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HEALTH-SEEKING BEHAVIOUR OF BURULI ULCER AFFECTED PEOPLE IN A RURAL SUB DISTRICT OF THE EASTERN REGION, GHANA

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Summary

Introduction

Buruli ulcer (BU) is one of the least studied neglected tropical diseases. It is a chronic necrotising skin and soft tissue disease that may also affect the bone. The majority of BU affected people seek medical care only at an advanced stage of the disease. This is often associated with severe disabilities and goes along with social implications (e.g. increased treatment expenses, impaired capacity to work, stigmatisation and social exclusion). Early diagnosis and antibiotic treatment would simplify the treatment and reduce morbidity as well as the involved social and economic constraints. Nevertheless, research into reasons for delayed medical treatment and local perceptions of BU is still insufficient.

Aim of the Study

This study draws on the need for a better understanding of the local BU specific disease concept and the related health-seeking behaviour. Its primary aim was to adapt an existing instrument (Kroeger’s Framework (1983)) to explain the BU specific health-seeking behaviour as well as to apply and evaluate it on the basis of different research methods. In this course characteristics of people who reported late to governmental health facilities were identified. In addition, measures for improving the disease specific treatment and control as well as health education activities were identified. The suitability of the applied research methods to assess the individual variables of the framework was evaluated to collect relevant data easier and more efficient in the future.

Methods

The research was carried out in a rural sub district of the Eastern Region (Ghana). An iterative process using qualitative as well as quantitative research methods was applied. To explore the published evidence on aspects influencing BU specific health-seeking behaviour and to analyse them in a structured way Kroeger’s Framework for health-seeking behaviour (1983) and a systematic literature search served as starting points. To obtain details about local disease concepts, perceptions and treatment practices expert interviews were done. An active community case search (door-to-door screening) in the study area (48 communities, about 23,000 inhabitants) allowed for conducting a knowledge, attitude and practice (KAP) survey among presently and previously BU affected people (N=122) as well as matched non-affected community members (N=122) (similar age and same sex) to identify and assess differences between these two groups. Focus group discussions (FGDs) in selected communities were organized to reveal differences with respect to the disease perception across the research area as well as between previously BU affected and non-affected people.

Results

The analysis of 22 retrieved papers allowed for an assessment of the different aspects of health-seeking behaviour according to the literature and the development of the *‘Adapted BU specific Framework for Health Seeking Behaviour’* (version I). 33 expert interviews provided details about the local disease perceptions (e.g. only traditional herbal treatment may heal the spiritual aspects of BU) and treatment practices (e.g. home-based herbal treatment as the preferred treatment option for pre-ulcerative lesions) within the research area. These findings led to further modifications of the framework (*‘Modified BU specific Framework for Health-Seeking Behaviour’* (version II). This framework was also used for the development of the KAP questionnaire. The active community case search allowed for identifying and recruiting the participants of the KAP survey. The findings of the survey underlined that the non-affected study participants were less informed about the disease and its treatment options than the (previously) BU affected study participants and allowed for quantifying some of the aspects of the framework. The assessment of the characteristics of *'Late Care-Seekers'* revealed that this sub group was more likely to depend on transportation to access governmental health facilities, was less informed about the disease, less satisfied with governmental health facilities and less familiar with the fact that antibiotic treatment for BU is provided free of charge. The 12 FGDs in six selected communities have shown that the perception of the disease differs between the communities and that non-affected participants are more informative than the previously BU affected participants.

Discussion

The *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) and the findings provide disease specific information on the health-seeking behaviour and thereby contribute to the understanding of the local disease concept. The study has shown that there is a need – besides BU specific health education – for an improved access and generally increased attractiveness of government health facilities (including improved supply of medicines and supplies). The research design allowed for an evaluation of the validity of the framework. The results of the systematic literature search provide an overview of the various aspects of the BU specific health-seeking behaviour according to the current research literature. Expert interviews provided explanations for particular local and cultural phenomena (*'Characteristics of BU and Disease Perception'*) and allowed to include personal experiences (*'Enabling Factors'*). The KAP survey yielded quantified background information on the study population (*'Predisposing Factors'*), knowledge about BU and its symptoms as well as the *'Choice of Health Resources'*. In addition, the data set provided the opportunity to examine various subgroups. FGDs were mainly suitable for assessing sensitive aspects (*'Aetiological Model'*, *'Stigma/ Social Exclusion'*, etc.) to identify and disclose controversial aspects.

Conclusion

The *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) is a valuable tool to explain the health-seeking behaviour in a structured and quantified way. Due to the different variables of the framework the use or adaptation of the instrument for other endemic areas in Africa appears to be possible. The study delivers knowledge on the local population's knowledge, attitudes and perceptions of BU as well as challenges regarding the accessibility and use of the available health services in the research area. These insights should be used to develop target group specific interventions to improve both treatment as well as BU specific health education. Moreover, this output underlines further research needs with respect to health-seeking behaviour and the specific reasons for delayed medical treatment as well as the mode of transmission, on-site diagnosis and an improved (home-based) treatment of BU.

Zusammenfassung

Hintergrund

Das Buruli-Ulkus (BU) zählt zu den am wenigsten untersuchten vernachlässigten Tropenkrankheiten. Es handelt sich um eine chronische Erkrankung der Haut und Weichteile, die auch die Knochen befallen kann. Die Mehrheit der betroffenen Personen nimmt erst in fortgeschrittenem Krankheitsstadium medizinische Hilfe in Anspruch. Dies geht häufig sowohl mit schweren körperlichen Behinderungen als auch sozialen Auswirkungen (z. B. erhöhte Behandlungskosten, eingeschränkte Arbeitsfähigkeit, Stigmatisierung und soziale Ausgrenzung) einher. Eine frühzeitige Diagnose und Behandlung mit Antibiotika würde die Behandlung vereinfachen, und die Morbidität sowie die sozialen und wirtschaftlichen Folgen mildern. Die Gründe für die verzögerte Inanspruchnahme medizinischer Versorgung und die Wahrnehmung der Krankheit durch die betroffene Bevölkerung sind noch nicht ausreichend erforscht.

Ziel

Die vorliegende Arbeit greift den Bedarf nach einem besseren Verständnis des lokalen BU spezifischen Krankheitskonzepts und dem diesbezüglichen Patientenverhalten auf. Das primäre Ziel der Studie war es, ein bestehendes Instrument zur Erklärung von Patientenverhalten (Framework von Kroeger (1983)) für BU spezifisch anzupassen, durch den Einsatz verschiedener Forschungsmethoden anzuwenden und zu bewerten. In diesem Zuge werden Charakteristika von Personen, die verspätet staatliche Gesundheitseinrichtungen aufsuchen, identifiziert. Zudem wurden Maßnahmen zur Verbesserung der Behandlung und Kontrolle der Krankheit sowie spezifischer Aufklärungsbedarf abgeleitet. Abschließend wurde die Eignung der eingesetzten Methoden zur Untersuchung der einzelnen Variablen des Frameworks bewertet um die Erfassung relevanter Daten zukünftig einfacher und effizienter zu gestalten.

Methoden

Die Studie wurde in einem ländlichen Unterbezirk der Eastern Region Ghanas durchgeführt. Ein iterativer Prozess, der qualitative und quantitative Forschungsmethoden umfasste, wurde angewandt: Als Ausgangspunkt für die strukturierte Erfassung des Patientenverhaltens diente der konzeptionelle Framework von Kroeger (1983) sowie eine systematische Literaturrecherche. Um Details zum lokalen Krankheitskonzept, der Wahrnehmung und dem entsprechenden Patientenverhalten zu erfassen, wurden Experteninterviews durchgeführt. Eine aktive Fallsuche im Untersuchungsgebiet (48 Dörfer, rund 23.000 Einwohner) ermöglichte die Durchführung eines Surveys zu Wissen, Einstellungen und Verhalten unter allen gegenwärtig und ehemals von BU betroffenen Personen (N = 122) sowie gematchten nicht betroffenen Dorfbewohnern (N = 122) (ähnliches Alter und gleiches Geschlecht), um Unterschiede zwischen beiden Gruppen zu erfassen. Gruppendiskussionen in ausgewählten Dörfern erlaubten die Untersuchung von Unterschieden in Bezug auf die Wahrnehmung der Krankheit zwischen ehemals an BU erkrankten und nicht erkrankten Personen.

Ergebnisse

Die Analyse von 22 identifizierten Publikationen zum Patientenverhalten ermöglichte eine Bewertung der verschiedenen Aspekte des Patientenverhaltens sowie die Entwicklung des *‚Angepassten BU spezifischen Frameworks zum Patientenverhalten’* (Version I). 33 Experteninterviews lieferten Details zum lokalen Krankheitskonzept (z. B. nur die traditionelle Kräuterbehandlung kann die spirituellen Aspekte von BU heilen) und Behandlungspraktiken (z. B. eigenhändige Kräuterbehandlung als bevorzugte Praxis für die Behandlung präulzerativer Läsionen). Diese Erkenntnisse führten zu weiteren Anpassungen des Frameworks (*‚Modifizierter und spezifischer Framework zum Patientenverhalten bei BU’* (Version II). Dieser Framework wurde zur Entwicklung des Survey-Fragebogens genutzt. Die daraus resultierenden Ergebnisse unterstreichen, dass die nicht erkrankten Studienteilnehmer einen geringeren Wissensstand zu BU und dessen Behandlungsmöglichkeiten haben als die (ehemals) an BU erkrankten Studienteilnehmer. Zudem liefert der Survey quantitative Informationen zu einigen Variablen des Frameworks. Die Analyse der Charakteristika von Personen, die verspätet medizinische Hilfe in Anspruch nahmen, ergab, dass diese überwiegend auf Transportmittel angewiesen sind um staatliche Gesundheitseinrichtungen aufzusuchen, einen geringeren Informationsstand über BU aufwiesen, mit den staatlichen Gesundheitseinrichtungen unzufriedener waren und weniger vertraut waren mit der Tatsache, dass die Antibiotika-Behandlung für BU kostenfrei zur Verfügung gestellt wird. Die zwölf Gruppendiskussionen in sechs ausgewählten Dörfern haben gezeigt, dass sich die Wahrnehmung der Krankheit von Dorf zu Dorf unterscheidet und dass nicht-betroffene Teilnehmer in der Regel auskunftsfreudiger sind als die ehemals an BU erkrankten Teilnehmer.

Diskussion

Das Instrument und die Ergebnisse stellen Informationen zum BU spezifischen Patientenverhalten zur Verfügung und tragen somit zum Verständnis des lokalen Krankheitskonzepts bei. Die Studie hat gezeigt, dass neben BU spezifischer Gesundheitsaufklärung der Bedarf nach niedrigschwelligem Zugang und allgemein gesteigerter Attraktivität der staatlichen Gesundheitseinrichtungen (inklusive verbesserter Versorgung mit Medikamenten und Material) besteht. Das Forschungsdesign ermöglichte die Bewertung der Gültigkeit des Frameworks. Die Ergebnisse der systematischen Literatursuche bieten einen Überblick über die verschiedenen Aspekte des Patientenverhaltens gemäß der aktuellen Forschungsliteratur. Experteninterviews lieferten insbesondere Erklärungen für lokale und kulturelle Phänomene (*‚BU Symptomatik und deren Wahrnehmung‘*) und ermöglichten den Einbezug persönlicher Erfahrungen (*‚Charakteristika der Gesundheitsinfrastruktur'*). Der Survey lieferte quantifizierte Hintergrundinformationen über die Studienpopulation (*‚Prädisponierende Faktoren‘*), Wissen über BU und dessen Symptome sowie die *'Wahl der Gesundheitsressourcen'*. Zudem bietet der Datensatz die Möglichkeit verschiedene Subgruppen zu untersuchen. Gruppendiskussionen waren v.a. geeignet um sensible Aspekte (*‚Ätiologisches Modell’*, *‚Stigmatisierung/ Soziale Ausgrenzung’* etc.) offen zu legen und kontroverse Aspekte herauszuarbeiten.

Schlussfolgerung

Der *‚Modifizierte und spezifische Framework zum Patientenverhalten bei BU’* (Version II) ist ein geeignetes Instrument, um das Patientenverhalten in strukturierter Weise zu erfassen und zu beschreiben. Durch die verschiedenen detaillierten Variablen des Frameworks erscheint die Nutzung bzw. Anpassung des Instruments für weitere endemische Gebiete Afrikas möglich. Die Studie liefert sowohl Erkenntnisse über Wissen, Einstellungen und Wahrnehmungen bzgl. BU als auch über Herausforderungen in Bezug auf den Zugang und die Nutzung der verfügbaren Gesundheitsdienste. Diese Erkenntnisse sollten genutzt werden um zielgruppenspezifische Interventionen zur Verbesserung der Behandlung und Aufklärung zu entwickeln. Darüber hinaus unterstreichen diese Ergebnisse den Forschungsbedarf zum Patientenverhalten und die konkreten Gründe für die verzögerte Inanspruchnahme medizinischer Hilfe, die spezifischen Übertragungswege, verbesserte Diagnosemöglichkeiten sowie neuer Therapieformen, die von den Patienten besser angenommen werden.

Table of Contents

List of Tables

List of Figures

Acronyms and Abbreviations

€	Euro (European Currency)
BU	Buruli ulcer
CBSV	Community-based Surveillance Volunteer
CHPS	Community Health Planning Services
CI	Confidence Interval
DALYs	Disability adjusted life years
DHMT	District Health Management Team
DNA	Desoxyribonucleic acid
DRC	Democratic Republic of Congo
e.g.	example given
FGD	Focus Group Discussion
GBUI	Global Buruli Ulcer Initiative
GHC	Ghanaian Cedi (Ghanaian Currency)
HIV	Human Immunodeficiency Virus
i.e.	in extend
IEC	Information, Education and Communication
KAP	Knowledge Attitude Practice
Max	Maximum
Min	Minimum
MOTT	Mycobacteria other than tuberculosis
MU	Mycobacterium ulcerans
N	Number of Study Participants
NBUCP	National Buruli Ulcer Control Program
NGO	Non-Governmental Organization
No.	Number
OPD	Outpatient Department
OR	Odds Ratio
P	P-Value
PCR	Polymerase Chain Reaction
POD	Prevention of Disabilities
SD	Standard Deviation
SHEP	School Health Education Program
SSNIT	Social Security and National Insurance Trust
TAG	Technical Advisory Group on Buruli Ulcer
TB	Tuberculosis
TV	Television
US$	US Dollar (Currency of the United Stated of America)
WHA	World Health Assembly
WHO	World Health Organization
Exchange rate August 2010	1 € = 1.32 US$ 1 € = 1.80 GHC

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Meda w´ase

1. Introduction

> *"The fact that Buruli ulcer is not painful at the onset* [is the reason why people do not report for early medical treatment][1]*. When you have the nodule* [pre-ulcerative lesion] *you maybe hardly notice that it is on you, and the fact that in our local parlance a boil is not supposed to be taken to the hospital. A boil does not take injection. A boil does not take a cut. If you do that you die. We grow up with it and it's so much ... Everybody in Ghana knows that boils are not supposed to be taken to the hospital. So, Buruli ulcer looks like a boil. So first of all, you wouldn't seek medical attention, secondly it is painless so you wouldn't go, you know. And then thirdly, because of other people around, even when it breaks up and it comes into an ulcer, this is just a normal ulcer. And people don't really take wounds, like cuts like that to the hospital for treatment"*[2].

1.1 Background of the Study

Buruli ulcer (BU) is a tropical and infectious disease, which is caused by an infection with *Mycobacterium ulcerans* (MU) (Wansbrough-Jones and Phillips, 2006). In the early stages the disease is often painless and non-specific (i.e. nodule, plaque or oedema); without timely medical treatment it leads to large ulcers (WHO, 2008). In most cases these ulcers develop in a relatively short time (within approximately one to two months), affect the subcutaneous fatty tissue and may cause necrosis (En et al., 2008). The bone may become involved, as the disease worsens (WHO, 2008).

The disease is spread in approximately 30 countries (Adu et al., 2011) – mainly in rural and marshy areas of West, Central and East Africa (Asiedu et al., 2000). In Ghana, for example, about 1,000 new BU cases are registered every year (Amofah et al., 2002), while the disease occurs in more than 80% of the districts all over the country (Renzaho et al., 2007). The infection with MU presumably occurs through skin abrasions or insect bites (Jacobsen and Padgett, 2010). However, the specific mode(s) of transmission are unknown until today (Merritt et al., 2010).

Until 2003 the recommended medical therapy was surgical excision (Schunk et al., 2009). Since 2004, the WHO has recommended an eight-week therapy with Streptomycin and Rifampicin (WHO, 2004). This protocol has also been followed in Ghana (since 2005). If this combination therapy is started in time (category I and II lesions[3]) surgery may be avoided (Etuaful et al., 2005).

Due to the fact that more than 50% of BU affected people report late (category II and III lesions) to governmental health facilities (Stienstra et al., 2002, Mulder et al., 2008, Renzaho et al., 2007), the health system in endemic areas is greatly challenged: the sooner the specific antibiotic therapy is done, the lower the burden of the disease is for the affected people and the lower the costs for the health care system are. The elaborate laboratory-based diagnosis[4] (Portaels et al., 2001) is often not available in rural health facilities. Furthermore a lack of clinical diagnostic skills of the local health personnel as well as a lack of general awareness of the people about BU and the appropriate treatment options may be observed (Ackumey et al., 2011b). For further information on the disease characteristics,

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[1] Insertion by the Author refers to his initial question the interviewee answers

[2] Expert Interview No. 13: 306-318;

[3] BU lesions are divided into three categories:
- Category I: single lesion < 5 cm in diameter
- Category II: single lesion 5-15 cm in diameter
- Category III: individual lesion > 15 cm in diameter, as well as multiple lesions, lesions at critical location, and osteomyelitis

[4] Securing a clinical BU suspicion is performed by microscopy, culture, PCR and/ or histology of wound swabs (ulcerative forms) or tissue biopsies and fine needle aspirations (non-ulcerative forms, fine needle aspirations even for scarred wound edges). For a definite diagnosis WHO recommends two positive test results each.

epidemiology, diagnostics, treatment options etc. see the *‘Background’* chapter of this thesis.

1.2 Rationale of the Study

In particular for diseases whose cause or mode(s) of transmission are not known the population often has diverse explanations (i.e. natural, supernatural or explanations that include a combination of different causes) (Singer and Baer, 2007, Liefooghe et al., 1997), so that the choice of the health care resource by the affected person is not only determined by the availability or accessibility, but also by various other internal and external factors (such as the perception of the disease, general trust in governmental health facilities, etc.) (Aujoulat et al., 2003).

For the explanation of health-seeking behaviour numerous models are available: One, which was specifically designed for the use in developing and transitional countries, is the framework by Kroeger (1983): This is a conceptual framework based on the *‘Healthcare Utilization Model’* by Andersen and Neumann (1975). According to this model, the choice of the appropriate health services is determined by a sequence of three variables: the predisposing (e. g. age, gender, etc.), enabling (e.g. access to appropriate resources, financial resources, etc.) and necessary factors (e.g. perception of the severity of the disease, disease duration, etc.) (Andersen and Neumann, 1975).

Kroeger extended Andersen’s and Neumann’s model after an extensive literature search and through the introduction of various independent variables (i.e. social and cultural background, characteristics of the disease as well as local health infrastructure). These independent variables are interrelated with each other and influence the affected person’s perception of the disease. The interaction between the different variables ultimately determines the affected people’s selection of the respective health care resource (self-treatment, traditional healer, government health facility etc.) (Kroeger, 1983). For more and detailed information on models of health-seeking behaviour and the selection of the model which served as the starting point for the research see section *‘Health-Seeking Behaviour’* in chapter 2.

1.3 Aim of the Study and Research Questions

This study draws on the need for a better understanding of the local BU specific disease concept and the related health-seeking behaviour. Its primary aim was to adapt an existing instrument (Kroeger’s Framework (1983)) to understand the local disease concept (qualitative approach) as well as to systematically describe the respective health-seeking behaviour (quantitative approach). The modified tool was applied and evaluated on the basis of different research methods. The evaluation of the applied research methods to assess the individual variables of the framework should allow collecting relevant data easier and more efficient in the future. Thereby it is meant to be subsequently used by the institutions of both the national and the local health care system (e.g. the National BU Control Program (NBUCP), the District Health Management (DHMT) as well as local NGOs in Ghana) to improve the BU specific disease control and to design appropriate target group-oriented health education as well as training programs for local health personnel.

For this purpose, the following specific research questions were raised:

(1) Is Kroeger’s framework applicable to explain BU specific health-seeking behaviour in general and if so, are there any modifications necessary respectively?
(2) Are there any differences in knowledge, attitudes and practice between (previously) BU affected and the non-affected people in the study area?

(3) What are the characteristics of BU affected people who report late/ early for care at a governmental health facility?
(4) Are there age related differences with respect to the behaviour of BU affected people?
(5) Are there gender related differences with respect to the behaviour of BU affected people?
(6) Are there differences in the perception of the disease and the available treatment options between the different communities of the research area?
(7) Which research methods serve best to assess the aspects that are involved in the process of BU specific health-seeking behaviour?

