

A Macro-Micro Analysis of Stigma in Buruli Ulcer and Yaws in the Atwima Mponua District
of Ghana

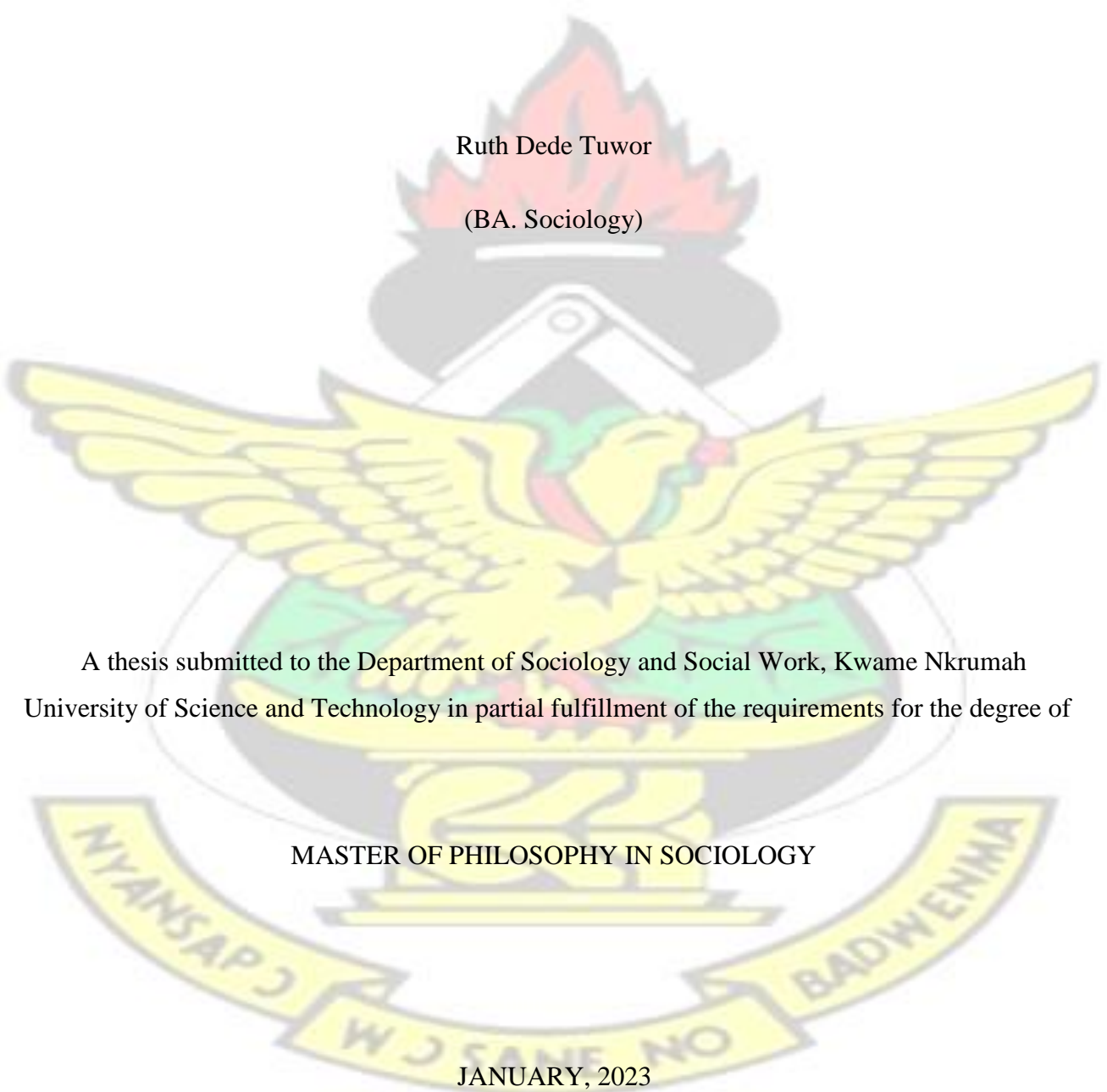
KNUST
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A thesis submitted to the Department of Sociology and Social Work, Kwame Nkrumah
University of Science and Technology in partial fulfillment of the requirements for the degree of

MASTER OF PHILOSOPHY IN SOCIOLOGY

JANUARY, 2023



DECLARATION

I, hereby declare that this submission is my own work and to my best knowledge and belief, contains no material previously published or written by another person nor material which is to a substantial extent has been accepted for the award of any other degree or diploma at Kwame Nkrumah University of Science and Technology, Kumasi or any other educational institution, except where due acknowledgement is made in the thesis.

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DEDICATION

I dedicate this work to the Almighty God, who's favor and blessings continue to abound in all I do. To all teachers I have met in my journey; in the classrooms, at the workplace, at home, I say God richly bless you all!

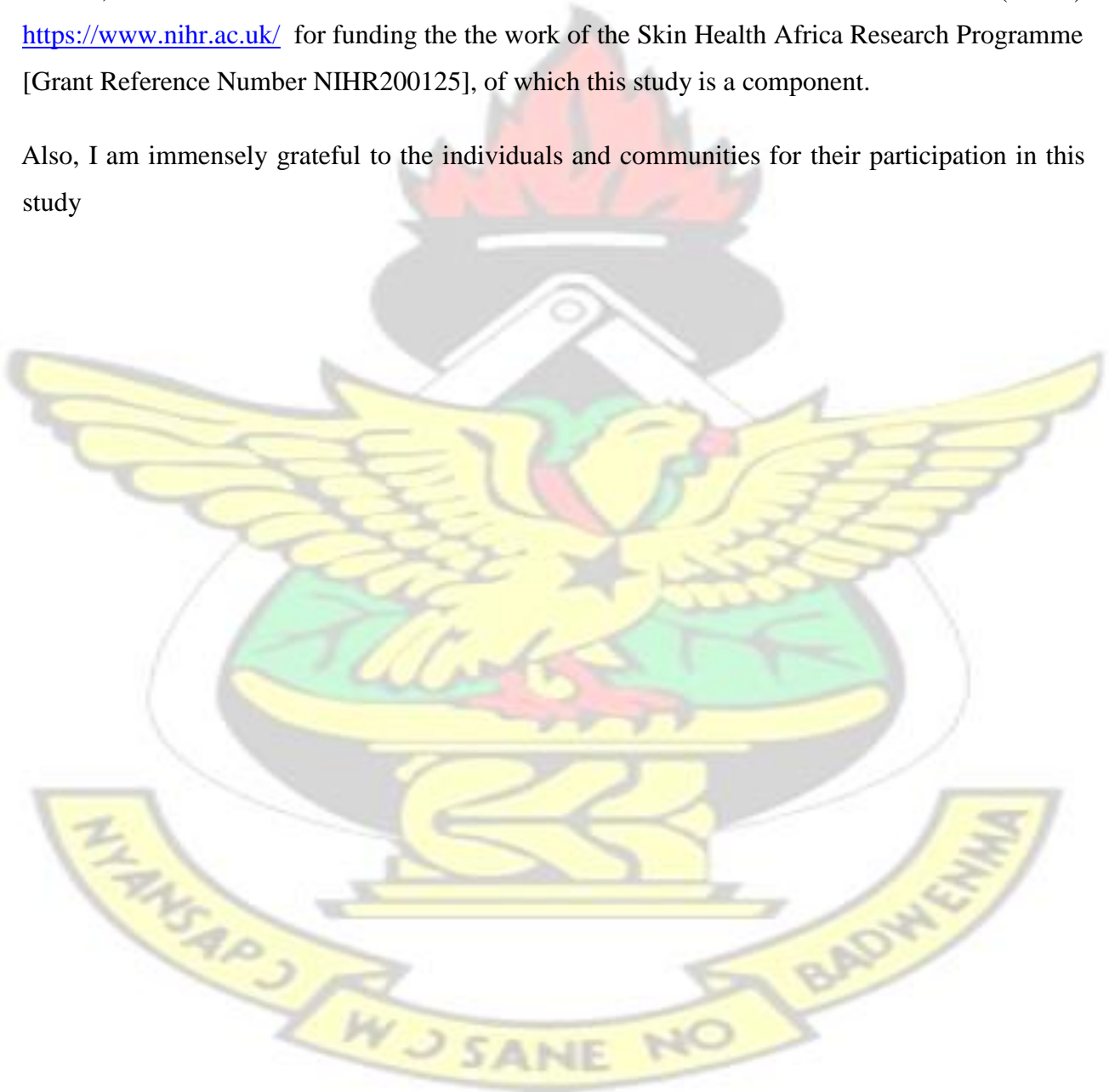


ACKNOWLEDGEMENTS

My immense gratitude goes to several people for the role they played in making this work a success. I would like to thank all Professors, Doctors, Coaches, Senior colleagues, friends, teammates and my family who have supported me through thick and thin. I say, may God richly bless you all!

Further, I am thankful to the National Institute for Health and Care Research (NIHR) <https://www.nihr.ac.uk/> for funding the the work of the Skin Health Africa Research Programme [Grant Reference Number NIHR200125], of which this study is a component.

Also, I am immensely grateful to the individuals and communities for their participation in this study



ABSTRACT

Stigma related to Neglected Tropical Diseases has been a global concern for several decades now. Notwithstanding, it has remained an issue, contributing to poorer health outcomes and posing a significant psychosocial burden on patients and their care-givers. However, studies have remained sparse and aimed at investigating stigma in selected singular diseases within limited social contexts. This study therefore aimed to holistically explore stigma associated with buruli ulcer and yaws.

A concurrent mixed methods design was adopted. Three-hundred and eighty-four (384) community members from 16 communities within the Atwima Mponua district were surveyed to understand community knowledge, beliefs and attitudes reinforcing stigma. Additionally, in-depth interviews were conducted for 31 past and active buruli ulcer and yaws patients to explore the experiences, effects and coping strategies they used in managing stigma.

Misconceptions in community knowledge were associated with stigmatizing attitudes towards patients. Levels and types of stigma however, varied between buruli ulcer and yaws. Common manifestations of stigma were exclusion from group participation, name-calling, teasing, discrimination and avoidance. Stigma experiences led to negative effects including psychosocial burden, academic underachievement and strained social relationships between affected people and social groups. However, increased health seeking behavior was also recorded as patients sought to overcome disease stigma attaining cure. However, patients coped with stigma through problem-focused (concealment, confrontation, selective disclosure and information management) and emotion-focused strategies (religion and self-isolation), which contributed to mental health suffering among patients.

Education is required to increase community knowledge and awareness of skin NTDs. There is the need to incorporate and strengthen psychosocial measures in the management of affected persons.

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LIST OF ABBREVIATIONS

BU	Buruli Ulcer
HRS	Health Related Stigma
MDG	Millennium Development Goal
NTD	Neglected Tropical Disease
SDG	Sustainable Development Goal
WHO	World Health Organization
GHS	Ghana Health Service
KCCR	Kumasi Centre for Collaborative Research in Tropical Medicine

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CHAPTER ONE

INTRODUCTION

1.0 Background

Stigma related to Neglected Tropical Diseases has been a global concern for several decades now. However, it has remained an issue, contributing to poorer health outcomes and posing a significant psychosocial burden on patients and their care-givers. Broadly defined, stigma is a social process experienced or anticipated by an individual or a group characterized by segregation, rejection, blame or devaluation that results from an adverse social judgment (Weiss, Ramakrishna & Somma, 2006). Major attention to stigma began in 1963 with the introduction of Goffman's influential work, where he contended that stigma discredits and reduces the 'whole' person to a 'tainted' or 'discounted' person, thus a 'spoil' in identity (Goffman, 2018, Goffman, 1997). Following this, social scientists have paid some level of attention, although inadequate to the subject, particularly to stigma associated with race, ethnicity, religion and few health conditions (Howarth, 2006, Frost, 2011, Tyler, 2018, Pescosolido and Martin, 2015).

Specifically, stigma associated with health conditions is noted as particularly harmful as it does not only contribute to poorer health outcomes but also impairs the self-esteem of patients and contributes a significant psychosocial burden (Scrambler, 1998). Over the years, health related stigmas (HRS) have been associated with conditions such as mental disorders, HIV/ AIDS, tuberculosis, small pox, venereal diseases, breast cancer, and some skin conditions (Ben-Zeev et al., 2010, 2018, Datiko, Jerene & Suarez, 2020). HRS is found to be the product of a number of factors including the cultural meanings associated with a disease, presence of a socially discomforting condition and an inflated fear of contagion of a disease condition (Weiss, 2008b).

More recently, overwhelming evidence suggests that HRS has deadly implications for health outcomes in the Neglected Tropical Diseases (NTDs). These are a group of 20 mostly non-fatal but chronic diseases of the poor, found within the tropic and sub tropical regions of the world (Engels, Huang & Zhou, 2021, Hotez, 2008, Dofitas, Kalim, Toledo & Richardus, 2020b). These group of abandoned diseases, according to the World Health Organization (WHO) contribute a substantial burden and negatively impact the quality of life of more than 1 billion people, with Africa carrying about 40 % of the global disease burden (WHO, 2021).

Hotez (2008) notes that, the disease burden associated with NTDs contends other devastating diseases such as HIV/ AIDS, malaria and tuberculosis especially in poverty-stricken communities typically in developing countries.

Stigma associated with NTDs contributes to further suffering, disability and mortality by inhibiting timely detection and access to required care (Tsutsumi, Izutsu, Islam, Maksuda, Kato & Wakai, 2007, Casulli, 2021a). Physical or bodily stigma constitutes the worst form of stigma as attributes are readily seen and in some cases unchangeable. This constitutes a 'hidden burden' on the social and economic life of patients, care givers, family members and communities (Gussow and Tracy, 1970). Consequently, these come with dire consequences such as a reduction of social support, physical and psychological wellbeing of the patient (Casulli, 2021b).

Within the 20 NTDs is a sub group known as the Skin Neglected Tropical Diseases (Skin NTDs). This group according to the WHO find their semblance in skin manifestations, typically affecting poor and marginalised people. They include leprosy, Buruli ulcer, cutaneous leishmaniasis, lymphatic filariasis (lymphoedema and hydrocele), post-kala-azar dermal leishmaniasis, yaws, mycetoma, onchocerciasis, scabies, and fungal diseases. These group of diseases have been found to contribute significantly to the global disease burden and disability, coming second only to HIV/AIDS on the Disability-Adjusted-Life-years (DALYs) scale. These diseases account for 4657 years of healthy life lost globally as a result of living with disability (YLDs) or NTD related premature death (YLLs) (Norris, Adelman, Spantchak, & Marano, 2012).

To explore the stigma associated with Skin NTDs in this study, Buruli Ulcer and Yaws have been selected, among other reasons such as similarity of causative organism, skin involvement, likelihood of ulcer, clinical manifestations (Chang and Ochoa, 2019), The co-endemicity of the two conditions in the study site has served an opportunity to explore cross-cutting findings. This is aimed to give a more comprehensive and holistic account of stigma associated with skin NTDs.

1.1 Problem Statement

Evidence from more explored skin NTDs such as leprosy and podoconiosis suggest that stigma is devastating and has the capacity to do equal, if not more harm than the disease condition itself, especially as these diseases are perceived as symbols of disgrace in many contexts (Yakob, Deribe, & Davey, 2008, Nyblade, Stockton, Giger, Bond, Ekstrand, Lean, Mitchell, Nelson, Sapag, & Siraprapasir, 2019). In addition to promoting socio-cultural consequences, evidence form some contexts suggesst that stigma contributes to poor mental health, delay in accessing care and retention, which can lead to the loss of life, prolonged periods of illness and disability (Owusu & Adamba, 2012).In spite of these effects, the subject remains woefully underexplored in the skin NTDs (Weiss, 2008a, Cross and Choudhary, 2005, Stevelink, Van Brakel, & Augustine, 2011, Sermrittirong and Van Brakel, 2014, Hofstraat and van Brakel, 2016). Particularly, within the plethora of sociological studies, there is a general neglect of stigma in the skin NTDs. Little is known of the role of community knowledge and beliefs in the perpetuation of stigma, as well as patient account of stigma experience, impact and coping strategies (Ukwaja, Alphonsus, Eze, Lehman, Ekeke, Nwafor, Ikebudu, Anyim & Chukwu, 2020).

In addition, amongst the limited studies in more forthcoming neighboring social science disciplines such as social psychology, evidence has not only concentrated on giving micro accounts, but has also remained typically disjointed, unveiling stigma accounts in pockets of social contexts and singular diseases. Thereby not giving cross-cutting evidence as well as inhibiting the possibility of developing generic measuring instruments and reduction strategies for conditions which may manifest similar types of stigmas. With the new WHO directive for an integrated management for NTDs, a holistic account of stigma in the skin NTDs is particularly crucial to understanding the problem (Bennis, Thys, Filali, De Brouwere, Sahibi, & Boelaert, 2017b, Hu, Ramdas, Nieuwkerk, Reis, Lai, De Vries & Schallig., 2020, Bennis et al., 2017a, Grifferty Et Al., 2021, Otoo, AppiahAgyekum & Adzei., 2021).

Furthermore, although the Ashanti Region of Ghana remains one of the biggest hubs of Yaws and particularly BU, existing studies to find community knowledge and beliefs, perceived causes and socio-cultural features have been focused in other parts of the country like the Ga West and Ga South Municipalities which have recorded greater endemicity (Owusu and Adamba, 2012, Kargbo-Labour, 2010, Anokye, Acheampong, Mprah & Sarpong, 2018, Ackumey, 2013). Few studies in

the region like Anokye et al (2018) have focused on the patient knowledge and beliefs, neglecting community perspective, which is key in the propagation of social or enacted stigma.

Consequently, there is the need for a holistic account of stigma across different levels of social contexts and among similar skin NTDs. This way, a broad view of stigma can be achieved. Similarities, differences and nuances in stigmas can be assessed to help inform generic measuring scales and reduction strategies which are efficient and cost-effective.

Additionally, previous findings in the Skin NTDs have been based on adult patients. This study provides an opportunity to unravel the experiences of younger patients who are principally affected by BU and Yaws, to compare to the experiences of older patients.

Thus, stigma is comparatively explored using the sociological construct of macro and micro social interaction to give a comprehensive account of stigma within the context of the community and within affected individuals and their families. This study is novel, in terms of rationale, location, aim, participants, sample size and approach, improving upon previous social science studies, which have remained typically vertical, geographically skewed, and sparse. Differences and similarities of stigma experience, effect, coping strategies are unveiled. Additionally, community knowledge and beliefs that perpetuate stigma are explored in more than one skin NTD within the same setting at the same time.

1.2 Study Objectives

1.2.1 General objective

Generally, the study aims to comparatively explore stigma associated with BU and Yaws in selected co-endemic communities in the Ashanti region of Ghana.

1.2.2 Specific objectives

Specifically, the study seeks to;

1. Determine the community stigma related knowledge, beliefs and attitudes associated with BU and Yaws
2. Analyze the stigma experiences of BU and Yaws patients

3. Assess the effects of stigma on BU and Yaws patients
4. Examine coping strategies patients of BU and Yaws use in managing stigma

1.3 Research Questions

The study aims to answer the following research questions:

1. What are community stigma related knowledge, beliefs and attitudes associated with BU and yaws?
2. How do patients of BU and Yaws experience disease related stigma?
3. How does stigma experiences affect patients of BU and Yaws?
4. What are the coping strategies patients of BU and Yaws use to manage stigma?

1.4 Hypothesis and Assumptions

1.4.1 Hypothesis

H:0 Community knowledge and beliefs about BU/ Yaws has no relationship with stigmatizing attitudes towards BU/Yaws patients

H1: Community knowledge and beliefs about BU/ Yaws has a significant negative relationship with stigmatizing attitude towards BU/Yaws patients

1.4.2 Assumptions

1. Stigma experiences are similar for patients of BU and Yaws
2. Stigma associated with BU and Yaws has similar implications for patients of BU and Yaws
3. Patients of BU and Yaws develop common negative or positive coping strategies to manage the stigma.

1.5 Justification of the Study

Numerous global and national efforts have been made to attain economic growth, eradicate poverty and attain sustained development. However, none of this is possible without a healthy population. Every investment in health is worthwhile as this creates a ripple effect in other important facets such as the economy and education (Yahaya and Gunduz, 2018).

In recognition of this, prominent development agenda such as the Sustainable Development Goals (SDGs) and the Millennium Development Goals (MDGs) have made the attainment of a global health and wellbeing a primary target. In line with these targets, the World Health Organization (WHO) aims to end the neglect that NTDs face and stop the suffering of the world's bottom billion through its 2030 NTD road map. In this agenda, Yaws is targeted for eradication by 2030, while the proportion of late stage (category 3) lesions of Buruli ulcer is expected to go down to less than 10% (WHO, 2020).

However, these targets remain elusive as long as stigma remains underexplored and not fully understood. Aside contributing in no small way to poorer health outcomes, stigma also fuels a vicious cycle of poverty and social consequences as stigmatized individuals and their associates face economic and social implications (Yotsu, 2018).

Given the available evidence of the adverse relationship between stigma and the skin NTDs, there is a critical need for a comprehensive and holistic account to provide evidence for a sustainable, feasible and cost-effective stigma reduction strategies in line with global goals such as the WHO Skin NTD goal for 2030.

1.6 Significance of the Study

The use of a mixed method approach provides a well-rounded insight from both quantitative and qualitative methods, giving in-depth experiences of stigma associated with BU and Yaws as well as providing evidence on community knowledge, attitude and beliefs associated with the diseases. This holistic evidence contributes to a better understanding of stigma associated with the diseases.

In addition, study findings provide evidence for the Ghana Ministry of Health (MoH), NGOs and other health related international bodies to design, refine and implement appropriate interventions in the skin NTDs.

Moreover, evidence gathered serves as a basis for more research to identify best practices in the integrated management of stigma. Helping to mitigate the harmful effects of stigma and promoting early case detection and treatment, thereby reducing late-stage case presentation, morbidity, increased suffering, disabilities and mortality.

Lastly, investigating stigma in more than one skin NTDs within the same population at the same time point provides important evidence showing the nuances and interplay of stigma in cooccurring skin NTDs.

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1.7 Scope of the Study

Contextually the research is bound within discourse on stigma in skin NTDs. Broadly, the study explores social experiences of NTD patients and their care-givers in varied contexts.

Geographically the study is confined to the southern part of Ghana. A sample of 384 community members in 16 co-endemic communities within the Atwima Mponua District in the Ashanti region are included in a community survey to provide evidence on community knowledge, beliefs and attitudes about BU and yaws to find their association with stigmatizing propensities.

1.8 Operational Definition of Concepts

Stigma	The process of marking an active patient/past patient for social disapproval
Micro-level stigma	Felt, internalized and self-stigma a patient may experience
Macro-level stigma	Overt stigma expressed against patients by other social actors
Past/ expert patient	Former BU/Yaws patients healed for not more than 2 years
Psychosocial burden	Mental health risks associated with disease related stigma
Coping strategy	The strategies used by stigma stigmatized patients to manage stigma
Young participants	BU/Yaws participants who are 24 years and below
Older participants	BU/Yaws participants who are 25 years and above
Category one lesion	BU wound with a size lesser than 5 cm
Category two lesion	BU wound size between 5 cm to 15 cm
Category three lesion	BU wound size above 15 cm

1.9 Organization of the Study

The study is divided into six chapters, with each chapter tackling a key component to achieve the overall research objective.

