEMENT

I interpreted the purpose and contents of the Participants' Information Sheet to the afore named participant to the best of my ability in the (English/Twi) language to his proper understanding. All questions, appropriate clarifications sort by the participant and answers were also duly interpreted to his/her satisfaction.

Name of Interpreter.....

Signature of Interpreter..... OR Thumb Print .....

Date:.....

STATEMENT OF WITNESS

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the languages, he/she understood (English/Twi)

I confirm that he/she was given the opportunity to ask questions/seek clarifications and same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Name: .....

Signature..... OR Thumb Print .....

Date.....

INVESTIGATOR STATEMENT AND SIGNATURE

I certify that the participant has been given ample time to read and learn about the study.

All questions and clarifications raised by the participant have been addressed.)

Researcher's name.....

Signature .....

Date.....

APPENDIX: C INTERVIEW GUIDE FOR PATIENTS

Experiences of Buruli Ulcer Patients with the ANESVAD Intervention in Endemic Districts in Ghana.

Study Population: Buruli Ulcer Patients and Program Implementers (disease control officers, field technicians and wound care nurses)

Demographics

1. Ages
2. Gender
3. Education
4. Religion
5. Occupation
6. Marital status

A. To explore the experiences of Buruli Ulcer patients with the ANESVAD intervention.

1. Please, do know about the ANESVAD intervention?
2. Please, can you explain your experiences with Buruli Ulcer before the ANESVAD intervention was implemented?
3. How has the ANESVAD intervention supported you to cope with Buruli Ulcer?
4. What specific activities have the ANESVAD intervention implemented that helped you to manage Buruli Ulcer?
5. Please, can you say that the ANESVAD intervention has helped you managed Buruli Ulcer better than when it was not implemented?

B. To explore partnership and inter-sectoral collaboration of the ANESVAD intervention among relevant stakeholders.

6. Please, can you identify the various agencies and institutions who were involved in the roll out the ANESVAD intervention?
7. What was the roles and responsibilities of the various agencies and institutions from the key sectors that was involved the implementation of the ANESVAD intervention?
8. How has these stakeholders helped in the effective implementation of the ANESVAD intervention?

9. How significant has the partnership and inter-sectoral collaboration to helped in reducing Buruli Ulcer among patients?

C. To identify barriers and facilitators influencing the implementation of ANESVAD intervention in endemic districts.

10. In the course of implementing the intervention, can you outline the challenges experienced at the institutional level and with patients in the implementation of the intervention in the district?
11. Please, can you outline the facilitators in the district that ensured the effective implementation of the intervention?
12. Who are these facilitators and what significant roles did they play in the implementation of the program at the local level?

APPENDIX: D INTERVIEW GUIDE FOR PROGRAM IMPLEMENTERS

Experiences of Buruli Ulcer Patients with the ANESVAD Intervention in Endemic Districts in Ghana.

Study Population: Buruli Ulcer Patients and Program Implementers (disease control officers, field technicians and wound care nurses)

Demographics

1. Ages
2. Gender
3. Education
4. Religion
5. Occupation
6. Marital status

A. To explore program implementers experiences with the ANESVAD intervention.

1. Please, do know about the ANESVAD intervention?
2. Please, can you explain how the district managed Buruli Ulcer cases before the ANESVAD intervention was implemented?
3. How has the ANESVAD intervention supported the district to treat Buruli Ulcer cases?
4. What specific activities have the ANESVAD intervention implemented that enabled the district to manage Buruli Ulcer?
5. Please, can you say that the ANESVAD intervention has supported the district managed Buruli Ulcer better than when it was not implemented?

6. To explore partnership and inter-sectorial collaboration of the ANESVAD intervention among relevant stakeholders.
7. Please, can you identify the various agencies and institutions that were involved in the roll out the ANESVAD intervention?
8. What was the roles and responsibilities of the various agencies and institutions from the key sectors that was involved the implementation of the ANESVAD intervention?

9. How has these stakeholders helped in the effective implementation of the ANESVAD intervention?
10. How significant has the partnership and inter-sectorial collaboration to helped in reducing Buruli Ulcer among patients?

11. To identify barriers and facilitators influencing the implementation of ANESVAD intervention in endemic districts.

12. In the course of implementing the intervention, can you outline the challenges experienced at the institutional level and with patients in the implementation of the intervention in the district?
13. Please, can you outline the facilitators in the district that ensured the effective implementation of the intervention?
14. Who are these facilitators and what significant roles did they play in the implementation of the program at the local level?