1.4 Research Setting and Iterative Research Process

The study area is located in rural a sub district of the Eastern Region of Ghana. The setting was chosen due to the fact that it was a relatively unexplored area regarding BU by the time of the investigation. A moderate occurrence of BU cases was documented (8% of the national cases in 2009 (NBUCP, 2010)). For further information on the research setting see chapter *‘Field of Research’*).

In order to answer the questions raised above an iterative research process was chosen (for a detailed description of the methodology of this thesis see chapter *‘Methodology’*): A systematic literature search and a subsequent analysis of the available literature on patient behaviour were used as a starting point (step 1). In the next step, the results from the literature were matched/ assigned with the existing variables of Kroeger’s framework (step 2). This was followed by an adaptation of Kroeger’s framework in order to be specifically applicable for BU (*‘Adapted BU specific Framework for Health-Seeking Behaviour’* (version I) – step 3). After that empirical data were collected by the author: Expert interviews (N = 33) were conducted (step 4) to assess the specific local conditions and develop the *‘Modified BU specific Framework for Health-Seeking Behaviour’* (version II) (step 5). The expert interviews and the modified framework served as a basis for the development of a setting-specific questionnaire to assess knowledge, attitudes and practices (KAP) with respect to BU. The questionnaire was then used in a cross-sectional survey among as many (previously) BU affected people of the years 2007 to 2010 who were encountered in the study area in the context of an active community case search (N = 122). At the same time, a comparison group of non-affected people matched by age and sex (N = 122; from the same village as the corresponding affected person) was interviewed with the same instrument to detect potential differences between the two groups. After that, focus group discussions (FGDs) were conducted in six selected villages to assess regional and cultural differences in the study area (step 6). In the next step the empirical results were compared with the developed and applied framework (*‘Modified BU specific Framework for Health-Seeking Behaviour’*) (step 7) (see chapter *‘Discussion’* of this thesis).

The thesis ends with the final *‘Conclusions and Recommendations’* chapter where the study’s contribution to answering the research questions, its recommendations and limitations as well as needs for possible further research are pointed out.

2. Background

The following chapter provides the theoretical background of the research project. It gives a general overview of the different aspects of BU and describes Kroeger's Framework for health-seeking behaviour, which serves as a starting point to develop a BU specific model to explain the respective health-seeking behaviour.

2.1 Buruli Ulcer

This section provides a description of BU disease: its definition and characteristics, history, epidemiology, microbiology, pathogenesis, clinical assessment, laboratory diagnostics, possible modes of transmission, treatment options, socio-economic and cultural factors, and public health aspects.

2.1.1 Definition, Characteristics and History of BU

BU is a tropical, chronic, and devastating disease caused by an infection with *Mycobacterium ulcerans* (MU) (Renzaho et al., 2007, Wansbrough-Jones and Phillips, 2006)*.* The bacterium belongs to the same family of organisms that cause leprosy (*Mycobacterium leprae*) and tuberculosis (*Mycobacterium tuberculosis)*. The disease affects mainly the skin – but can also affect the bone. It forms large skin ulcers, which extend into subcutaneous tissues and cause necrosis if not treated early and adequately. BU is one of the 13 so called *'neglected diseases* (Hotez et al., 2009)[5]. These diseases are also known to hinder economic development, to cause chronic life-long disability and impair childhood development in the affected settings. It is suggested that treatment and control of these diseases may be an efficient way to fight poverty (Liese et al., 2010).

The first description of BU was by the British physician Sir Albert Cook in 1897, who worked in Mengo Hospital in Kampala, Uganda. In the 1960s, many patients were reported from Buruli County (nowadays called Nakasongola District) in Uganda. This was also the origin of the commonly used name for BU (WHO, 2013). An Australian team (Peter MacCallum et al.) described six BU cases from the Bairnsdale region near Melbourne (Australia) in 1948. This group was also the first to succeed with the isolation of MU. Due to the origin of the first Australian patients the disease is also known as *'Bairnsdale ulcer'*.

2.1.2 Epidemiology of BU

The disease prevails in wetland areas in the equatorial regions of the world and is considered to be endemic in 33 countries in Africa, Asia and the Western Pacific (WHO, 2014) (see Figure 1 for the global distribution). Between 5000–6000 cases are reported annually from 15 of the 33 countries (WHO, 2014) so that it is not possible to propose global prevalence or incidence data (WHO, 2007). Furthermore, it is not possible to give estimations of the global disease burden (Disability adjusted life years (DALYs)).

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[5] 13 core parasitic (helminthic and protozoan) and bacterial tropical infections are commonly considered as *'neglected tropical diseases'*: ascariasis, trichuriasis, hookworm infection, lymphatic filiariasis, onchocerciasis, dracunculiasis, schistosomiasis, leishmaniasis, Chagas disease, human African trypanosomiasis, BU, leprosy, trachoma (Hotez et al., 2009).

Even though BU has been reported on other continents, West Africa is the most affected region (Stienstra et al., 2002, WHO, 2013): in Ghana more than 80% of the administrative districts are affected (Renzaho et al., 2007). A national health survey in 1999 detected a prevalence of 20.7 cases / 100,000 population (Sizaire et al., 2006, Amofah et al., 2002). For one community in Amansie West district a prevalence of 22% was reported (Amofah et al., 1993). These findings suggest that BU is the second most prevalent mycobacterial disease in Ghana after tuberculosis (Renzaho et al., 2007). Epidemiological data show that especially children under the age of 15 (Renzaho et al., 2007, Ellen et al., 2003, Amofah et al., 1993, Marston et al., 1995) as well as women (Renzaho et al., 2007, Asiedu et al., 2000) in impoverished, rural and remote areas do have a higher risk of contracting BU (Tacquet et al., 1973, Renzaho et al., 2007, Rook et al., 1979, Hayman and McQueen, 1985, Asiedu et al., 2000, Duker et al., 2004).

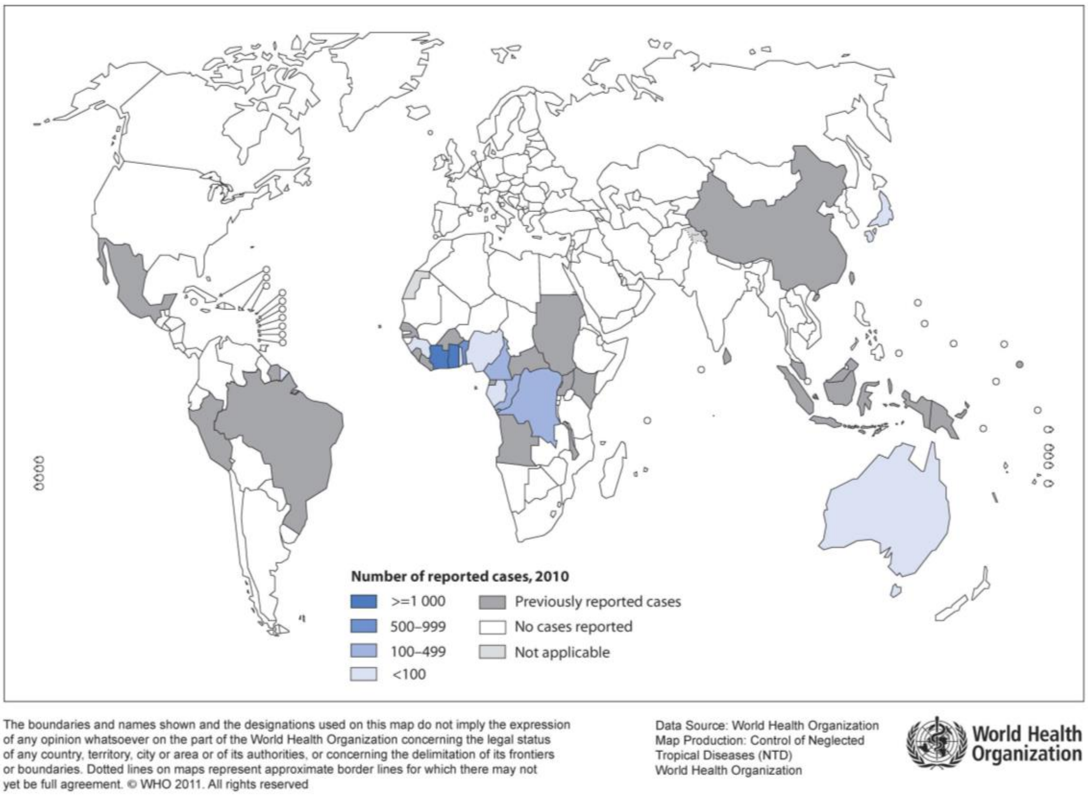

FIGURE 1: Geographical Distribution of BU in 2010
Source: WHO, 2011

2.1.3 Microbiological Classification and Pathogenesis

MU – the causing agent of BU – is a slow-growing mycobacterium, which thrives well in warm climates around 30-33°C and produces a soluble polypeptide toxin called mycolactone. Mycolactone plays a critical role in bacterial virulence and leads to the formation of progressive ulcers, with extensive destruction of the skin and soft tissue. It has also been shown to be a potent cytocidal molecule (molecule which causes cell death) in vitro and in vivo (Sarfo et al., 2010b). It displays significant immunosuppressive properties towards a wide range of immune cells at non-cytotoxic doses. Another important feature of the toxin is the lack of pain amongst BU infected patients despite the presence of extensive lesions (Coutanceau et al., 2007), which may be one probable reason for late reporting.

MU is a slow-growing, gram-positive bacterium from the family *Mycobacteriaceae*. The genus *Mycobacterium* belongs to the atypical mycobacteria (MOTT: mycobacteria other than tuberculosis) (Portaels et al., 2001). Its genome consists of two circular replicons and shows a homology of sequence of more than 98% with *Mycobacterium marinum.* Research by Doig et al. (2012) showed that MU and all mycolactone-producing mycobacteria are specialized variants of a common *Mycobacterium marinum* progenitor that have adapted to live in restricted environments. Genetic typing allows distinguishing between eleven different MU genotypes. According to the geographic origin of the isolates they can be divided into four different clusters: Asia, South-East Asia, West Africa and East Africa (Stragier et al., 2007).

2.1.4 Transmission and Contraction of BU

The exact mechanism of infection with BU has not been clearly identified and is still under research (Raghunathan et al., 2005, Merritt et al., 2010). However, MU infection foci are typically associated with proximity to stagnant and slow-flowing water bodies (Raghunathan et al., 2005, Johnson et al., 2005, Thangaraj et al., 1999, Aiga et al., 2004, Duker et al., 2004). Nearly all epidemiological studies found increased numbers of BU cases in communities in proximity to aquatic habitats (Merritt et al., 2010) (see Figure 2). It is commonly assumed that skin trauma, abrasions (Meyers et al., 1974, Sizaire et al., 2006, Marsollier et al., 2002, Portaels et al., 1999, Wagner et al., 2008b), insect bites or contact with water and vegetation transmit MU into the subcutaneous tissue (Merritt et al., 2010).

Only one pure culture of MU could ever be obtained from an aquatic water bug (*Hemiptera*) collected in Benin (Portaels et al., 2008). At present environmental studies are focused on the detection of MU genomic DNA sequences such as the insertion sequence (IS) element *2404*, which has been detected by PCR in various environmental samples (e.g. water (Ross et al., 1997), aquatic insects (Portaels et al., 1999) and plants (Marsollier et al., 2004b), snails (Marsollier et al., 2004a), small fish (Eddyani et al., 2004), the salivary gland of aquatic insects (*naucoridae* and *belostomatidae*) (Sizaire et al., 2006) as well as in *'salt marsh mosquitoes'* (*Aedes* etc.) in Southeast-Australia (Wansbrough-Jones and Phillips, 2006). Since PCR does not allow for proving the presence of viable bacteria, results are difficult to interpret. A study in South-Eastern Australia has implicated tree-dwelling native possums as a possible animal reservoir (Fyfe et al., 2010) and mosquitoes as potential vectors (Johnson and Lavender, 2009, Lavender et al., 2011) of MU in BU endemic settings of Victoria. But so far no similar potential animal reservoir has been identified in BU endemic regions of Africa. However, there are indications that the spread of MU from chronic, ulcerated lesions to insect vectors or other currently unknown environmental reservoirs and subsequent infection of individuals living in the same setting should be considered (Röltgen, 2012).

Case-control studies have identified different risk factors for contracting BU; namely the use of non-purified water from swamps (Debacker et al., 2006) and rivers (Aiga et al., 2004, Raghunathan et al., 2005) as well as agricultural land use (Wagner et al., 2008a), contact with infected insects or their bites, swimming in a river or a pond and residence near a swampy and riverine area (Renzaho et al., 2007) (compare with Figure 2). There is also some evidence that alteration of the landscape which affects the aquatic environment leads to the presence of BU (Wagner et al., 2008b). Further reported risk factors are poor wound care (Bratschi et al., 2013) as well as arsenic-enriched surface environments (e.g. oxidation of arsenic-bearing minerals, occurring naturally in mineral deposits) (Duker et al., 2004). HIV infection is not a risk factor for BU but it weakens the immune system and makes the disease progression of BU more aggressive (e.g. co-infected patients often present multifocal lesions and osteomyelitis) (WHO, 2013). Person-to-person infection is very unlikely; only a few cases have been reported in the literature so far (Debacker et al., 2002, Muelder and Nourou, 1990, Debacker et al., 2003, Exner and Lemperle, 1987).

As opposed to the risk factors, there seem to be various circumstances contributing to reducing the risk of contraction: firstly, shared indoor living space together with livestock appears to protect against BU compared to only handling or owning livestock and not living together with the livestock (Raghunathan et al., 2005). Secondly, the daily use of wrapped toilet soap seems to reduce the BU risk as well (Raghunathan et al., 2005). Thirdly, the limitation of skin exposure (e.g. wearing long pants) (Renzaho et al., 2007, Raghunathan et al., 2005) is discussed as another protective factor. In addition to that several research teams suggest that the availability of pumped water is an important factor in reducing the risk for the contraction of BU (Debacker et al., 2006, Wagner et al., 2008a).

FIGURE 2: Pond surrounding Grassland in the Study Area
- Typical Setting, where increased numbers of BU cases are reported
Source: Author's own

2.1.5 Clinical Assessment

Around 60% of the lesions caused by MU affect the lower limbs, 30% the upper limbs and 10% the rest of the body. BU does not only affect the skin and the subcutaneous tissue, but may also involve the bone (*osteomyelitis*[6]). Typically, the disease is painless and evolves in three phases: pre-ulcerative stage, ulcerative stage and chronic stage. In the first stage it manifests as firm, non-tender, subcutaneous nodules of 1-2 cm in diameter (see Figure 3A) at the sites of penetrating skin trauma and sometimes plaques (Figure 3B) or oedema (Figure 3C) (Portaels et al., 2001).

Within the next 1-2 months these areas become fluctuant, followed by the formation of a generally painless, undermined ulcer (second phase or ulcerative phase, see Figure 3D). At this stage the disease is diagnosed in the majority of the patients. The ulcers can involve up to 15% of the patient's skin surface and destroy nerves, appendages, and blood vessels – occasionally the bone is invaded. The large ulcerations with the characteristic undermined

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[6] Osteomyelitis is an infection of the bone or bone marrow and is usually sub-classified on the basis of the causative organism (pyogenic bacteria or mycobacteria), the route, duration and anatomic location of the infection.

edges may develop within a few days. BU lesions are commonly divided into three categories:

- **Category I:** single lesion < 5 cm in diameter
- **Category II:** single lesion between 5 and 15 cm in diameter
- **Category III:** A single lesion > 15 cm in diameter, multiple lesions, lesion(s) at critical sites (eye, breast, genitalia) and osteomyelitis (WHO, 2008)

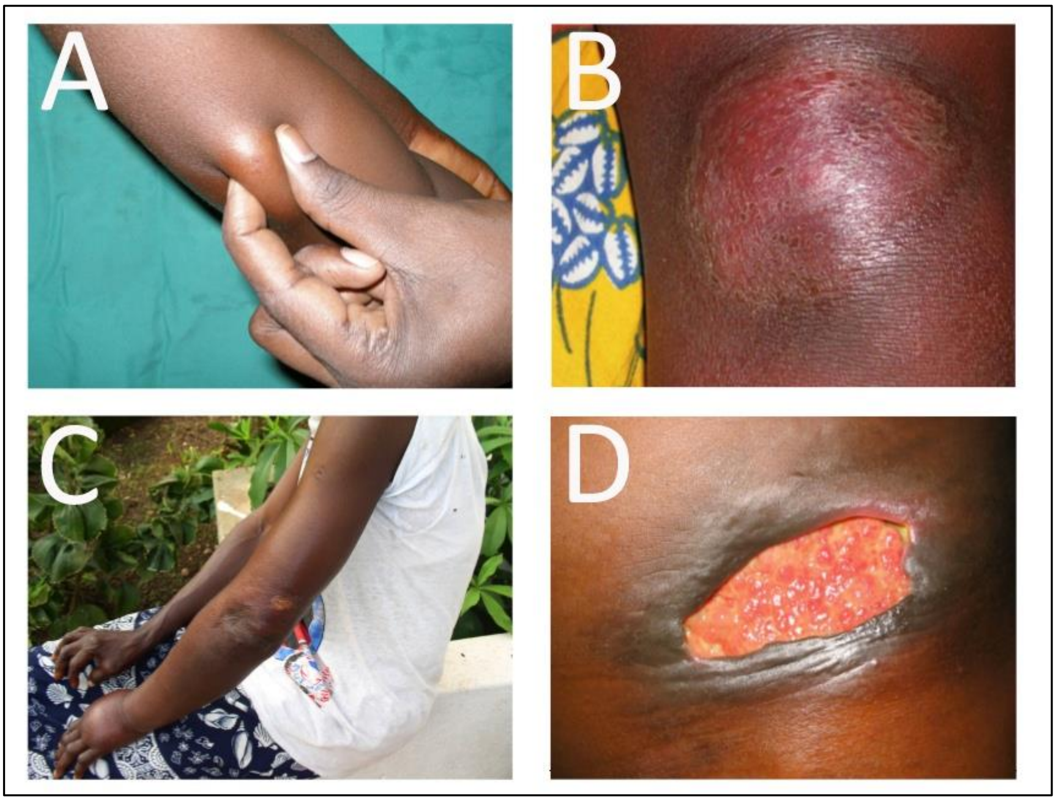

FIGURE 3: Different Stages of BU Symptoms
A: Nodule, B: Plaque, C: Oedema and D: Ulcer
Source: WHO, 2010

In the third phase of the disease ulcers may heal spontaneously, but they frequently cause chronic lymphedema, significant deformity, disfiguring scarring and contractures (see Figure 4) (Stienstra et al., 2002, Stienstra et al., 2005, Renzaho et al., 2007, Asiedu and Etuaful, 1998, Stienistra et al., 2004).

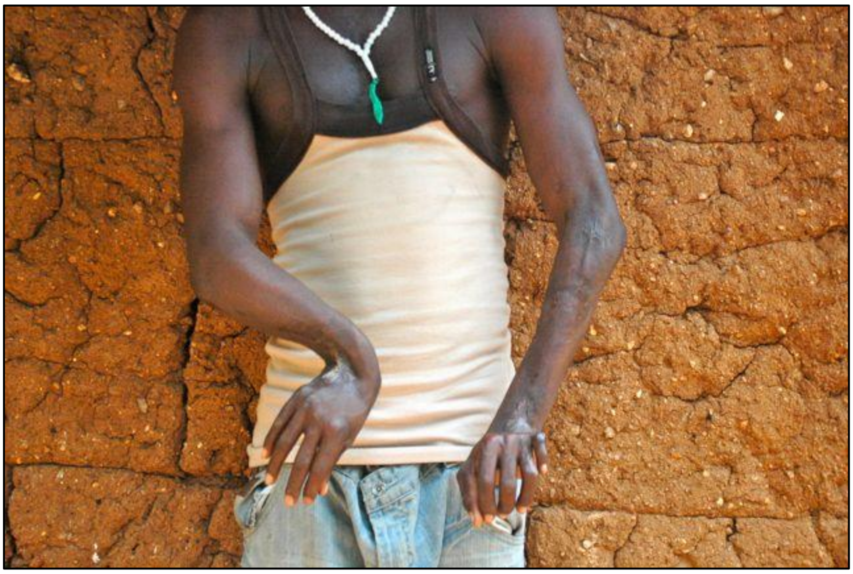

FIGURE 4: Contractures caused by BU
Source: Author's own

2.1.6 BU Diagnosis

With regard to the therapeutic decision a suspected BU nodule has to be differentiated from onchocerciasis, abscesses, lipoma or enhanced lymph nodes, ulcerative forms of other tropical ulcers, cutaneous leishmaniasis, tuberculosis, leprosy, mycosis, or neoplasm (Portaels et al., 2001). For the confirmation of MU swabs and skin biopsy samples are suitable. For a positive laboratory BU diagnosis the WHO recommends two positive laboratory results of the four different tests:

1) Acid-fast bacilli in a smear stained by the Ziehl-Neelsen technique (simplest and most accessible diagnostic technique)
2) Positive culture of MU (primary isolation requires 6-12 weeks)
3) Histopathological study of excisional biopsy specimen (rapid result available)
4) Positive polymerase chain reaction (PCR) for DNA from MU (sensitivity depends on the PCR technique) (Portaels et al., 2001)

The published data on BU reports an overall sensitivity of 29-78% for microscopy, 34-70% for culture, > 90% for histopathology and 79-85% for PCR (Asiedu and Wansbrough-Jones, 2007, Guarner et al., 2003, Guimaraes-Peres et al., 1999, Mensah-Quainoo et al., 2008, Portaels et al., 1997, Siegmund et al., 2007, Stienstra et al., 2003, Yeboah-Manu et al., 2004). These diagnostic techniques pose a problem in resource poor settings so that early detection (stage I) largely depends on the populations' previous sensitization and the clinical diagnostic skills of health workers at the community level. In addition, the diagnostic accuracy is of great importance: both false diagnosis of BU and false or missing/ absent treatment may have substantial negative impacts both on patients and communities (Johnson et al., 2007). A simple point-of-care diagnostic test which can directly be applied at peripheral health centres and hospitals is needed urgently (Röltgen, 2012).