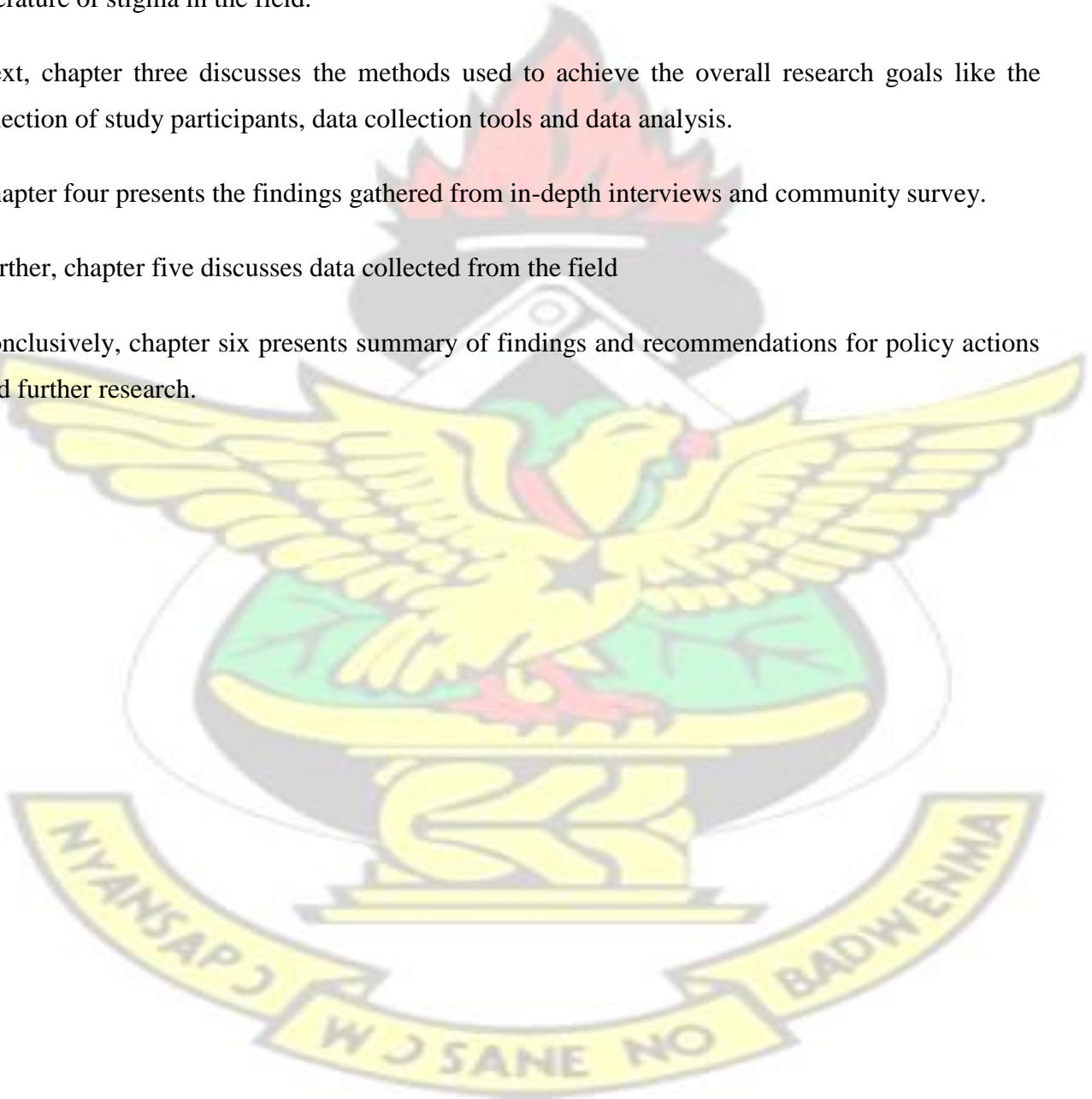
First, chapter one focuses on the background of the study, the statement of problem, research objectives and questions, significance and the organization of the work. Chapter two reviews the literature of stigma in the field.

Next, chapter three discusses the methods used to achieve the overall research goals like the selection of study participants, data collection tools and data analysis.

Chapter four presents the findings gathered from in-depth interviews and community survey.

Further, chapter five discusses data collected from the field

Conclusively, chapter six presents summary of findings and recommendations for policy actions and further research.



CHAPTER TWO

LITERATURE REVIEW

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2.0 Introduction

This chapter examines relevant literature within the scope of stigma in Skin NTDs. Important concepts such as stigma and skin NTDs are reviewed, unveiling differences and similarities in their usage across differing contexts.

Other themes such as community knowledge and beliefs associated with skin NTDs, stigma experiences, effects of stigma on Skin NTD patients, and coping strategies used in the management of Skin NTD stigma are empirically examined.

Important theories such as Goffman's stigma theory and Becker's labelling theory are also discussed.

The chapter ends with a conceptual framework which summarizes the relevant literature and how it is organized to aid in achieving study objectives.

2.1 Conceptual Review of Stigma

2.1.1 Stigma

Stigma is a social process where people or groups are devalued based on real or perceived distinctive characteristics, including sexual orientation, race, gender, disease and ethnicity (Ogden and Nyblade, 2005). According to the preposition of Goffman (1997), stigma confers a 'tainted' or 'discounted' identity on the bearer(s). On the macro level, forms of stigma, including enacted stigma, social stigma and structural stigma has been conceptualized as behaviors originating from existing norms and practices which confer stigma on bearers. In practice, the individual is avoided, ostracized, labelled, avoided, and devalued (Goffman, 1997, Link and Phelan, 2001, Pescosolido and Martin, 2015, Tyler and Slater, 2018). While enacted stigma is commonly proposed to be an overt form of stigma where stigmatizers resort to excluding, discriminating, ostracizing and outrightly troubling the stigmatized, other conceptualizations portray enacted stigma as an inactive form of social stigma where people may not entertain society's negative and discriminatory

treatment of the stigmatized group, but also fail to fight it. Generally, enacted stigma is denoted by an imposed stigmatized status which 'Normal' people, within a social structure enforce on individuals for belonging to a discreditable group or bearing a dishonorable distinguishing characteristic (Wakefield, Zempsky, Puhl & Litt, 2018, Munro, Voight, Bryson & Bogart, 2022).

Closely associated with enacted and social stigma is the concept of courtesy stigma where caregivers, health workers and other close associates are stigmatized not on the basis of their possession of 'undesirable' characteristics, but rather by association or acquaintance to someone or a group who possesses the undesirable characteristic (Birenbaum, 1970, Birenbaum, 1992, Angermeyer, Schulze & Dietrich, 2003, Russell, 2020, Tian, Li, Xie & Li, 2022, Liu and Kozinets, 2022). Straight bar tenders in gay bars and restaurants, relatives of criminals, prisoners, acquaintances of people living with health conditions such as mental disorders, autism, HIV/AIDS, etc., have been found vulnerable to this type of stigma in many settings (Alareeki, Lashewicz & Shipton, 2019, Bachleda and El Menzhi, 2018, MacRae, 1999).

Beyond the macro level where attention is given to how others perceive the stigmatized individual, is a micro level, where felt, internalized and self-stigma has often been discussed. Here emphasis is usually on how the stigmatized individual perceives himself and his feelings about how others will perceive him upon discovery of his discreditable attribute (Major, Spencer, Schmader, Wolfe & Crocker, 1998). The process of adapting to social stigma, characterized by acceptance and anticipation constitutes self-stigma (Moore, Tangney & Stuewig, 2016). This adaptation process is often characterized by a sense of hopelessness, lowered self-esteem, income loss, impaired social adaptation, lowered self-efficacy, among others (Karakas et al., 2016, Jahn et al., 2020, Pingali et al., 2018). In their meta review, Livingston and Boyd (2010), similarly found no 'strong correlation' between levels of internalized stigma and socio-demographic characteristics, however, sturdy relationships with psychosocial variables such as self-esteem and empowerment were unveiled.

Felt stigma occurs when the stigmatized individual 'internalizes a blame frame' (Barlösius and Philipps, 2015). An internal feeling of shame and guilt which comes from the expectation of being excluded or discriminated by others, eventually leading to social withdrawal or self-isolation (Goffman, 2009). In 2015, Bautista et al found that characteristics relating to marital status, race,

work status and age are important in determining the level of felt stigma in epilepsy patients , likewise single patients and patients with poor health literacy, culminating in a poorer quality of life.

Table 2.1. Levels and Types of Stigma

levels	Types of stigma	Description
Macro stigma	Enacted stigma	Overt stigmatizing practices such as discrimination and exclusion from group activities
	Courtesy stigma	Stigma directed towards associates of a stigmatized person due to closeness of relations
Micro stigma	Felt stigma	Internalizing feelings of shame or guilt associated with one's stigma label
	Self-stigma	Stigmatizing attitudes and aimed at oneself, usually in anticipation of stigma from others

2.1.2. History of stigma theory

Many charges have been laid out on the concept of stigma as many authors allege the term as not only being 'overused' but also as poorly defined, prone to many obscurities and vagueness (Manzo, 2004, Lekas, Siegel & Leider, 2011, Omori and White, 2014, Hurst, Dotson, Butterfield, Corbett & ONeal, 2020, Griffiths, Williamson, Zucchelli, Paraskeva, & Moss, 2018, Link And Phelan, 2001). To trace from the beginning however, stigma originated in Greek literature in reference to bodily signs that signify a poor or unusual moral standing of the bearer (Coleman Brown, 2013). Here, the bodies of criminals, slaves, traitors and all other people, considered to be impure or blemished are typically cut or burnt to show symbols and signs which advertise their tarnished status to observers (Goffman, 1997).

In modern times however, the term typically is used to signify general attributes or qualities that lead to disgrace rather than a bodily representation on bearers. Thus any differences in people in terms of character, financial status, disease, physical characteristics, etc. stands a fair chance of being either stigmatized or esteemed depending on the social context which changes what is defined as stigma and the consequences of bearing a stigmatized attribute (Coleman Brown, 2013).

In similar vein, Gray (2002) acknowledges Goffman's conceptualization as 'sociological' as the later maintains that, stigma is the result of an undesirable distinctiveness borne by an individual or a group. He highlights three types of stigmas; body abnormalities, character blemishes and tribal (status) stigma (Pescosolido and Martin, 2015, Gray, 2002). Fiske (2011) introduces the terminology 'stigma signatures' to stand in for these distinguishing characteristics that confer stigmatized identity on the bearer. However, Stangl et al (2019) asserts that a 'move away' from conceptualizing stigma in terms of an 'us' versus a 'them' as typical of earlier conceptualization where occupants of the 'us' compartment stigmatize bearers is imminent.

The labelling theory, which is classically used in the explanation of deviance, explains that the weight of social norms and expectations attached to a label play an active role in constructing the identity of the labelled individual (Appleby, 2010). Labelling has the potential to perpetuate selfstigma, reinforcing a diminished self-esteem, safety and trust that the individual has in other people (Frieih, 2020).

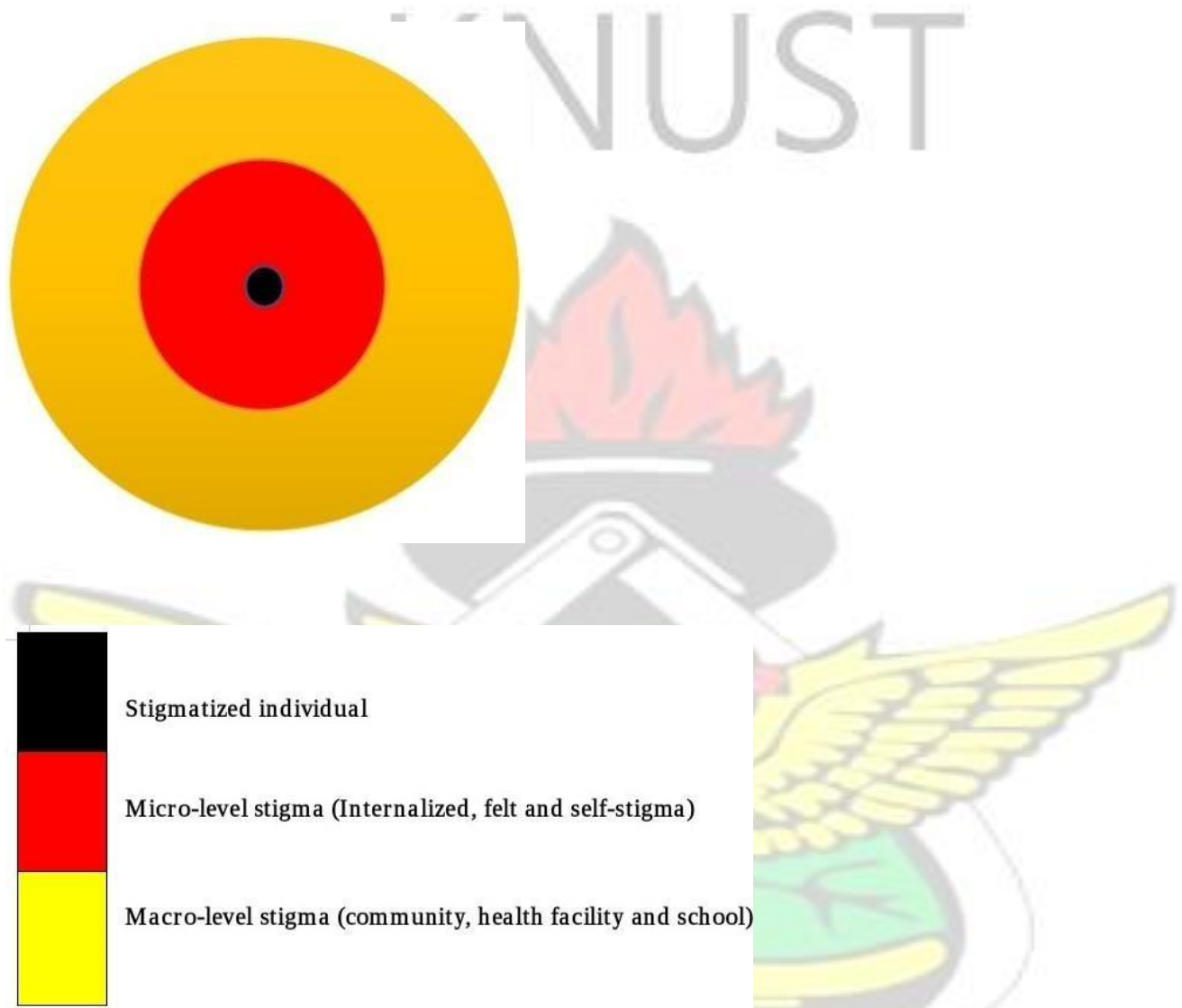
2.1.3 Levels of Social Interaction and Stigma

The discourse on the micro, meso and macro levels of social interaction have been in focus since the dawn of the social sciences. It is well established that human behaviors vary depending on the context and level of interaction (Serpa and Ferreira, 2019, Kapiriri et al., 2007, Barbour, 2017, Beirão et al., 2017, Van Wijk et al., 2019).

Particularly, sociologists have used these levels of analysis to provide comprehensive insight into social phenomena such as religion, racism, poverty, nostalgia, education and life course (Collins, 2011, Silverstein and Giarrusso, 2011, Clair and Denis, 2015, Jacobsen and Wilson, 2021, Jenkins, 2005, Boeren, 2019).

However, limited attempts have been made to use this multi-level approach to find out the differences and similarities in stigma experiences in varying social contexts and between different disease experiences. This is especially true for stigma in the skin NTDs, an area which remains to be benefitted through the use of holistic approach to provide evidence for effective management.

Figure 2.1 Conceptualization of levels of stigma along varying levels of social interaction



Researcher's construct, 2022

2.1.2 Skin NTD Co-endemicity

Co-endemicity of skin NTDs implies a geographical occurrence where more than one NTD is prevalent within a particular setting and relatively within the same time point. This may provide opportunities for successful integrated disease management within that locality (Cano et al., 2018; Noviyanti et al., 2015). Although some attempts have been made to compare stigma in different

health conditions such as tuberculosis, HIV and SARS, HIV, depression, hypertension and diabetes found in similar geographic settings (Mak et al., 2006, Wakawa et al., 2014). However, minimal attention has been given to investigating stigma within the Skin NTDs.

2.1.3 Buruli Ulcer

BU is a flesh wasting skin disease named after Buruli country, currently known as Nakasongola district in Uganda. After tuberculosis and leprosy, BU is recognized as the most common mycobacterial infection in humans, caused by microorganisms known as *Mycobacterium ulcerans* (Collinson, et al., 2020). The disease is clinically seen as papules, nodules, plaques, oedemas, and ulcers (Henry, 2020). Like other skin NTDs, BU is typically found in remote and rural areas where access to health care is limited.

A total of 33 countries in Central and South America, Africa and The Western Pacific region have recorded BU. Out of this, within 2002 and 2016, Africa was noted to bear 98% of the global disease burden, with a figure of 57, 500 cases (Tabah et al., 2019). West and Central Africa harbour majority of these cases with countries such as Ghana, Côte d'Ivoire, Benin, and Cameroon emerging as the four most endemic countries (Amoako et al., 2021a, Tabah et al., 2019). BU is particularly found in poor areas where there is limited access to water, health facilities and sanitation.

In Ghana, more than 46 out of 170 districts routinely record BU cases (Otoo et al., 2021). Amofah et al (2002), found that more than 11,000 cases of Buruli ulcer have been recorded in Ghana since the first case was recorded in 1993. Since then, the country records about 1000 cases every year (Ackumey, 2013).

Districts within southern Ghana such as Asante-Akim North district, Amansie West and Ga west have recorded some of the highest prevalence in the country (Amofah et al., 2002).

Over the years, scientists have been committed to improving the experiences of people affected by BU. Currently, a less painful and efficient treatment with oral antibiotics (rifampicin and clarithromycin) over a period of 8 weeks alongside wound management where necessary are recommended (Phillips et al., 2020). However, diseases detected in the late stage are especially associated with long term consequences including disability, socio-economic losses, mental health burden and poor quality of life (Amoako et al., 2021b, Amoako et al., 2021a).

Koka (2018) notes that, although the causative agent of BU is found in the same family as the organism that causes tuberculosis and leprosy, BU has received far less attention in comparison to these two diseases.

Largely, this narrative is not untrue for stigma in BU when compared to stigma in leprosy and tuberculosis. Although important milestones have been achieved by biomedical scientists, stigmatizing practices identified from different settings are likely to frustrate these efforts, as patients may be unable to access and retain the improved care as recorded in HIV (Sullivan et al., 2020, Sayles et al., 2009, Mbonu et al., 2009)

2.1.4 Yaws

Yaws is a disease of poverty caused by *Treponema pallidum subspecies pertenue*; a germ which targets the skin, bone and cartilage of the patient (Asiedu et al., 2014b). Yaws is a global health concern, and thrives in tropical and sub-tropical areas such as West Africa, the Pacific and South east Asia (Marks et al., 2015). The disease is highly prevalent under conditions of overcrowding, poor sanitation and inadequate water supply; situations which are characteristic of marginalized and vulnerable populations (Ben-Zeev, Young, & Corrigan, 2010; Bravo & Ezzedine, 2019). In the estimation of (Basing et al., 2020), about 84% of global Yaws cases are concentrated in Papua New Guinea, Solomon Islands and Ghana. The disease is transmitted through person-to-person contact, and is a major cause of suffering and significantly reduces the quality of life of patients. Yaws can lead to disability and disfigurement, especially when there is delayed or absence of medical treatment (Dofitas et al., 2020b).

This highly contagious disease affects children, typically below 15 years, targeting the skin, and bone. It causes painful and sometimes disfiguring lesions on the face, cartilage and soft tissues of the mouth. Yaws can be cured with a single-dose of oral azithromycin (Asiedu et al., 2014a).

Clinically, Yaws is a chronic skin disease and the earliest stage is the papilloma. In the absence of required treatment, this may ulcerate to give a round shaped wound with a raised edge. Yaws can also be in the form of squamous macules (scaly, thickened, or discolored skin patches) or palmar and plantar (holes, cracks or discoloration of the soles of the feet or palms of the hand) (2012).

Further delay or non-treatment of Yaws could lead to serious disabilities like gangosa syndrome; degenerative changes of the nose, throat (pharynx), and the roof of the mouth (hard palate). Bones in the limbs (forearm, fibula, tibia) could also swell, affecting joint function and mobility.

Global efforts to eradicate Yaws began in 1948, following the World Health Assembly's Resolution WHA 2.36(1949). In spite of some successes, total eradication has remained elusive (Asiedu et al., 2014b).

Following a successful break in transmission in India in 2020, the World Health Organization (WHO) aims to replicate this in 97 countries by 2023, 136 countries in 2025 and finally in 194 countries by 2030, leading to a complete eradication in all Yaws endemic countries.

In Ghana, although almost all regions have recorded Yaws cases, school children in the Eastern, Ashanti, Volta, Western and Brong Ahafo regions have recorded some of the highest disease burden in the country (Otoo et al., 2021).

In the observation of Dofitas (2022), the literature on Yaws has remained 'pharmacologic'. Much attention is being given to the disease presentations, risk factors and public health implications. Although this is a step in the right direction, the psychosocial component of this discourse has been neglected

2.2 Stigma Related Knowledge, Beliefs and Attitudes Towards Patients of Skin Neglected Tropical Diseases (Skin NTDS)

Globally, skin conditions constitute the fourth principal cause of nonfatal disease burden (Hay et al., 2014). Neglected Tropical Diseases such as lymphatic filariasis and scabies constitute the 4th and 5th causes of morbidity among the NTDs, with associated 2.02 million and 1.71 million years lived with disability respectively (Chandler and Fuller, 2018). Skin conditions in Skin NTD endemic African communities typically ranges from 26% to as high as 80% (Yotsu et al., 2018, Ogunbiyi et al., 2005, Hogewoning et al., 2013, Mahé et al., 1995, Komba and Mgonda, 2010, Murgia et al., 2010).

There have been accounts of stigmatizing attitudes and behaviours recorded towards people affected by Skin NTDs. Patients as well as caregivers often have to suffer a double burden with mental health effects associated with the skin NTD (Amoako et al., 2021a). Patients of podoconiosis and

other skin NTDs such as leprosy and Lymphatic Filariasis are stigmatized in all areas of their lives, ranging from inclusion in social functions, marriage, employment and in the leadership roles (Tora et al., 2018).

Although varying socio-cultural contexts may interpret illness and disease experience in a different manner, guided by culture, community knowledge about Skin NTDs have increasingly been recorded as important predictors of attitude and practices meted out to patients of such diseases (Kleinman, 1980). For example, Jopling (1991), maintained that the problem with leprosy is not the disease, but rather what people believe it to be. Consequently, it was found that beliefs about the diseases such as being hereditary, supernaturally caused, attribution to bad blood, curse, punishment for sexual offences, witchcraft, soul destruction, have led to significant stigmatizing practices towards patients and their care-givers or family members (Rao et al., 1996, Bekri et al., 1998, Scott, 2000, Wong, 2004, Try, 2006, White and Franco-Paredes, 2015, Bainsong and Van den Borne, 1998).

In some Hindu societies, Seddon and Seeley (2006) recorded the crucial role played by traditional and religious beliefs in perpetuating stigma against leprosy patients. The condition is interpreted in terms of punishment meted out to the sufferer for a grave misdeed perpetrated in previous lives, as such patients are to be blamed for the disease condition. Thus the sufferer alongside family members are deemed as deviants and ostracized from good society (Chang and Ochoa, 2019). Further, Shieh et al (2006) in an earlier study adds that patients may be rejected by their families and community members may mount pressure on the patient to vacate the community as similar to the findings of McCurry (2004) in Japan, where he reported that patients suffering from leprosy were subjected to forceful incarceration by the government, their only crime being the disease condition. In Morocco, patients with cutaneous leishmaniasis reported depressive disorder which led to the conception of suicidal thoughts, owing to a series of severe societal rejections suffered (Bennis et al, 2017).

In Africa, beliefs and attitudes towards patients of Skin NTDs are not any different. For instance, in Benin, BU is attributed to thievery, predisposing patients to further psychological distress in addition to the strain associated with the disease (Grietens et al., 2012). In Ghana, lymphatic filariasis is attributed to witchcraft, leading to the blaming and neglect of patients (Ahorlu et al., 1999).

While studying community knowledge and perceptions about BU in the Ga west district of Ghana, Koka (2018) found that, 36.7% of the study participants blamed the disease on witchcraft while 21% believed that victims were to blame for the disease condition for not taking good care of themselves. Additionally, while exploring the patient perceived causes and risk factors of Buruli Ulcer in Ghana, it was found that, 38% of participants attributed the disease to witchcraft, 15% to enemies, and 16% to not pouring libation (Anokye et al., 2018).

2.3 Effects of Stigma on Skin NTD Patients

Generally stigma has been associated with some implications for both sufferers and close associates.

2.3.1 Psychosocial Burden of Stigma

According to the Merriam Webster dictionary, psychosocial is relating social situations to mental health. Thus, psychosocial burden is evident when social factors pose treats on individuals' mental health, typically manifested in the forms of depression, anxiety, uneasiness and sadness.

In the assertion of Wojtyna et al (2017), skin diseases often alter the body image conceptualization and impact psychosocial health as well as well as Quality of Life (QoL) of patients. Likewise Neglected Tropical Diseases (NTDs), which are increasingly being associated with high levels of psychosocial burden for patients and their families or care-givers.

Closely associated with many Skin NTDs are outright community disapproval, demonstrated in exclusion from full societal participation, discrimination, reduced access to services, diminishing access to in-come generating opportunities, education and employment opportunities (Wojtyna et al., 2017, Litt et al., 2012, Bailey et al., 2019, van Wijk et al., 2021). Due to deep-seated stigmatizing attitudes within most communities, affected individuals also experience self-stigma, manifested in low self-esteem, suicidal ideation, and avoidance of interactions with nonaffected community members (Tora et al., 2014).

In their systematic review of stigma in Skin NTDs such as buruli ulcer, lymphatic filariasis, onchocerciasis, human African trypanosomiasis, chagas disease, leishmaniasis, podoconiosis, and trachoma, Hofstraat and van Brakel (2016) found that stigma associated with the diseases negatively impact the social relationship, work, education opportunities, suicidal ideation,

depression, anxiety and health outcomes. These, contributed to psychosocial dysfunction or changes in the emotional and social functioning of patients and their close associates.

While studying the beliefs and attitudes towards BU in Ghana, Stienstra et al (2002) found that the disease posed a number of challenges for marriage sustainability and the maintenance of sexual relations. Male participants voiced that they are unlikely to engage in sexual activities for fear of revealing the condition to sexual partners. Some female participants also expressed that their inability to find husbands is due to the disease as most men fear contacting the disease and hence do not want to come close to them (Stienstra et al., 2002).

Similarly in Eastern Columbia, patients of Chagas disease reported mental distress in response to disease progression and its incurable nature (van Wijk et al., 2021). Additionally, having leprosy was found to diminish marriage prospects and negatively affected the roles and positions of married women within their households (Le Grand, 1997).

Additionally, children affected by scabies, another Skin NTD, are not spared as severe itch, disfigurement and discomfort associated with the disease leads to significant emotional distress and poor quality of life (Cox et al., 2021). Adult skin NTD patients reported social isolation alongside expulsion from family and community activities (Walker et al., 2017).

Stigma related stress is posited to be specifically daunting as the stress contributes to poorer health outcomes and summons other co-morbid conditions such as mental health burden (Link and Phelan, 2006). Thus, social isolation, anxiety, exclusion from familial and other forms of social relationship are common psychosocial burdens constantly associated with the skin NTDs (Walker et al., 2017, Cox et al., 2021). However, Bennis et al (2018) argues that psychosocial burdens of diseases could be time dependent, thus while some stigmatizing tendencies could be maintained, others may change positively or negatively in the course of time, regardless of the state of the lesions.

2.3.2 Socio-Economic Burden

The outcomes of skin NTDs are further worsened by stigma, contributing to a drop in social and economic opportunities among affected persons (Weiss, 2008a). In the estimation of Houweling et al (2016), the impoverishing effects are further augmented among poor and vulnerable

communities where physical activity such as subsistence farming, trading and fishing constitutes the the main economic activites. Additionaaly, the absence of social security such as inurance against ill-health and disability worsens the experiences of the affected people, their care-givers and family members. Thus, creating a cylcical relationship between skin NTDs and poverty.

Further, health related expenses and time lost to productive activities have been recorded in skin diseases such as leprosy, podoconiosis and leishmaniasis (Tembei et al., 2018, Uranw et al., 2013, Lenk et al., 2016, Alonso, 2010). Additionally, the financial cost, inclusive of direct and in-direct costs (surgery, drugs, hospitalization, laboratory tests, ; transportation to facility, amenities, feeding) and time spent in health seeking poses a significant impoverishing threat to most patients and their families (Chukwu et al., 2017). This is further amplified when cases are sent to the health facilities in progressed stages, meaning more time and resources have to be invested (Owusu, 2012). Further, the disability, disfigurement and death that may arise from this poses a more serious bankrupting effect.

2.3.3 Health Seeking Behaviour

Stigma in skin NTD has commonly been attributed to have a negative association with patient health seeking behavior, resulting in late-stage disease presentations which leads to serious consequences, including mental health implications (Chang and Ochoa, 2019). Symptoms of skin NTDs may be concealed out of fear of societal rejection or isolation (Alonso, 2010, Bennis et al., 2018, Bennis et al., 2017c, Al-Kamel, 2017, Tchounkeu et al., 2012, Khatami et al., 2018). Further, Alonso (2010) maintains that the absence of education about drug side effects contributes significantly to failed mass drug administration activities, However, other evidence suggests that other factors such as apprehension of societal disease recognition and exclusion may encourage patients to end treatments which are accompanied by visible presentation of disease (Bainson and Van den Borne, 1998, White, 2008).

Late-stage presentation to health facilities has been associated with more time consuming and expensive care, temporal or permanent physical disabilities and impairments, leading to further economic and social implications such as loss of job, inability to go to school, loss of self-esteem, break in social relationships such as marriages and mental problems (Tsutsumi et al., 2004).

While conducting a gender sensitive study to find the differences between male and female leprosy patients in Nigeria, Peters and Eshiet (2002) unveiled that female patients who have a longer interval between first and subsequent disease presentation are more likely to report to health facilities late and consequently suffer more complications and deformities (Peters and Eshiet, 2002),

Moreover, evidence from varying settings show that, gender plays an important role in health seeking behavior for persons with stigmatizing diseases. Studies conducted in India on leprosy revealed that women are more likely to hide their symptoms as compared to men for fear of social consequences (Vlassoff et al., 1996, Rao et al., 1996, Le Grand, 1997). Similarly, Kumar et al. (Barnett et al.), found female leprosy patients less likely to adhere to treatment due to the fear of social consequences.

Findings from Northern Indian, Paraguay and Nepal show that although government supported treatments for skin NTDs may be available free of charge, most patients prefer to use the services of local private practitioners, as patients preferred to keep their conditions from public scrutiny and subsequent rejection. Some patients are also reluctant to travel to far places to seek care for the fear of recognition. Additionally, patients who are already on treatment may also relent in the face of rejection (Barrett, 2005, Nicholls et al., 2003, Heijnders, 2004, Rafferty, 2005, Boonmongkon and Group, 1994, Paz et al., 1990, Stienstra et al., 2002).

2.3.4 Academic Achievement

Although some scholars have mentioned the impact of Skin NTDs on academic work, most have been brief and in passing, not investigating the subject in a thorough manner (Engelman et al., 2016, Ukwaja et al., 2020, Yotsu et al., 2020, Mphande, 2020).

However, few evidence available suggests a serious consequence. In BU, findings from central Cameroon showed 88% of hospitalized BU patients who are children had lost some schooling time. Of this number, 68% had lost a median of one year of schooling and 20% had abandoned schooling completely due to the disease (Grietens et al., 2008). Similarly in Ga south district in Ghana, findings from a study in 2013 revealed that 19 BU patients lost a total of 365 school days. Additionally, although most children outpatients proceeded to school after receiving care, about 33% of them reported to school late. Further, it was noted that in comparison to out-patients,

hospitalized BU patients who are students lose more school days. It is argued further that being hospitalized is linked to late health seeking behavior and hence the need for intensive care (Amoakoh and Aikins, 2013).

Although stigma recorded for some skin NTDs, little attention has been given to the impact it has on academic achievement. Moreover, evidence from Yaws suggests that affected children are likely to miss school as a result of bullying from peers Dofitas et al. (2022).

2.4 Coping Strategies in Skin NTD stigma Management

Although it is widely acknowledged that stigma is associated with the Skin NTDs, little attempt has been made to investigate coping strategies used. Meanwhile, coping strategies have been found helpful for patients of other chronic conditions and even care-givers, contributing to a reduction in stress, anxiety, depression, burnout, behavioral and psychological symptoms (Li et al., 2014, Chun et al., 2007, García-Alberca et al., 2012). This empowers the stigmatized persons to minimize, tolerate, avoid or overcome their stressors (Folkman and Lazarus, 1980, Lazarus, 1993, Tora et al., 2011).

Generally, there exists broad categorizations of coping strategies (problem-focused and emotion focused strategies). When faced with a stressful situation, the choice of a strategy plays an important role in health consequences of the individual.

Problem-focused strategies are inherently aimed at resolving or changing the stressful situation (Carroll, 2020). On the other hand, emotion focused strategies are reactive and focused on response given to the stressful situation. Problem-focused strategies are considered more efficient and associated with higher self-esteem, meanwhile emotion-focused strategies are closely associated with poorer self-esteem and higher levels of poor mental health and emotional toll or stress (Noh and Kaspar, 2003).

Notwithstanding, the choice of a coping strategy do not solely depend on the personal resources of the discriminated, nor the nature of the stressing agent, but also on the associated culture and social context involved (Lazarus, 2000, Krieger, 2000, Gee, 2008) .

Further in the coping literature, strategies have been separated into broad levels; active and avoidant coping strategies. Active coping strategies help reduce stress for the stigmatized and also has a positive alteration to the nature of social relationship between the stigmatized and the person stigmatizing (Folkman and Lazarus, 1980, Holahan and Moos, 1987, Allen-Meares and Garvin, 2000). Whereas avoidant coping strategies negatively impact the individual by reducing contact with healthcare, social support, employment, education and other important social needs (Tora et al., 2011). Limited attention has been given to how patients cope, however, the way patients cope contributes to significant negative or positive effects on health outcomes (Lazarus, 1993, Folkman and Lazarus, 1980).

2.4.1 Concealment with Clothing

While adaptive clothing helps to promote the independence, easy mobility and movement of disabled or handicapped people, clothing has recorded further uses in the management of stigmatized identities. Here, clothing is used to hide/camouflage bodily disfigurements to take away attention from one's 'imperfections' from public scrutiny (Frith and Gleeson, 2008). Although some authors have advanced for the use of clothing to veil disability in all manner possible, this is generally contested, especially by social model theorists who argue that the disability is not a problem, but rather the stigmatizing attitude towards the disability (Wilkinson and Carter, 2016). While investigating the emotional difficulties faced by patients of lymphatic filariasis, Abdulmalik et al (2018) found that some patients resort to covering affected legs with trousers and other clothing to divert attention from the condition. This enables them go about normal activities, corroborating Goffman's (1963) argument that clothing helps the individual pass off as 'normal', hence limiting the stigma an unveiled person with bodily defect may face.

2.4.2. Religious coping strategy

Religion is commonly noted as a coping strategy for varying stigmatizing condition, ranging from severe and chronic conditions such as cancer, renal diseases, heart diseases, leprosy, HIV and COVID-19 to stigmatized orientations such as transgender and homosexuality (Mizock and Mueser, 2014, Naemiratch et al., 2022, Shilo et al., 2016, Lauricella et al., 2017, Lee et al., 2014, Ai et al., 2007, Askari and Doolittle, 2022). With the exception of a few instances, religion is often posited as a positive strategy. Religion denotes 'a fighting spirit' while a lesser reliance on religion

suggests a ‘hopelessness’ about one’s condition (Cassibba et al., 2014). In arthritis, a link was found between beliefs about causation and coping, thus, patients who perceived supernatural causation were more likely to depend on a supernatural source for healing or making meaning of the disease condition (Niu et al., 2011). These strategies have been shown to give a ‘sense of control’ to the individual in addition to giving the endurance to positively cope with the stressful condition (Ayten et al., 2012, Aflakseir and Mahdiyar, 2016, Latifnejad Roudsari et al., 2014). Women were especially found to resort to religious coping strategies when faced with stressors such as infertility as compared to men (Sharma et al., 2014).

2.4.3 Confrontational Coping

In severe stigmatizing conditions such as HIV and cancer, findings of confrontational strategies have been shown. Here, patients directly challenged various forms of stigma, whether blatant or subtle. Attempts of other people to tease, exclude, ignore or isolate patients are met with opposition. While studying racial discrimination and sexism of women, Chaney et al (2015) argued that this strategy can come in handy in the protection of the women’s health and wellbeing and thus, an important health promotion tool useful for reducing prejudiced behavior.

It is posited that, adequate social resources, education and frequent sensitization programs empower discriminated people to confront stigma, instead of passive acceptance, which is noted to be a maladaptive strategy (Sun et al., 2007). However, this conflicts with the assertion of Silva et al (2018), where confrontation falls in the same group with other ‘dysfunctional; coping mechanisms such as denial, behavioral disengagement, self-distraction and substance use (Silva et al., 2018). Meanwhile, confrontation has been recorded as particularly useful in the management of life-threatening diseases (Rodrigue et al., 2000). In HIV and breast cancer, it was found that patients who confronted stigma by speaking up or responded to the disease with a ‘fighting spirit’ recorded decreased disease progression and better outcomes compared to patients who accept stigma or were helpless or in a state of denial (Mulder et al., 1995, Greer et al., 1979, Mulder et al., 1992). In other findings, the confrontation fostered good social interaction in the work environment by promoting psychosocial forgiveness for both parties (Mulder et al., 1995, Hershcovis et al., 2018).

2.5 Theoretical Perspective

In both macro and micro level analysis of stigma, sociologists and other social scientists have propounded many theories, Goffman's theory of stigma, Framework Integrating Normative Influences on Stigma (FINIS), labelling theory, social psychology of prejudice and discrimination, limited capacity model of media influence are exemplified (Pescosolido Et Al., 2008, Goffman, 1997, Hayward And Jenifer A. Bright, 1997, Link and Phelan, 2013) However, Goffman's theory of stigma has been selected to guide this work.

2.5.1 Goffman's stigma theory

The luminary work of the American sociologist, Erving Goffman, in his book; *Stigma: Notes on the Management of Spoiled Identity* (1963) has made waves and continued to remain relevant to the stigma literature. To Goffman, stigma discredits and reduces the 'whole' person to a 'tainted' or 'discounted' person, leading to a spoil in identity (Goffman, 1963). In this conceptualization, other individuals or groups who do not bear this 'discrediting' characteristic are said to be 'normal' and full human beings as opposed to the 'flawed' and 'compromised' individuals bearing stigma symbols (attributes that makes them different from 'normal' people).

Collective conscience then provides a guide by which symbol bearers (prostitutes, negroes, homosexuals, blind, members of a racial minority, ex-mental patients.) are separated and set aside for differential treatment. The stigmatized persons typically dislike discriminatory treatment. He is therefore responsible for managing or coping with his new identity, typically through attempts to conceal 'stigma symbols' (DeFleur, 1964).

The process that culminates in stigmatization, Goffman (1963) asserts, begins in the mind where humans, in a bid to order their social world learn to create categories with associated attributions. Thus, the 'tedious' process of learning and relearning how to treat new people is shortened and eased. In categorizing, individuals who fall outside one's stereotype are likely to end in a stigmatized compartment reserved for the worst; 'dangerous, weak and bad'. Consequently, such people are 'reduced' in the mind and moved from the position of a 'whole' person to a 'tainted or discounted' person. Until such individuals are reclassified up and out of this compartment, they are subjected to discriminatory treatment, contributing to a significant reduction in life chances.

Goffman proceeds to outline three broad forms of stigmas; tribal, moral and physical stigmas. Tribal stigma comes from membership of an unapproved group; nation, religion, race etc. Moral stigma on the other hand reflects flaws in character, typically manifested as dishonesty, treachery, domineering, unnatural passions, weak will, etc. which can be gleaned from existing records or histories such as suicidal attempts, homosexuality, unemployment, addiction, mental disorder, radical political behavior and alcoholism. Next is physical stigma, manifested by bodily abominations (all forms of physical disability, disfigurements and defacements).

Additionally, Goffman discusses stigma within the context of familiarity. He proposes a dialectical perspective where there is first deepening of stigmatizing tendency with continued exposure to the individual and secondly a possibility of developing more tolerant and accommodating demeanor upon continued exposure to the stigmatized person(s). In the first instance, he argued that, familiarity necessarily breeds and sustains contempt. Here he alludes to stigmatizing propensities within neighborhoods where stigmatized tribes live together with 'normal' people. Thus, in spite of living in such close proximity, 'normals' manage to sustain their prejudices, especially in the presence of long-lasting and close relationships with the prejudiced group.

In his second argument, 'normals' learn to accept the abnormal over time. Thus, neighborhoods or individuals who are in constant contact with disabled or disfigured people eventually learn to see them beyond their attributes, bringing some form of 'normalcy' to the social interaction.

Within Goffman's treatise is also the subject of information control where individuals bearing stigmatized attributes cleverly conceal such attributes to pass off as 'normal', in a bid to reap the rewards of being 'normal'. This he continues, may however be revealed to selected intimate associates or the stigma bearer faces an intense guilt that comes with withholding such information. In relating this theory to the current study, the form of stigma evidenced by bodily abominations in Goffman's proposition is linked with stigma in skin diseases such as BU and Yaws. Here, the disease condition alongside any disability, disfigurements or defacements that come with them are posited as discreditable attributes by which patients or past patients of BU and Yaws are treated poorly, such as exclusion from social arrangements (marriage, leadership and employment) (Tora et al., 2018). Patients are therefore reduced from being 'normal human beings', to taking on a disease identity, consequently 'normals' relate with them based on this new identity.

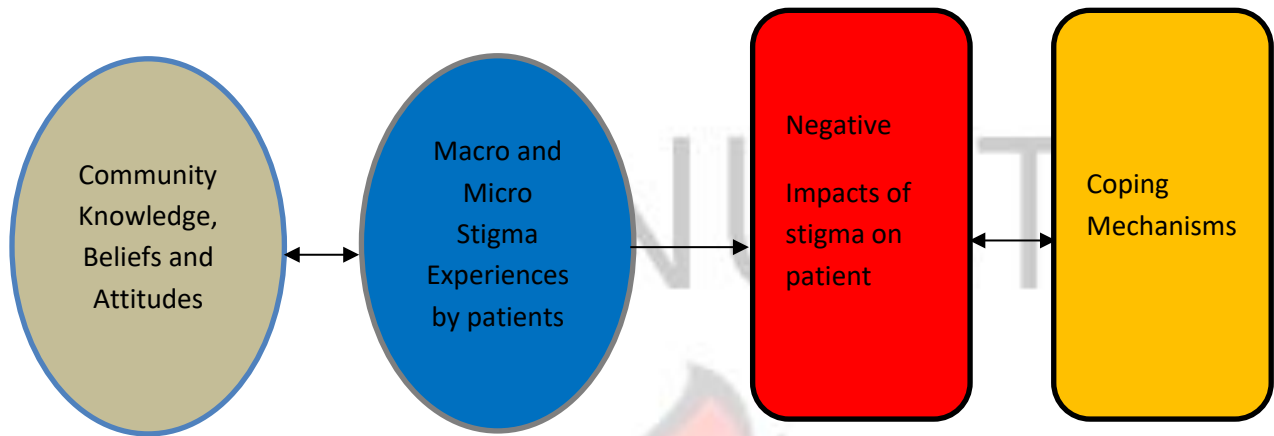
Also, in reference to Goffman's next proposition where the stigmatized person stands the risk of being stigmatized or accepted by those in constant interaction, it is posited that active and former patients of skin NTDs such as BU or Yaws living in endemic communities where many such disease-associated disabilities and disfigurements are seen are, will be exposed to lesser stigmatizing attitudes compared to patients who move to communities where there is no or limited knowledge about such diseases.

Conclusively, Goffman proposes that stigmatized persons conceal their stigma symbols to pass of as 'normal'. Consequently, the study examines the strategies that patients manage stigma associated with BU and Yaws.

2.6 Conceptual Framework

Figure. 2.2 Conceptual framework on interplay between community role in stigma enacted, experiences, impacts and coping strategies adopted by patients





Researcher's construct, 2022

The Conceptual framework above explains the role of the community (Knowledge, Attitudes and Beliefs in reinforcing stigma together with macro and micro experiences of stigma by patients. In the literature, these are likely to have harmful effects on the individual. These may have an impact on the individual, leading to the adoption of coping mechanisms or strategies which may be functional or dysfunctional to the individual and or his associates



CHAPTER THREE

RESEARCH METHODS

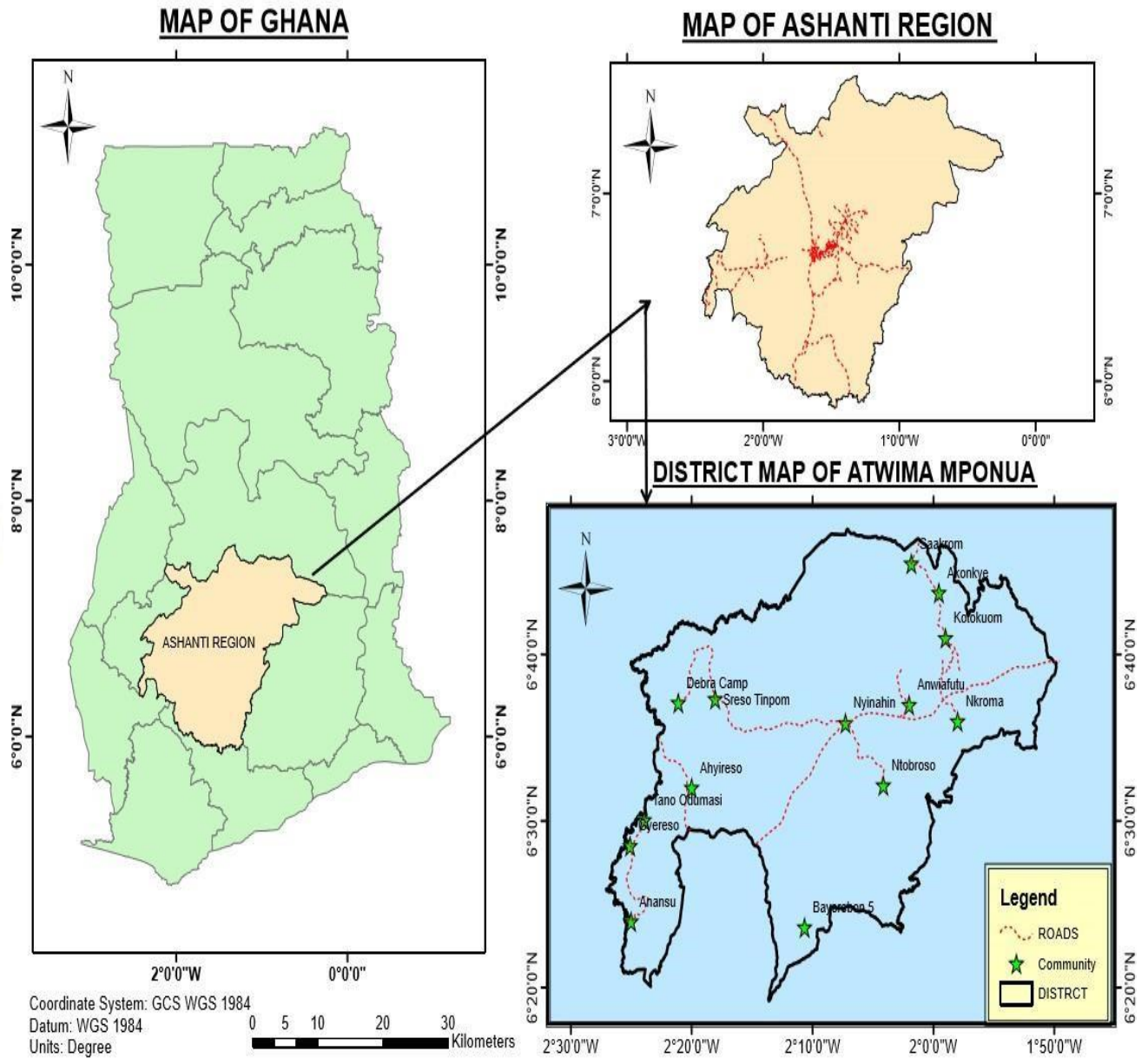
3.0 Introduction

This section of the work addresses the overall approach used to understand the research problem. The research design, study population, methods of data collection, analysis as well as ethical consideration are presented.