2.1.7 Treatment Options

Until 2003 the standard treatment for BU was surgery with wide excision of the affected skin and subsequent skin grafting. In association with the surgical technique and experience of surgeons recurrence rates lie between 6% and 32% (Debacker et al., 2005). The main reason for recurrence is that the macroscopic characteristics of the adjacent tissue alone are not a good indicator (Herbinger et al., 2009): MU may also be detected in macroscopic healthy tissue within the margins of excised BU lesions. Therefore, it should be considered that a relatively small number of mycobacteria may cause recurrence (Bretzel et al., 2005, Rondini et al., 2006, Rondini S et al., 2006) so that wide excisions are necessary.

Since 2004 the WHO has recommended a daily treatment with Rifampicin[7] (10 mg/kg/d) and Streptomycin[8] (15 mg/kg/d) for eight weeks (56 doses) as a first-line treatment and standard therapy (WHO, 2004, Sizaire et al., 2006, WHO, 2005). Clinical trials suggest that antibiotics alone may only cure lesions of category I and II (i.e. nodules, papules, plaques, and ulcers < 5 cm in diameter; compare with section 2.1.6 on clinical BU assessment) (Nienhuis et al., 2010). According to the present knowledge, up to 80% of cases detected early can be cured with a combination of antibiotics (WHO, 2014).

Apart from its medical effect the antibiotic regime was also introduced to Ghana because it allows for a non-invasive medical treatment and for case management at the peripheral level of the health system. Apparently, this approach has the potential to reduce cost, to provide medical care closer to the homes of patients and to encourage patients to report at health facilities earlier as the fear of surgery may be reduced (Nienhuis et al., 2010). However, for advanced stages of the disease (lesion > 5 cm in diameter) antibiotics alone may minimize – but not heal – the lesion (Etuaful et al., 2005). In this case WHO recommends additional surgery. Therefore, any BU control programs promote early detection and medical treatment.

Recurrence of patients treated with antibiotics is about 2%, which is considerably lower than for surgical excision without antibiotic therapy (Sarfo et al., 2010a, Chauty et al., 2007). But before antibiotic treatment starts, the clinical suspicion has to be confirmed by laboratory tests. In case needed, the treatment will be combined with surgical excision followed by skin grafting or even amputation. Reasons against antibiotic treatment are osteomyelitis, the wish for surgical treatment or contraindications against antibiotics (e.g. kidney problems, pregnancy) (Chauty et al., 2007, Johnson et al., 2007, WHO, 2008, WHO, 2004).

One reported challenge of antibiotic treatment are newly recognized events (*'paradoxical reactions'*), which occur during or after antibiotic treatment for BU: In about one out of five BU cases treated with antibiotics in Africa the lesion or its surrounding tissue deteriorates or new lesions appear – either locally or in a distant body site (O'Brien et al., 2009).

Thermotherapy showed already promising results in the 1970s. At the moment the effectiveness of further heat treatment with using phase change material to cure BU has been tested in a single centre proof-of-principle trial (Junghanss et al., 2009) and is further evaluated. The theory behind this treatment technique is to heat the infected lesion/ tissue up to temperatures of 40°C, which inactivates and kills the bacteria.

Further alternative treatment therapies to antibiotic or surgical treatment that can be found in the literature are the use of special minerals and ozone. The use of certain illites – a non-expanding, clay-sized, micaceous mineral – is supposed to have a healing response and could allow for cost-effective treatment. The absorptive properties of clay minerals debilitate the bacteria; its application on the affected party of the body may heal BU lesions (Williams et al., 2008). The application of ozone for two weeks to manage and treat the disease has

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[7] Rifampicin is a bacterial antibiotic drug of the rifamycin group. Rifampicin was introduced in 1967 to treat tuberculosis and inactive meningitis; but it has also been used to treat other Mycobacterium infections, such as leprosy and BU since then.

[8] Streptomycin is also a first antibiotic remedy for tuberculosis. It must be administered by regular intramuscular injections and cannot be given orally. Ototoxicity is an adverse effect of this medicine, which can lead to hearing loss.

brought about promising results as reported in a case study by Bertolotti and colleagues (Bertolotti et al., 2013)

BU case management is not sufficient by taking antibiotics or surgical/ wound treatment as it is known that BU may result in functional limitations and disabilities. Hence, medical staff more and more aims at reducing or even preventing BU related impacts in order to maintain the patient's independence, his social integration, and to improve the patient's quality of life. As an integral part of BU case management Prevention of Disability (POD) should start immediately after the diagnosis in order to increase the likelihood of the success. Its three main objectives are

- to maintain or improve skin conditions to prevent soft tissue contractures, which can lead to joint contractures and deformity,
- to minimize or reduce oedema, infections, pain, adhesions as well as scars, and
- to encourage, enable, and empower BU patients to maintain or improve their ability to perform their daily activities and to participate in family and community life (Lehman et al., 2006):

This aspect of BU case management is gaining more and more importance, and it is suggested that health workers, affected patients, their families as well as the communities are involved in the process of POD (Lehman et al., 2006, WHO, 2008).

2.1.8 BU in the Context of local Beliefs and its social as well as medical Implications

A striking phenomenon amongst BU patients is their tendency to delay medical treatment (Aguiar et al., 1997, Asiedu and Etuaful, 1998, Stienstra et al., 2002). This observed treatment delay may result in severe disabilities or significant disease related costs or social implications (i.e. stigmatization) for the patients (Asiedu and Etuaful, 1998, Stienstra et al., 2002).

The reasons for the treatment delay seem to be manifold. Both social and cultural factors seem to have a significant influence on the treatment seeking behaviour of BU patients. Some studies conducted in Ghana and Benin report that both BU patients and non-affected people believe in sorcery, witchcraft and curse as being the cause of the disease: Stienstra et al. (2002) found that 59% of their study participants in three different sites in Ghana believe in witchcraft being the cause of a BU infection; 47% are sure that curses are the reason. According to Stienstra et al.'s study (2002) magico-religious explanations are common among the rural population – especially in cases where the healing process is very long, the person has to stay in hospital for a long time or other difficulties occur during in the treatment (also compare with Mulder et al., (2008). Renzaho et al. (2007) used a different questionnaire and conducted a study with a random sample among the population of Ga West district (Ghana) used a different questionnaire and conducted a study with a random sample among the population of Ga West district (Ghana). Here it was found that more than half of the population (53%) have no idea about the aetiology of BU and only 5% ascribe the disease to witchcraft or curse. The authors of the study assessed that a biomedical explanation did not generally exclude an answer in the magico-religious domain: Their conclusion is that the perceptions of the aetiology of the disease may change if the situation worsens (Renzaho et al., 2007).

Further challenges that BU affected people have to face are social stigmatization and exclusion: Due to the perception of the disease as having no natural causes as well as the specific features of the lesions (e.g. large malodorous lesions) the affected people may abstain from seeking medical treatment. It is reported that the disease may have a negative influence on their social acceptance within their home community and also have a negative impact on partnership and marriage so that some BU affected people hide their disease (Asiedu and Etuaful, 1998, Stienstra et al., 2002). Reasons for stigmatization and social isolation are fear of acquiring BU, the mysterious nature of the disease, the lack of knowledge about the mode of transmission and a lack of proper treatment. It is interesting to note that non-affected respondents in some studies and people in less endemic locations mentioned stronger stigmas than people in highly endemic communities (Renzaho et al., 2007).

2.1.9 BU und Public Health

In the beginning of the 1980s an increase of BU cases – especially in West Africa – was noticed (Senior, 2009). As a reaction to the rising number of cases, the lack of knowledge regarding the source of infection and the mode of transmission community control strategies the WHO initiated the Global Buruli Ulcer Initiative (GBUI) in 1998. Furthermore the first International Conference on BU control and research took place in Yamoussoukro, Côte d'Ivoire. A result of this conference was the *'Yamoussoukro Declaration on Buruli Ulcer'*, which drew attention to the disease (WHO, 2011).

In 2004 the World Health Assembly (WHA) adopted a resolution for increased surveillance and control as well as for intensified research to develop tools for diagnosis, treatment and prevention of BU in 2004 (WHO, 2008, WHO, 2013). Since then national and international activities have been carried out to improve control and accelerate research; more than 40 NGOs, research institutions, and foundations are members of the GBUI. Nonetheless, Buruli ulcer remains a neglected disease (WHO, 2008, WHO, 2013).

In order to improve and harmonize the reporting, monitoring and control of the disease at national levels BU Control Programmes have been established in some of the endemic countries. Their major working area is the coordination health education activities, supply of necessary items and logistics (e.g. uninterrupted supply of the antibiotics, the necessary recording forms, specimen containers and transportation of samples etc.) to enable the health facilities in endemic communities to provide the necessary services (i.e. diagnosis, treatment etc.).

2.1.10 BU in Ghana

Worldwide Ghana is the second most endemic country for BU after Cote d'Ivoire; in 2009 851 cases were reported (NBUCP, 2010) (see Table 1).

The first BU cases were described around 1971 in the Greater Accra Region with the foci being along Densu River and its tributaries (NBUCP, 2012). In 1989 further cases were described in the Afram valley (Asante Akim North district, Ashanti Region) (Werf et al., 1989). Starting from this point the spread and public health importance of the disease remained latent until political and media interests on BU surged around 1992. By 1993, the Ministry of Health (MOH) established a passive surveillance system to report BU cases (NBUCP, 2012). The aim of this surveillance system was to provide information about the spread of the disease and to gather information about who is affected (i.e. geographic distribution and disease burden), as well as to plan and develop treatment and/ or prevention strategies.

By the end of 1998 the surveillance system established recorded approximately 1,200 cases from five different regions (Ashanti, Eastern, Greater Accra, Brong Ahafo and Central) (NBUCP, 2012). In 1999 a national case search was conducted, where 5,619 cases with

6,332 lesions from all regions were identified. This case search demonstrated the spread of BU across the country but also revealed gross underreporting compared with the routine reporting system (Amofah et al., 2002).

Soon after the *'Yamoussoukro Declaration on Buruli Ulcer'* the MOH established the Ghanaian National Buruli Ulcer Control Programme (NBUCP), which was initially subordinated by the National Tuberculosis Control Programme (NBUCP, 2012). Prior to the establishment of the NBUCP, Ashanti, Central and Greater Accra regions, were running regional projects to control the disease in their catchment areas. In 2002, a national programme manager was appointed to coordinate the different activities of the NBUCP (NBUCP, 2012).

TABLE 1: Reported BU Cases in Ghana in 2009

Region	No. of Cases	Total Population	Prevalence/ 100,000	Sex		Age			
				Female (%)	Male (%)	0-5 years (%)	6-15 years (%)	16-49 years (%)	> 50 years (%)
Ashanti	428	4,839,100	8.84	231 (54.0)	197 (46.0)	49 (11.4)	139 (32.5)	132 (30.8)	103 (24.0)
Brong Ahafo	66	2,257,304	2.92	35 (53.0)	31 (47.0)	0	21 (31.8)	31 (47.0)	14 (21.2)
Central	162	1,864,104	8.69	90 (56.6)	72 (44.4)	15 (9.3)	28 (17.3)	63 (38.9)	56 (34.6)
Eastern	65	2,297,565	2.83	33 (50.8)	32 (49.2)	2 (3.1)	17 (26.2)	20 (30.8)	26 (40.0)
Greater Accra	113	4,358,263	2.59	66 (58.4)	47 (41.6)	11 (9.7)	40 (35.4)	49 (43.4)	13 (11.5)
Western	17	2,558,113	0.66	10 (58.8)	7 (41.2)	0	1 (0.6)	13 (76.5)	3 (17.6)
National Total	851	23,951,519	3.55	465 (54.6)	386 (45.4)	77 (9.0)	246 (28.9)	308 (36.2)	215 (25.3)

Source: NBUCP, 2010

2.2 Health-Seeking Behaviour

While medical science is mainly concerned with diagnostics, progression and therapy of diseases ethno medicine and medical anthropology follow a broader understanding of diseases: The latter research disciplines deal with medical systems and therefore include traditional medicine and its remedies as well as the social aspects and patient's concepts of the cause of the disease (compare with Friessem, 2007, Schenda, 2002, Ferber, 1975, Pfleiderer and Bichmann, 1985).

In medical anthropology the focal point is on the perspective of the affected person so that the character and severity of the disease, its cause and social connotation are not necessarily appraised by objective criteria. The investigation rather focuses on the rationality of activities which are conveyed by the patient's behaviour (Chrisman, 1977, Pfleiderer and Bichmann, 1985). In order to describe, compare and assess this patient behaviour between various individuals and groups in a structured way models of health-seeking behaviour have been established.

2.2.1 Models of Health-Seeking Behaviour

Studies on health-seeking behaviour point out the fact that findings on the disease perception and delay causing factors remain inadequately acknowledged. Nevertheless, understanding human behaviour is essential to change the behaviour of the people and improve access to governmental health facilities. In order to respond to the perspectives and needs of the people in rural communities, the health system and the respective health providers need to adapt their strategies – based on findings from behavioural studies (compare with Hausmann-Muela et al., 2003).

It is recognized that the behaviour of patients cannot be explained by monocausal interpretations and single case studies: There are not only several explanatory variables but also dependent variables, which usually lead to different therapy levels or treatment options (Kroeger, 1983, Pfleiderer and Bichmann, 1985). Health-seeking behaviour models are one tool to extend and combine exploratory and explanatory variables: The models' objectives are to describe the patient's behaviour as well as to identify problematic areas with regard to access care and to develop strategies to improve the patient's health situation.

These models contain several variables which are considered relevant for explaining or predicting the process of health-seeking behaviour. Yet, they should not be considered as behavioural models themselves. For this reason mainly statistical data are used to determine the relevance of different factors in health behaviour (e.g. use of preventive provisions/ specific therapeutic treatment, the choice between different health facilities, non-compliance with treatment, or reasons and consequences of late reporting) (compare with Hausmann-Muela et al., 2003).

2.2.2 Health-Seeking Behaviour of BU affected People

To the knowledge of the author one simplified BU specific model to explain the health-seeking (Mulder et al., 2008) had been published before the time of research of this study: The intention of Mulder et al. was to propose *"a model to capture the therapy choice of patients and healthy community members"*[9]*.*This model was the first one to entail both internal and external factors of the health-seeking behaviour of BU patients, summarising the

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[9] The research was conducted in Benin and used in-depth-interviews with patients treated in hospital (N = 107), patients treated traditionally (N = 46), as well as healthy community control subjects (N = 107).

BU patients' decision taking as a dynamic and continuous process. The model comprises three different stages of health-seeking behaviour (see Figure 5).

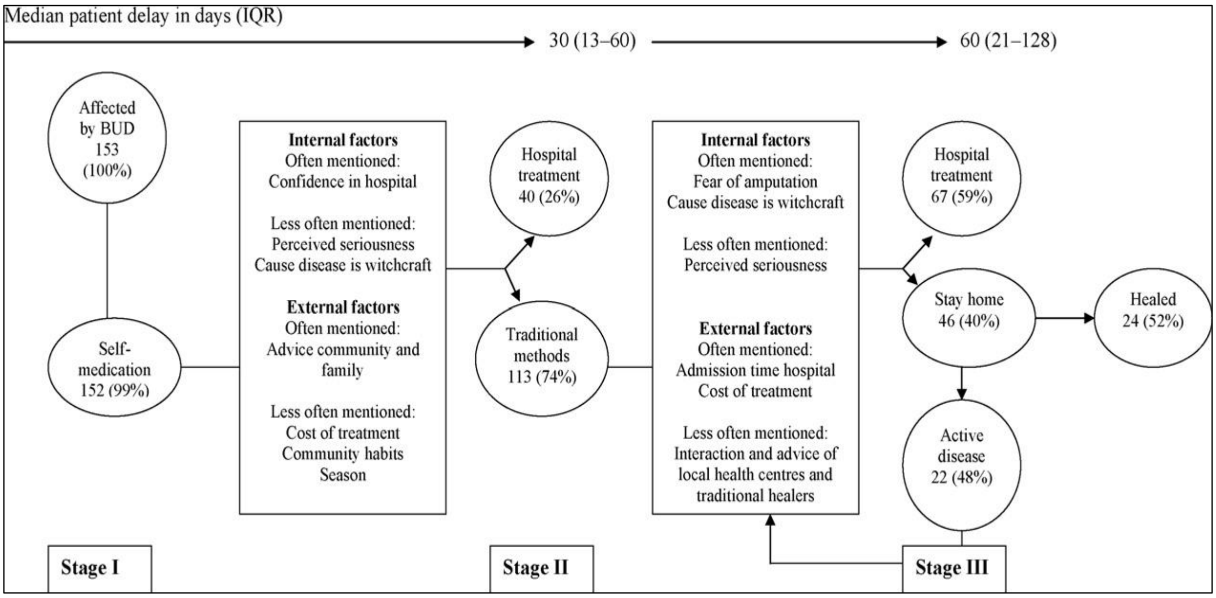

FIGURE 5: Simplified Model for Health-Seeking Behaviour of BU Patients
Source: Mulder et al., 2008

According to this model, in the first stage literally all of the BU affected individuals use self-medication (e.g. purchase of medications or traditional methods). In case of the failure of self-medication the affected people draw on various experiences and influences from other people, which Mulder divided into internal (i.e. confidence in hospital) and external factors (i.e. advice from community or family members) before choosing between two different treatment options: hospital treatment and traditional methods.

In the second stage, BU affected people reconsider further internal (i.e. fear of amputation, disease is caused by witchcraft) and external factors (i.e. admission time in hospital, cost of treatment) before they report to hospital or stay at home. In the end the majority of them are healed but according to Mulder et al. about 15% are not get healed and still consider the different treatment options.

This simplified model was developed from information about the health-seeking process provided by the interviewed BU affected people in Benin (inductive approach). The categories *'internal'* and *'external factors'* are rather broad, non-specific and the authors give no references to any existing conceptual model. Furthermore, the researchers assessed the patient delay in days (according to narratives of the interviewed patients). Due to these reasons as well as the fact that this study is meant to give an extended overview on the health-seeking behaviour of BU affected people in the study area (rural sub district in the Eastern Region of Ghana, see chapter 3.3) the author decided to develop a model based on an existing and conceptual framework, where the findings of other studies on health-seeking behaviour of BU affected people will be included to modify and adapt it.

2.2.3 Kroeger's Framework and its Genesis

A health-seeking behaviour model that has been specifically designed to be used in developing and transitional countries, is the conceptual framework developed by Kroeger (Kroeger, 1983). The network of interacting explanatory variables for the use of health services in transitional societies may be even more complex than in industrial countries so that factors such as the continuing process of cultural change (i.e. supernatural and natural concepts as well as health behaviour) may play an important role. Furthermore a wider range of services – both in quality and quantity as well as in socio-economic conditions (e.g. family size, income and social networks) – exists (Kroeger, 1983). This was the reason why Kroeger conducted an extensive literature search and extended the *'Health Care Utilisation Model'* by introducing various independent variables such as social and cultural origins, characteristics of the disease as well as local health infrastructure. In his model the independent variables influence each other and thereby determine the perception of the disease. The interaction between the different variables ultimately leads to the choice of the health care resources and services by the patients (*'self-treatment'*, *'traditional healer'*, *'modern healer'* etc. – dependent variables) (see Figure 6).