3.1 Study Area

Atwima Mponua is one of the most populous districts within the Ashanti region with a total population of 155,254 comprising of 80,235 males and 75,019 females according to the 2021 Ghana population census. In the words of Ampah (2016) the first BU case search in Ghana in 1999 identified the Offin river valley as one of the most endemic foci in the country. Some communities in Atwima Mponua are found along this river, which is closely associated with *M. ulcerans*, the causative organism for BU. Additionally, the district has also been counted as endemic for Yaws as several cases are recorded yearly, the co-endemicity of both BU and Yaws within the Atwima Mponua district, provides a unique opportunity to study stigma which is a social construction associated with the two diseases in the same population with similar socio-cultural characteristics. The district, being the second largest in the Ashanti region of Ghana is situated within the south western corner, covering an estimated area of 1883.2 square kilometers, thus 7.7 % of the region. A total of 310 communities are found within the district. Although the area has increasingly been recording BU and Yaws more recently, there is a clear absence of accurate information on the true nature of the prevalence as the area remains largely underexplored.

Figure. 3.1 Map of Atwima Mponua and surveyed communities



3.2 Research Design

The study adopted a cross-sectional research design, using a concurrent parallel mixed method. The research had two components, thus the use of face-face interviews with patients and a second component, a community survey involving community members in endemic communities. This means that, both quantitative and qualitative data was collected within the same time frame, which was then integrated in the interpretation of overall results. The use of quantitative research technique allowed the researcher to obtain results that may be generalizable to the district due to the presence of relatively similar socio-cultural attributes (Dowd, 2019). On the other hand, qualitative research technique was used to collect non-numerical data and to solicit in-depth information on the stigma experiences, effects and coping strategies, used by patients and past patients in managing stigma (Miles and Huberman, 1994, Weil, 2017, Richard, 2013). The use of mixed methods research approach is justified in the accumulated strength that becomes available to balance the weaknesses of qualitative and quantitative research (Bryman, 2004).

Specifically, the concurrent mixed-methods approach was used as a result of the complexity of the identified research questions. There was the need to use both words and figures which tend to combine inductive and deductive thinking to unveil the holistic stigma experiences and the probable causes of the experience. For instance, stigmatizing knowledge, attitudes and practices of community members will be quantified with the help of figures, which is characteristic of quantitative methods, while past patient perspective will be gathered using qualitative method to solicit individual stigma experiences.

3.3 Philosophical Foundations

The epistemological and phenomenological philosophical underpinnings have been selected for the purposes of achieving the research objectives of the study. Epistemology focuses on the theory of knowledge and the ways by which knowledge is gathered from available sources. Within this umbrella, the positivist stand-point has been adopted to provide evidence on the community knowledge, attitudes and practices related to BU and Yaws which constitute precursors of stigma. This approach has been selected to provide a robust and generalizable evidence which can be replicated within similar contexts.

Phenomenology, propounded by Edmund Husserl highlights the key role of the human consciousness and the role it plays in shaping individual experiences. This orientation gives accounts of lived experiences of the 'life world', highlighting the use of qualitative methods such as interviews, focus group discussions and participant observation to gather 'deep' information from research participants (Ashworth, 1997, Lester, 1999). This philosophical orientation has been selected as it gives the researcher the freedom to recount the subjective experiences of stigma, effects and coping among people affected with BU and Yaws.

3.4.1 Study Population and Target Group

For the qualitative component of the study, the population includes the total number of people in the district who have been affected by NTDs in the past or currently. The target group constitutes those affected by either BU or Yaws. Due to the absence of previous research in the district, the NTD prevalence in the district remains largely unknown. However recent anecdotal evidence points to a substantial burden.

The population for the quantitative component includes community members in the Atwima Mponua district. However, the target group constitutes members who have either seen or heard about BU or Yaws.

3.4.2 Sample Size and Sampling Technique for Quantitative Data

The quantitative component of the study was achieved by soliciting the views of members of Buruli Ulcer and yaws co-endemic communities within the Atwima Mponua District. The Krejcie and Morgan (1970) formula for sample size calculation which proposes that a sample of 384 from a total of one million is representative and therefore appropriate to generalize findings from the sample to the total population. Using this formula and guided by the total population of the district, 384 people were sampled to respond to the study questionnaire. Community members in selected communities who consented to the study therefore qualified to partake in the study.

To partake in the study, inclusion criteria were set. First, the prospective participant was required to be an active patient of either Yaws or BU, clinically confirmed through detection of *Mycobacterium ulcerans* using PCR test for buruli ulcer and the DPP test to identify *Treponema pallidum* for Yaws. On the other hand, past patients were also included to provide nuances in

stigma experiences before, during and after the disease. Current patients were met in the hospital on clinic days to conduct interviews. However, past patients were met in the communities or in nearby health care facilities, depending on the availability of participants.

Past patients of BU and Yaws who met the inclusion criteria of being healed for not more than two years were therefore purposively selected to share experiences of stigma, the impacts and strategies of coping. To attain data saturation, additional past and active patients within surrounding endemic districts such as the Ahafo Ano North district in the region were also recruited to share their experiences as data saturation could not be attained solely from participants from the main study district.

Thus, participants for this component of the study were recruited from Atwima Takoradi in the Atwima Mponua District, Ahafo Ano North District and also patients recruited during the Skin Health Africa Research project (SHARP) conducted in Ghana and Ethiopia by the London school of Health and Tropical Medicine (LSHTM) between 2019-2024.

Data for both components of the study was collected within a two-month period (June-July, 2022). Research Assistants from the Skin NTD team in KCCR were recruited and trained using the study tools to facilitated data collection.

3.4.3 Selection of Participants for Qualitative Data and Eligibility Criteria

Operationally, a BU or Yaws active patient in this study is someone who has been clinically confirmed through detection of *Mycobacterium ulcerans* using PCR test for BU and *Treponema pallidum* subspecies *pertenue* using the DPP test for yaws. Meanwhile, a past patient is someone who has been diagnosed within the past two years, treatment and declared clinically healed.

Furthermore, age criterium was set to ensure coherence in recounted experiences, the main caregivers of active and past patients below 9 years were interviewed. However, participants between 10-17 years capable of sense-making were directly interviewed after they signed assent forms and their legal guardians also signed assent forms. Active and past patients who are 18 years and above were directly interviewed after they consented and signed the informed consent forms.

3.5 Sources of Data

Primary data for the study was gathered through interviews with current and past patients. Furthermore, a community survey in selected communities within the study district provided additional data to achieve other study objectives.

Secondary data from articles, journals and other electronic sources were important in complementing the primary data and situating the study within existing findings.

3.6.1 Data Collection Methods

Qualitative data

Data for this component of the study was collected through in-depth interviews using a semistructured interview guide. This approach is flexible and allowed for probing, to gain access to indepth subjective experiences, while also ensuring that the research interaction is guided and focused to the research objective. Also, the approach solicited comparable accounts of stigma from study participants as the set of questions in the interview guide were addressed by all participants. This helped to find various nuances (McIntosh and Morse, 2015)

Quantitative data

On the other hand, questionnaires, having open and close-ended questions, input into redcap (Research Electronic Data Capture) was used to collect quantifiable data from community members through a community survey. This approach was particularly useful in soliciting generalizable information from study participants.

3.6.2 Data Collection Procedure

This process began with application for an introductory letter from the Department of Sociology and Social Work, KNUST. This aided the community entry process where the research objectives and procedures were officially out doored and explained to community leaders who assured the researcher of communal cooperation and willingness to partake in the study. After this, participants for the quantitative and qualitative study were recruited using different approaches

Qualitative

Participants for this study component were purposively selected using health facility records data to follow up on prospective study participants. This non-probability sampling method is used to identify participants who are most likely to provide useful and appropriate information for achievement of study objectives (Kelly et al., 2010, Robinson, 2014, Rai and Thapa, 2015).

Quantitative

The multi-stage sampling technique was used in the quantitative component of the study. First, geographical positioning aided the partitioning of the 310 communities in the district into four clusters. Next, 4 communities were chosen at random from each of these 4 clusters, totaling a number of 16 communities included in the study as primary participants. Subsequently, simple random technique was used to identify the secondary participants, thus 24 community members from each community to respond to the study questionnaire. This added a total of 384 participants, from 16 communities within the Atwima Mponua District.

3.6.3 Data Management

Quantitative data was collected using a Redcap based questionnaire (redcap, University of Vanderbilt version 5.20.11), hosted at School of Medical Sciences-KNUST electronic data capture system. The data was then exported to excel, cleaned and saved in cloud storage upon completion of analysis using SPSS version 26. On the other hand, audio records of the interviews taken on a mobile audio device was also uploaded in cloud storage alongside the transcripts and the coding frame generated.

3.7 Data Analysis

Qualitative data

Interview data was translated from the local language (Twi and Krobo) and transcribed verbatim into English and reviewed. Afterwards, the first coding process was done to generate first level segments emanating from the data using QDA miner lite (version 4). This was reviewed further by supervisors to ensure consistency and credibility. Segments were then merged and refined into 3

broad thematic areas based on study objectives. Remaining segments were then coded, refined and generated sub themes under various themes.

Quantitative data

This data was taken using the redcap data manager. This was extracted to excel and then to a data analysis software SPSS (version 28). Descriptive statistics such as ratios and percentages were run to compare results for Yaws and BU. Further, relationship between socio-demographic variables as well as other independent and dependent variables were assessed using the chi-square tests. Additionally, multivariate analysis, and logistic regression were run to determine the relationship between variables.

3.8 Validity and Reliability

Study tools (interview guide and questionnaire) were both pretested in a recognized endemic district in southern Ghana (Upper Denkyira East) after which required minor revisions were made. For example, the quantitative tool which originally sought to measure the community Knowledge, Attitudes and Practices (KAPs) were refined to measure the community Knowledge, Beliefs and Practices (KBPs). Thus, attitudes were replaced with beliefs as these were much prevalent and played a significant role in influencing the practices towards patients in the community. Also, some questions in the interview guide were rephrased to make more meaning and better capture the experiences of patients.

This process helped refine the tools to guarantee the access to quality data necessary to attain study objectives. Also, the use of both quantitative and qualitative methods served the purpose of triangulating findings as different strategies were used in each component, ensuring consistency and a holistic account of the research problem.

According to Multon and Coleman (2012), the reliability of an instrument could be determined using the following rule of thumb: 0.90 and above (high), 0.80-0.89 (very good), 0.70-0.79 (good), 0.60-0.69 (adequate). Based on this criterion, the reliability of this instrument was estimated to be: 0.694.(n=78)

3.9 Ethical Consideration

Ethical approval was sought from the institutional review board of the Noguchi Memorial Institute for Medical Research, NMIMR (FWA00001824).

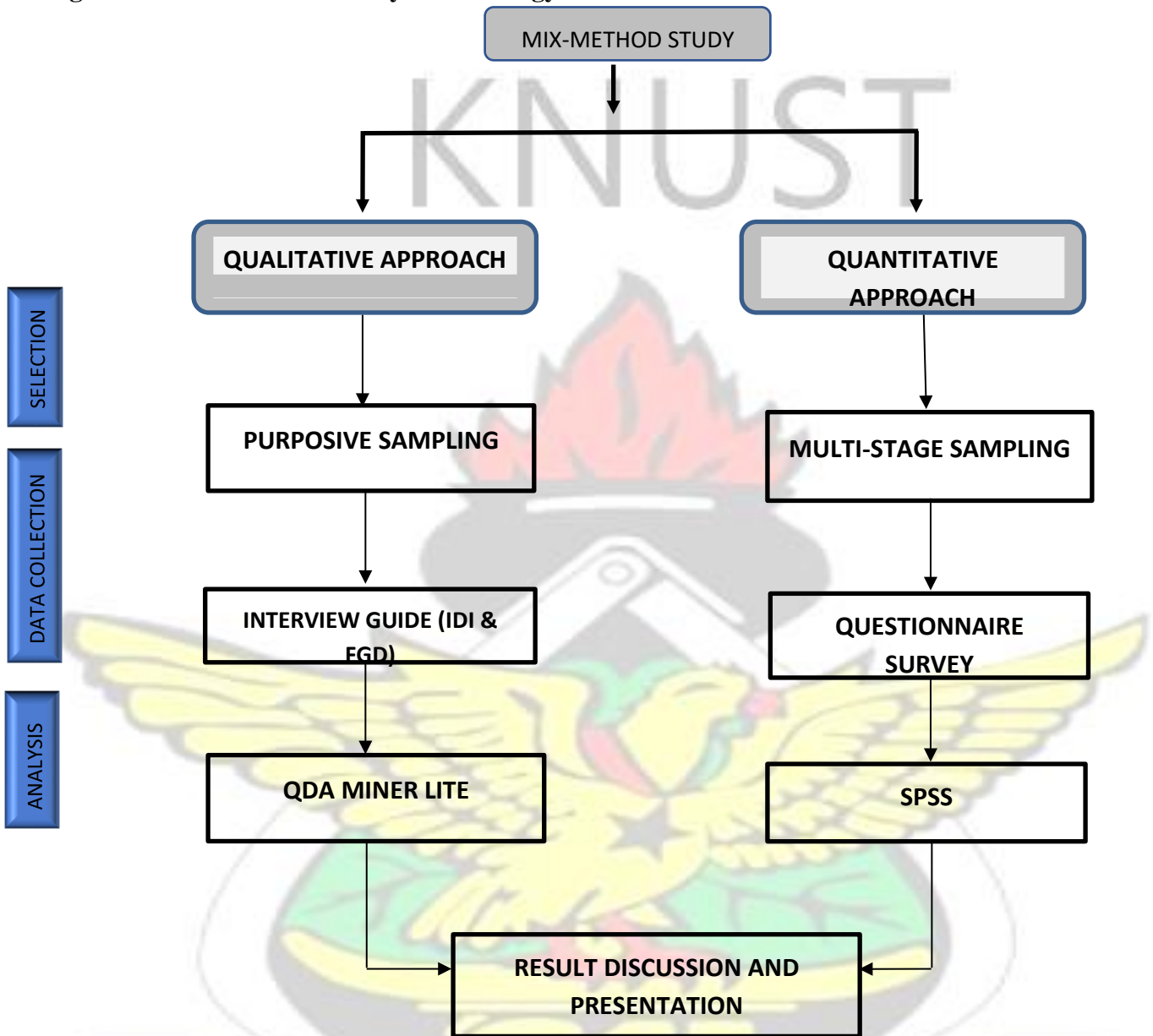
Additionally, written informed consent forms were signed by participants who partook in interviews who were 18 years and above. Assent forms were signed by interview participants above 13 years in addition to consent forms signed by legal guardians. Oral consenting was solicited from community members who partook in the community survey. Furthermore, written consent from legal guardians of interview participants below 18 years was sought. Confidentiality, privacy and anonymity are key principles which guided the study.

3.10 Limitations and Challenges encountered

The study faced a number of limitations which had to be navigated to achieve the study objectives. First, due to the sensitive nature of the subject, getting BU and Yaws past and active patients to recount their experiences of stigma was challenging. To overcome this, the researcher assured participants of privacy, anonymity and confidentiality which made participants comfortable to recount their experiences.

Also, due to bottlenecks in patient record keeping and changes in residence of past patients, the required number of interview participants (former BU and Yaws patients) who met the inclusion criteria could not be recruited solely from the Atwima Mponua district within the study time frame. The researcher had to fall on another district (Wassa Amenfi East) to recruit participants to partake in the qualitative component of the study.

Figure. 3.2 Flow-chart of study methodology



Researcher's construct, 2022

CHAPTER FOUR

DATA PRESENTATION

4.0 Introduction

This chapter presents the data that was collected on the field. Data was collected in two phases, quantitative and qualitative components. Results are presented as such.

4.1 Quantitative Data

In this component of the concurrent mixed methods study, a cross-sectional survey was conducted to find community knowledge, attitudes and beliefs about BU and Yaws. The community survey was completed by a total of 393 community members living in 16 co-endemic communities within the Atwima Mponua district in the Ashanti region of Ghana. All participants were asked to respond to either BU or Yaws exclusively, depending on their knowledge and familiarity with the diseases. In all, one hundred and ninety-two (192) participants provided responses on Yaws, likewise, 192 responded on BU and 9 had no idea about either BU or Yaws even though they currently live in the district. Communities surveyed include: Naagole, Anwiafutu, Nyinahin, Tano-Odumase, Gyeresu, Anansu, Kotokuom, Saakrom, Nkromah, Sreso-Timpon, Debra Camp, Ahyiresu, Ntobroso, Achiase, Akonkye and Bayerebon number 5.

Descriptive analysis was used to summarize the characteristics of study participants. Data was presented as frequencies/percentages. Associations between variables were assessed using chisquare/ fisher's exact test. Regression analysis was used to ascertain association between knowledge and stigmatizing attitudes.

4.1.1 Socio-Demographic Characteristics of Participants

As shown in table 4.1.A and 4.1.B below, a total of 384 participants completed the community survey. The participants consisted of 203 (52.8%) males, and 131 (34.1%) were aged \geq 16-30 years, followed by 126 (32.8%) aged \geq 31-45 years. Primary education was dominant 206 (53.65). Most participants 195 (50.7%) are either single or married 170 (44.3%). Agriculture 134 (34.8%) dominated economic activities followed by small scale mining and related activities 125 (32.5%). Akans 273 (71.1%) and Mole-Dagbani (21.1%) dominated other ethnic groups such as Ewe 12

(3.1%) and Ga-Adangme 8 (2.1%). The minimum age recorded was 11 years, and a maximum age of 76 years.

There was no significant difference between socio-demographic characteristics such as age, marital status, religion, occupation and ethnicity of participants who provided responses on BU and Yaws. However, the gender and educational status of varied significantly for participants who provided responses on BU as compared to those who responded on Yaws. Gender recorded a Pvalue of (P=0.003) as more males (116) were recorded for BU, whereas more females were recorded for Yaws (181).

Table 4.1 A Socio-demographic characteristics of survey participants stratified by respondents for BU and Yaws questions

Variables	BU (n = 192)	Yaws (n = 192)	Total (n = 384) (%)	P – value
Age group				0.127
1 – 15	15	23	38 (9.90)	
16 – 30	73	58	131 (34.11)	
31 – 45	66	60	126 (32.81)	
46 – 60	30	34	64 (16.67)	
>60	8	17	25 (6.51)	
Gender				0.003
Male	116	87	203 (52.86)	
Female	76	105	181 (47.14)	
Educational status				0.002
No formal education	32	62	94 (24.48)	
Primary education	112	94	206 (53.65)	
Secondary education	36	32	68 (17.70)	
Tertiary education	12	4	16 (4.16)	

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at p=0.05

Table 4.1 A Continued; Distribution of socio-demographic characteristics of respondents (stratified by respondents for BU and Yaws)

Variables	BU (n = 192)	Yaws (n = 192)	Total (n = 384) (%)	P – value
Marital status				0.864
Single	94	101	195 (50.78)	
Married	89	81	170 (44.27)	
Separated	5	5	10 (2.60)	
Widowed	4	5	9 (2.34)	
Religion				0.194
Christianity	147	162	309 (80.47)	
Islam	31	21	52 (13.54)	
Traditional	6	2	8 (2.08)	
No religion	8	7	15 (3.90)	
Occupation				0.364
Professional	7	3	10 (2.60)	
Agric	63	71	134 (34.89)	
Self-employed	9	13	22 (5.73)	
Mining	70	55	125 (32.55)	
Others	45	50	95 (24.74)	
Ethnicity				0.367
Akan	133	140	273 (71.09)	
Ga-Adangme	6	2	8 (2.08)	
Ewe	3	9	12 (3.13)	
Mole-Dagbani	45	36	81 (21.09)	
Others	5	5	10 (2.60)	

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p=0.05$

4.1.2 Other Participant Characteristics and General Participant Background

Majority of participants 260 (67.7%) lived in Atwima Mponua for 11 years and above, prior to study conduction. Most had seen either BU or Yaws 326 (84%). Out of this number, 218 (57%) had seen case(s) of BU (115) and yaws (105) within Atwima Mponua, while 163 (43%) saw both BU and Yaws cases in other adjoining districts within the country and in other neighboring countries (Table 4.1. C below).

Table 4.1. B Other Participant Characteristics Duration of stay in BU Yaws Total (n = 384) district

≤1 year	20	16	36 (9.38)
2-5 years	20	22	42 (10.94)
6-10 years	22	24	46 (11.98)
11 years and above	130	130	260 (67.71)
Ever seen BU/ Yaws patient?			
No	35	23	58 (15.10)
Yes	157	169	326 (84.89)
Ever seen BU/ Yaws patient in district?			
No	76	87	163 (42.45)
Yes	115	105	218 (56.77)

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p=0.05$

Generally, BU was commonly known as 'bru ulcer'. A few communities also identified BU as '*ku ankro*' to mean sore that does not heal in spite of remedy. However, there was a discrepancy in disease identification for yaws. The ulcerated or papilloma presentation of yaws were the only presentations recognized to be Yaws and locally known as '*Dei*' or '*Jator*'. However, when yaws pictures in the 'WHO booklet for recognizing yaws' (WHO, 2012) was shown to participants to identify the disease, different local names such as *nkrosakrosa*, *twifale* and *Ntwide* emerged for other presentations.