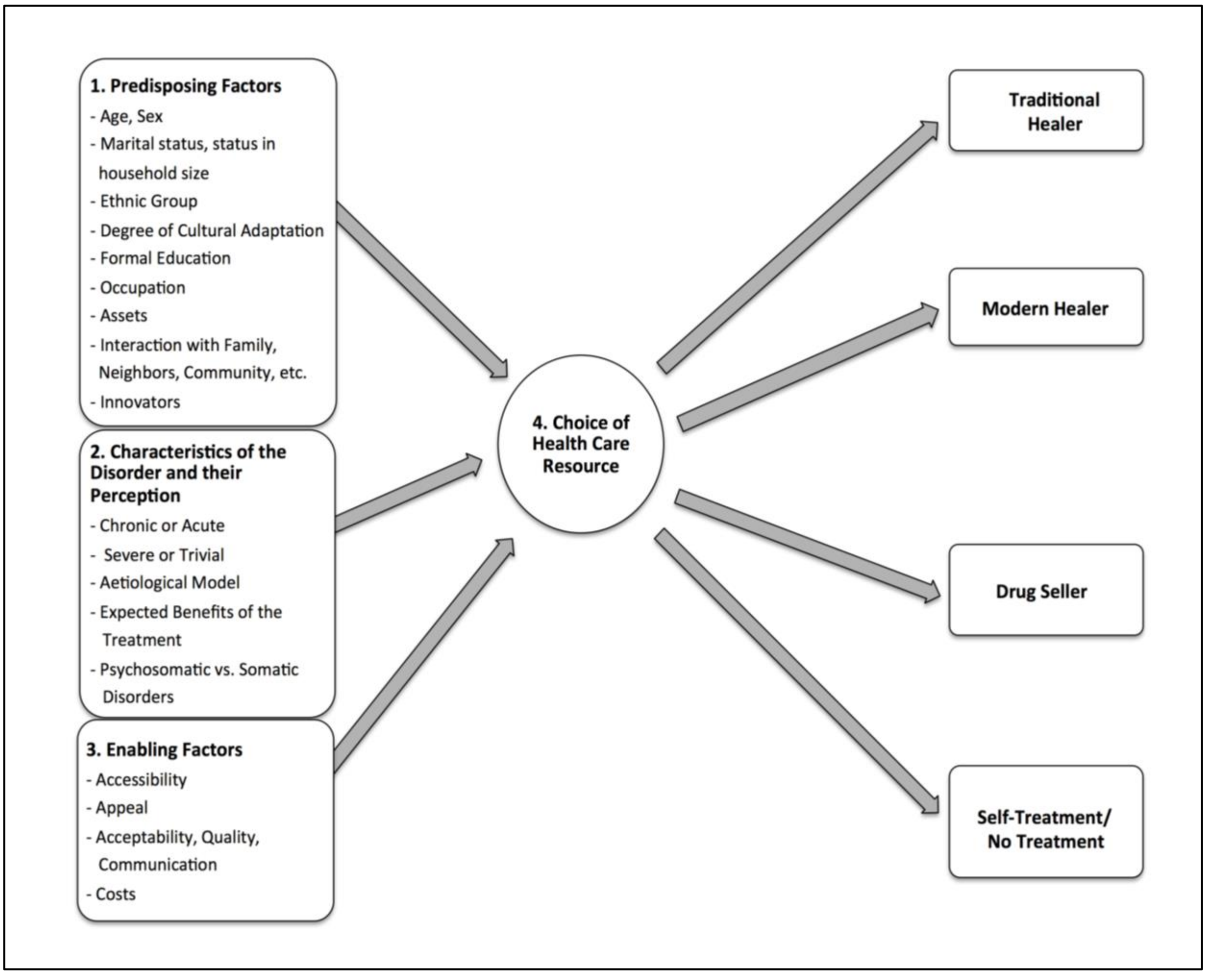

FIGURE 6: Kroeger's Framework
Source: Kroeger, 1983

An overview of the different variables determining health-seeking behaviour is given in Table 1. In addition to that Kroeger's findings for the different variables of his model are summarized below.

TABLE 2: Variables determining Health-Seeking Behaviour

Explanatory Variable	Factors
Predisposing Factors	(1) Age/Sex (2) Marital status, status in the household, household size (3) Ethnic group (4) Degree of cultural adaptation (5) Formal education (6) Occupation (7) Assets (land, livestock, cash, income) (8) Interactions with family neighbours, community, etc.) (9) Innovators
Characteristics of the Disease and its Perception	(1) Chronic or acute (2) Severe or trivial (3) Aetiological model (natural or supernatural) (4) Expected benefits of a treatment (modern vs. traditional) (5) Psychosomatic vs. somatic disorders.
Enabling Factors	(1) Accessibility (2) Appeal (opinions and attitudes towards traditional/modern healers) (3) Acceptability, Quality, Communication (4) Costs

Source: Kroeger, 1983

Predisposing Factors

(1) Age and sex often have a discriminatory function in the choice between traditional and modern health care. In many transitional settings specific age groups (mostly elderly, sometimes children) prefer the consultation of traditional practitioners. The choice of modern services seems to depend less frequently upon the age of the affected people. Sex-specific utilization patterns may be expected particularly in societies where sex roles are strictly defined (e.g. in Islamic societies). (2) Special attention is often paid to the head of household in extended families. They are found to behave more traditionally than those of nuclear families. The social interaction in large families and the interaction with the corresponding network may therefore be more intensive. (3) The disease perception and the resulting choice of health care resources usually differ between ethnic and religious groups respectively. (4) Cultural adaptation – or the individual adaptation to a particular culture was also found to influence the choice of treatment and consists of different dimensions. The exposure to another culture (e.g. through formal education, contact or occupation) and the acceptance of associated attitudes and behaviour (e.g. Western clothing style, hairdressing, housing) allows for some implications as to whether the people are familiar with seeking medical care. (5) Formal education may be one of the severest exposures to *'Western culture'* and therefore have an influence on the health behaviour of an individual. (6,7) Occupation and socio-economic status have rarely been analysed in relation to health care in rural societies of third world countries, but they are indicators for social and cultural change. (8) The importance of social interaction and bonds for the choice of the respective health care resource is proven: in a case of illness relatives and friends are usually consulted first. (9) Individuals who operate as *'innovators'* in traditionally oriented communities will choose new alternatives first. Hereby they influence other members of their community (Kroeger, 1983).

Characteristics of the Disease and its Perception

(1) The more the affected person's condition turns into a chronic one, the more time the affected person has to have recourse to different treatment options or health care resources. Evidence points to the fact that chronic diseases in developing countries are predominantly treated by traditional methods. (2) In contrast: Diseases perceived to be severe are predominantly treated by modern health practitioners. (3) The aetiology of a disease does also play an important role: a dichotomy between supposedly magical supernatural diseases on the one hand, and physical diseases on the other hand may be observed in rural settings: this is usually related to respective popular strategies of treatment (e.g. in rural settings of Ghana, modern medicine is mainly used for infectious or digestive conditions; traditional and self-treatment is used for musculoskeletal problems). (4) The basic determinant for resorting to a treatment option is probably the expected outcome of a therapy. Its choice is closely linked with the perceived aetiology and satisfaction with therapies in the past (Kroeger, 1983).

Enabling Factors

Various external and internal factors influence the individual or the population in their health-seeking behaviour. In his model regarding the choice of a specific treatment option Kroeger considers geographical accessibility, communication between health care providers and patients, quality of care and costs as major enabling factors – without distinguishing between external (e.g. access or costs) and internal factors (e.g. appeal of the health care providers as assessed by the patients). (1) The low degree of accessibility to modern health services is supposed to be a major argument for the use of traditional resources in health care delivery. (2) Information on people's attitude (appeal) towards different forms of care is not easy to assess in transitional societies. (3) Attractiveness (acceptability, quality and communication) is another aspect of health care services. (5) Treatment costs are another frequently mentioned obstacle to modern health facilities. Traditional treatments are therefore often perceived to be cheaper and within the vicinity of the rural population (Kroeger, 1983).

Choice of Health Care Resource

The explanatory variables (e.g. *'age/sex'*, *'cultural adaptation'*), which are associated with the choice of different types of health services, may give the impression that such choices are mutually exclusive. But the concurrent or serial use of different healing systems (*'healer-shopping'*) seems to be a typical feature of transitional societies of the developing world. Included dependent variables of the model are traditional healer, modern healer, drug seller and self-treatment/no treatment (Kroeger, 1983).

2.2.4 Health Care Utilization Model

Kroeger's framework was based on the *'Health Care Utilisation Model',* which was developed in 1975 (also known as *'Andersen's Model'* (Andersen and Neumann, 1975)). It was developed with the main aim to investigate the use of biomedical health services, but later versions have also included other health care sectors such as traditional medicine and domestic treatments. The model postulates a sequence of three clusters or categories of factors influencing health behaviour: the predisposing factors, enabling factors and need factors (Figure 7).

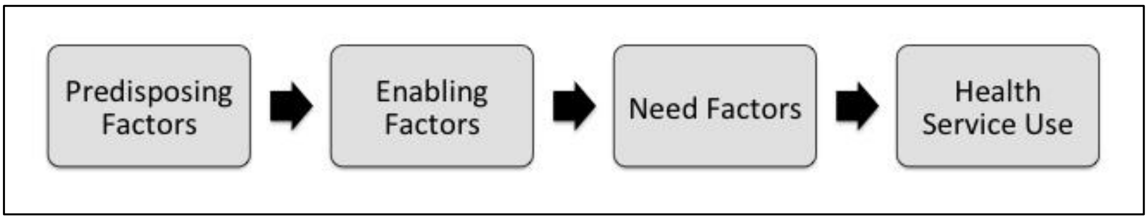

FIGURE 7: The Health Care Utilization Model
Source: Hausmann-Muela et al., 2003

It centres specifically on treatment selection, includes both material (i.e. living conditions) and structural factors (i.e. economic, social, policy, and organizational environment) and has also been used to gain evidence on the relevance of different factors for health service use (Hausmann-Muela et al., 2003). An overview on the different categories and the respective factors of the *'Health Care Utilization Model'* are provided in the following table (Table 3).

TABLE 3: The different Categories of the Health Care Utilization Model

Category	Factors
Predisposing Factors	- Age - Gender - Religion - Global health assessment - Prior experiences with illness - Formal education - General attitudes towards health services - Knowledge about the illness
Enabling Factors	- Availability of services - Financial resources to purchase services - Health insurance - Social network support
Need Factors	- Perception of severity - Total number of sick days for a reported illness - Total number of days in bed - Days missed from work or school - Help from outside for caring etc.
Treatment Actions	- Home remedies (e.g. herbal treatment, pharmaceuticals) - Pharmacy - Over the counter drugs from shops - Injectionists - Traditional healers - Private medical facilities - Public health services

Source: adapted from Weller at al., 1997

The original model has been mainly criticized for not recognizing the impact of culture and social interaction (Portes et al., 1992, Guendelman, 1991). Furthermore it was reviewed that Anderson has put an overemphasis on the need factors (e.g. perception of severity and days missed from work or school) as well as on health beliefs and the social structure (Wolinsky and Johnson, 1991). Another aspect, which is relevant for this study is that it was not specifically developed for the rural African setting.

2.2.5 Justification for the Use of Kroeger's Framework as a Starting Point

Kroeger's framework is based on a recognized conceptual model to explain the use of health services (i.e. *'Health Care Utilization Model'*) and it was developed for the use in developing and transitional countries. Besides this it seems to be interdisciplinary recognised as it was included in a definitive book on Ethno Medicine (see Pfleiderer and Bichmann, 1985), where it serves as an example for a model to explain health-seeking behaviour in a rural African setting.

Due to these facts it may be assumed that most of the relevant aspects which may influence the patient behaviour in a rural Ghanaian setting are taken into account. The socio-behavioural framework by Kroeger includes a variety of variables, which are structured in categories (i.e. *'Predisposing Factors'*, *'Enabling Factors'* etc.). This allows for a BU and setting specific adaption and modification. These were the reasons why this model was selected as a starting point to adapt it for BU and develop a specific model to assess and explain the respective health-seeking behaviour in the study area. This process is described in chapter 4.

Nevertheless the findings of the model developed by Mulder et al. (2008) will be considered and included whenever possible. At the end of this research the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18) will again be compared with this simplified model to evaluate differences and probable benefits of this process (see chapter 6.1).

3. Field of Research

The following chapter depicts the field of research of this study. It gives a short overview on the general circumstances of living in Ghana (geography and economy, culture, politics, education and the national health situation) and the setup of the ACBRIDGE-Project – a collaborative project between the University of Ghana, the University Hospital Heidelberg, the Swiss Tropical Institute in Basel and Bielefeld University, which provided the frame and facilities for this research). Furthermore the situation within the Eastern Region, which was chosen for the fieldwork of this study, will be depicted in more detail.

3.1 Ghana

Ghana was the first sub-Saharan country in colonial Africa to gain its independence (1957) and is characterized by considerable natural wealth. Therefore it is also considered to be one of the leading African countries. Since 1993 it is denominated as a *'model country'* by the International Monetary Fund (IMF) (Girrbach and Fleischhacker, 2002).

3.1.1 Geography and Economy of Ghana

Ghana lies on the coast of the Gulf of Guinea in western Africa and borders Burkina Faso to the north, Togo to the east, the Atlantic Ocean to the south and Côte d'Ivoire to the west (see Figure 8).

FIGURE 8: Map of Ghana
Source: Central Intelligence Agency (CIA), 2012

The country covers an area of 238,537 km^2, and in 2009 Ghana had a total population of 23,832,495 people with an annual growth rate of 1.882% (CIA, 2012). Relief throughout Ghana is generally low and the north is dominated by a large basin, which is also the catchment area of the lake Volta – one of the longest artificial lakes in the world (8,500 km^2). The highest elevation of Ghana is mount Afadjato with 880 m (Sahin-Adu, 2012b).

Ghana is divided into ten administrative regions[10] (Girrbach and Fleischhacker, 2002), which can be categorized into five geographic and economic regions. A high development gap between the north and the south can be observed (Girrbach and Fleischhacker, 2002).

The vegetation of the country may be divided into three different zones: (1) The *'High Forest'* in the south, which consists of wet evergreen to dry semi-deciduous forests, represents also the region with the highest precipitation in the country. (2) The *'Savannah Region'* in the north is the driest area within the country and covers approximately two thirds of the country. (3) The *'Transition zone'* is located between these two zones, where most BU patients are living. Ghana is relatively rich in biodiversity and the constantly relatively high temperature (annual mean temperature 26 to 29 °C) and humidity boost the growth of plants. The annual precipitation reaches 1,000 mm in the north and up to 2,200 mm at the western part of the coast; but in Accra precipitation hardly reaches 800 mm (Sahin-Adu, 2012b) (see Figure 9).

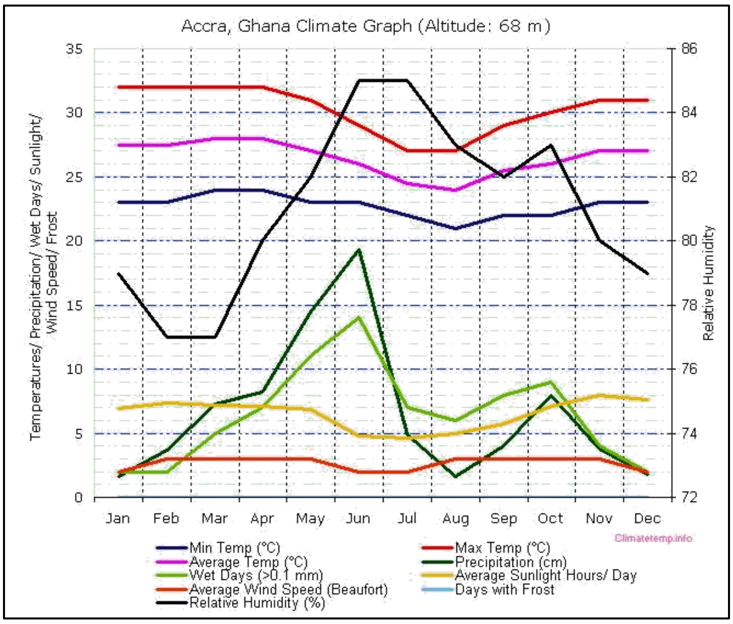

FIGURE 9: Temperature and Precipitation throughout the Year (Accra)
Source: Climatemps, 2012

In 2011 Ghana was ranked 135 of 187 in the HDI (0.541) of the United Nations Development Programme (UNDP) Human Development Index (HDI) (UNDP, 2010). The estimated per capita GDP in 2011 was 3.100 US $ (CIA, 2012) – without taking into consideration any social differences (Thiemann, 2003). According to the Central Intelligence Agency (CIA) 28.5% (2007) of the Ghanaian people live below the poverty line (CIA, 2012). People who are particularly affected by poverty are mainly agricultural and informal workers (UNDP, 2007) – as the majority of the BU affected people.

Economically important regions are mainly located in the low plains along the coast: Here the majority of the natural resources (gold, diamonds, manganese and bauxite) and local subsidies are adjudged or produced. Infrastructural development is mainly concentrated on the triangle between Accra, Kumasi and Sekondi-Takoradi, where 60% of the population reside. The degree of the country's urbanisation is 50% (2008) (CIA, 2012) and the internal migration aggravates regional disparities, which contributes to the development of urban marginalized sectors (Girrbach and Fleischhacker, 2002).

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[10] (Ashanti, Brong Ahafo, Central, Eastern, Greater Accra, Northern, Upper East, Upper West, Volta and Western)[10]

Livelihood opportunities can be found in both public and private sectors but food crop farming represents the largest share of the poor. For a long period of time the Ashanti Region was the main production area for cocoa and constituted the backbone of the Ghanaian export economy (Girrbach and Fleischhacker, 2002). But since 1995 Gold has replaced cocoa as the major source of foreign currency (Girrbach and Fleischhacker, 2002, CIA, 2012). Hence, the most important export goods of Ghana are cocoa, gold and timber (CIA, 2012). In terms of location, 61% of all informal economic activities are undertaken in urban areas. The public sector and the private formal sectors employ about 7.1% and 6.9% respectively, while as much as 43% are in the informal sector, mainly agriculture. Non-agriculture livelihoods engage 26.2% (UNDP, 2007).

Agriculture and the informal economy employ 91% of the economically active population – 92% of all employed persons in the rural and 75% in the urban areas are engaged in this sector (UNDP, 2007). The agricultural economy is structured rurally: large parts of the country outside of the so-called *'cocoa belt'* are still subsistence oriented and dominated by traditional methods (Girrbach and Fleischhacker, 2002). The fact that most lands in Ghana have poor fertility and poor physical properties with low organic matter content represents one of the major challenges of the sector (UNDP, 2007).

Many Ghanaian farmers predominantly produce subsistence subsidies (e.g. cassava, yams, plantains, corn and rice, tubers and vegetables[11]). Besides this they also cultivate tropical fruits (e.g. bananas, pineapple, pawpaw and mangoes) and cash crops (coffee, copra, kola nut, rubber tree, jute, palm oil and tobacco) (Girrbach and Fleischhacker, 2002, Thiemann, 2003). Due to the risk of trypanosomiasis (through tsetse flies) cattle rearing do not play a major role but many households have small livestock (e.g. chicken, goats, and pigs), which they use for personal consumption as well as for vending. Overall a transition from subsistence farming to plantation agriculture with cash crops may be recognized. Therefore, the situation of the peasants lies somehow between *'traditional'* and *'modern agriculture'* (Sahin-Adu, 2012a).

Besides agriculture trade ranks second: agricultural products and handicraft (e.g. leather goods, shoes and clothes) are the main items. Since the construction of lake Volta (1961-1966), fishery does also play an important role in this region (Thiemann, 2003).

3.1.2 Language and Religion

Ghana is a multicultural and multi-ethnic country: 98% of the population are black African (Girrbach and Fleischhacker, 2002). At present it is estimated that more than 70 idioms are spoken (Sahin-Adu, 2010). The most important languages of communication are: Akan, Ewe, Dagbani and Ga-Adangbe. The Akan people (Ashanti, Fanti, Brong) constitute about 45% of the population, followed by Mole-Dagbani (15%), Ewe (12%) and Ga-Adangbe (7%). English is the official language – with approximately 60% of Ghanaians being able to speak it (CIA, 2012).

The religious composition within Ghana is mainly divided by two: according to a census in 2000 the monotheistic religions such as Christianity (approximately 69%: Pentecostal/ Charismatic 24%, Protestant 19%, Catholic 15%, other 11%) and Islam (approximately 16%) and the more and more diminishing traditional religions of the different ethnic groups

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[11] Commonly grown vegetables in Ghana are tomatoes, okra, onions and eggplants.

(approximately 9%) are represented (CIA, 2012). Often there is a smooth transition between different religions (Sahin-Adu, 2010).

3.1.3 History and Politics

Although Ghana was the first African country to gain independence (in 1957) it has not always been a *'model country'*: Soon after independence Ghana fell victim to corruption and mismanagement. In 1966 the first president – Kwame Nkrumah – was deposed in a coup. Years of mostly-military rule were following until Flight Lieutenant Jerry Rawlings in 1981 staged his second coup (BBC, 2012). The 1980s were then dominated by economic decline, corruption and political change. In April 1992 a multiparty republic with a president as head of state and a vice president was established. Starting from this time Ghana began to move towards economic stability and a parliamentary democracy (Girrbach and Fleischhacker, 2002).

From 2001 to 2008 John Agyekum Kufuor was head of state. He as well as his numerous predecessors was in a tense relationship with Kwame Nkrumah. In December 2008 John Atta Mills won the election with a thin margin of victory over the candidate of the then governing New Patriotic Party, Nana Akufo-Addo (BBC, 2012) until his death in July 2012.