Also, local believes dichotomized ulcers in two; "ekuro papa" (good sore) and "ekuro bone" (bad sore). Here, "ekuro papa" is seen to come from legitimate sources such as motor accident, a fall, cutlass wounds, etc. This type of sore responds to treatment and heals in expected time. However, "ekuro bone" normally has mysterious or unknown causes, does not respond to treatment and remains same or even gets worse with time. Spiritual beliefs were usually attached to this type of sores. BU ulcers typically fell in the second category "ekuro bone".

4.1.3 Perceived Causes of BU and Yaws

As shown in (Table 4.1.C) below, from a total of 384 respondents, 221 (57.55) affirmed knowledge on causes of BU and Yaws. From this number 120 (31.25%) stated that the diseases are caused by micro-organisms. General misconceptions about disease causation were found. Significant differences were found in responses for BU and Yaws. In BU, 22 (11.46) people mentioned curses compared to 11 (5.73) for yaws. Bad blood recorded 32 (11.98) for BU and 56 (29.17) for Yaws. Hereditary recorded 23 (11.98) for BU and 39 (20.31) for Yaws. Additionally, flies and insects recorded 39 (20.31) for BU and 67 (34.90) for Yaws.

Table 4.1. C Causes of BU and Yaws

	BU		Yaws		P – value
	No (%)	Yes (%)	No (%)	Yes (%)	
Do you know disease causes					
	77 (40.1)	115 (59.9)	86 (44.79)	106 (55.21)	0.353
What are the causes	No (%)	Yes (%)	No (%)	Yes (%)	
Micro-organisms	20 (25.97)	57 (74.03)	23 (26.74)	63 (73.26)	0.353
Poor personal hygiene	141 (73.44)	51 (26.56)	117 (60.94)	75 (39.06)	0.009
Drinking unclean water	135 (70.31)	57 (29.69)	126 (65.62)	66 (34.38)	0.325
Swimming in unclean water	132 (68.75)	60 (31.25)	124 (64.58)	68 (35.42)	0.386
Evil spirits	168 (87.5)	24 (12.50)	171 (89.06)	21 (10.94)	0.634
Curses	170 (88.54)	22 (11.46)	181 (94.27)	11 (5.73)	0.045
Punishment for misdeeds	169 (88.02)	23 (11.98)	173 (90.10)	19 (9.90)	0.513
Bad blood	160 (83.33)	32 (16.67)	136 (70.83)	56 (29.17)	0.004
Hereditary	169 (88.02)	23 (11.98)	153 (79.69)	39 (20.31)	0.026
Flies/insects	153 (79.69)	39 (20.31)	125 (65.10)	67 (34.90)	0.001
Mining activities	152 (79.17)	40 (20.83)	144 (75.00)	48 (25.00)	0.331
Bleaching creams	163 (84.9)	29 (15.10)	173 (90.10)	19 (9.90)	12.500

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p=0.05$

4.1.4 Signs and Symptoms of BU and Yaws

Table 4.1. D, below indicates that, a total of 244 (63.54) participants knew signs and symptoms of BU and Yaws. Common varying signs and symptoms mentioned were swelling in affected part ($p = 0.000$), round yellowish-looking ulcers ($p = 0.000$) and ulcer with drainage ($p = 0.000$). In BU, notable misconceived signs and symptoms included; round yellowish looking ulcers 22 (18.03) and unhealing ulcers 9 (7.38). Yaws was also recognized by swelling in affected part 22 (18.51) and unhealing ulcers 7 (5.74).

Table 4.1. D Signs and Symptoms

	BU		Yaws		p-value
	No (%)	Yes (%)	No (%)	Yes (%)	
Do you know signs and symptoms					
	70 (36.46)	122 (63.54)	70 (36.46)	122 (63.54)	1.000
What are the signs and symptoms					
	No (%)	Yes (%)	No (%)	Yes (%)	
Swelling in affected part	72 (59.02)	50 (40.98)	100 (81.97)	22 (18.51)	0.000
Round yellowish ulcer	100 (81.97)	22(18.03)	69 (56.56)	53 (43.44)	0.000
Loss of extremities	117 (95.9)	5 (4.100)	121 (99.18)	1 (0.82)	0.098
Ulcer with drainage	48 (39.34)	74 (60.66)	107 (87.70)	15 (12.3)	0.000
Bone involvement	116 (95.08)	6 (4.92)	114 (93.44)	8 (6.56)	0.582
Unhealing/death	113 (92.62)	9 (7.38)	115 (94.26)	7 (5.74)	0.605

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p=0.05$

4.1.5 Knowledge on Transmission of BU and Yaws

From Table 4.1. E below, out of the total of 384 participants, 62 (32.29) alleged BU to be transmissible while 113 (58.85) perceived Yaws as transmissible. In Yaws, transmission routes recorded were; sharing of personal items 107 (94.69), playing with patient 60 (53.1) and living with patient 50 (44.25), eating from the same bowl with patient 51 (45.13), contact with patient blood 32 (28.32), buying food from patient 25 (22.12) and taboos 16 (14.16). In BU, transmission routes mentioned include; sharing of personal items 52 (82.26), playing with patient 34 (54.84), eating from same bowl with patient 28 (45.16), living with patient 27 (43.55), contact with patient blood 25 (40.32) and buying food from patient 18 (29.03). A significant difference was noted for sharing of personal items ($p = 0.008$), where more participants responded ‘yes’ for Yaws 107 (94.69) in comparison with BU 51 (82.26).

Table 4.1. E Disease transmission

	BU		Yaws		P-value
	No (%)	Yes (%)	No (%)	Yes (%)	
Is disease transmittable	130 (67.71)	62(32.29)	79(41.15)	113(58.85)	0.000
Disease transmitted by	No (%)	Yes (%)	No (%)	Yes (%)	
Living with patient	35 (56.45)	27 (43.55)	63 (55.75)	50 (44.25)	0.929
Sharing items	11 (17.74)	51 (82.26)	6 (5.31)	107 (94.69)	0.008
Eating from same bowl	34 (54.84)	28 (45.16)	62 (54.87)	51 (45.13)	0.997
Playing with patient	28 (45.16)	34 (54.84)	53 (46.90)	60 (53.10)	0.825
Air droplets	50 (80.65)	12 (19.35)	92 (81.42)	21 (18.58)	0.901
Contact with patient's blood	37 (59.68)	25 (40.32)	81 (71.68)	32 (28.32)	0.105
Buying food from patient	44 (70.97)	18 (29.03)	88 (77.88)	25 (22.12)	0.310
Visiting patient	51 (82.26)	11 (17.74)	100 (88.5)	13 (11.50)	0.251
Taboo	49 (79.03)	13 (20.97)	97 (85.84)	16 (14.16)	0.247
Sexual activity	60 (96.77)	2 (3.23)	109 (96.46)	4 (3.54)	0.913

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p = 0.05$

4.1.6 Perceived Cure and Preventive measures for BU and Yaws

As shown in Table A total 4.1. F below, a total of 368 (95.83) participants classified BU and yaws as curable, while 16 (4.17) indicated otherwise. Also 193 (50.26) indicated the diseases to be preventable, while 189 (49.22) stated the diseases as not preventable. Additionally, good personal hygiene 88 (90.78), avoiding close contact with patient 37 (38.13) and prompt wound care 8 (8.45) were commonly preventive measures noted.

Table 4.1. F Cure and Prevention

	BU		Yaws		P-value
	No (%)	Yes (%)	No (%)	Yes (%)	
Is disease curable	6 (3.12)	186 (96.88)	10 (5.21)	182 (94.79)	0.307
Prevention					
Is disease preventable	99 (51.56)	93 (48.44)	92 (47.92)	100 (52.08)	0.475
Disease can be prevented by					
Avoid drinking/swimming in unclean water	10 (10.75)		10 (10.00)		
Prompt wound care	6 (6.45)		2 (2.00)		
Good personal hygiene	37 (39.78)		51 (51.00)		
Avoiding close contact with patients	15 (16.13)		22 (22.00)		
Taking balanced diet	3 (3.23)		3 (.00)		
Others	22 (23.66)		12(12.00)		

Statistical significance based on Chi-square or Fisher's exact test where appropriate and set at $p=0.05$

4.1.7 Four 4-Stage Linear Regression Between Knowledge and Stigmatizing Attitudes.

The relationship between knowledge and stigmatizing attitudes were analyzed using a four-stage hierarchical regression model (Table 4.1.G below). In the first model, knowledge of causation, with variables including micro-organisms, flies and insects, evil spirit, poor personal hygiene, swimming and drinking unclean water were used. The second model consisted of knowledge on disease transmission (living with patient, blood contact, sharing personal items and buying food from patient). The third model included knowledge on disease curability. The last model added knowledge on disease prevention.

Table 4.1.G Four 4-Stage Linear Regression Between Knowledge and Stigmatizing Attitudes.

Variables	Model 1	Model 2	Model 3	Model 4
(Constant)	2.583(0.03)	2.637(0.04)	2.623(0.06)	2.646(0.07)
Knowledge of causation	-0.010 (0.02)	0.006(0.02)	0.004(0.02)	0.014(0.02)
Knowledge of transmission		-0.105 (0.03)**	-0.106 (0.03)**	-0.098 (0.03)**
Knowledge of curability			0.020 (0.07)	0.030(0.07)
Knowledge of prevention				-0.092 (0.06)
R ² (%)	0.024(2.4%)	0.164(16.4%)	0.164(16.4%)	0.183(18.3%)
p-value	0.636	0.006*	0.016*	0.012*

** $p < 0.005$, * $p < 0.05$

Standard errors are reported in brackets

As shown in Table 4.1 G above, Model 1 (causation) recorded a negative coefficient (B = -0.010). This indicates a negative direction, meaning that an increase in knowledge of disease causation is likely to contribute to a decrease in stigmatizing attitudes. However, this was not significant Model 2 (disease transmission), similar to model one also recorded a negative coefficient (B = -0.105), recording a significant effect on stigmatizing attitudes. Model 3 (disease curability) showed no

significant relationship (R Square = 16.4%) (B = 0.020). Model 4 (disease prevention) like model 1 and 2 recorded a negative coefficient indicating that negative effect of knowledge of disease prevention on stigmatizing attitudes. From the above, there is enough evidence to accept the alternate hypothesis (Community knowledge BU/ Yaws has a significant negative relationship with stigmatizing attitude towards BU/Yaws patients) while rejecting the null hypothesis which stated no significant relationship between knowledge of the diseases and the stigmatizing attitudes of community members.

4.2 Qualitative Data Presentation

In the qualitative component, patients and former patients were interviewed to achieve three (3) research objectives. In all, 31 interviews were conducted for past and current patients of BU (15) and Yaws (16). Twenty-two (22) had been declared clinically healed for not more than 2 years prior to data collection and 12 were on treatment (had active disease) at the time of data collection. Broad thematic areas found include experiences of stigma in BU and Yaws (enacted and internalized stigma experiences of patients /macro and micro level stigmas), impact of stigma on patients, and common coping strategies adopted in disease related stigma management.

4.2.1 Socio-Demographic Profile of Interview Participants

To provide background data needed to contextualize the thematic findings, socio-demographic information was gathered from interview participants. A total of 31 participants partook in this aspect of the study, of which 15 provided responses for BU and 16 responded on Yaws. Among all interview participants, there was male dominance of (18) as compared to females (13). However, there were more female BU patients (9) compared to Yaws where male patients (12) dominated. An overwhelming majority of study participants were single (27). Most are Christians (19) and Muslims (8). Additionally, Majority are students (23) and from the Akan ethnic group (19). Other less represented ethnic groups were Mole-Dagbani (9) and Ga-adangme (1) (Table 4.2. A below).

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Table 4.2. A Socio-demographic profile of interview participants

Variables	BU n (15)	Yaws n (16)	Total
Age group (years)			
≤24	11	15	26
≥25-64	3	1	4
≥65	1		1
Gender			
Male	6	12	18
Female	9	4	13
Educational status			
No formal education	3	2	5
Primary education	8	14	22
Secondary education	3	0	3
Tertiary	1	0	1
Marital status			
Single	11	16	27
Married	2	0	2
Widowed	2	0	2
Religion			

Christianity	10	9	19
Islam	3	5	8
Traditional	2	2	4
Occupation			
Professional			0
Farmer	1	0	1
Self-employed	3	1	4
Unemployed	3	0	3
Students	8	15	23
Ethnicity			
Akan	9	10	19
Mole-Dagbani	4	5	9
Ga-Adangme	1	0	1
Others	1	1	2

4.2.2 Experiences of Disease Related Stigma in BU and Yaws

4.2.2.1 Macro-level stigma

There was a divergence in levels of macro stigma recorded for BU and Yaws. Significant enacted stigma was recorded in BU as compared to Yaws which recorded more social support. Both community enacted and structural stigma were shown as community members and school mates were commonly mentioned to stigmatize patients and sometimes past patients.

Community Stigma

In the community, enacted stigma was noted especially in BU. Common forms of stigma were teasing, name-calling, avoidance, discrimination and staring. These were not found in participants who responded on Yaws. However, exclusion from group activities were noted for both BU and Yaws, especially among children. Notwithstanding different motives were recounted for this common manifestation of stigma in the two diseases. Whereas *exclusive* behaviors towards BU

patients were perceived to emanate from an unwillingness to associate with seeming socially discomfoting presentations of the disease, *exclusion* in Yaws was deemed to be motivated more by a desire for the wellbeing of patients rather than the alleged stained identity or unwillingness to associate with patients as is characteristic of stigmatizing attitudes found in BU.

Abeiku, a former yaws patient narrated his experience on the playground within the neighborhood;

When I get up to go and play, they mostly fear the sore will be bruised so they don't allow me to play [Abeiku, former yaws patient in primary 3].

His care-giver, Afi adds;

They (patients' playmates) mostly think the sore on the leg will be bruised because for the boys, they usually play football. As a result, they mostly tell him to sit down in order not to bruise the sore.

However, for BU most exclusive behaviors stemmed from perceived undesirable characteristics of patients due to the disease condition.

The care-giver of Yao, a young BU male patient recounts his experience;

Before the disease came, they (neighbors) use to come around and even eat with us. But when the disease came, they all stopped... Oh, a lot of children came to our house to play but after the disease came, none of them comes there again. All of them [parents] now leave home with their children when going out.

Furthermore, in BU which was extensively stigmatized, some dynamics were shown. First, age appeared to be an important factor in determining the type of stigma experienced. while older participants (25 years and above) mentioned that they typically endured constant looks and staring in public, younger patients (24 years and below) classically iterated avoidance, teasing and namecalling.

An 18-year-old patient, Felicia narrates her experience;

You see, my friends really like to tease, I also used to like teasing other people, so if my friends had seen my condition, they will make fun of me for a long time, they will also laugh

at me, they will also not want to get close to me again if they know [Felicia, BU patient in secondary school, form 2].

Meanwhile, Mary, a 58-year-old former patient narrates;

Sometimes because of the bandage, they (community members) can stare at me because I think they wonder why such an old person like me has a bandage on her leg. Especially, when I walk around with my stick, I bow down my head because, they can stare at you for a long time that I don't even know how to walk again [Mary, former BU patient, Farmer].

For instance, Miriam, the mother of a BU patient describes how she had to stop going to church due to enormous staring endured from church members;

...they will stare at us, because of that, I have stopped going to church. People come there a lot and they always stare at the sore on the leg. And this embarrasses me.

Portia, an 11-year-old participant who is a former BU patient narrated her experience, where more concern is given to the teasing and name calling suffered:

...when I leave it open without dressing it, some people will see me and say, look at the torch (reference of ulcer on patient leg to a torchlight) [Portia, former BU patient in primary 5].

Miriam, the care-giver of a 6-year-old BU patient, also recounted how the patient's sibling resorts to name calling and teasing about the condition to get the patient, Emmanuel interested in playing with him instead of self-isolation after onset of disease;

They do but it is his own sibling. He calls him "Emmanuel Apakye (Emmanuel bad leg)" and say the sore smells.

Stigma Within the School

In the school setting, although some social support was recorded for patients, stigma was commonly perpetuated by school and class mates, teachers and food vendors.

For BU patients, most school peers were unwilling to sit together or associate with patients in the classroom.

For example, Tracy, a former BU patient in primary 5 shared her story, narrating how her friends treat her because of the disease;

They (class mates) do not even get close to me, it is only one of my friends called Akos, who would come closer and usually tells them; so, because of this disease, you people do not want to get close to her, even my sitting partner left the sit but Akos came to sit by me.

Abigail, who is a 13-year-old BU former patient also narrates her ordeal as she becomes the target for avoidance:

During worship in the school, my friend and I can combine our desks and sit together, but some of the other students will come close and tell her that I have a disease so she should not get close to me...

Hmmm ... [participant looks down and is a little hesitant to continue talking] my friends started behaving some way. When I did not have BU, my friends used to be okay with me, we could play and talk together, but after I had BU, they do not seem friendly again. They behave as if my wound is smelling and act someway when I go near them. I sit on my desk in the class alone. When it is closing time, I come to my house alone [Abigail, Former BU patient in Primary 6].

Evidently, this experience is not limited to the classroom as Felicia narrates her experience in the school canteen as they queue to buy food;

They [other pupils] will tell me not to stand close to them. They will ask me to wait for them to finish buying before I come to buy my own. So, I go to stand at the back and wait for all of them to finish buying their own. Sometimes the food finishes when I am waiting for them to finish buying. But when I tell the headmaster that the food has finished, he gives me permission to go to the roadside to buy my food there...[Felicia, former BU patient in primary 2].

In Yaws, a few school teachers sent patients home and asked them to return to school only after their lesions healed. Akuba, the mother of a young Yaws patient narrates;

The school fears that other pupils will also get the rashes from him, so they ask him not to come to school when the rashes are there. Whenever they appear on his body, he does not go to school.....the school madam tells him to come home whenever he goes to school with the disease.

However, for majority of the participants, school teachers did not mind the presence of patients in the school, likewise, other students were also willing to associate with patients, as recounted by Muna, the care-giver of a Yaws patient;

Oh, for children, even if they are told not to play with the patient, they will do exactly that. They do not care about anything. As an adult, I would have advised myself about where to go and where not to go, but for the children, it does not concern them.

Stigma Perpetrated by Teachers and other Adults within the School Setting

Within the school setting, stigma perpetuation in BU was not limited to students. Although some teachers were supportive during the experience, other teachers and food vendors exhibited discriminatory and avoidant behaviors towards affected persons, as narrated by Abigail;

... except one of my teachers who liked me. There were some of the teachers, whenever they see me, they will say; so, you will not stay home for you to be healed and you have come to school? But the teacher who likes me will respond; 'why are you asking your student to stay in the house when exams are being done'? So, the teacher normally takes my exams papers from them and reads it to me so that I am able to write the exams too.

The poor treatment may be borne out of a desire for the wellbeing of patients as well as other students or simply unwillingness to associate with patients as is typically reported by some study participants. Portia recounts her experience;

...before the community volunteer came to take me to the hospital, it was very bad. Even the teachers wanted to change the chair that I was sitting on in the class room. They wanted me to start bringing my own chair to school before I sit down. Even the headmaster asked me later to take my chair home and stay in the house till I am healed. But my mother was also not happy that I should stay in the house...even one of my teachers too, when she is teaching and there is a question on the blackboard, even when I know the answer or solution to the question to solve the question on the black board, she makes me write the answer on a paper and asks someone closer to me, my relative to bring her the paper. They do not allow me to get close to the black board].

Felicia, another participant who had BU adds;

...When I go to the canteen to buy food, I have to send my own bowl, unless I do that, they will never sell the food for me with their own bowl, so when I am going to school, I have to send my own bowl, then Akos [only supportive friend of respondent] will send it to buy the food, for me to eat... yes, they will ask me to hold the bowl, while they will put the food inside for me.

In addition, although a general acceptance was recorded in neighborhoods for both BU and yaws, a few outstanding responses were recorded for BU as some participants felt some actions were taken simply to avoid them due to the disease condition. The care-giver of Yao, a young BU male patient recounted;

Before the disease came, they use to come around and even eat with us. But when the disease came, they all stopped... Oh, a lot of children came to our house to play but after the disease came, none of them comes there again. All of them [parents] now leave home with their children when going out.

Additionally, Comfort a thirteen-year-old BU patient notes how her school mates and friends stopped visiting after some time;

They have stopped coming, and I cannot also go and ask of them. if I do so, I would not gain anything from it. When they heard about my leg, they used to visit but now they have stopped [Comfort, BU patient in Junior High School, form 1].

4.2.2.2 Micro-Level Stigma (Internalized, Self, felt and Anticipated Stigma) Experiences

Micro-level stigma was also observed for both BU and Yaws participants. In BU, most patients after being treated poorly by others internalized the treatment and began to withdraw from social situations in anticipation of similar treatment from other people. Although a few patients anticipated stigma regardless of the state of the disease due to how their communities perceived the disease, a majority of patients who expressed this form of self-stigma had the progressed forms of the disease such as large ulcers.

Felicia, who had a category 2 ulcer on her thigh expressed this succinctly;

I was shy that I had such a wound on my leg.

Hannah, a 60-year-old former patient when asked if she felt okay to share her food with neighbors as she did before onset of BU reported she stopped this on her own and decided to rather share the uncooked food items with neighbors rather than cook it, since this may be rejected or thrown away; *Well, because I knew my own problem, I didn't even try that. Some people might take [the cooked food] it but they won't eat it and pour it away. So, I didn't do that [Hannah, former BU patient, Farmer].*

In Yaws, there was a twist as patients themselves reported no self or anticipated stigma. Most of them felt okay to associate with peers in the neighborhoods and in schools as little regard was given to the disease. However, their care-givers exhibited high levels of felt, self and anticipated stigmas. Ajoba, the mother of a Yaws patient narrated;

As for the children, they do not care. They are able to play with their friends. They go to school every day. They are not shy. It is me who is worried, some people may say that you are not taking good care of the child and not being attentive to them when they are sick.

Afiba, another parent of a Yaws patient noted:

It is even better when it is on the body, but when it is on the face, everyone will be asking what is wrong with your child, what is wrong with your child.... that makes me embarrassed

Akuba, also expressed how her child's condition made her feel;

As a mother, you do not feel okay if your child gets this disease. When in public you compare your child's skin to his peers you do not have the disease, it makes you feel bad as a mother. It makes you shy.

In many instances, age and knowledge about the disease was clearly evidenced to account for the dominance of self-stigma, felt and anticipated stigma recorded amongst care-givers. As many participants narrated that they are not likely to be care-free about yaws as their wards have been, assuming they had the condition. They mentioned that not only will it be embarrassing to have such a disease as adults, but also believed that the popular attribution of the disease to poor personal hygiene throws a negative light on adult patients, as many female care-givers iterated that they are very unlikely to marry a man who has the disease.

As an adult, it would have been difficult to go to the mosque or the market if the sores are on visible parts of the skin. It is embarrassing. Someone can see you and go and gossip about you to his friends, see what has happened to this person's skin? very soon, you will see that they are all staring at you. You will know that they are all gossiping about you but you wouldn't be able to do anything about it [Abena, mother of Yaws patient].

I would have been very shy, I don't think I could have been able to go out....sometimes some people may not like to get close to me, and I would also not want to get close to anyone because if I had the disease, how can I go near them if they do not get close to me first [Araba, mother of a Yaws patient]

Causes of Enacted Stigmatizing Attitudes and Practices by Community

In the quantitative component of the work, surveyed community members held a number of misconceptions on disease causes, prevention, signs and symptoms. This contributed to

stigmatizing attitudes. This was reflected in interviews with patients who also iterated that community members and school mates are likely to avoid, exclude, or discriminate against them due similar reasons.