3.1.4 Education

The government dominated education system obliges a compulsory school attendance from age six to 16. National expenses for education in 2005 accounted for 5.4% and a national census in 2010 showed that the literacy rate reached 67.3%: 73.2% of the male population were counted as literate, but only 61.2% of the female citizen were able to read and write (CIA, 2012).

Higher education is provided in six universities and ten polytechnics. Additionally to these governmental institutions ten private universities offer tertiary education (Sahin-Adu, 2010).

3.1.5 National Health Situation

The national health expenditures in Ghana (2009) account for 10.6% of the GDP. The physician density reaches 0.085 physician/ 1,000 population (2009) and 0.93 hospital beds are available for 1,000 people (CIA, 2012). The national health situation is more or less typical for an African country and is characterized by a high burden of communicable (690 per 100.00 population/ year) but also a rising number of non-communicable diseases (699 per 100.00 population/ year) (WHO, 2010). Injuries account for 80 cases per 100.000 people/ year and do also play a noticeable role (WHO, 2010). For an overview about the major infectious diseases see Table 4.

Compared to other African countries the HIV-prevalence among adults (15-49 years) is low (1,9%) (WHO, 2010). Maternal mortality (451 per 100,000 life birth) and childhood mortality (under 5 mortality: 76 per 100,000 life birth) do also play an important role (WHO, 2010).

Another challenge of the Ghanaian health sector is migration of medical personnel to the United States, United Kingdom and Canada. According to a report by the International Organization for Migration (IOM) 56% of medical doctors and 25% of the nurses, which were trained in Ghana, are now working abroad (IOM, 2009). As a result especially rural areas are lacking medical care: cuts in public expenditure due to structural adjustments affect mainly the health and educational system (Girrbach and Fleischhacker, 2002). Approximately 60% of the population do have access to health care facilities (Thiemann, 2003) and a large part of the incident diseases are treated traditionally. For many diseases, as well as for BU, people in rural areas consult mainly traditional healers and/ or traditional birth attendants/ midwives (Sahin-Adu, 2012a).

TABLE 4: Major infectious Diseases in 2008

Infectious Disease	Number of Reported Cases
Cholera	1,223
Leprosy	447
Malaria	3,200,147
Measles	82
Meningitis	288
Rubella	459
Tetanus	8
Tuberculosis	7,9047904

SOURCE: WHO, 2010

3.2 The ACBRIDGE-Project

The ACBRIDGE-project belongs to the family of five African Centres of Excellence funded under the African Excellence Program[12] of the German Foreign Office and facilitated by the German Academic Exchange Service (DAAD). The prominent feature of this undertaking was its interdisciplinary setup with the aim of finding holistic solutions for major health issues within the West African region. The aim of this PhD program was interdisciplinary joint research (public health, clinical sciences, and biosciences) and a North-South partnership between the students. This allowed for an interdisciplinary and partnering working group, which was built on interactions between the individual projects. Further information about this project may be found on the net: http://www.uni-bielefeld.de/gesundhw/ag3/projekte/01_acbridge.html.

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[12] The African Centres of Excellence are funded by the Federal Foreign Office under the *'Aktion Afrika'* program and facilitated by the German Academic Exchange Service (DAAD). The program is a network of five centres in Ghana, Tanzania, DR Congo, Namibia and South Africa with the aim of offering education and research facilities at international level. These *'Centres of Excellence'* specialize in micro-finance, law, development and health research as well as logistics. Synergies are generated through networking among all of the centres; regular meetings of representatives from all the centres offer an opportunity to share experiences and discuss common issues.

3.3 Eastern Region of Ghana

The study was carried out in a rural sub district of the Eastern Region of Ghana, which comprises 21 districts. The area was chosen as target area due to the fact that research about BU was not yet done in this area (NBUCP, 2010).

3.3.1 Location and Features of the Eastern Region

The Eastern Region is the sixth largest region in total area and can be divided in two main ecological zones namely the moist semi-deciduous forest and coastal savannah grassland. The region is made up of 21 districts[13] and 139 sub districts with Koforidua[14] being the regional capital. It borders the Ashanti Region and Brong Ahafo in the North, the Volta River in the East, Central Region and Greater Accra region in the South, and Ashanti region and the Central region in the West (see Figure 10). The region covers an area of 19,323 km^2, and has a population of 2,633,154 people (2010 census). 253 health facilities of different ownership (clinics, health posts, hospitals etc.) are available to serve the health needs of the people (Ghana Health Service, 2010).

FIGURE 10: Eastern Region of Ghana
Source: BBC, 2008

3.3.2 Health Situation in the Eastern Region

A detailed health profile of the Eastern Region – comprising data on the most prevalent diseases – was not available/ accessible. But according to the information gained during the research process it may be stated that the disease pattern resembles the national health situation with the highest burden in the field of infectious diseases (malaria, tuberculosis, cholera etc.; see Table 4). In 2010 65 BU cases (7.6% of the BU cases in Ghana) were reported in the study area (see Table 1).

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[13] The names of the 21 districts are (in alphabetical order): Akuapim North, Akuapim South Municipal, Akyemansa, Asuogyaman, Atiwa, Birim Central Municipal, Birim North, Birim South, East Akim Municipal, Fanteakwa, Kwaebibirem, Kwahu East, Kwahu North, Kwahu South, Kwahu, West Municipal, Lower Manya Krobo, New-Juaben Municipal, Suhum/Kraboa/Coaltar, Upper Manya Krobo, Yilo Krobo, East Akim.

[14] Koforidua has a population of about 127,334 inhabitants (2012 census) and lies on the road from Accra via Nsawam and Suhum.

4. Methodology

The following chapter describes the methodology of the study: At first, an overview of the methodological procedure and study design will be given. Then the respective methods of the systematic literature search, the expert interviews, the cross-sectional KAP survey as well as the FGDs will be elucidated.

To approach the specific objectives of this study (see chapter 1.3) an iterative research process was chosen. Both qualitative as well as quantitative methods were applied successively to gain insight into the beliefs and attitudes towards BU amongst the local population in the research area (see Figure 11).

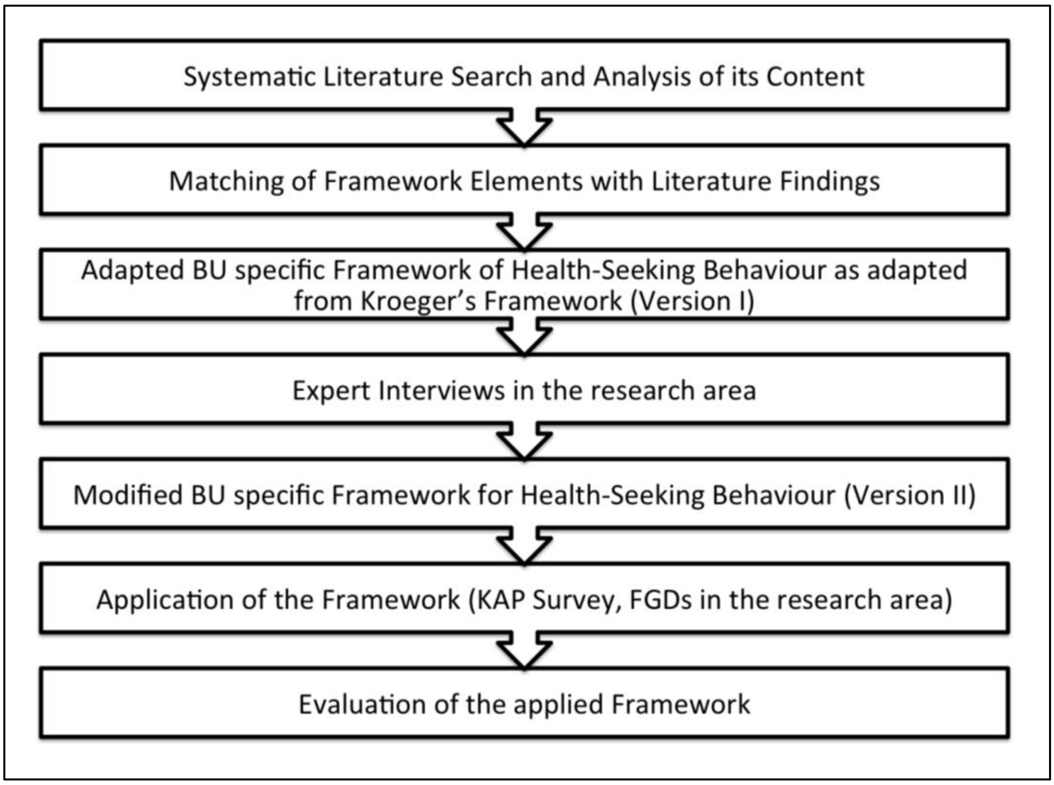

FIGURE 11: Iterative Research Process
Source: Author's own

A systematic literature search (see chapter 4.1) and a subsequent analysis of the available BU specific literature on health-seeking behaviour served as a systematic start of the research to get an overview of the published evidence (step 1). In the next step, the results from the literature were matched with the existing variables of Kroeger's framework (see chapter 2.2) (Kroeger, 1983) (step 2). This was followed by an adaptation of the model specifically for BU: existing variables were partially modified, deleted, and/ or added based on the literature findings (step 3 – *'Adapted BU specific Framework for Health-Seeking Behaviour'* as adapted from Kroeger (version I)).

After the adaptation of the framework empirical data was collected: Expert interviews (see chapter 4.2) were conducted to assess the specific local conditions (step 4) and to modify the adapted framework according to the local settings (*'Modified BU specific Framework for Health-Seeking Behaviour'* (version II), step 5). As qualitative research focuses on how individuals and groups consider and understand the world and perceive diseases according to their own experience expert interviews are open for the social environment of the study population and gather information on issues which are relevant to the local community (compare with Mayring, 1996). As a consequence, the findings of the expert interviews fed into the development of the questionnaire for the KAP survey as well as the interpretation of the quantitative results (next step of the research process).

The KAP questionnaire was used in a cross-sectional survey (see chapter 4.3) among all (previously) BU affected people of the years 2007 to 2010 who have been encountered in the study area in the context of an active community case search. At the same time, a comparison group matched by age and sex was interviewed with the same instrument to detect probable differences between the two groups.

As a next step FGDs (see chapter 4.4) were conducted in six selected villages to assess differences in the perception of the disease and the available treatment options between the different communities of the study area and to allow for an in-depth-analysis of the observed phenomena in selected communities (step 6).

In the last step the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) was evaluated on the basis of the empirical results (step 7) in order to describe its value for public health professionals as well as researchers in similar settings.

The approach of the study was a so-called '*triangulation'*, which means that different perspectives and methodologies were taken into account to study the health-seeking behaviour of BU patients (Flick, 2008, Razum and Gerhardus, 1999). The aim of this approach was to interrelate the different steps and methods of this cross-examination with the purpose to extend the single perspectives and to allow for a broader understanding than only the application of a single step or methodology (Flick, 2008). The focus of this study lies on methodological triangulation, which means that the results of different methods (*between method;* e.g. expert interviews and KAP survey) and differences within one method (*within-method;* e.g. patient's perspective vs. non-affected population or experts).

The different methods were considered as equal and independent findings: the results of the expert interviews did not only serve for the development and pre-test of the quantitative KAP-questionnaire and the development of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) but were also considered as individual findings. This made it possible to identify which research method or type of interviewee applies best to assess the different aspects of the framework. The same applies to the other applied research methods.

4.1 Systematic Literature Search

The aim of this review was to give an overview of possible factors influencing the health-seeking behaviour for BU. For a structured preparation of this research process a systematic literature search was done to identify, appraise, select and synthesize the available research evidence relevant to health-seeking behaviour for BU in Africa. The following questions were covered and answered in the literature:

1. What are possible promoting factors for seeking medical care for BU?
2. What are possible obstacles to seeking medical care for BU?

The synthesis of the answers to the above-mentioned questions was then applied to Kroeger's existing conceptual framework (see chapter 2.2), making adaptations necessary. As a result, a BU specific framework for health-seeking behaviour could be established (*'Adapted BU specific Framework for Health-Seeking Behaviour'* as adapted from Kroeger (version I)) – compare with Table 5.

TABLE 5: Systematic Literature Search

Specific Aims	Expected Results
- Adaptation of Kroeger's framework to assess, analyse and describe health-seeking behaviour for BU	- Overview of the published evidence - *'Adapted BU specific Framework for Health-Seeking Behaviour'* as adapted from Kroeger (version I, see Figure 17)

Source: Author's own

4.1.1 Search Strategy

The search strategy was based on various inclusion criteria. Those were: (1) empirical studies evaluating the care-seeking behaviour and patient preferences for BU, (2) publication language English, French or German (3) all publications ever published until December 2011 (4) study conducted in Africa. Exclusion criteria were: (1) conceptual articles, (2) editorials and (3) letters without empirical findings.

A comprehensive systematic search of the available literature was performed for all articles ever published in Medline (PubMed), PsycINFO®, Medical Anthropology Quarterly and Sowiport until December 2011.

To investigate the above-mentioned questions several search strategies were used. The most sensitive method for the topic of health-seeking behaviour was a free-text search with the term "Buruli ulcer treatment" in PubMed ("buruli ulcer"[MeSH Terms] OR ("buruli"[All Fields] AND "ulcer"[All Fields]) OR "buruli ulcer"[All Fields]) AND ("therapy"[Subheading] OR "therapy"[All Fields] OR "treatment"[All Fields] OR "therapeutics"[MeSH Terms] OR "therapeutics"[All Fields]), which retrieved 278 publications and covered a reasonable array of treatment aspects. In the other databases only the term "Buruli ulcer" was used.

In addition to the articles retrieved via database search the reference lists of the relevant studies were scrutinized to identify further publications. Searching the internet, screening the library of the School of Public Health, University of Ghana, and the newsletter of the STOP Buruli consortium complemented this search. The principal investigator (LS) screened all publications provided with title and abstract of the retrieved articles to identify potentially eligible publications (promoting factors, delay causing factors). If the article's relevance could not be determined from the title and/ or if an abstract was unavailable, the document was selected for further review such as those who seemed to match the inclusion criteria.

4.1.2 Data Extraction and Presentation

The following study characteristics were extracted from all included studies: Study setting (African countries), study design and methods, sample size, aim of the study, and reasons for patient's delay/ early reporting. A standardised form was used for the extraction of the relevant data. The studies were categorized according to the applied methodology. A quality assessment of the literature was not done due to limited personal resources. The results of this analysis are presented in chapter 5.1.

4.2 Expert Interviews

The word *'expert'* implies that a person is skilled and knowledgeable in a specific domain and has special knowledge, which may be made available on request or can be used to solve particular problems (Gläser and Laudel, 2009). Yet 'expert knowledge' does not require working in senior positions: a patient is an *'expert of his own disease'* since he has special experience – without holding a specific position in a job. In the context of this study the term 'expert' refers to the specific role of the interviewee as a source of special knowledge or facts to be explored (Gläser and Laudel, 2009). Expert interviews are a widely accepted method to tap the aforementioned expert knowledge (e.g. about a specific disease). The purpose of the interviews in this study was therefore to make this specific knowledge (i.e. about specific situations and processes) about BU available for scientists (compare with Gläser and Laudel, 2009).

Within this study expert interviews aimed at gaining a broader understanding of the local concepts regarding BU, ascribed causes, challenges and burdens of BU as defined by the interviewees. Furthermore, these interviews were relevant to check, modify and extend the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I). The 'expert' definition in this study is rather broad: a) people with either first-hand experience of BU affected people and their caregivers, b) people with direct work related experience with the disease (e.g. health staff, community based volunteers researchers (CSBVs)[15], herbalists, teachers etc.) were interviewed. The common characteristic was that they were all subjected to BU or confronted with BU for quite some time in various ways. The following figure (Figure 12) depicts the different angles of the aspects within the study.

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[15] Every community is supposed to have a CSBV, who stays in the community and knows every community member. By the time of research the sub district had 24 CBSVs to facilitate the cooperation between the local health workers and the DHMT so that they served as an *"interface between health providers and the communities"*. Generally the DHMT does not provide them with any regular compensation but a per diem for daily activities or some consumer goods (e.g. a bicycle or raincoat etc.) for specific campaigns. In theory the communities are supposed to support CBSVs in some kind (e.g. weeding his farm so that he has the time to do his work, fetch water etc.), but it depends on the members of the community how they actually support the activities of *"their CBSV"*. In some communities they provide them with food and other things but other communities do not provide much support. Therefore it is not out of the ordinary if CBSVs get tired of their job and quit their duty after some time (e.g. because they find it difficult to work with the people). During the time of research the principal investigator got to know that three of the CSBVs quit their job: one because he was *"too old and tired to continue the activities"*, another CSBV died himself due to an infectious disease, and the third had quit after his wife died. Until the principal investigator left the research area only one of them was replaced by another person. Ideally the communities elect their CBSVs but according to the reports of a health official some nominations may not be fair as they depend upon choice of the community leader. One of the health officials complained that some become very arrogant and that their expectations are not met.

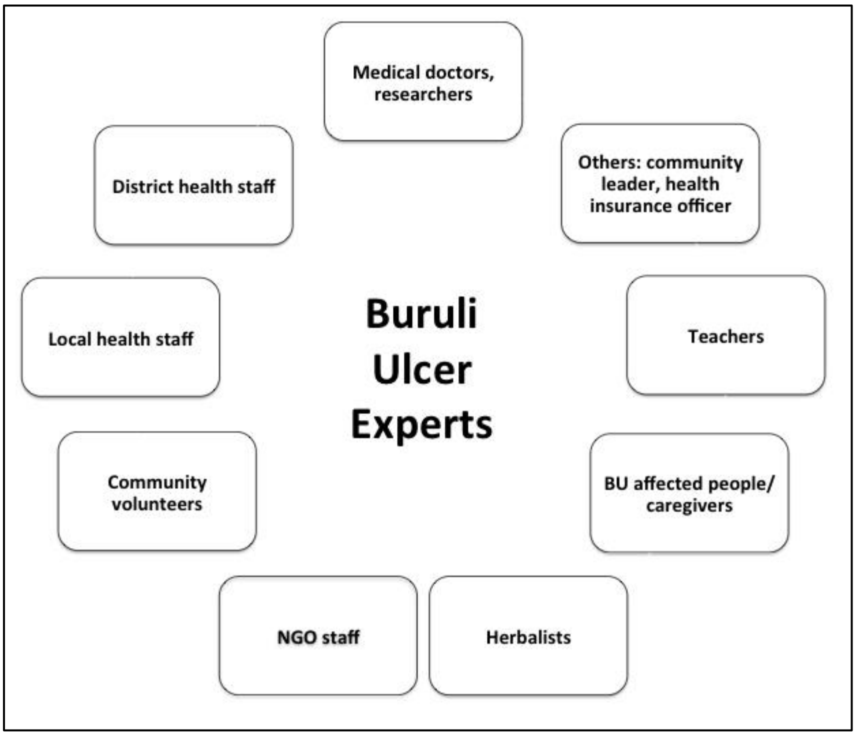

FIGURE 12: Overview of various Groups of Interviewees for Expert Interviews
Source: Author's own

With the help of expert interviews it was possible to investigate the phenomenon of health-seeking behaviour in an explorative way and to elicit the subjective perceptions regarding BU and its treatment. Furthermore, the interviews delivered traces and references for the formulation of the quantitative KAP-questionnaire. The benefits of this approach were – firstly - the disclosure of subjective perceptions and interpretation patterns. Secondly it allowed for gathering the relevant data, and thirdly it allowed for adapting to the local setting with its specific norms and experiences (Rieker and Seipel, 2003, Gläser and Laudel, 2009).

The insights gained from the adaptation were valuable and adjuvant in various ways: the local challenges to seek medical care from a health post and the people's interpretation of causation and symptomatology became clearer and understandable. Furthermore questionnaire based interviews during the KAP survey (see chapter 4.3) and conversations in the communities had shown that people do not have a good perception of time and distance so that valid answers for these parameters were not easy to generate within the given setting. As opposed to the KAP survey the expert interviews provided the possibility to approach the above-mentioned problems from different angles (e.g. knowledge and perception of different treatment options, the use of different sources of information).

The information retrieved from the expert interviews was adjuvant for the interpretation of the quantitative results of the survey[16]. The *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) is a product of the expert interviews. The following table (Table 6) gives an overview of the function of expert interviews in the context of this study.

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[16] Furthermore, the quantitative questionnaire made a quantification of the questions possible. Only the combination of both methods (expert interviews and KAP survey) provided the opportunity to investigate the different facets of treatment seeking for BU.

TABLE 6: Function of Expert Interviews in the Context of the Study

Specific Aims	Expected Results
- Understanding of the specific local challenges of BU treatment - Gaining knowledge and interpretation of aetiology and symptoms of BU - Identification of attitudes towards BU and BU affected people patients	- Background information for the construction of KAP-questionnaire - '*Modified BU specific Framework for Health-Seeking Behaviour'*, (version II)

Source: Author's own

4.2.1 Guidelines

An open interview situation reveals the relevance of the topic, the underlying experience and perception of the different interviewees better than a standardized interview or a questionnaire (Gläser and Laudel, 2009, Flick, 2005, Schnell et al., 2011) – especially if the research setting/ culture differs from the original setting of the researcher. The reason for choosing guideline oriented expert interviews was therefore to achieve an open interview situation.

The guideline structures the topic beforehand but only serves as a mind memory. This allows better for the interviewees to "talk" openly and freely rather than to answer fixed and standardized questions. Other commonly used terms for these expert interviews are semi-structured interview or partly standardized interview (Gläser and Laudel, 2009, Flick, 2005, Schnell et al., 2011, Kruse, 2009). All interview guidelines were based on the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I) but were adapted for the specific group of interviewees (i.e. specific guideline for patients, medical doctors, local health staff, traditional healers, caregivers and teachers)[17]. The guidelines were structured into subtopics (e.g. sources of information, appeal of the treatment, social integration, structural challenges, and the aetiological model). These sub-topics reflected the topics of the adapted framework (version I) (see Figure 17), which was developed after the systematic literature search.

In order to create rapport with the interviewee and to create a comfortable setting for the interviewee a *'warming-up-question'* such as *"How did you get involved into the topic of BU?"* or *"When did you first encounter a BU patient?"* was part of the guideline. The focus of the interview guidelines was to:

- Allow for fact-based questions (e.g. about the different sources of information)
- Allow for the assessment of the interviewees' attitudes towards BU (e.g. perception about/ experience with antibiotic treatment and early detection of BU)

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[17] Each guideline included a range of topics with questions, which were relevant to every interview and some questions, which were specific to certain interviewees. The guidelines can be found in the annex (Annex B) of this thesis.

4.2.2 Selection of the Interviewees and Research Procedure

The interviewees were recruited by the snowball system[18]. On the basis of the *'Adapted BU specific Framework for Health-Seeking Behaviour for BU'* (version I) (see Figure 17) 33 expert interviews were conducted (for an overview of the interviews see Table 7).

TABLE 7: Expert Interviews conducted between June 2010 and July 2011

Stakeholder	No. of Interviews
BU patients or their caregivers	8
Local health staff	5
Medical doctors, researchers	3
District health management team (DHMT)	3
Community based surveillance volunteers (CSBV)	3
NGO staff	2
Herbalists	2
Teachers	2
Other interviewees (BU control program, community leader, representative of national health insurance, research assistant, international volunteer)	5
Total number of interviews	**33**

Source: Author's own

The access to the interviewees with BU specific experience and/ or expertise was established by various different people – all of them in the context of the ACBRIDGE-project. Apart from some of the researchers and the NGO staff all interviewees were unknown to the investigator before the interview. The investigator received the contact data from the project environment and got in touch with the prospective interviewees either via email, telephone or personal introduction. Interviewees were from various geographic backgrounds within the research area.

Most interviews (N = 25) were conducted in English, recorded and then transcribed. Eight interviews – predominantly with BU affected people or their caregivers – were done (by trained research assistants) in the local language Twi (N = 7) or Ewe (N = 1) respectively. The interviews were done within the period of June 2010 to July 2011. The interview participation was voluntarily; all approached interviewees consented for an interview and signed the respective consent form (see Annex B). Most interviews took place at the interviewee' workplace; some were also conducted in the participants' homes. Interviews with patients were mainly done at the health post. For this purpose an enclosed interview setting – where no other persons were able to disturb the conversation – was created. In principle, the interviewer hewed to the questions of the guideline; but during the interview she

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[18] The snowball system is a social process, which recruits interviewees who are recommended by previous interviewees. Usually it is an easy approach and the number of recruited interviewees rises fast.

was free to choose the moment and sequence of the questions. It was also possible to leave some questions out or to enquire more details, which allowed for a natural flow of the interaction.

The interviews were recorded with a portable audio-recorder (Zoom H2), which allowed the researcher to fully concentrate on the colloquy. This made it also possible to document setting specific information and simplified a competent handling of unplanned or spontaneous incidents (Gläser and Laudel, 2009, Rieker and Seipel, 2003). For reasons of anonymity names of the interviewees were not documented; basic socio-demographic data were collected with a rapid questionnaire (see Annex B). At the end of the interview the interviewees were given the opportunity to ask questions or to add further specific aspects. This chance was taken by almost all of the interviewees with professional background.

4.2.3 Data Management

Depending on the language the interview was conducted in different transcription processes occurred. All recorded interviews were transcribed (and – if necessary – directly translated) into computer-written text. Interviews in the local language were directly translated and transcribed into English and not into the original local language and then into English. Although this shortcut may result in a slight loss of information the researcher holds the view that this disadvantage is far outweighed by an easier, faster and cheaper processing of the information (compare with Bertrand et al., 1992).

The degree of detailedness and the choice of the adequate transcription system (see Appendix B) were adjusted to the research approach: The interviews were fully and literally transliterated so that core texts were available for the analysis. The focus of the transcription was on the content and on what the interviewee reported rather than on its modality. Breaks, irregularities and accentuations are not indicated in the transcript. The transcription was done in two steps: in the first step a local research assistant transcribed the interviews. To ensure a consistent quality of the transcripts the material was compared with the recording by the principal investigator (LS) herself; spelling and hearing mistakes were clarified and adapted to the transcription system; unique information was made anonymous. The research assistant, who had conducted the interview, did a further crosscheck to ensure the validity the transcripts. A CD-ROM with the transcribed material is attached to this thesis (Appendix B).

4.2.4 Qualitative Data Analysis and Interpretation

The analysis of the expert interviews within this study is based on the *‘qualitative content analysis’,* a method which is well adapted to the research question. This type of analysis is appropriate particularly for analysing subjective attitudes, which are assessed in partly standardized expert interviews (Mayring, 2008, Mayring, 2000, Gläser and Laudel, 2009). Qualitative content analysis allows for a systematic and theory-based analysis of the interview material and makes conclusions on selected aspects possible.

The qualitative content analysis involves three steps of coding: (1) Summarization, (2) explanation and (3) structuring. The aim of these steps is to reduce the text material; yet the essential content should be maintained. The result is a text body, which represents the basic material for further summarizing steps. Theoretical assumptions are applied and the summary of the text tends to be more abstract. Depending on the research question different approaches for coding and categorisation may be used. Coding is utile for approaches where the original text is paraphrased, summarized and structured into new categories; at the same time the text is reduced (Flick, 2005, Gläser and Laudel, 2009).

For the interpretation of the interview material two main strategies are available: (1) a deductive coding of the interview material with the aim to develop categories and theories and (2) the inductive or sequential analysis which aims at reconstructing the case structure (Flick, 2005). The summarizing content analysis either inductive or deductive category sets of categories may be used (Schnell et al., 2011). In practice, a mixture of both approaches (inductive and deductive) is common: Ambiguous passages are explained with additional information, which may be gathered from external material (e.g. research literature) or additional background interviews (e.g. interviews specifically about traditional medicine or health insurance). This step is important for the contextual analysis of the data. Another way to obtain background information is to access the context of the respective material (narrow contextual analysis).

The aim of this analysis was to retrieve all relevant passages on a specific topic within the text. Furthermore it aimed to identify cross-references, patterns and similarities to general cross case or generalizing results. A verification whether new conclusions according to the set of categories still corresponded to the original material stood at the end of the reduction phase (Mayring, 2008). With the aim of reducing the data to a manageable text for further analysis the deductive approach was chosen as the main method for this study. The structuring content analysis was particularly appropriate, since it examines whether the selected framework may be applied to describe the health-seeking behaviour of BU patients. This was carried out through the systematic analysis of the summarized data. First the categories of the *‘Adapted BU specific Framework for Health-Seeking Behaviour’* (version I) (see Figure 17) were applied as a set of categories. Then the text fragments and the corresponding category of the framework were extracted and summarized. As a result the fundamental content and information was summarized and reduced in order to elaborate the statements on a general or higher level of abstraction (Gläser and Laudel, 2009, Flick, 2005, Mayring, 2008, Mayring, 2000).

This means in short, that the text’s relevant passages were matched with the categories/ codes of the *‘Adapted BU specific Framework for Health-Seeking Behaviour’* (version I) (see Figure 17), then compared and analysed. The application of deductive categories is displayed in Figure 13.

Relevant passages of the text which did not fit in the predefined framework/ categories were subsumed under new categories (Kelle and Kluge, 2010) and added in an inductive way. The inductive analysis tried to generate theory grounded in specific instances of empirical data. The result of this analysis/ interpretation is the *‘Modified BU specific Framework for Health-Seeking Behaviour’* (version II) (see Figure 18).

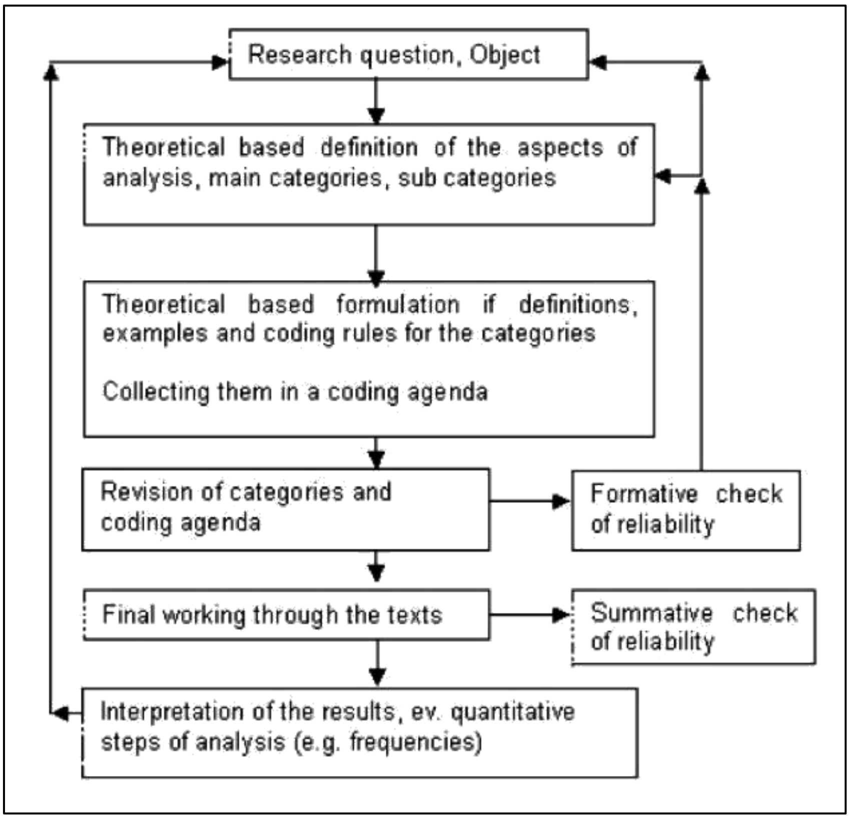

FIGURE 13: Deductive Application of Categories
Source: Mayring, 2000

4.3 Active Community Case Search and Knowledge, Attitude and Practice (KAP) Survey

With the aim to identify and interview all suspected and healed BU cases (from the years 2005 and 2010) in the research area an active community case search (door-to-door screening) was conducted. The procedures are described below.

4.3.1 Active Community Case Search

The active community case search/ screening was done to locate all (previously) affected BU patients within the study area (see Table 8). This activity was a joint research conducted by Mr Schindler-Piontek (MS) and his fieldworker as well as the principal investigator of this study (LS) and her two research assistants. Both research teams received professional support from community based surveillance volunteers (CSBVs [19]).

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[19] CSBVs in the research area are regularly trained (by the District Health Management Team or NGOs) in the detection of a variety of diseases among which is BU. Their training includes e.g. clinical features, diagnostic approaches, as well as clinical management. Usually they work independently in their community identify suspected cases of BU or other diseases and refer them to the next health post for diagnostic work-up and treatment.

TABLE 8: Function of the active Community Case Search in the Context of the Study

Specific Aims	Expected Results
- Locate and interview all BU affected people within the study area	- To identify BU cases and assess the prevalence of the disease within the study area - To observe the local living circumstances/ environment

Source: Author's own

Before the start of the case search and to allow for a detailed data collection and better management of the case tracing the communities of the study area were numbered and divided into geographic study units; community register information was obtained to compare the data with census data for its accuracy regarding the community population. After that, unique identification numbers (community-IDs) were assigned to the communities.

The active cases-search/ screening procedure was done in two rounds: (1) Mr Schindler-Piontek (MS) and his team conducted a first door-to-door community screening and registered all suspected BU cases. (2) The respective registration forms were then passed to the principal investigator (LS) who conducted a second focused screening (about a week later) in each community to trace further suspected BU cases. For a detailed description of the procedures see the standard operation procedure – SOP (Appendix C).

4.3.2 Registration Process

All encountered people (both BU patients/ cases and matched community members) who consented to participate in the study signed or thumb printed or had a witness to sign. Unique ID-numbers were assigned to every participant to allow for an easy patient tracing and follow-up. All recruited patients received free medical treatment through the Ghanaian national health system (see Figure 14).

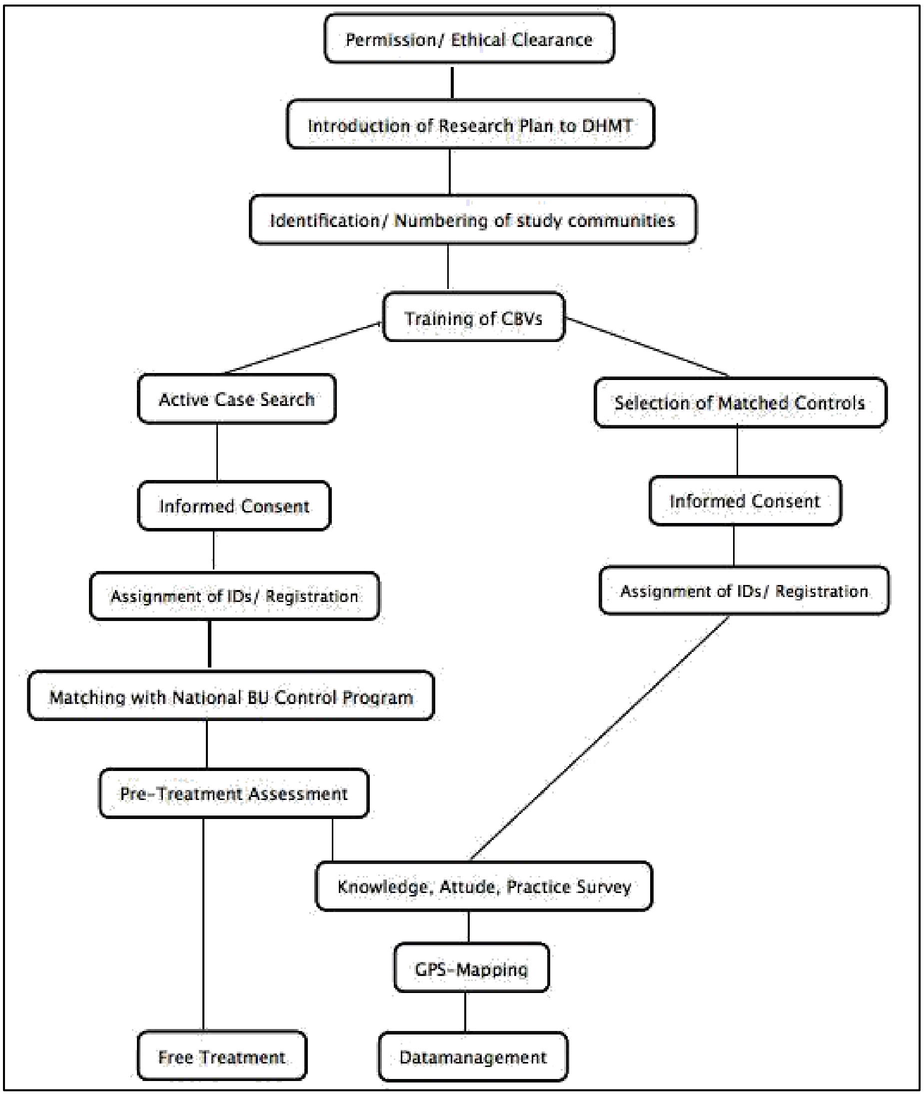

FIGURE 14: Recruitment of Study Participants
Source: Author's own

4.3.3 Pre-Treatment Assessment and Case Confirmation

Active BU cases were included in the study if they were clinically diagnosed as BU by MS and his research assistant. MS also assessed the basic demographical characteristics and relevant clinical data of the identified cases. If possible swabs were taken at the local health facility and then sent to Noguchi Memorial Institute in Accra for BU diagnosis/ case confirmation.

Old healed cases (from the years 2007 to 2010) were eligible and included in the study if they had a self-reported history of BU.

4.3.4 Treatment

All enrolled BU affected people with active lesions received antibiotic treatment for BU according to the national protocol [20]. Local dressings were provided for patients with ulcerative lesions. Recruited patients, who were not infected with BU, received free medical treatment for their wounds/ lesions.

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[20] BU patients received a combined daily therapy of with a combination of rifampicin (10mg/kg/d) and Streptomycin (15mg/kg/d) (= SR) for 56 days (recommended by WHO).

4.3.5 KAP Survey

All registered study participants were enrolled for the survey to assess knowledge, attitude and practice. Furthermore it was meant to determine differences between BU affected people and the non-affected population. In the end it should allow for a quantified version of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18).

Knowledge, Attitude and Practice (KAP) surveys are commonly used in countries in the south to understand and assess local knowledge and values as well as underlying belief systems. They are employed to analyse how these factors affect the health-seeking behaviour and are meant to identify relevant obstacles on the patient's side for seeking medical care. KAP surveys originate from family planning and population studies in the 1950s. Between the 1960s and the 1970s this concept was commonly used to gain insight into the perception of family planning in Africa (Schopper et al., 1993). The findings of these KAP surveys were then supposed to be applied globally (Launiala, 2009, Cleland, 1973, Ratcliffe, 1976). In parallel the number of studies on community perspectives and human behaviour increased immensely and thereby reacted to the requirements of the primary health care[21] approach, which was taken up by the international aid organisations.

In these KAP surveys *'Knowledge'* is usually assessed by looking at whether the people do have a certain understanding about symptoms, aetiology and prevention of the disease – and whether they behave accordingly. The answer options provided include predominantly biomedical explanations; other reported knowledge is mainly summarized in categories such as *'witchcraft'* or *'other believes'* and does not cover the local concepts or understandings. Enquiries about other types of knowledge may rarely be found in KAP studies. Information on knowledge about and access to the local health facilities may also be assessed.

The most difficult aspect to be assessed in KAP surveys is the attitude of the study participants: An *'Attitude'* is defined as "*a learned predisposition to think, feel and act in a particular way towards a given object or class of objects*" (Ribeaux and Poppleton, 1978) and this predisposition results in a multifaceted interaction of beliefs, feelings, and values. It is essential to understand as changing attitudes is the most important aim for designing health promotion campaigns. The challenge of this aspect is that they are very likely to be influenced by statements and answers. Direct asking might be problematic as respondents usually react with what believe to be the 'correct' or most desired answer (compare with Launiala, 2009).

The *'Practice'* section within a KAP survey usually enquires about the use of preventive measures or different treatment options. Here questions such as *"What did you do when you had symptoms like this?"* are used. The answers options are usually fixed and provide only limited space for statements about actual practices. This section therefore rather yields information on normative behaviours or on what they perceive should be done. In practice, the survey mainly checks on people's knowledge about socially accepted practices. Hence, explaining health-seeking behaviour only by looking at KAP data might be difficult (Yoder, 1997, Hausmann-Muela et al., 2003).

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[21] Primary health care (PHC) is defined as *"essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination".* This health approach goes beyond the traditional health care system and mainly focuses on health equity-producing social policy. PHC was adopted in the Alma Ata-declaration of the International Conference on Primary Health Care (1978).

The framework and the information gained through the expert interviews and observations during fieldwork were used to construct a structured questionnaire for a KAP survey, which served to achieve the following specific aims and expected findings (see Table 9).

TABLE 9: Function of the KAP Survey in the Context of the Study

Specific Aims	Expected Findings
1. Assess socio-demographic characteristics of (previously) BU affected people 2. Understand Knowledge, Attitude and Practice of (previously) BU affected people 3. Determine differences between (previously) BU affected people (N = 122) and the non-affected population (N =122 matched community members) 4. Assess characteristic differences of (previously) BU affected people by gender 5. Assess characteristic differences of BU affected people between the generations (up to 15 years and above 15 years) 6. Determine characteristics of *'Early Care-Seekers'* (medical treatment for pre-ulcerative stages (nodule, plaque, oedema) of the disease; N = 59) vs. those, who use other treatment options	- Socio-demographic characteristics of study participants - Knowledge, attitude and practice of BU and its treatment - Characteristic differences between BU affected people and the non-affected population - Characteristic differences of (previously) BU affected people by gender - Characteristic differences of (previously) BU affected people between the generations - Characteristics of *'Early Care-Seekers'* - Identification of high endemic and low endemic communities → Quantified results for the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II)

Source: Author's own

The variables of the KAP data, which were then analysed with respect to the specific aims, are displayed in Annex C.