Fear of contagion

Fear of disease contagion was demonstrated to account for stigmatizing tendencies in both BU and yaws. In BU, the general sentiments are evidenced by many participants, including Tracy, Peter and Felicia respectively in the following quotes;

They (friends) were scared that they will get some of the disease from me.

...They (play mates) assumed that the disease was contagious, when I arrive where they have grouped, some will get up while others remain...when I ask those who get up to leave, they will say they have something to do at home but when I leave, I see that they go to gather at a different place

So, there is this woman who sells rice, so one time I asked her, Mum please, why is it that at first (when participant had BU ulcer) you were asking me to bring my own bowl before you sell the food for me, she said, it is because of the disease that I had, that is why. But now that the disease is gone, they can now serve me using their bowl

Similarly, Yao, the care-giver of a Yaws patient reported;

I advise my son that he needs to be careful of making friends because he got this disease from some of his friends who had it. I tell him, imagine it was a dangerous disease which could kill you, what would you have done? You need to be careful.

Community Awareness and Knowledge

Participants noted that the nature and level of community awareness of diseases are important precursors of enacted stigma. First, the frequent exposure to the condition and supposed susceptibility of all community members to get the diseases was perceived to significantly reduce stigma attached to the disease.

Adae and Abeiku, who are Yaws patients reported;

The disease is quite common so most people are not surprised by it. They know that, it may be my turn today but they could also have it tomorrow so people do not behave like that towards me.

...for this place, we take it normal, for example, when I saw the one on the child and told someone, the person said, oh this is normal, even I have some on my skin but nothing has happened to me so it is not a matter of concern, so there is no reason to be shy having it. Similar responses were given by many BU participants. Abigail and Hannah recounted;

As for the people who have seen this disease before, they are not surprised when they see it. It is the people who have not seen some before that will feel bad for you or not want to come close to you. Because sometimes, even the other diseases aside buruli ulcer are the same. When people have not seen some before, they will behave some way towards the patient.

The disease had really come to this town at the time. There were many people who had some. Some of them, their hands and legs have even been deformed now. At the time, when people got to know that the disease has also affected my two sons, they will say...you have to be careful oo, so that this bad disease does not spoil these handsome boys.

Additionally, yaws participants particularly who perceived the disease in terms of negligence on the part of patients exhibited more stigmatizing tendencies towards patients.

For example, Awusi, a care-giver of a seven-year-old yaws patient who in spite of a DPP positive diagnosis and treatment of son's ulcer did not believe the condition to be yaws, had the following to say about the disease;

Most of the time, filth is the cause of yaws, for instance if you get a cut on your body today and you do not bath, next day you do not bath as well, some animals can come to the surface of the cut, before you realize, other wounds will also appear close to the first cut.... oh I really know yaws well oo by the time you realize, it is spreading all over. It

can get itchy and as you continue to scratch it, it also keeps spreading. It's all filth, because if you bath well and always apply ointment on cuts on the body, you will not get yaws.... In the past, Yaws was normal because it was common. But now that there are not many cases, so if you allow yourself [practice poor personal hygiene] and get yaws, then you have yourself to blame, it is your problem.

Improvement in Condition and Economic Independence

In BU, 2 participants who had larger ulcers reported that the level of stigma they experienced typically decreased with improvement in the condition. Also, aside the changing lesion characteristics and seeming curability of the condition, it was hinted that stigma also diminished when affected people were proved to be economically independent and not likely to become a burden on other people. This experience was not recorded among yaws patients. Ben, the caregiver of a 10-year-old BU patient reported;

... I think that when the disease came, people didn't want to be around because, they thought we might burden them with our problem or even demand for money from them. But now that they have realized that we didn't need their help and won't burden them with our problem, they have changed their behavior towards us.

Additionally, Botwe the parent of a 6-year-old BU patient noted a favorable change in behavior of their neighbors towards them after the child's condition had seen some improvement

what I meant was that, now the kids come around to play with him. But before, they didn't and even now their parents don't call them back home. They just leave them to play.

When asked what he thought accounted for the behavioral change, he responded:

...they have now realized that the sore is better than before. At first, it used to be very bad, now it looks better. He can now walk and do things on his own so they have seen that he is better....

4.2.2.3 The Effects Stigmatizing Experiences on BU and Yaws Patients

Generally, it was clear that both enacted and internalized stigma significantly impacts patients in diverse ways. However, as BU patients reported greater stigma compared to Yaws, more evidence on the effects of stigma was found among BU patients as compared to Yaws patients. In broad terms, stigma experiences in both diseases had positive and negative effects.

4.2.2.3.1. Positive effect of stigma; Good care-seeking behavior

Although the fear of stigma led to behaviors such as secrecy about the condition and selective disclosure to only intimate family members and few trusted friends, no linkage could be made to poor health seeking behavior. Rather, overt stigmatizing practices and internalized stigma manifested in hardened determination to seek and adhere to healthcare for both BU and Yaws participants.

This typically led to the build-up of a strong resolve to get better as a way of getting back at the people who stigmatized them and also ridding themselves of their current stigmatized status. Past patients principally recounted how they religiously sought care from different pathways inclusive of traditional and medical care among others. Additionally, patients who were placed on hospital regimens confirmed that the frustrations of being treated poorly by others fueled their desire to get better. This was demonstrated in timely clinic attendance, proper wound care practices as well as administration of prescribed drugs as directed.

Jonas, the care-giver of a category 3 BU patient noted;

Well, I can't really tell. Some didn't even want my son to come play around them, but since he has completed with the medicine, I dress the wound every three days, I know that it will heal soon even though it is being slow right now

Another participant, Felicia noted;

It is ok. But sometimes I feel bad that my friends in school did that to me. I never knew they will treat me that way. It was like nobody wanted me to talk with them. I don't care about them anymore. by God's grace, my wound is almost healed now, I only have to continue the treatment.

Similar sentiments were expressed amongst Yaws participants as Awusi, a care-giver reflected;

It is embarrassing, so as an adult, you will do all you can to get a cure so you will be free and be able to go out.

4.2.2.3.2 The Negative Implications of Stigma in BU and Yaws

Irrespective of the role played above, stigma associated with BU typically proved to have several negative impacts.

Psychosocial Burden Associated with Stigma

Significant psychosocial burden in the forms of mental health issues such as anxiety and sadness were recorded. Younger BU patients particularly maintained that it made them very sad to be treated poorly by their friends as they never imagined the possibility of this occurrence. Although no suicidal ideation was evidenced, many participants mentioned feeling hurt, crying and withdrawing from group activities after the experience.

One of my friends, I had an issue with her, I don't know of how she got to know about my condition, while I was arguing with her, she said; that is why you have a sore on your leg, your big sore on your leg...so I was surprised and wondered how she got to know that I have a sore on my leg.... she did that when we were in class, our class mates were there... I cried. I was really hurt. Because of what happened, I did not feel comfortable to get close to my classmates anymore.... when I go to school, I sit by myself, during break time, I get up and go and buy my food to eat, afterwards, I come back and come to sit down... some of my friends came to ask me why I am always quiet and do not talk to anyone now....and one of our teachers also asked me what was wrong with me, and I told him that it was nothing [Felicia, BU patient].

it made me feel very sad, there were even times that I cry when they refer to my wound as torch [Portia, BU patient].

At home, aside a noted withdrawal from social activities due to pain and discomfort of the disease, there was some preference by BU patients to stay in rooms and watch television or read or remain

in the house rather than go out to be shunned by friends whom patients used to enjoy interacting with.

I made sure that he does not go out to try to play with anyone because of their behavior. He can play with his siblings or watch tv... The child has no power so, whatever I tell him is what he will do. When he wants to go out, I shout at him then he stops.... [Botwe, caregiver of 6-year-old BU patient].

When I am sad, I watch movies or listen to music so that I will be less sad, my mother was also always sad, but people used to come around to comfort my mother that all will be well so she should give everything to God. So, when we are sad, we watch movies and listen to music in the room then we become okay [Tracy, BU patient].

Stigma and Academic Underachievement

There was some evidence to suggest non-school attendance due to stigma. Additionally, absentmindedness during class sessions was related to BU patients principally reflected on how they are being treated due to their condition and the stigmatized labels attributed to them.

I used to think a lot that how could my own best friend whom I shared everything with, and go everywhere with do that to me? So, I can be thinking about this during classes [Dora, BU patient].

When researcher asked if the experience had any implications on her academic performance, Dora continued;

Yes, I was second position in class before I got the BU that was in form one. But after, I got the eighth position in the class in form 2, now in form 3, I was 5th in position. The most recent one we had after my leg got healed, I was 3rd in the class.

Abigail also recounted her experience;

Well, my learning became someway and I also did not want to go to the school anymore so that they will keep sacking me to go home, go home. And I kept asking myself, when at all

will this my wound heal? There are times I think about this so much that even when someone calls me, I cannot hear the person unless the person touches me.

Moreover, the desire to conceal disease from peers for fear of teasing and avoidance led to some changes in existing school arrangements such as leaving the boarding house to become day-student in anticipation of stigma. However, it could not be established if this occurrence had implications for academic output.

I wait for all of them to finish bathing before I go to bath... I had only told one of my teachers about the condition, so he was always giving me permission to go out for dressing whenever it is due...later I asked for permission from the school authorities to allow me to become a day student, so I was staying with my mother in the house... [Felicia, BU patient].

Additionally, although not directly connected to stigma, some disease-related implications on academic work were evidenced as many participants who are students particularly recounted that, they frequently had to go for wound dressing and miss some school time because of associated pain or movement restrictions.

By the time I am back from Tewa to do my wound dressing, they had finished some of the exams and are even on break. So sometimes, I am allowed to write when I come back to the school, before I go home. There were also times that my exams papers were brought to me to do, but the instructions are not explained so I do not understand what to do...all the exams' papers have names of each student on them, but sometimes when they bring my paper, the name on it is not my name, they give mine to someone and bring the person's own to me [Portia, BU patient].

Again, although not recorded in Yaws, some BU participants had to stop school for several months as they sought solution to the condition. This was more related to the physical limitations of the disease. Botwe, who is a care-giver of a BU patients noted;

No, from the time the disease started around October last year till now (October, 2021 June 2022), he has not been able to go to school. I want him to get well before going [Botwe].

Economic implications

Some BU participants and their caregivers reported economic implications which is not directly related to stigma but rather a reflection of working time spent to seek care and attend to the condition

Oh yes, it has really affected me and it was part of the reasons why I started treating him at home because I couldn't go to the clinic. This is because, by the time I take him to the clinic and come back I would always be late for work. They weren't able to tell me directly that, they didn't like me being late. But they used another way by starting a rumor, saying hurtful things to me to make me stop the work. I remember that, I even cried at my work place before I left the place to come home...oh, they were like you are not the only person who has given birth and you don't come to work early. And you know how much it hurts when someone tell you these things. They didn't tell me that they can't work with me but because of the things they were saying I decided to leave the work. I didn't even take my payment [Ben, care-giver of BU patient].

However, there was little evidence to suggest that stigma associated with the disease contributed to economic consequences for both BU and Yaws.

Effect of Stigma on Social Relationships

Generally, number of BU participants reported a strained social relationship with people who stigmatized them during the disease phase. This suggests an inverse relationship between disease related stigma experience and community social standing. Some participants iterated that they did not care to associate with former friends anymore after what they did to them when they had the disease. While others maintained that they still associate with friends but the relationship was not as it used to be.

We talk, but our relationship is not like it was at first.... I still talk with some people, but it is not like the first that I will gather with my friends and be chatting with each other. It is not like that anymore [Dora, BU patient].

hmmm, because of what happened, I did not feel comfortable to get close to my classmates anymore [Felicia, BU patient].

On the other hand, even though many social relationships were affected after experiences of stigma, it was noted that intimate social relationships are likely to elicit supportive behavior and hence limit stigma. This was especially observed in Yaws and in some cases BU patients. The family and spousal relationships emerged as particularly important;

Familial Attachment

In both diseases, family members dominated in being supportive as participants recounted how their family are principally acceptive and willing to live together, eat together and share personal items with them. In cases where family members perceive the disease to be contagious, sheer bravado alongside reliance on religion were deemed as forms of protection against the disease. Familial ties are maintained and particularly strengthened in the face of enacted stigma and also when patients are perceived to be in the disease-related pain and discomfort.

Some BU participants recounted;

When I go to school, I focus on my classes and come home. I do not want to go to someone again. But in the house, my siblings and parents and the children who come to our house are always there so it is fine... They treat me very well. They try to help me especially when it was very painful [Mary, BU patient].

My family relates with me the same way they did before I had the condition. I still perform the same chores I used to perform” [Abigail, BU patient].

Some of my family members also travelled all the way to come and stay with us for a while when they heard that the disease which has affected my children and even brother in the past has also affected me [Hannah, BU patient].

If I need anything, they help me [Comfort, BU patient].

To this response, her care-giver, Patience adds;

The moment she stands up, her youngest sibling meets her with a stick (to help her walk).

Similar observations were made in Yaws;

Everything is still normal. We cook and eat together [Afiba, care-giver of a Yaws patient].

If something happens to someone and you do that [stigmatize the patient], you make the person sad. As a result, we all eat in one bowl... I wasn't afraid I will get infected [Abeiku, care-giver of a Yaws patient].

Additionally, In Older BU participants (25 years and above), spouses have generally been cited to be supportive of patients. Older female participants specifically iterated this;

My husband has been taking care of me, he asks me every morning how I am doing and he also cooked for me [Mary, BU patient].

oh, he was very kind to me. He stopped me from performing some of the house chores, so he and the children were doing most of the things in the house, oh hmmm. He was so good to me [Hannah, BU patient].

Marital sexual relations seem unaffected by the disease as an older BU participant whose lesion was located in her inner thigh responded on the subject;

...oh why not? Everything was normal. We always dress the wound so it was not looking bad and it was not very big. But I could tell that he was always careful not to hurt me [Sarah, BU patient].

Intimate Social Standing

Friends and playmates also played some role in supporting patients in both skin NTDs in the study. For Yaws, it was observed that most peers were willing to continue in-group activities with patients, with little knowledge and regard for contagion.

Abu, the caregiver of a young female who is a former Yaws patient narrated;

For playing, she does that a lot, she and the children. Some young girls even come from the community to play. It is not easy; at some point I even sack them. Because of the mess they make I sack them, but in the next morning, they come back to continue. Even after the disease started, they still mingled together.

Araba, the care-giver of a male active Yaws patient added;

As he is going to the farm today, he took plantain, salt, onion, and other ingredients to cook. He had a friend who will eat this food with him on the farm. As for children, they do not care. Assuming it was an adult, he would be thinking that this boy has sores, I could get some, but for the children, they do not think that way.

However, for BU, although a few participants had support from some friends, this was typically patients who had non ulcer lesions and smaller ulcers. However, many participants with larger, more visible and chronic ulcers lost many friends, except in some cases a few who stayed and defended patients against stigma from other peers. These supporters also offered support such as keeping company and running errands on behalf of patients who wished to avoid public contact.

When I go to play with them, they will say, leave here, leave here. But as for my friend who likes me, she will leave them and come and play with me alone.... When they send me to go to the market, I go and tell my friend, take the money and go instead. Then I wait for her to go and buy the item then I take it from her and send it home. Sometimes I tell my mother that when I go out, people look at me and some even ask me how I have such a big wound on my leg. I did not like some of their questions and comments. They will say, so what kind of disease is this? Won't your mother be bothered to send you to the hospital? [Portia, BU patient].

... everything was normal. But you see, because the students are many, some of them are ruffians, so they say to my boys, leave me alone, you have a sore, I do not want to walk with you.... but other students will say...stop that, don't you know that the sore is a disease? [Priscilla, BU patients care-giver].

I had someone who comforted me that it shall be well [Dora, BU patient].

4.2.2.2.4 Coping Strategies Used in The Management of Stigma Associated with Buruli Ulcer and Yaws

In response to both macro and micro-level stigmas, patients have been shown to devise a number of ways to manage the experience. Typical maladaptive strategies such as substance abuse were not seen. Broadly, two broad themes emerged; problem-focused and emotion-focused strategies. Problem-focused strategies included confrontation and education, concealment with clothing and selective disclosure and information management. Emotion-focused strategies shown were selfisolation and behavioral change, religious coping and resignation.

4.2.2.2.4.1 Problem-Focused Coping Strategies

Concealment with Clothing

Clothing was used extensively to conceal lesions and scars in an attempt to limit or prevent stigma. Many participants, both young and old typically used clothing not as adaptive clothing in aid of managing physical disabilities or aiding movement, but rather as a means to limit attention to affected body parts. Although few participants reported that the clothing served other functions such as protection of lesion surface from contamination by dirt, clothing, including trousers, long skirts, dresses and socks were used extensively to veil affected parts from public scrutiny.

I was shy that I had such a wound on my leg...yes, when I am sent anywhere, I wear long dresses [Dora, BU patient].

No, I still wear my clothes the same, but now, I wear longer clothes to cover the wound especially when I am sent to the market or I am going out of the house. Sometimes too in the house, I try to wear dresses that cover the wound so that people who come to the house will stop asking me what is wrong with my leg, yes so there is a little change now [Felicia, BU patient].

I wear long knickers so that nobody sees that there is a wound on my legs...some people are always asking me what happened to me [Portia, BU patient].

Moreover, there is some evidence to suggest that clothing remains useful in concealing scars even after patients heal. Although many participants seemed unaffected by the presence of scars upon healing, a younger female particularly maintained that she is uncomfortable about comments people made about her condition and preferred to keep it covered in public;

When people see it, they will be asking, so when will this scar heal completely and disappear from your skin? Even some old people keep asking me the same thing. But for those who knew how the wound was big at first, they are relieved when they see the scar, they will say, yes, now the scar is reducing in size.... [Portia, BU patient].

Yaws participants on the other hand had no use for clothing to conceal lesions as the disease is largely not stigmatized among children.

Everyone knows that the children like to engage in dangerous play, and most of the children here also have similar sores on their bodies, and even the other people may have children who also have the sores on their legs so they cannot talk about my children in a bad way. Also, for children it is normal for them to get hurt as they play [Ajoba, care-giver of a Yaws patient].

Interestingly, adult care-givers of yaws patients who recorded more anticipated stigma may be more likely to use clothing as a form of concealment if they had the disease.

Akuba, who sells food was asked if she will continue selling the food if she had yaws lesions on her body, she replied;

It depends on the location. For having a sore that is in a visible place where other people can see, then I would not be able to sell, but a sore that is not in a place like that, I can wear my dress on it and sell the food [Afiba, care-giver of a Yaws patient].

Selective Disclosure and Information Management

Participants, specifically BU participants admitted to carefully selecting whom to disclose information about their condition and whom not to. Thus, in ulcerated cases, other people may see the wound with bandages, but few are given the privilege to know that the ulcer was due to BU. While conducting the community survey component of this study, a community member shared the story of a how her neighbor who had BU preferred to tell other people that her ulcer was from a car accident. According to the narration, the patient did this because of the myths attached to the disease which exposes sufferers to community avoidance and gossip. In line with this, many interview participants also seemed to think that disclosing the cause of the ulcer will result in further community stigma;

For my school mates, when they ask, I tell them my arm is paining me. I never mentioned the type of disease to them...I did not want them to behave like how, my friends from my neighborhood were behaving [Peter, BU patient].

They do stare but they eventually take their eyes off since they know that it is just a sore [Yao, BU patient].

People relate to my family well. It is good. Even the children who come to our house to play with us before I got the disease, they still come now, and we all cook and eat together, but I am careful not to open the wound in the house for anyone to see. I do not want anyone to start asking many questions. We do not even open it unless I go to the hospital for dressing, so all that they see is the bandage around my knee [Abigail, BU patient].

Sometimes, because my walking was affected, people will keep asking me what is wrong with me anytime they see me walking around. But I tell them that I have a small problem [Mary, BU patient].

Typically, family members were thought to be the most legitimate and unlikely to stigmatize the patients with the condition. Hence most participants felt the family is the first choice in considering disclosure. There was no evidence of delayed disclosure to family as parents typically are those

who are given the diagnosis about the condition of their wards. Older patients also did not hesitate to relay their condition to their spouses, children and extended family members.

When I woke up one morning and was going to have my bath, I saw that, that part of my thigh was so hard to touch, so after bathing, I came to show it to my husband... [Hannah, BU patient].

I will only tell my family members so that we send it to the hospital, but to tell my friends and other people, no, I will not do that [Abigail, BU patient].

Confrontation and Education Coping Strategy

A number of younger BU and Yaws patients also admitted directly challenging people who perpetuate blatant or subtle stigmatizing behaviors such as discrimination and avoidance towards them. A participant particularly reported how she tried educating her playmates about the condition to dispel their fears of contagion which was manifested in sacking her from partaking in group activities.

I ask them; why are you sacking me? You will only get BU when it is in your blood. The Community Based Surveillance Volunteer told me that, it is not everybody who is susceptible to get BU. he told me that the organisms that cause the disease can sometimes be found in dirty bath water and near water bodies, for instance associating myself with rivers or streams, but even after I explain to them, they will still ask me to leave them alone [Portia, BU patient].

However, this approach is shown to have worked later on, as participant continues;

... as for that my friend, she did not believe that she will get the disease from me. She did not believe so, because I told her that the Doctor said that the disease, I have can't be contracted by coming closer to me, but rather be acquired from some small animals which live at some specific places. So she did not believe that I will give her the disease [Portia, BU patient].

Another participant also confronted neighborhood friends who tend to avoid his company after he got the disease;

I could ask a couple of them, why they always leave anytime they see me coming. They respond by saying, it is nothing. They do not give specific reasons as to why they are leaving [Peter, BU patient].

In response to persistent enquiry and teasing about the disease condition, another participant responds;

I tell the person to keep quiet and warn him that I will deal with him if he tells anyone about it. When I do that, the person stops talking about it [Tracy, BU patient].

4.2.2.2.4.2 Emotion-focused Coping Strategy

Religious Coping Mechanism

An overwhelming majority of BU study participants resorted to religion to comfort and manage the frustrations of the poor treatment they suffered. When asked what they did after their stigma experience, most of them mentioned praying or performing other religious activities as their only hope was God.

I used to pray as well and go to church [Abigail, BU patient].

My sole prayer was that, my arm heals and God has helped heal my arm [Peter, BU patient].

Oh, I just rely on God. I have nothing except for God ...Oh, I sit, I pray in my head, God heal me, heal me. God wants work to do so if you don't give him work, he won't save you. So I say, God heal me, so I give God work and he is working. God does not rush in the things he does. Now, I can walk without using my stick. I can go to the road and come back but previously; I wasn't able to do that...[Mary, BU patient].

Isolation and Behavioral Change

Lastly, Both BU and Yaws participants reported self-isolation and behavioral change after onset of disease. While yaws patients did this typically because they felt pain or uncomfortable because of the condition, BU patients specifically withdrew in response to stigma. Participants reported that they tend to avoid other people and prefer to be by themselves. Some previously out-going

participants mentioned that they have become reserved as a result of how they were treated because of the disease.

when I go to school, I sit by myself, during break time, I get up and go and buy my food to eat, afterwards, I come back and come to sit down [Rita, BU patient].

Upon returning, I told my grandmother about it [Friends shunning his company]. She told me not to go out then [Peter, BU patient].