4.3.6 KAP Questionnaire for BU

There was no research tool for a survey with BU affected people and their matched community members readily available, which covered all the aspects of the research questions/ framework. Therefore, it was necessary to adapt existing questionnaires (Renzaho et al., 2007, Stienstra et al., 2002, Mulder et al., 2008) and develop a new research tool, which was specific for the target group and the research setting. The questionnaire was translated into the two predominant local languages (Twi and Ewe).

The KAP questionnaire was meant to be administered by local research assistants and consisted of 21 pages, included an introductory page and 60 questions in different formats. The covering page of the questionnaire included information about the aim of the study, responsible institutions, how to fill it in as well as a statement regarding the anonymity of the respondent and instructions on how to ask the questions (careful probing rather than providing the answer options). The first questions covered the socio-demographic characteristics of the study participant. The questions regarding knowledge, attitude, practice and access to health care facilities followed. The questionnaire ended with a "*thank you for your participation*" and provided the chance to give a feedback/ comment on the research.

Five different question formats were used – multiple choice and open questions were the predominant types. The questionnaire was based on the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18) and included questions regarding *'Predisposing Factors'* (socio-demographic characteristics and information about probable social interactions), *'Characteristics of BU and Perception of the Disease'* (e.g. characteristics about encountered BU lesions, aetiological model and probable stigmatization), *'Enabling Factors'* (e.g. accessibility of health facilities, appeal of treatment, cost of treatment as well as acceptability, quality of health services and health communication) as well as *'Choice of Health Care Resources'* (e.g. herbalist, spiritualist, church/ prayer-camp and governmental health facility).

As it had to be assumed that the knowledge about the inquired topics differed among the participants the questionnaire used filters to adapt and guide the interview respectively. This guidance was designed as concrete as possible by providing the number of the following question at the end of each answer option (Porst, 2009). The majority of the questions were close-ended and provided anticipated answers. In order to avoid missing out on possible or important aspects (see Jacob and Eirmbter, 2000) the researcher drew back on research literature and the results of the expert interviews to cover most possible answer options. For additional or not anticipated answers open text fields were given. The fact that the questionnaire was only used by the research assistant for the interview made it possible to include answer options from every angle to minimize anticipated answers (compare with Jacob and Eirmbter, 2000). Situations, where the interviewee might get the feeling of an examination or interrogation, were prevented by the inclusion of questions about experiences or opinions rather than knowledge based facts (compare with Jacob and Eirmbter, 2000).

The questionnaire was handed to several experts (clinicians, health and social scientists) as well as some layperson for revision. Feedback was also received from a sociologist and a communication scientist regarding structure, layout and handling of the questionnaire. Two pre-tests (June 2nd 2010 and June 18th 2010) were done before a pilot phase (between June 29th and July 7th 2010) in the research area. In total 51 interviews were conducted during the pre-test/ pilot phase to ensure that the questionnaire was understandable, the filters were set adequately and to assess whether it fitted the research questions (Porst, 2009). The pre-test/ pilot phase was also essential to check whether the questions were understandable, socially acceptable, and whether the interviewees were willing to answer and collaborate with the research. A rapid pre-analysis with the available data was done in an Excel-sheet to assess whether or not the answer options were selected adequately. The questionnaire was constructed for an interview duration of 20 to 30 minutes to avoid excessing the time budget and loss of concentration of the participants. The final version of the KAP questionnaire is located in Annex C.

4.3.7 Interview Training and Function of CSBVs

The field workers/ research assistants were already involved at an early stage of the study (e.g. translation of documents, conducting the pre-test of the questionnaire). Additionally they received an intensive and comprehensive introduction into the topic of BU, general interview training as well as a concrete and specific introduction to the questionnaire by the principal investigator. Additionally a guideline (fieldworker guidelines; see Appendix C) was provided for further consultation.

The main function of the CSBVs was to serve as liaison persons between the researcher/ research team and the community: For the purpose of this case search they were introduced to the exact research procedures and its requirements right before the research activity.

They introduced the researcher(s) and their intended activities to the chiefs of the communities, the community as a whole and to the individual cases. They were also responsible for the administration of the written consent form and read/ explain it for illiterate participants. Furthermore they assisted to find matched controls and to schedule interviews with the participants.

4.3.8 KAP Interview and Matching Procedure

BU affected people, who consented to participate in the survey, were interviewed using the KAP questionnaire. As mentioned above this research tool was based on the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18). Two trained research assistants interviewed the BU cases in the respective community. In the case of children under the age of ten the interview was done with the child accompanied by with one of their parents/caretakers.

To investigate differences regarding KAP between BU affected people and the non-affected population (specific research question (2)) previously affected cases and matched community members (similar age [22] and the sage sex) were identified within the same community (compare with Bland and Altman, 1994). To determine the direction of a house with a relevant matched community member the next house right hand of the house with the BU affected person was approached. The first person in this house with similar age (participants up to 18 years: max 1 year older/ younger; participants above 18: max. 5 years older/ younger) and sex, who consented to participate in the study, was enrolled as matched interviewee. If this person refused to participate, the second person in the same house was approached until a control was identified and interviewed. If no matched person could be identified in one house the next house to the right was visited. The same procedure was carried out until an appropriate control was selected and interviewed. These matched community members were interviewed with the same questionnaire as the suspected BU cases.

4.3.9 Informed Consent and Ethical Considerations

All participants were orally introduced to the study and the research team first. Then the potential participants were requested if they were willing to participate in the research. In case they agreed they received the written consent form (see Annex C); alternatively it was read and translated to them by the research assistants. Finally, they were requested to sign/ thumbprint the form to prove their agreement. Additionally a witness signed that the interviewee participated voluntarily and freely – under the condition that no compensation would be paid.

The research proposal for this study was reviewed and approved by the institutional review board (IRB) of the Noguchi Memorial Institute for Medical Research as well as Ghana Health Service [23]. Permission for this research activity was sought from the National Buruli ulcer Control Program (NBUCP) and the District Director of Health Services of the research area. After ethical clearance the research plan was introduced to the District Health Management Team (DHMT) for information and support of the case search.

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[22] Participants below 18 years were matched with a community member, who was max. 2 years older/ younger. Participants, who are 18 years and older were matched with a community member, who was max. 5 years younger/ older.

[23] A further proposal was sent to the ethical committee of the medical faculty of Münster University, Germany who then stated that they were not responsible for studies being conducted in Ghana.

4.3.10 Data Collection, Documentation and Management

Survey data were collected between August and November 2010. A unique ID number was assigned to each study participant. The name and the respective ID were documented in a hand written list, which was only available for the principal investigator. This list was kept separately and safely from the questionnaires. The questionnaire included only the participant-ID and did not bear the name of the participant.

In order to assure adequate documentation of the response rate the principal investigator documented the number of participants who declined and who agreed to participate within the study. All questionnaires were checked after the interview for probable missing information. If this was the case the team tried to retrieve and add this information during the next field visit. Information, which was refused by the participant him-/herself, was not requested from other household members.

All completed questionnaires were kept anonymous and secured in a locked room. Data were entered in a secured Access-database by the principal investigator (LS). After that, the data was imported into the statistical programme SPSS for MAC (version 20, IBM, USA) for analysis.

For a quality check of the data set a random sample of 22 questionnaires was selected to double check the accuracy of the data entry. Furthermore the data set was checked for consistency: every variable and its answers were counted. A combination of variables, which were contradictory, was used to check the plausibility of the data. In case variables were recoded all respective changes were documented in an Excel-sheet.

4.3.11 Statistical Analysis

The main aim of the data analysis was to describe specific characteristics of the people in the rural communities in order to be able to assess how these characteristics relate to their health-seeking behaviour in the study population and its subgroups. The analysis was characterized by an explorative proceeding: Standardized/ fixed answers were predominant in the questionnaire, which resulted in nominal and ordinal variables. Only very few variables had (quasi-) metric scale.

In the first step a descriptive analysis of the data was done: This involved the calculation of frequencies and percentages of categorical variables such as gender, education status, marital status, profession, ethnical background, as well as the health related variables (e.g. use of traditional medicine, membership in the national health insurance scheme). For the variables with metric scales (e.g. age and chop-money) valid frequencies, number of missing values, mean (M), standard deviation (SD), median (Med) as well as minima/maxima were calculated. Certain characteristics/variables were displayed by histograms for continuous data or by bar charts for discrete data. Open answers (to questions as "*Why do you like the local health facilities?*") were summarized in Microsoft Excel and reduced by using qualitative content analysis (Mayring, 2008). These answers are displayed together with the standardized answers.

In addition, a univariate analysis was conducted to detect differences between affected vs. non-affected participants, differences by gender, by generation and to identify characteristics of *'Early Care-Seekers'* In order to determine whether the participants differed significantly for these characteristics the chi-square-test or Fisher's exact test (if required) were used for comparison (a detailed analysis table – grouped by specific research question – is located in Annex C). A p value < 0.05 was considered statistically significant.

The characteristics of *'Late Care-Seekers'* (people who sought medical care only for ulcerated BU lesions, N = 63) were tabulated by cross-tables and assessed by using Chi-square/ Fisher Exact tests respectively. Furthermore the odds-ratio was calculated if the p-value of the Chi-square/ Fisher Exact tests were < 0.25.

4.4 Focus Group Discussions (FGDs)

One of the main aims of this study was to determine the health-seeking behaviour in BU endemic communities and in communities with low endemicity. Yet the above-mentioned methods did not prove efficiently enough whether and how the disease perception and the resulting health behaviour differ between the communities. Secondly the FGDs were used to assess specific differences regarding the disease perception between previously affected patients and non-affected community members. This method was used as it allowed for in-depth discussions of questions associated with the local health-seeking behaviour and to allow for an evaluation of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18).

4.4.1 Characteristics of FGDs and their Function within the Study

FGDs are a specific kind of group interview whose main feature is to evoke interaction between the members of the groups in order to generate topic specific data. The FDG method is considered useful in particular to explore the knowledge and experiences of the participants and may be used to elicit not only what people think but also *how* they think and *why* they think or behave that way (Kitzinger, 1995). In order to give the researcher an understanding of the participants' perspective they are encouraged to talk among each other rather than to respond to a question of the moderator. Questions, anecdotes and comments, which arise during a discussion, may stimulate a discussion about different experiences and points of view (Kitzinger, 1995) of different meanings, beliefs and cultures (Rabiee, 2004).

Six major advantages of FGD research (e.g. advantages with regard to efficacy of data collection, taking into consideration of cultural and pragmatic aspects) are mentioned in the literature: (1) Compared to in-depth interviews, group-interaction stimulates richer responses as it allows the participants to agree or disagree. Questioning is flexible and it may be easier to reveal participants' real perceptions: It is said that this method reaches areas of the examination that other methods cannot reach (Liefooghe et al., 1997) as it allows the participants to express their own ideas in a spontaneous manner and according to their own perception (Bertrand et al., 1992). (2) The group-synergy allows studying the communities in a more natural setting than in a one-to-one interview (Dreher and Dreher, 1991) so that the FGDs provide in-depths knowledge about the how and why a community feels on specific issues (Bertrand et al., 1992). (3) Discussions can be conducted in a relatively short span of time with limited financial resources (Bertrand et al., 1992). (4) Tapping into interpersonal communication may highlight (sub) cultural values or norms: Analysing humour, consensus, and dissent as well as different types of narratives shared and common knowledge may be revealed. This makes FGDs particularly sensitive to cultural variables. This does also explain why this method is not only used in cross cultural and minority research but also to assess reasons why some communities make differential use of health services (Kitzinger, 1995). (5) FGDs allow local researchers with only little formal training to gather and organize information for program planning (Bertrand et al., 1992). (6) And last but not least FGDs are easily digestible by local decision makers as findings are presented in a narrative form – often with actual quotations (Bertrand et al., 1992). These arguments explain why the FGDs are increasingly advocated in health research such as public experience and understanding of illness (Wong, 2008): In short FGDs may help to express the essential public spirit, to discuss strategies for an improved access to adequate treatment, and to set priorities (Dreher and Dreher, 1991).

Two major aims of this study are to – first – determine the health-seeking behaviour in BU endemic communities as compared to communities with lower endemicity, and – second – to assess any differences regarding the disease perception between previously affected patients and non-affected/ inexperienced community members. In order to achieve valid information on the community's beliefs, values and the understanding of health problems are assessed. The FGDs allow to analysing the care-seeking behaviour of BU affected people and the non-affected population living within high endemic communities as compared to those who live in low endemic communities. This also permits to assess the main barriers or determinants to seek medical care for BU. As a result of this research step the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18) may be evaluated and discussed. For a functional overview of this research step see Table 10.

TABLE 10: Function of FGDs in the Context of the Study

Specific Aims	Expected Results
- To assess care-seeking behaviour in high endemic villages as compared to communities with lower endemicity - To determine differences within the disease perception between BU affected people and the non-affected population	- Specific characteristics of BU affected people living in high endemic communities - Description of differences regarding the perception of BU between affected people and the non-affected population - Evaluation of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II)

Source: Author's own

4.4.2 Planning of the FGDs

The planning and the operational phase of this study required a lot of time and many meetings with different stakeholders. People within the communities needed to be contacted personally (no phone connection). Yet, the principal investigator was familiar with the local structures, had met all previously BU affected people and worked with each of the local CSBVs during previous research activities. The results of the preliminary data analysis (expert Interviews and KAP survey) were essential for this study. A plan and a schedule for this study was presented and discussed with the local authorities (district health manager, NBUCP manager).

4.4.3 Development and Pre-test of the Question Route

The aim of the FGD question route was to provide a framework for the moderator and to increase the questions' comprehensiveness by the participants during the discussion. The set-up of this question route/ guideline was similar to the guidelines for the semi structured interviews – and needed not be followed in detail/ in order. The initial questions were more general than those, which followed at a later stage of the discussion. All questions were open-ended, simple and unbiased (Krueger and Casey, 2009). A preliminary version of the question route was discussed with various people (e.g. a previous BU patient and founder of an NGO), social scientists as well as the NBUCP manager). The questions were modified accordingly.

The final FGD guide included the following topics/ aspects:

1. Sources of Information on BU (*'Health Education and Communication'*)
2. General Perception and Beliefs about BU (*'Severity of the Symptoms'*)
3. Knowledge and Perception of the Mode of Transmission (*'Aetiological Model'*)
4. Preferences, Knowledge & Beliefs about Treatment Options & Therapeutic Itineraries (*'Appeal of Treatment'* and *'Choice of Health Care Resources'*)
5. Stigmatization of BU affected people (*'Stigma/ Social Exclusion'*)
6. Perception about Health Services and Facilities (*'Acceptability and Quality of available Health Services'*)

The detailed question route/ guideline can be looked up in Annex D.

In the next step the question route was translated into the predominant local languages (Twi and Ewe). Both research assistants had knowledge about BU and were familiar with the research setting as they were part of the team to conduct the KAP survey. Pre-test and back translation of the question route was done during the facilitator training (see section 4.4.5).

4.4.4 Selection of Communities and Participants

The total number of FGDs was mediated by four factors: (1) the total number of BU endemic communities, (2) the number of previously BU affected people, (3) saturation of information as well as (4) the available resources (time and financial means). The respective communities (high endemic and lower endemicity) were selected in a purposive way after the active case-search and after preliminary data analysis. A list with the selected communities was presented to the DHMT, which was then further discussed with the local health personnel.

The discussions took place in three communities with high prevalence as well as in three communities with lower prevalence. The first FGD (with previously BU affected people) determined the composition of the second FGD group (with non-affected community members): In order to allow for adequate comparisons between the groups the participants of the latter were selected according to age and sex of the participants of the first FGD group (matched for age and sex) and were selected by the local CSBV. The CSBV was also responsible for inviting the participants with the respective characteristics. Furthermore he suggested an adequate place and time for the discussion, so that the setting was comfortable and convenient for all participants. A caregiver accompanied previously affected people who were younger than 18 years and took the position of the previously affected child within the discussion.

The selection of the communities was mainly influenced by the availability of participants (i.e. the total number of previously affected people within a community) and meant that a small community with less than six patients could not be considered. In turn, this had the advantage that a group of six previously BU affected people might also have occurred naturally (compare with Kitzinger, 1995) as they all came from the same community. This meant that they could relate well to each other's comments and challenge each other within the discussion (compare with Rabiee, 2004).

In total 12 discussions in six different communities (in each community one FGD with previously BU affected and one with non-affected people) were organized. The groups consisted of four to six participants each. The selected participants were invited by the local CSBV, who also made sure that every participant was aware that all other participants have also been affected with BU. This was also important for another reason: the selected and previously BU affected people were deprived members of the community with probable lack of confidence and low self-esteem. This might have prevented the selected people from participating in the group (Rabiee, 2004). The fact that the discussion rounds took place in the respective community avoided transportation challenges between the communities. The discussions were either held within the chief palace, in schools, in a church or other commonly used community meeting places. Background noise within the communities was sometimes unavoidable (i.e. rain during rainy season, music from neighbours, animal sounds).

Each CSBV received a small amount of money for each participant he had invited. The participants received a *'mineral'* (soft-drink), biscuits, a BU picture card (see Appendix D) and a group picture as incentives for their commitment and endeavours.

4.4.5 Facilitator Training

FGD moderators/ facilitators are the discussion leaders who are not only responsible for guiding the participants through the discussion, but also for monitoring the group and ensuring the group members' participation (Krueger and Casey, 2009, Wong, 2008). A skilful moderator should create an environment where the participants feel relaxed and encouraged to exchange their experiences and views. Two teachers from a local school were selected for this position. Both of them had gained some experience with BU and were introduced to the study design at an early stage. The principal moderator had to make sure that the questions were phrased in a locally understandable way. For this reason both moderators were made responsible for the back translation of the question route. In addition to that the moderators conducted a pre-test among their other teacher colleagues. This allowed them to familiarize themselves with the questions as well as to explore and anticipate the local perceptions of the questions. This process was also valuable for a final discussion and revision of the respective questions. Additionally they received an intensive and comprehensive introduction into the topic of BU, a specific moderator training as well as a concrete introduction to the question route and the respective procedures through the principal investigator. Additionally a short introductory text about moderator skills (see Appendix D) was provided and discussed before the FGDs. For the purpose of a memory hook a keyword was identified for each question.

4.4.6 Informed Consent and Ethical Considerations

Before the start of each discussion the moderator first welcomed and introduced all participants to the research team and the aim of the study. It was explained to the participants that their participation was a voluntary activity, and that they were free to leave even after the discussion began. In case they agreed they were requested to sign the written consent form or to give a thumbprint to prove their agreement respectively (see Annex D). Additionally a witness (the local CSBV) signed that the interviewee participated upon free and voluntary conditions. All discussions were conducted in a manner intended to be as comfortable for all participants as possible, so they were able to speak honestly and openly.

The proposal of this study was reviewed and approved by Noguchi IRB and GHS respectively (compare with survey). A short questionnaire inquiring basic socio-demographic data was administered before the start of the discussion (see Annex D).

4.4.7 Schedule of the Discussion, Documentation and Data Processing

After the welcome and the introduction of the research topic the objective of the discussion, the ground rules and the fact that the session was recorded with an audio-recorder were mentioned. It was emphasized conveyed that each contribution was valuable and that every statement would remain confidential and anonymous (Wong, 2008, Krueger and Casey, 2009). All discussions were held either in Twi or in Ewe and took 30 to 60 minutes. The principal investigator herself did not take part in the discussion but served as note-taker and drew a sketch of the seating arrangements (see Figure 15) with the respective names/ numbers of the participants and documented the order of the speakers to ensure that each contribution could be matched correctly to the respective participant. In doing so helpful information could be provided to the person responsible for translation/ transcription (compare with Wong, 2008).

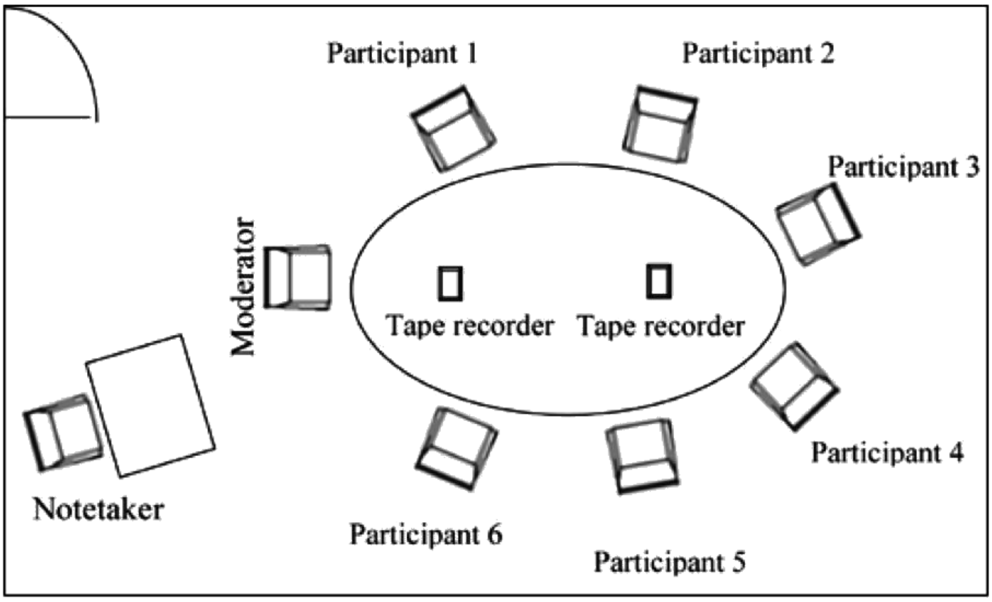

FIGURE 15: Example Sketch of Seating Arrangement for a FGD
Source: Wong, 2008

The twelve discussion rounds in six different communities took place between June and July 2011. Two FGDs each (in six different villages) were conducted in Twi and Ewe. After the discussions the content was directly translated into English. Although this shortcut might have resulted in a slight loss of information the disadvantage was far outweighed by an easier and faster and cheaper processing of the information (compare with Bertrand et al., 1992). The detailedness and the choice of the adequate transcription guideline (see Appendix D) were adjusted to the research question: This means that the discussions were fully and literally transcribed so that core texts were available for the analysis. The focus of the transcription was the content and what the interviewees reported rather than the modality of the discussion. Breaks (e.g. through rain), irregularities and accentuations are not indicated in the transcript.