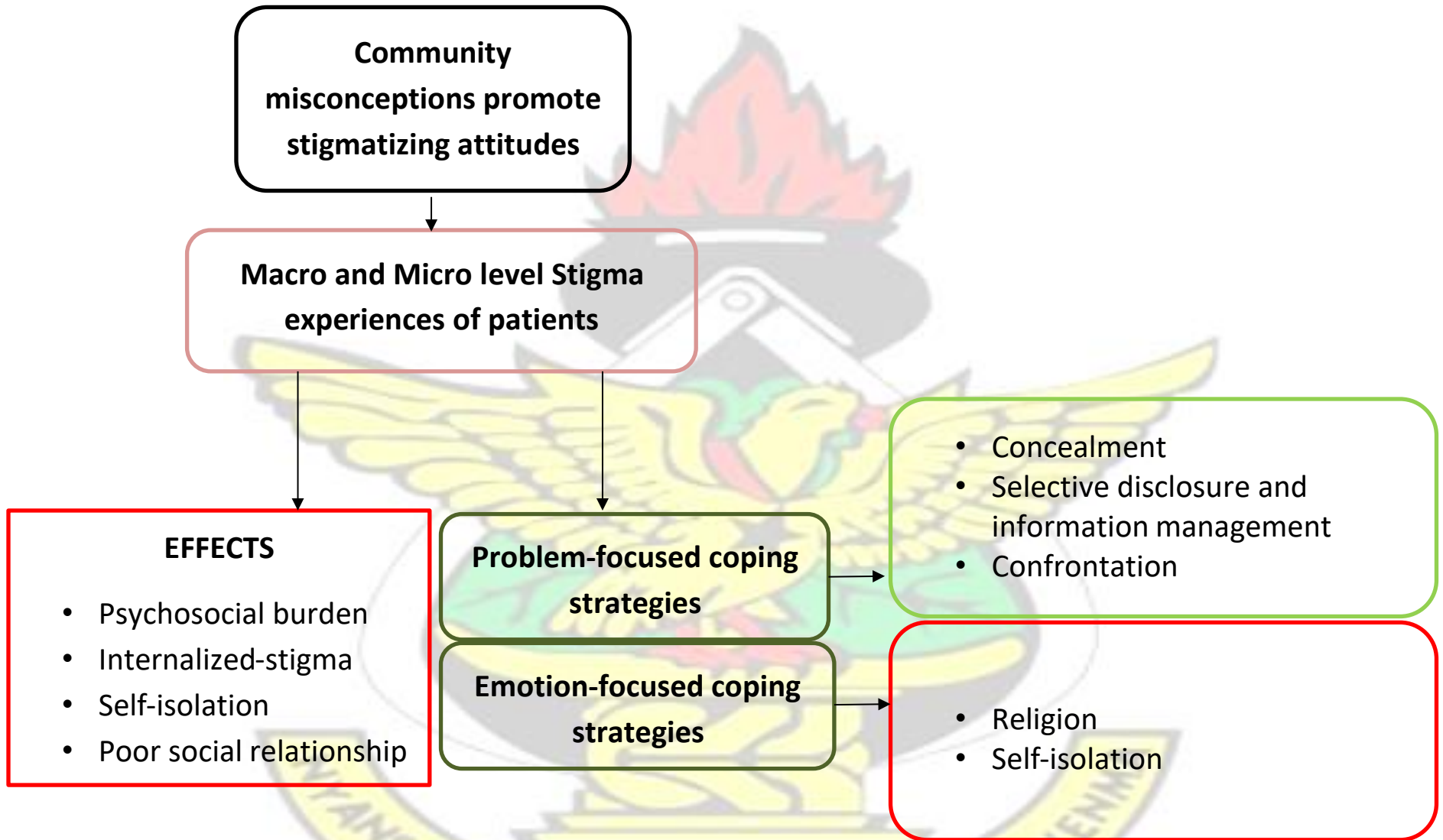
Even after healing from BU, some participants reported that they are uncomfortable to go close to their friends and playmates anymore. Rather, they are much withdrawn and are likely to remain so;

... I am quiet now, and will continue to be [Felicia, BU patient].

...Because of what happened, I did not feel comfortable to get close to my classmates anymore.... when I go to school, I sit by myself, during break time, I get up and go and buy my food to eat, afterwards, I come back and come to sit down... some of my friends came to ask me why I am always quiet and do not talk to anyone now....and one of our teachers also asked me what was wrong with me, and I told him that it was nothing [Rita, BU patient].

Oh, people just ask what has happen to your child's leg. For this reason, we don't take him anywhere. We are always in the house [Miriam, Care-giver of BU patient].

Fig. 4.1 Diagrammatic representation of findings from quantitative and qualitative components



KNUST



CHAPTER FIVE

DISCUSSION

5.0 Introduction

The study explored stigma associated with two (2) skin NTDs; BU and Yaws. The community knowledge, attitudes and beliefs about the diseases were analyzed. The stigma experiences of patients, impact and coping strategies were also assessed.

5.1 Socio-demographic Factors and Stigma in the skin NTDS

The level of education recorded for interview participants were principally primary education, only one participant had tertiary education. While this may be a reflection of the relatively young ages of interviewees which was twenty-four years and below (≤ 24 years; 83.8%), further sociodemographic evidence from the community survey such as dominance of primary economic activities, i.e. agriculture 134 (34.8%), small-scale illegal mining 125 (32.55), dominance of primary education 206 (53.65), housing materials and nature of road network as observed in the study district during the community survey, corroborated a key characteristic of Skin NTDs; prevalent in mostly rural, vulnerable and poor populations, and further impoverishing them (Adamba and Owusu, 2011, Asiedu and Etuaful, 1998, Dofitas et al., 2022b, Cooper et al., 2022).

Additionally, the dominance of young aged interview participants is consistent with existing literature from varying settings where BU and Yaws are noted to affect young people, typically under fifteen (15) years (Yotsu et al., 2015, Amoako et al., 2021a, Bylicka-Szczepanowska et al., 2021, Singh et al., 2021). Kwyer and Ampadu (2006), noted age distribution for BU in Ghana to be 53.1% for people under 15 years, 33.9% between 15-49 and 12.9% 50 years and above, thus making young age a key risk factor in BU. Likewise Yaws where children below age fifteen (15) are noted as the most affected in many endemic countries (Dofitas et al., 2020a, Dofitas et al., 2022b, Abdulai et al., 2018).

Socio-demographic factors have always been noted as important to the process of social interaction (Rosenthal and DePaulo, 1979). Similarly, evidence from patients and care-giver interviewed in this study showed that age may have an impact on the form, interpretation and intensity of stigma of BU and Yaws patients experience.

In BU, while younger patients mentioned overt stigmatizing practices such as teasing and name calling, older patients typically mentioned avoidance and staring. Available published evidence suggests teasing and name-calling as prevalent and sometimes normalized among children (Hayden-Wade et al., 2005, Macklem, 2003, Barnett et al., 2004, Dofitas et al., 2022a, LewisJones and Finlay, 1995), validating the experiences of young BU patients in this study.

However, staring and furtive glances mentioned by older participants may not be exclusive to their age-group. Meaning that, although such stigmatizing practices may be perpetuated against young and older participants, younger participants may nevertheless be unbothered compared to older participants who are perceived to be more socially conscious and better at interpreting non-verbal cues and symbolic interactionism. The older participants specifically conveyed how staring embarrassed them anytime they ventured into the public arena with their children who had the disease. This was supported by studies which found that, staring contributed to feelings of being ignored, rejected and excluded among older participants with some forms of disability, eventually leading to social isolation (Renwick et al., 2018, Bull and Rumsey, 2012). In another study, participants particularly attributed more negative feelings, to staring from adults as compared to children, as adult stares are perceived as ‘saturated with judgment and discrimination’ (Galvin, 2005).

Similarly in Yaws, some age-related observations were evident. Within the patient group, which is primarily below 24 years (93.8%), there was limited evidence to suggest substantial self and enacted stigma. However, the exact opposite was recorded for older care-givers of these participants. Care-givers showed a great inclination to engage in enacted stigma towards adult yaws patients. Similarly, these care-givers also exhibited higher levels of anticipated and feltstigma for the condition of their wards, analogous to findings in Hong Kong where old age emerged as one of the important socio-demographic correlates of public stigma (Lo et al., 2021).

5.2 Community Knowledge, Attitudes and Beliefs Associated with BU and Yaws

Overall evidence suggested varying community knowledge and stigmatizing beliefs and attitudes associated with BU and yaws. Knowledge of causes (Table 4.1.C), showed general

misconceptions, stigmatizing beliefs and attitudes. Significant associations were also made between misconceptions about disease causes and transmission and stigmatizing attitudes.

The Role of Community Knowledge on Causation, Transmission and Preventability in Stigmatizing Tendencies

Over the years, perceived knowledge of causation, transmission and preventability have proved important in determining stigma associated with singular Skin NTDs (Renzaho et al., 2007, Akoachere et al., 2016, Koka, 2018). Likewise in this comparative study, the nature and level of community knowledge were important in both BU and yaws. Knowledge on causality ($P = 0.045$) and transmission ($p = 0.000$) emerged particularly significant in influencing stigmatizing attitudes. This was also supported by evidence from the qualitative component as patients and care-givers who perceived the diseases to come from poor personal hygiene showed a greater anticipated stigma compared to those who did not. Similar observations have been made in other settings. In scabies, imprecise community perceptions about the disease contributed to negative attitudes towards patients, likewise findings from leprosy, where community knowledge proved crucial in determining stigma (Bainson and Van den Borne, 1998, Lopes et al., 2020, Misganaw et al., 2022).

Additionally, fear of contagion, was a recurrent theme in patient interviews and further supported by misconceptions about disease transmission from community members. In BU, although no human-to-human contact has been established, some participants in the study believed BU to be transmittable, common transmission routes indicated were *living together with patient, sharing personal items, contact with patient's blood* amongst others (Walsh, 2008). Similar misconceptions including a notion of Yaws not being transmittable through close human contact was recorded. These findings are in consonance with other results in Skin NTDs such as leprosy, buruli ulcer, cutaneous leishmaniasis and lymphatic filariasis where fears of disease contagion contributed to stigmatizing tendencies (Bennis et al., 2018, Jacob and Franco-Paredes, 2008, Kuper, 2019, Person et al., 2009, Bandyopadhyay, 1996). Further the fear of contagion was seen working in two ways as community members expressed anxiety about getting close to patients. Some patients on the other hand also showed some hesitancy to get closer to their friends and family for fear of infecting them with the diseases, leading to increased self and anticipated stigma. In Nigeria, although a section of study participants recounted a compassionate feelings for BU patients, they feared patients due to false believes about infection (Nwafor et al., 2019).

Similarly, other severe stigmatizing diseases have concluded similarly. In HIV/AIDS, false perceptions about transmission and fear of contagion contributed to significant stigma against patients (Audet et al., 2013, Weiss, 2008b). Likewise findings in Zambia where incorrect ideas about contagion in mental illness contributed to stigma towards patients (Kapungwe et al., 2010).

Thus, in settings where there is fear for the disease, the bearers pay the price through stigma (Yeshua-Katz and Martins, 2013).

Relationship Between Perceived Curability and Economic Independence on Stigma

Although fewer number of community members saw BU and Yaws as incurable 16 (8.33%), interview participants hinted of diminishing community stigma following onset of healing. Akoachere (2016) also found a positive influence of knowledge on BU. The perception of the disease as ‘treatable’ influenced community acceptance of patients. This is supported by findings from Nigeria, where Nwafor (2019) noted that few participants (26.5%) had a positive attitude towards disease curability, contributing to an overall stigmatizing attitude towards patients.

However, findings from HIV differed. In Iran, HIV positive women retained the fear of stigma and feelings of shame even after onset of treatment (Oskouie et al., 2017). Similar findings were unearthed in China, deep-seated misconceptions about HIV continued to fuel stigma long after commencement of treatment (Wu et al., 2018).

However, the differences in findings may be an impact of the differing socio-cultural contexts or an indication of differing knowledge levels about the diseases

Additionally, economic independence was evidenced to influence stigma as, corroborating the findings from Nigeria where leprosy and associated impairments were less stigmatized compared to the individual’s inability to perform social and family duties (Ebenso and Ayuba, 2010).

Factors influencing social support for patients of BU and Yaws

Although stigma was recorded in Yaws and BU especially, some social support was shown, especially for Yaws patients. Some factors including familial attachment and the endemicity status of the communities were found to influence community support and acceptance of patients.

Familial attachment

Evidence from both quantitative and qualitative components of the study showed family as the most supportive social unit of patients. Community members commonly mentioned staying married to an affected partner and helping him/her to seek cure. Likewise, patients recounted how supportive their family members or marriage partner have been throughout diagnosis, treatment and stigma management phases of the diseases. These deviate from findings in leprosy where patients lost the rights to touch, sleep together, have sex, share personal items and eat together with spouses or family members (Valencia, 1989, Vlassoff and Bonilla, 1994, Kushwah et al., 1981, Zodpey et al., 2000). In another account, although family members reported positive attitude for leprosy patients, a section of participants iterated excluding patients from decision making in the family (Arole et al., 2002). In BU, findings have been varied. Grietens et al (2008) found that, family members in a bid to save themselves from economic hardship and utter ruin did not hesitate to sever ties from affected relatives. On the other hand, Menlah et al (2022) maintained that BU patients are accepted by family members who helped them cope with the disease.

The variations in findings may be an indication of a number of factors. First, differing participant characteristics recorded in these studies may account for the varied findings, for instance, patients below 24 years dominated in this current study. Experiences may therefore differ as compared with a similar study with dominant adult patients. This is because, people of different age groups may play different societal roles. Additionally, the disease characteristics such as lesion type, size, body part affected, progression, treatment response and duration may all be important in influencing family support or otherwise. Lastly, the socio-cultural beliefs associated with the disease in a community may influence family response. In leprosy, it is noted that family members in highly stigmatizing communities where patients are not allowed to live or use public facilities record high stigmatizing tendencies towards patients. Some links could be made to the fear of courtesy stigma in explaining extreme tendencies to stigmatize affected family members.

Moreover, although several patients lost friends after onset of BU in the current study, some friends were supportive throughout the experience, aiding patients manage shame or stigma associated with the disease, validating the propositions of previous findings where such supports promote the psychosocial wellbeing of patients as well as improvement in health seeking behavior (Broman et al., 2022, Earnshaw et al., 2012).

Endemicity Status of Community

Additionally, interview participants observed that, the high prevalence of either BU or Yaws in their communities induced social acceptance towards them, confirming the assertion of Stienstra et al (2002) in other parts of Ghana where members in endemic communities eventually become ‘acquainted’ with the disease and learn to have more positive attitudes towards patients. However, evidence from other endemic settings have proved inconsistent with these findings as community members have been reported to maintain stigmatizing attitudes towards patients (de Zeeuw et al., 2014b, Tawiah et al., 2015, Ocaya et al., 2015). In Thailand, it is reported that in addition to other factors, staying for a longer duration near a leprosy colony raised the chances of perceived stigma (Kaehler et al., 2015).

Moreover, few participants hinted that community members perceived their condition to be the result of supernatural orchestration, however, few linkages were made to connect this to stigmatizing tendencies as consistent with the findings of Shiloh (2002) where beliefs of supernatural involvement in leprosy contributed to community acceptance among the Hausa of northern Nigeria.

5.3 Experiences of Disease Related Stigma in Buruli Ulcer (BU) and Yaws

5.3.1 Common stigma experiences in BU and Yaws

Exclusion of patients from group activities was recorded among both BU and Yaws participants. Until very recently, limited attention has been given to yaws, stepping away from this norm, Dofitas et al (2022) qualitatively explored stigma, psychosocial and economic burden of the disease in the Philippines. It was found that a section of study participants experienced disease related stigma. This was supported by an inaccurate community attribution of positive nontreponemal tests to syphilis and consequently to promiscuity or sexual laxity. Participants therefore suffered repercussions such as exclusion from income and employment opportunities. However, in the qualitative component of this study, we found yaws patients being excluded not on the grounds of disease causation, but rather as a reaction of appearance of yaws lesions. In other cases, not wanting to do physical harm to patients by pricking the wounds through play was a reason to exclude patients. However, some evidence from the community survey iterated that yaws patients may be stigmatized on the grounds of suspicious ideas on disease causation and transmission.

Additionally, BU participants also faced considerable restrictions in societal participation, corroborating findings in other parts of Ghana and beyond (Onwuka et al., 2021, Divine and Tochi, 2021, Amoakoh and Aikins, 2013, Stienstra et al., 2002). However, it was evident that participants who had the non-ulcerative forms of Buruli ulcer reported lesser exclusion from groups activities when compared with participants who had larger lesions which took longer time to heal.

Thus, aside socio-cultural interpretations, patients and their care-givers believed that, lesion characteristics such as appearance, size, state, visibility and duration are likely important predictors of stigma associated with BU and yaws, similar to findings of a scoping review where aside the social context, the lesion type, severity and scars were considered important in both social and self-stigma in localized cutaneous leishmaniasis (LCL). In Ghana, evidence from BU showed that, permanent scars and amputated limbs invited poor treatment from others, in addition to embarrassment, shame and low self-esteem experienced by former patients (Menlah et al., 2022).

However, other variables may be important as findings in other diseases like psoriasis showed that stigma levels and depression are not always ‘proportional to’ or ‘predicted by’ disease characteristics such as severity and body surface area affected. Thus in addition to lesion size, it was found that other variables such as being female and having a functional limitation are important in determining the social restrictions that Buruli ulcer patients are likely to face (de Zeeuw et al., 2014b). Similar findings were found in leprosy as Weiner (2012) gives some dimensions of attributions that determine and direct stigma associated with leprosy. Here, ‘help giving, sympathy and pity are likely to be engendered when the condition is perceived as ‘uncontrollable’ and not within the mandate of the patients such as environmental causation. On the other hand, attributions which suggest negligence on the part of patients such as sexual laxity, and other moral transgressions are likely to lead to anger, rejection and repulsion of the patient, confirming the current study findings of more stigmatizing tendencies recorded in participants who attributed disease causation to poor personal hygiene.

5.3.2 Micro-Level Stigma in BU and Yaws

Micro-level stigma was common to both BU and Yaws in this study. Participants and care-givers of BU and Yaws patients reported felt and anticipated stigma which led to significant self-isolation and psychosocial burden. The study corroborates findings in Indonesia where 75% of study participants who were leprosy recorded internalized stigma (Mulyani et al., 2018). Likewise

findings in Ethiopia where podoconiosis patients reported substantial self-stigma (Tora et al., 2018).

Meanwhile, these forms of stigma pay a heavy price on bearers as internalized stigma has been found to have a negative effect on the self-concept of sufferers (Lufianti et al., 2022). While our findings agree to the proposition of Barrett (2005) where internalized stigma contributed to the dissociation of the stigmatized from society, there was no evidence of 'self-neglect', rather stigma in the form of avoidance, teasing, name-calling and discrimination exhibited in this study contributed to an increased desire to seek and adhere to treatment.

5.3.3 Enacted Stigma Experiences Exclusive to BU

In BU, additional forms of stigmatizing behavior such as discrimination, teasing, name-calling and staring were recorded, similar to findings from Ghana and Benin where psychometric properties among BU patients indicated that there is the presence of a 'good discrimination' against patients (de Zeeuw et al., 2014a).

While teasing and name-calling have not been typically recorded in previous BU studies, findings from neighboring NTDs such as hydrocele and elephantiasis show teasing as typical and characteristic of chronic conditions accompanied by a foul odour, thus suggesting that large BU lesions on children of school-going age which are not properly dressed and emitting bad odour potentially invites teasing and name-calling from class-mates and playmates (Sehgal et al., 2022). Meanwhile, while conducting their study among adolescents who suffered from skin diseases such as psoriasis, atopic eczema and acne, Magin et al (2008) found that teasing is a very important instrument used to reinforce power relationships and exclude patients who in turn, suffer psychologically as they experience a dip in self-esteem, poor self-image and overall selfconsciousness.

Additionally, discrimination was another form of stigma perpetuated against BU patients both by peers as well as other actors in the education sector. These people who particularly perceived to have inadequate knowledge about the disease, similar to the findings in Southwest Cameroon where false beliefs of disease contagion were championed by administrators and professionals (Akoachere et al., 2016). This contrasts findings from Northern Nigeria where formal education

was unveiled to be an important predictor in informing good knowledge about the disease (Nwafor et al., 2019).

Conclusively, findings from this study indicated gap in stigma levels in BU and Yaws. This evidence of differing levels of enacted and internalized stigma in buruli ulcer and yaws respectively is a prominent and novel.

5.4 The Impact of Stigma on Patients

5.4.1 Positive care-seeking behavior

Generally, there is a divergence on the role of stigma in health-seeking behavior. While many studies indicate a negative linkage between stigma and health seeking behavior (Ochola et al., 2021, Yotsu et al., 2020, Ukwaja et al., 2020, Prochazka et al., 2020), other studies have found the presence of stigma a motivating factor in seeking and adhering to treatment.

The current study findings, being inconsistent with the wider literature, showed a positive relationship. It was found that the fear of stigma and labelling motivated participants to seek and adhere to various forms of treatment; orthodox, traditional or religious forms of care. Adult participants particularly iterated that the embarrassment from being socially excluded is a key motivation to seek care for themselves or their wards who suffer(ed) buruli ulcer or yaws. This sides with findings in the US where patients prone to substance abuse were found to seek and adhere to care in response to stigmatizing labels and associated internalized stigma (Benz et al., 2021).

In the opposite view, stigma associated with conditions such as depression, obesity, mental conditions, are revealed to inhibit the pursuance and adherence to treatment (Conner et al., 2010, Pont et al., 2017, Health and Services, 1999, Quah, 2016). For instance, in South Africa, to escape the stigma associated with the disease, HIV patients reported grinding their antiretroviral drugs into powder to conceal it from others, facilitating the possibility of inconsistent dosing (Mills, 2006). Likewise findings from Jamaica and Botswana showed that stigma contributed to late detection and unsuccessful treatment due to progression of disease(White and Carr, 2005, Kinsler et al., 2007).

5.4.2 Psychosocial Burden

A study by Stienstra (2002) in Ghana found that patients were hindered from functioning as leaders, felt ashamed or embarrassed and thought less of themselves for having BU. Frequently, patients said they were avoided by others and expressed more problems in getting married. In this study, marriage and leadership concerns were not expressed, this may be as a consequence of the relatively young age of participants recruited in this study ≤ 24 years (83.8%), of whom lesser attention has been given to, in Skin NTD studies (Rees et al., 2019).

However, significant psychosocial burden attached to the disease such as anxiety, sadness, feelings of embarrassment were recorded in BU especially as some patients narrated how they are mostly absent minded in class feeling worried about the condition and associated treatments meted out to them. This was more prominent among patients who had progressed lesions as found in other severe and mutilating Skin NTDs such as Cutaneous leishmaniasis, leprosy, lymphatic filariasis and podoconiosis (Bennis et al., 2018). The intensity of the burden found was consistent with the severity of the diseases, as consistent with previous observations in varying health conditions (Jacoby et al., 2005, O'Donnell and Habenicht, 2022, Bailey et al., 2019).

However, since the current study participants are active and past BU and Yaws patients who receive(d) 'free medical treatments' on clinical trials, findings may differ from patients in the communities, seeking other forms of treatment or not seeking treatment with likely more chronic and progressed forms of the diseases.

5.4.3 Academic Underachievement

Although some scholars have mentioned the impact of Skin NTDs on academic work, most has been brief and in passing, not investigating the subject in a thorough manner (Engelman et al., 2016, Ukwaja et al., 2020, Yotsu et al., 2020, Mphande, 2020).

Even fewer studies have attempted the effects of Skin NTD related stigma on academic work. The work of Dofitas et al (2022) is important as it was unraveled in the Philippines that, children affected by yaws miss school to avoid bullying associated with the disease (Dofitas et al., 2022a),. Although Yaws patients in the current study did not mention bullying, a number of them mentioned

being sent home from school by their teachers, for fear of infecting other school children, thereby causing academic underachievement for patients. Similar sentiments were expressed by BU participants in this study, in addition to absentmindedness and reduced abilities to focus on lessons due to disease related psycho-social burden such as embarrassment, teasing, avoidance, anxiety and sadness over treatment from peers and other unaffected people.

5.4.4 Strained Social Relationships

Generally, skin NTDs have been noted to promote a decline in household, religious, neighborhood and family relationships (Kurian, 2019, Bewley, 2017, Hay, 2020, Lopes et al., 2020, Chang and Ochoa, 2019), inclusive of marriage relationship as evidence from Ghana confirmed spousal neglect, poor treatment, divorce and marital conflicts in response to BU disease (Menlah et al., 2022). These have been validated in the current study as BU patients and their care-givers especially narrated strained social relationships, and a desire to stay away from playmates, friends and class mates following stigma experience. Most patients became socially isolated following the experience and preferred to be by themselves at home, in their rooms and sited at their desks in the classroom. Confirming previous findings in HIV where patients extensively used self-isolation from friends and family as a way of managing information about the condition (Audet et al., 2013), similar to the findings of Grietens et al (2008) where 84% of children suffering from BU were socially isolated.

Notwithstanding, evidence from few participants in this study also suggested an improvement and strengthening of some social relationships as a few friends remained loyal to patients and defended them from others who sought to stigmatize them. Patients particularly spoke affectionately about these friends and recounted the crucial roles they played in helping them cope with the disease.

This provides evidence on the key role of social support in the management of Skin NTDs.

5.5 Coping Strategies Patients Use in the Management of Stigma

Consistent with previous findings where patients of stigmatizing conditions adopt coping mechanisms, study findings showed a number of coping strategies used in the management of Skin NTD related stigma, particularly by patients with progressed stages of the diseases under study (Lazarus, 2000, Li et al., 2014, García-Alberca et al., 2012, Noh and Kaspar, 2003, Krieger, 2000, Gee, 2008). These were broadly categorized under two thematic areas; Problem-focused strategies

(Concealment with clothing, selective disclosure and information management, confrontation and education) and emotion-focused strategies (religious coping and self-isolation).

5.5.1 Problem-Focused Strategies

Concealment of Lesion/ Scars with Clothing

Long dresses, trousers, socks are some of the clothing extensively used in the management of stigma in skin conditions such as chronic diseases such as pododermatitis and psoriasis (Rakhesh et al., 2008, Muyinda et al., 1997, Uttjek et al., 2007). Most BU patients in the study actively coped by concealing lesions and scars with clothing such as trousers, long skirts, dresses and socks to veil affected parts as they visit public places like the market, school, health facility, public transports and church. In the assertion of Tora et al (2011) this is an active mechanism which relieves the stress of the individual as well as influencing the negative social interaction in a positive manner. True to the propositions of Goffman (1963), both young and old BU patients in this study extensively used clothing in an attempt to look 'normal' by concealing lesions. Consistent with findings from Nigeria where patients suffering from lymphatic filariasis covered their legs with clothing to pass off as 'normal' in a bid to engage in social activities (Abdulmalik et al., 2018).

Selective Disclosure of Disease and Information Management

Although the evidence BU and Yaws are likely shown on the skin, some participants in the study preferred to keep the disease status a close secret, only shared with selected few such as family members and selected friends. This is similar to findings in other stigmatized diseases such as HIV and epilepsy (Arrey et al., 2015, Bilardi et al., 2019, Alexias et al., 2015, Schneider and Conrad, 1980). Here, patients who are unable to veil lesions from public view withhold, give vague or incorrect information about the cause of the lesion when asked by community members. Patients therefore engaged in 'impression management' to avert anticipated stigma as recorded in leprosy patients (Gussow and Tracy, 1968).

Confrontational Coping Mechanism

The finding of confrontation as a coping strategy particularly digresses from previous findings in Skin NTDs where emotion-focused strategies have continually been recorded. However, our findings are consistent with the assertion that patients living in communities where sensitization

and education are regular are likely to display courage and confront people who attempt to stigmatize them (Sun et al., 2007). In consonance, patients in this study who confronted stigma iterated more accurate knowledge about the disease. Common media mentioned were education by community health volunteers and health workers. Thus, accurate disease knowledge may likely have a negative effect on macro and micro-levels of stigma. This is inconsistent with the assertion of Rodrigue et al (2000) where only patients of 'life threatening' diseases are likely to confront stigmatizers.

On the other hand, in spite of assertions that confrontation limits the rate of disease progression in addition to promoting psychological forgiveness and overall improvement in mental health, there was limited evidence in support of reduced psychosocial suffering in patients who used the strategy in comparison to patients who used other strategies (Mulder et al., 1995, Hershcovis et al., 2018).

5.5.2 Emotion-focused Strategies

Religious Coping Mechanism

A section of participants, particularly BU patients sought comfort by trusting religious beings to heal them in due time, consistent with most stigmatizing diseases associated with significant psychosocial burden such as HIV and leprosy (Zou et al., 2009, Cotton et al., 2006, Peters et al., 2013). In Bolivia, while studying Chagas disease, it was unraveled that patients frequently exhibited a calm state of mind, often backed by a faith in God as a way of gaining control of the disease and preventing escalation (Forsyth, 2017). In Indonesia, religion positively helped leprosy patients cope better as religious beliefs gave meaning to the disease i.e. punishment for past sins, challenge or test of faith (Peters et al., 2013).

Self-isolation and Behavioral Change

Self-isolation emerged as one of the most recurrent themes in the study, particularly among BU participants. This is consistent with evidence from HIV, leprosy and cutaneous leishmaniasis, (Sermittirong et al., 2014, Audet et al., 2013). This avoidant strategy has been noted as negative as it is commonly associated with low self-esteem, increased levels of anxiety, depression, quality of life, psychological well-being and suicidal ideation (Bennis et al., 2018, Nurdjana et al.). Consistent with this, patients with progressed diseases in the current study who used this strategy

experienced increased psychosocial burden, including worry, sadness and absent-mindedness in school, and became more introverted.

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CHAPTER SIX

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

This is the last chapter of the study. It has been organized to present the summary of study findings, conclusions, recommendations and suggestions for further studies.

6.1 Summary of findings

Overall, social and biomedical triggers of stigma in BU and Yaws were indicated. In the social triggers, there was evidence to suggest that community knowledge and beliefs about a disease play a vital role in stigma associated with BU and Yaws. Inaccurate community knowledge and beliefs, including misconceptions of disease causation, transmission, prevention and cure contributed to stigmatizing attitudes towards patients. On the other hand, biomedical triggers were also shown. Patients who had less progressed forms of the diseases such as small nodules or lumps recounted lesser stigma as compared to patients who had extensive ulcers which took longer time to heal. Thus, lesion characteristics such as visibility, size, location on the body, and state (well-dressed or otherwise) were important in predicting stigma.

Also, stigma experiences in the forms of exclusion, teasing and name-calling, discrimination and avoidance were perpetrated by community members, school mates and teachers towards BU patients especially. Moreover, there were nuances in enacted stigma, as some community members stigmatized patients in response to being undervalued, others did so for the perceived wellbeing of the patient. However, social support was also evidenced. Familial attachment emerged particularly important in predicting social support of BU and Yaws patients.

Further, although stigma encouraged increased health seeking-behavior, negative impacts, including psychosocial burden, underachievement in school and strained social relationships were noted.

To cope with stigma, patients adopted problem focused and emotion focused strategies including confrontation, concealment, religion, information management and secrecy. These strategies posed both good and harmful effects on patients.

6.2 Conclusion

Conclusively, stigma was found in both BU and Yaws, however, BU patients recorded more stigma and hence more harmful implications as compared to Yaws patients within the Atwima Mponua District in southern Ghana. It is important to incorporate psychosocial measures in the management of skin NTDs.

6.3 Recommendations

Study evidence showed that community knowledge, attitude and beliefs are important precursors of stigma, hence the Ghana Ministry of Health (MoG), NGOs, and international donors must give more attention to providing public education on skin NTDs. Endemic communities especially must be educated about the signs and symptoms, causes and treatment pathways available for skin NTDs. This education must be delivered in a combination of context-friendly and acceptable media to promote easy assimilation and to encourage appropriate care and promotion of social acceptance and support.

Secondly, the Ghana Health Service (GHS) must give policy attention to incorporating and strengthening psychosocial measures in the management of skin NTDs as stigma was found to pose significant problems for affected people

Also, Academics must focus on researching to understand the nature of stigma and the various predictors and how these can be ameliorated.

Also, community stake-holders such as assemblymen, chiefs, traditional healers and religious leaders must be encouraged to use their platforms to inspire community acceptance and social support of affected people to promote.

6.4 Suggestions for Further Studies

Community knowledge, beliefs, attitudes must be investigated in other endemic settings to find further socio-cultural and context specific evidences and their role in predicting stigma. In addition, underexplored skin NTDs must be explored to find important nuances among differing socio-cultural contexts. Sociologists are particularly encouraged to study the phenomenon using macro-micro lens to solicit more holistic evidence.

Also, while socio-demographic characteristics including age, gender and economic status have not been the focus of many stigma scholars, age especially proved to be an important factor, influencing the dynamics of stigma experienced by patients in this study. Further insight therefore remains useful to explore the role of socio-demographic factors in promoting disease related stigma among the skin NTDs, providing useful evidence for intervention programs and policy making

Conclusively, the role of health workers in promoting or averting stigma must be investigated to provide further evidence as they constitute important stake-holders in the management of the conditions.



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KNUST



APPENDIX 1: Photos of Skin NTDs of interest (Yaws and Buruli Ulcer).

A: Yaws in different clinical presentation



Photo credit; Skin NTD group, KCCR

B: Buruli Ulcer in different clinical presentations



Photo credit; Skin NTD group, KCCR .

APPENDIX 2: Interview Guide

Individual In-depth Interview (Griffiths et al.) Guide (BU AND YAWS PATIENTS/ PAST PATIENTS)

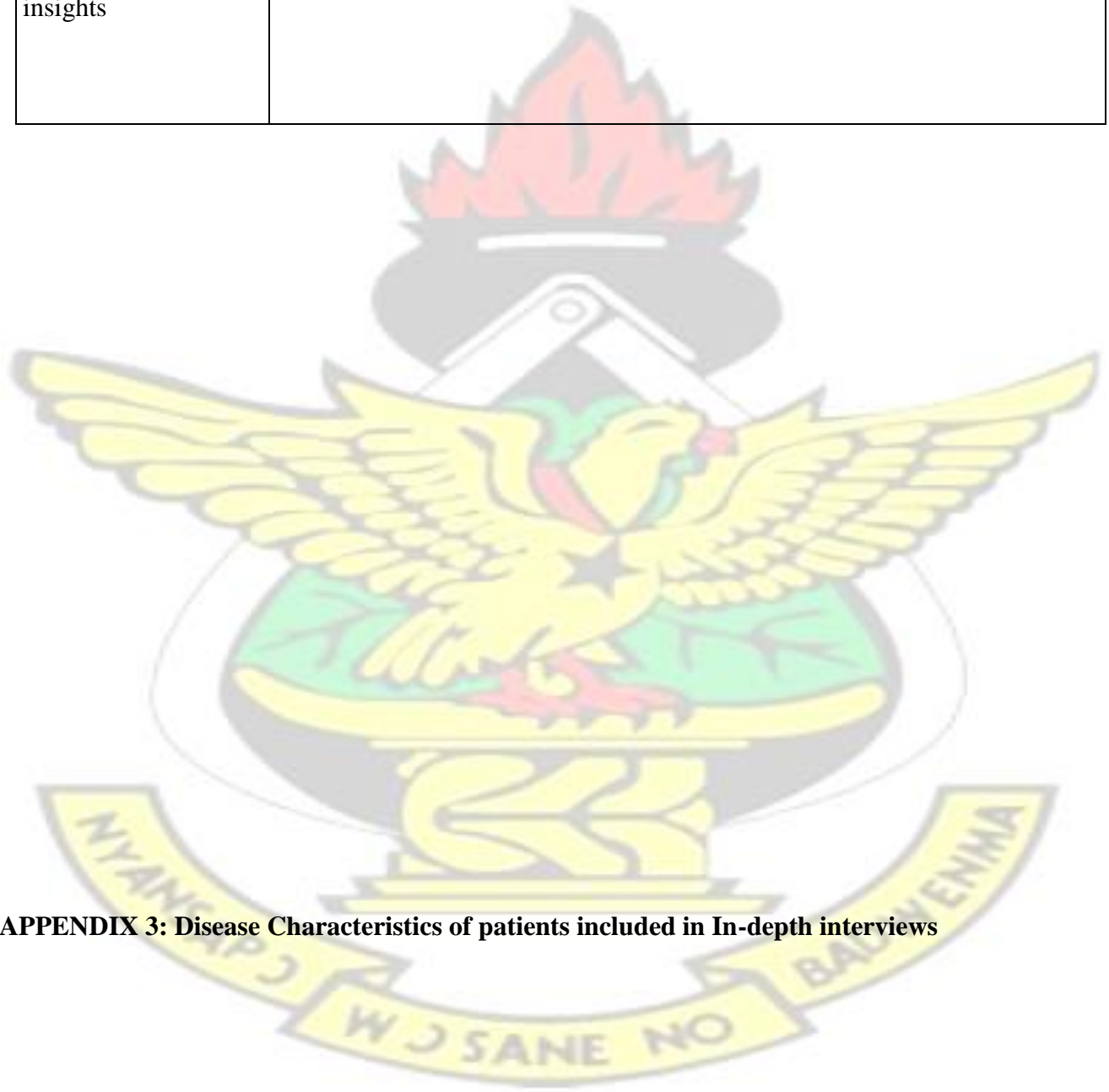
The researcher is an MPhil student affiliated to the Department of Sociology and Social Work, Kwame Nkrumah University of Science and Technology, Ghana. This interview guide is to gather data on your knowledge or Thought on the topic: “A comparative study of stigma in buruli ulcer and yaws in selected co-endemic communities in the southern Ghana”. Your thoughtful and truthful responses will be greatly appreciated. Please answer each question to the best of your knowledge. Your name is not required. The sole purpose of the research is for an academic

exercise and your responses will be kept strictly confidential. Thank you for taking time to complete this questionnaire.

	Questions
General question about patients	<p>Where do you live? Any changes after the disease? Why?</p> <p>What did you first do about the disease and why?</p>
Enacted stigma experience	<ul style="list-style-type: none"> <input type="checkbox"/> How do people treat you? Friends? Family? Community members? Any difference before, during and after the disease? <input type="checkbox"/> Are you able go to social gatherings? Market? School? Work? Changes? <input type="checkbox"/> Are you able to lead? Any difference before, during and after disease experience? Why? <input type="checkbox"/> How do people treat your family and friends? any changes? specific examples?
Internalized stigma	<ul style="list-style-type: none"> <input type="checkbox"/> How do you feel when people get to know about your condition? <input type="checkbox"/> How do you feel about the way people treat you? <input type="checkbox"/> What has your sociable life been before and after the disease? Any changes? <input type="checkbox"/> Did you stay more indoors or outdoors? Why? <input type="checkbox"/> Did you feel the need to cover up the lesion from the view of other people? Reasons? Any differences with changes in your social setting?

Health-worker stigma	<p><input type="checkbox"/> How were you treated by care-givers? Any changes?</p>
Effects of stigma	<p><input type="checkbox"/> How did the experience affect your life? Social life? work? Mental health? Mood? Academic pursuit?</p> <p><input type="checkbox"/> How did you handle this disease since it came up? When did you seek care? Why did you choose that pathway?</p> <p><input type="checkbox"/> Suicidal ideation?</p> <p><input type="checkbox"/> Were you happy with the way you were treated by people? any specific examples?</p>
Coping strategies	<p><input type="checkbox"/> How do you deal with the way you are treated on daily basis? Concealment? substance abuse? Alienation?</p> <p><input type="checkbox"/> How has your dressing been like since the onset of the disease? Any differences? Why?</p>
	<p><input type="checkbox"/></p>

	<p><input type="checkbox"/> What would you intervention do you suggest can be done to make the experiences of current or future patients better in terms of stigma</p>
<p>Any additional insights</p>	<p><input type="checkbox"/> Do you have further insights you would want to share with us?</p>



APPENDIX 3: Disease Characteristics of patients included in In-depth interviews

	Presentation				Stage				Healing status
			plaque	Ulcer	Cat I	Cat II	Cat III	NA	
BU(n=15)	Nodule (3)	Oedema (2)		(10)	(1)	(3)	(10)		Yes (8) No (7)
YAWS(n=16)	Papilloma (5)	Bone swelling (1)	Ulcer (10)	NA	primary	secondary	Tertiary	latent	Yes (11) No (5)

APPENDIX 4. Data collection Tools

KAPS Community Survey (Community members in BU and Yaws endemic communities)

The researcher is an MPhil student affiliated to the Department of Sociology and Social Work, Kwame Nkrumah University of Science and Technology, Ghana. This questionnaire is to gather

data on your knowledge or Thought on the topic: “A comparative study of stigma in buruli ulcer and yaws in selected co-endemic communities in the southern Ghana”. Your thoughtful and truthful responses will be greatly appreciated. Please answer each question to the best of your knowledge. Your name is not required. The sole purpose of the research is for an academic exercise and your responses will be kept strictly confidential. Thank you for taking time to complete this questionnaire.

GENERAL INSTRUCTION

Please write or tick your responses to the following questions as required.

Has the prospective participant heard about either BU/ Yaws before? Yes No

If ‘yes’ to the above, **please indicate whether the survey is for BU or Yaws and proceed**.....

Time at the beginning of the survey.....

a		SOCIO-DEMOGRAPHIC PROFILE OF PARTICIPANT	
Date of Survey (dd/mm/yyyy)/...../.....	Community
Participant Identifier			
Age			

Gender	(a) Male []	(b) Female []
Occupation	(a) Professional []	(b) Admin/managerial []
	(c) Clerical []	(d) Service []
	(e) Agric []	(f) Homemaker []
	(g) No work activity []	(h) Not applicable []
	(i) Self-employed []	(j) Other (specify).....
Marital Status	(a) Married []	(b) Single []
	(c) Separated []	(d) Widowed []
Religion	(a) Christian []	(b) Muslim []
	(c) Traditional religion []	(d) Other (specify).....
Highest level of education	(a) No education []	(b) Primary []
	(b) (c) Secondary []	(d) Tertiary []
Ethnicity	(a) Akan []	(b) Ga-adangme [] (c) Ewe []
	(d) Guan []	(e) Other (specify).....
Data collector's initial		

Section A: Knowledge on disease

How long have you lived in this district	(a) ≤ 1 year [] (b). 2-5 years [] (c) 6-10 [] (d)More than 10 years []
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A1b. Has participant ever seen a patient or past patient?	Yes.....No.....
A1c. Has participant seen a patient or past patient in this district?	Yes.....No.....
A2a. Do you know any sign and symptom?	Yes.....No.....

A2b. if YES to the above, then which of the following are signs and symptoms? [please do not read options below to participant]	
1= swollen affected part	
2= mostly round yelloweish looking-ulcers on the skin	
3= hardened affected skin	
4=lumps on the skin	
5= falling off of fingers and toes	
6= big ulcers emitting bad smell	
7=Other [please specify]	
A3. How did you get to know/ hear about disease? (Select all that apply)	
1= I am a current/past patient	
2= related to a patient/ past patient	
3= knew a patient/ past patient	
4= media	
5= school	
6= National/ international health promotion programs	
7=community health worker activities	
8=others [please specify]
A4. What are the causes of the disease ?	
0= Any idea idea? [If YES, read out the options below and select the appropriate option]	Yes.....No.....
1= micro-organisms	Yes.....No.....
2=poor personal hygiene	Yes.....No.....
3=drinking unclean water	Yes.....No.....
4= bathing or swimming in bodies of unclean water	Yes.....No.....
5= evil spirits	Yes.....No.....
6=curses	Yes.....No.....
7= punishment for misdeeds	Yes.....No.....

8= Bad blood	Yes.....No.....
9= hereditary	Yes.....No.....
10= flies/insects	Yes.....No.....
11=connected with minning activities	Yes.....No.....
12=Use of skin bleaching creams	Yes.....No.....
13=Other [please specify]	
A5a. Is the disease transmittable from one person to the other?	Yes.....No.....
A5b. If YES to A5a, how is it transmitted from an infected person to another?[Select all that apply]	
1=Living in the same house with a patient	Yes.....No.....
2=sharing of personal items such as clothing, sponge and towels	Yes.....No.....
3=eating from same bowl with patient	Yes.....No.....
4= playing together with the patient	Yes.....No.....
5= Through the air	Yes.....No.....
5=Through contact with the blood of a patient.	Yes.....No.....
6=By buying food from a patient	Yes.....No.....
7=By visiting the house of patient	Yes.....No.....
8=Committing taboo(s)	Yes.....No.....
9=Other [please specify]	
A6a. Is the disease curable?	Yes.....No.....
A6b. Where will participant first go, should they see the disease on the skin?	
A6c. If YES A6a, where should patients go to seek appropriate treatment?	
1= spiritual healers	
2=health facilities	
3= Undergoing self-medication	
4=religious leaders	

Section B: Beliefs and Attitudes towards patients with BU/Yaws

No	Item statements	Strongly disagree (1)	Disagree (2)	Neither agree or disagree(3)	Agree (4)	Strongly agree (5)
1.	The disease makes the family of the affected person unpopular					
2.	patients must not shake hands with other people					
3.	The disease is a punishment for dishonest behavior					
4.	patients must not eat from the same plate with unaffected people					
5.						
5-Using home remedies (Broman et al.)						
6= herbalist						
7=Buying drugs from the drugstore/ pharmacy						
8= Other [please specify]						
A6d; Is disease preventable?				Yes.....No.....		
A6e. If YES to A6d, how can the disease be prevented?					
A7. What typical signs are found on a person who had the disease in the past?					

Section C: Community acceptance of former patients						
No	Item statements	Strongly disagree (1)	Disagree (2)	Neither agree or disagree (3)	Agree (4)	Strongly agree (5)
1.	I do not mind living in the same house with someone who has Bu/ Yaws disability					
2.	Scars on former patients makes them look fearful					
3.	Former patients must wear clothes to cover their scars before going out of their homes					
4.	Former patients must be treated normally as any					
6.	Other community members prepared by a patient					
7.	It is normal for patients to feel ashamed					
8.	I am okay to travel together with a patient in the same car					
9.	I am okay to share personal items such as clothing, bowls and cups with patients					
10.	I will feel okay to buy food being sold by a patient					
11.	I have no problem marrying a patient					
12.	I do not mind if my children play with a patient					
13.	It is okay to stay married to a partner who is affected by the disease					
14.	A patient must stay at home and only come out only after they are healed					

Please write general comments or any other form stigma related knowledge, attitude or practice associated with the disease, not mentioned above

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Section X: Observations by interviewer

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Time at end of survey.....