In order to ensure a consistent quality of the data the transcription was done in three steps: in the first step a research assistant transcribed the interviews according to the chosen transcription guideline. The resulting material was then checked for general understanding and spelling mistakes by the principal investigator; unique information was also made anonymous in this step. No information allowing for the identification of the participants was kept in the notes or transcripts. All names were deleted if used in the discussion. In the last step the transcripts were crosschecked and edited by two research assistants who had already revised the transcripts of the expert interviews and had already research experience within this area.

4.4.8 Data Analysis and Interpretation

Analysing the transcripts of focus groups is similar to analysing any other qualitative data: large amounts of data need to be reduced to a manageable size. Same as for the analysis of the expert interviews the purpose should drive the analysis and start by going back to the intention of the research (Krueger and Casey, 2009). While trying to focus on the essential parts of the data it was useful to keep in mind that the process of qualitative research aims at bringing meaning to a situation rather than searching for the truth (Rabiee, 2004): The analysis may rather be described as an interplay between the researcher and the data (Strauss and Corbin, 1998). Most important is that the analysis of the data is systematic, sequential, verifiable and continuous (Krueger and Casey, 2009), so that the findings provide an consistent and conform overview about the topic and allows other researchers to verify this respectively (Rabiee, 2004).

The process of analysis of the FGD transcripts resembled the analysis of the expert interviews (for a detailed description see chapter 4.2.4) and the aspects of the *‘Modified BU specific Framework for Health-Seeking Behaviour’* (version II) (see Figure 18) served as codes for the deductive analysis. The distinct feature of the analysis of focus group data is the need to indicate the impact of the group dynamic and to analyse the sessions in a way that take advantage of the interaction between the participants (Kitzinger, 1995). As a result of this final research step the *‘Modified BU specific Framework for Health-Seeking Behaviour’* (version II) may be evaluated.

5. Results

This chapter displays the results of all applied research methods: (1) the systematic literature search, (2) the expert interviews with 33 people who were either confronted with BU in a professional context or due to their own infection/ infection of a family member, (3) the KAP survey, which was conducted after an active community case search in the study area as well as (4) the FGDs, which were organized in six selected communities within the study area.

5.1 Results – Systematic Literature Search

The following section describes the results of the systematic literature search along with the structure of the *'Adapted BU specific Framework for Health-Seeking Behaviour'* as adapted from Kroeger's Framework (version I, see Figure 17) (Kroeger's framework (Figure 6) was used as a starting point).

5.1.1 Search Results, Description of included Studies and Adaptation of Kroeger's Framework

The systematic literature search retrieved 263 publications; after removal of 1 duplicate, 262 publications were screened for relevance in title and abstract. Of these, 239 publications were not relevant for this review (being editorials, letters or texts that did not include any empirical findings). The remaining 23 publications seemed potentially relevant in the title and abstract screening and were appraised in full text. Finally, the systematic screening identified 18 relevant publications (see Figure 16). Four additional publications were included after manual searches in reference lists, the internet, the library at School of Public Health (University of Ghana), as well as the *'Buruli-Beat'*-newsletter[24]. In total 22 publications were included.

The identified studies investigated the health-seeking behaviour of study participants in BU endemic regions in Africa. Nine studies used mixed-methods to elicit the behaviour, seven used qualitative methods, three other quantitative methods; three employed other methods (clinical, observational and retrospective studies). Some studies included only BU affected people while others involved both affected and non-affected. This review may therefore hardly differentiate between the two study groups.

Relevant aspects in the BU specific literature were analysed by using qualitative content analysis. The variables of Kroeger's framework (see chapter 2.2) served as a starting point to analyse this information. Most of the retrieved material could be subsumed under the categories as established by Kroeger. Aspects, which should be considered as influencing factors but could not be subsumed under the original framework (see Figure 6), were put into new categories as introduced by the principal investigator (inductive inclusion). The respective categories of health-seeking behaviour for BU are summarized below, and the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I) is displayed in Figure 17. A detailed overview on the included publications and the coverage of the different aspects of the framework is displayed in Annex A. A table with the detailed matching of the findings upon the framework aspects is included in Appendix A.

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[24] Buruli-Beat-Newsletter: http://www.stopburuli.org/index.php/de/buruli-beat.html

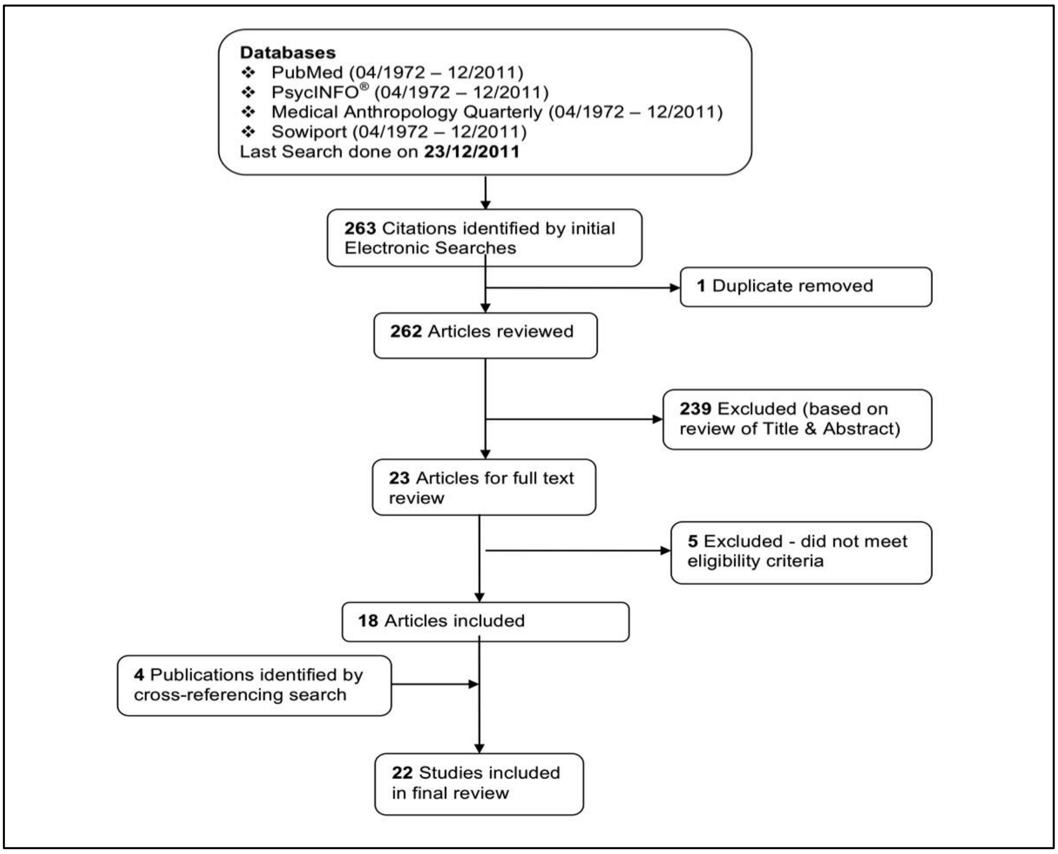

FIGURE 16: Search Strategy
Source: Author’s own

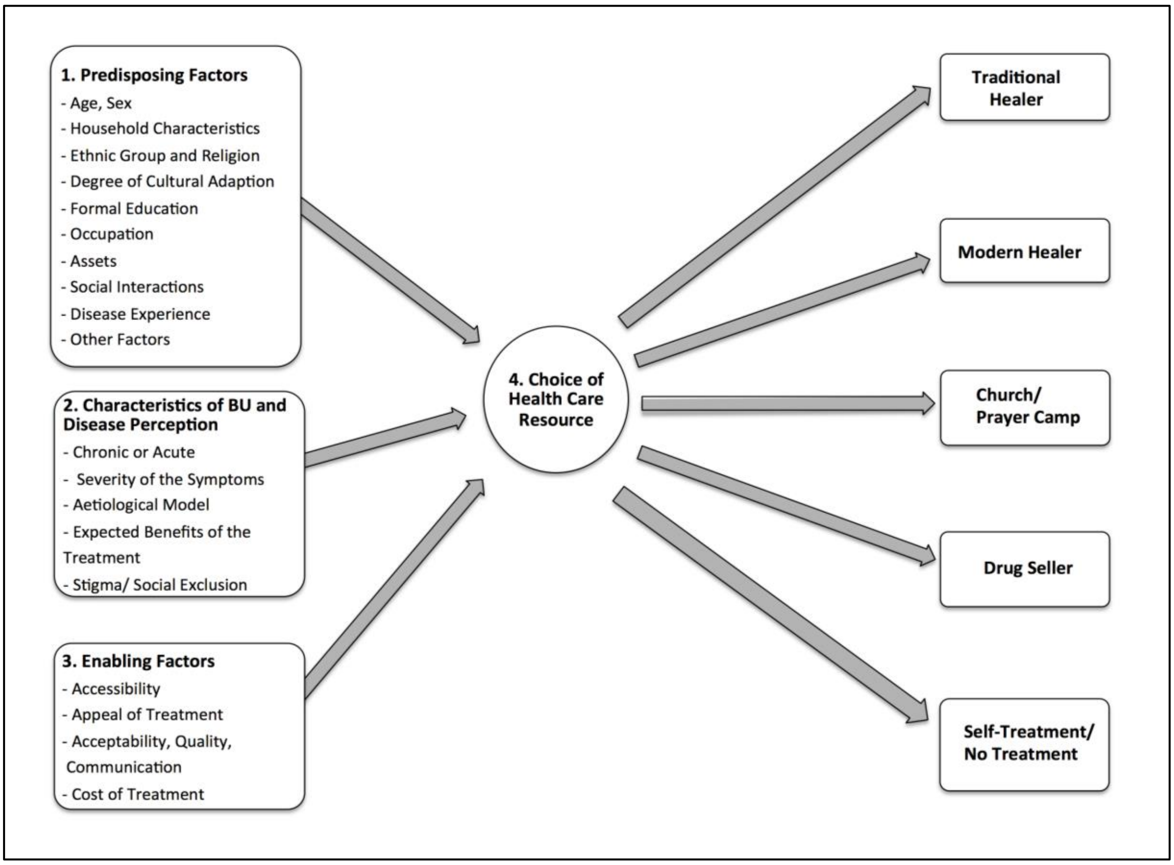

FIGURE 17: Adapted BU Specific Framework for Health-Seeking Behaviour (Version I)
Source: Author’s own

5.1.2 Predisposing Factors

‘Predisposing Factors’ such as *‘Age, Sex’*, *‘Household Characteristics’*, *‘Ethnic Group/ Religion’*, *‘Degree of Cultural Adaptation’*, *‘Formal Education’*, *‘Occupation’*, *‘Assets’*, *‘Social Interactions’*, *‘Disease Experience’* as well as *‘Other Factors’* were assessed in 18 studies (see Table 12, Annex A).

Age, Sex

Age and sex-specific information about BU affected people was described in nine of the included publications: About 50% of the BU affected people in Africa are younger than 15 years (Adamba and Owusu, 2011, Asiedu and Etuaful, 1998) and do not fall into the productive age group (15-59 years) (Agbenorku et al., 2011). No clear sex specific disease pattern may be observed for BU (Ackumey et al., 2011a, Asiedu and Etuaful, 1998).

Ethnic Group and Religion

Information about ethnic backgrounds and religion of BU affected people were assessed in six publications: According to them the different ethnic groups have their own local disease names for BU (Kibadi et al., 2007): It was found that these local representations may be influenced by (1) the geographical origin of the disease, (2) the specific features of the lesion as well as (3) aspects of incurability.

The influence of religious aspects was assessed in a study in Benin: Animists and Catholics were found to rely more on traditional treatment than Protestant Christians (Johnson et al., 2004). A survey in Ga West district (Ghana) showed that Muslims were more likely to consider BU as a sign of being plagued with evil forces than other religious groups (Renzaho et al., 2007), which may prevent them from seeking medical care.

Social Interactions

The relevance of *‘Social Interactions’* for the health-seeking process was mentioned in six of the included publications: Interactions with relatives and neighbours play an important role in labelling the symptoms of BU (Kibadi et al., 2009) or in conferring the type of treatment (Ackumey et al., 2011a). People with disease specific experience (previously BU affected) are regarded to be a reliable source of information regarding BU and may therefore influence the referral for treatment or the choice of a specific treatment option (Phanzu et al., 2006, Aujoulat et al., 2003). These interactions may either promote or hinder seeking medical assistance (depending on the previous disease experience of the person who provides this information). Further stakeholders for the referral of patients are *‘community based surveillance volunteers’* (CSBVs) (Agbenorku et al., 2011, Ackumey et al., 2011a), municipal health staff as well as community health/ outreach programs (Ackumey et al., 2011a, Phanzu et al., 2006, Agbenorku and Kporku, 2001).

Disease Experience

Kroeger’s framework aspect *‘Innovators’*, which was supposed to cover information about individuals, who choose new alternatives first (Kroeger, 1983), was renamed and defined as *‘Disease Experience’.* Four publications included information about previously BU affected people’s respective experience. A study conducted in Ghana found that previously affected adults were found to fall back on their prior disease experience to make their choice for help (Ackumey et al., 2011a). In that study it was reported that 62% of the patients with pre-ulcers and 63% of the patients with ulcers made their decisions about the treatment provider on their own (Ackumey et al., 2011a).

5.1.3 Characteristics of BU and Disease Perception

'Characteristics of BU and Disease Perception' – namely the framework aspects *'Severity of the Symptoms'*, *'Aetiological Model'*, *'Expected Benefits of the Treatment'*, *'Stigma/ Social Exclusion'* – were assessed in 20 studies within Africa (see Table 13, Annex A).

Severity of the Symptoms

Information about the perceived severity of BU related symptoms were found in twelve publications: It was reported that the widespread prevalence of the early symptoms in a rural environment irrespective of the real cause is one of the major challenges of the disease (Kibadi et al., 2009). Pre-ulcerative lesions are non-specific and may be confounded with other swellings such as insect bites or abscesses (Kibadi et al., 2009). Especially BU plaques and oedemas, which are less common than nodules, are difficult to identify by the local people (Ackumey et al., 2011a) so that they may not be aware of their BU infection. Nodules often resemble ordinary *'boils'*, which would burst in time (Ackumey et al., 2011a). In Ghana, people having *'boils'* rarely report to a governmental health facility (Stienstra et al., 2002). Another challenge is that nodules are mostly painless so that BU affected people do not anticipate an immediate health concern (Ackumey et al., 2011a).

As a result early symptoms of BU tend to be dismissed and perceived as trivial (Ackumey et al., 2011a, Kibadi et al., 2009). Perceived seriousness of BU increases as ulceration persists, increases in size or results in complications such as pain, fever, and disability (Kibadi et al., 2009). It is not before this stage of the disease when the majority of the affected people decide to go to the hospital; the lesion/ ulcer is already in an advanced stage and size (Stienstra et al., 2002). A commonly observed pattern is that BU affected people are more inclined to seek medical care for ulcers than for pre-ulcers (Ackumey et al., 2011a, Agbenorku et al., 2011, Stienstra et al., 2002, Mulder et al., 2008, Renzaho et al., 2007, Phanzu et al., 2006). More than 90% of the BU affected people who report to the hospital have already extensive ulcers (Agbenorku et al., 2011, Phanzu et al., 2006) or even suffer from BU related disabilities (25%) (Phanzu et al., 2006). An assessment among formerly BU affected people revealed that 57% had a functional limitation after a median period of almost four years (Stienstra et al., 2005).

Aetiological Model

A major problem for the prevention and control of BU is the fact that the mode of transmission for BU is not yet known (see chapter 2). This was also reflected in the analysed research literature: 13 publications assessed local explanations for the cause of BU: Both natural and supernatural explanations may be encountered in BU endemic areas. The literature points out that the unclear mode of transmission and aetiology as perceived by the people may partially explain the *'Therapeutic Itineraries'* of the patients (Kibadi et al., 2009, Mulder et al., 2008, Renzaho et al., 2007, Aujoulat et al., 2003). About 20% of the people in the studied areas do not have any idea/ explanation for the cause of the disease (Larbor, 2010, Renzaho et al., 2007, Aujoulat et al., 2003).

The most important natural explanation for BU according to the literature is the people's attribution to a lack of personal hygiene or dirty surroundings (8-59% (Larbor, 2010, Renzaho et al., 2007, Stienstra et al., 2002, Ackumey, 2002)). The perception that BU is contagious (contraction trough contact with a patient) is considered to be an important aspect and can be found in almost every study, yet it is not among the most important ones (19-31% (Larbor, 2010, Renzaho et al., 2007, Aujoulat et al., 2003, Ackumey, 2002, Stienstra et al., 2002, Guédénom et al., 1995)). Other frequently mentioned factors are the consumption of unsafe drinking water (18-31% (Larbor, 2010, Renzaho et al., 2007, Stienstra et al., 2002)), an increased risk during the rainy season by rainwater (17% (Renzaho et al., 2007)), sexual transmission (13% (Stienstra et al., 2002)) or swimming/ wading in rivers/ ponds (6-28% (Larbor, 2010, Renzaho et al., 2007)). Some BU affected people also believe that they contracted the disease through small scratches, bruises or swellings sustained through work-related activities or play (Ackumey et al., 2011a). Rarely encountered explanations for an infection with BU are insect bites/ snakebites, relapses of a tropical ulcer and contact with contaminated soil (Stienstra et al., 2002). In some endemic communities the people mention preventive measures such as provision of potable water (41%) and avoidance of swimming in the river (13%) (Renzaho et al., 2007)).

Most commonly mentioned supernatural causes are witchcraft and curse (5-59% (Larbor, 2010, Mulder et al., 2008, Renzaho et al., 2007, Aujoulat et al., 2003, Stienstra et al., 2002, Ackumey, 2002)). The interviewees perceive that they are bewitched because they are admitted in hospital for a long time, their lesion is severe, the drug treatment is not effective or they have family conflicts and believe that witch exists within their family (Stienstra et al., 2002). Further encountered causes were *'God's will'*, or *'evil eye'* (in Ghana) (Stienstra et al., 2002) or *'God'*, *'another person/ sorcery'* (Aujoulat et al., 2003) and *'theft in a garden protected by a fetish'* (in Benin) (Guédénom et al., 1995). In the Democratic Republic of the Congo BU was explained to be caused by *'malediction and punishment'* or *'bad origin'* (Kapay, 2004). As a consequence BU affected people who tend to have supernatural explanations are more likely to use self-treatment or traditional/ spiritual treatment options and report late for medical treatment (Kibadi, 2007).

Expected Benefits of Treatment

Information about the expected benefits of BU treatment was encountered in eight of the included publications. The most important benefit of medical BU treatment according to the literature is *"cleaning of the wound"* and *"fast or effective healing"* (Ackumey et al., 2011a). The patients expected a treatment to avoid surgery and hence preferred traditional herbal treatment (Kibadi, 2007). As opposed to so called school medicine approaches, herbal dressings are supposed to expose and remove necrotic tissue in pre-ulcerative lesions and to heal ulcers (Ackumey et al., 2011a, Johnson et al., 2004). The anticipated advantages of this treatment method are that the patient may stay within his/ her natural environment, the treatment is not invasive, will leave only a small scar and does not require hospitalization (Stienstra et al., 2002).

Stigma/ Social Exclusion

The aspect of *'Stigma/ Social Exclusion'* was not yet part of Kroeger's framework (1983). Due to the fact that this phenomenon plays an important role in the health-seeking behaviour of BU affected people the aspect *'Stigma/ Social Exclusion'* was newly introduced into the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (see Figure 17): Six publications covered this aspect, so that it was necessary to modify the original framework and introduce this aspect into the framework (inductive approach). Five major aspects such as (1) physical consequences of BU, (2) unpleasant features of the lesions, (3) behaviour of non-affected people towards the affected ones (4) prejudices of the non-affected population as well as (5) disease associated feelings and reactions were identified through the inductive analysis of the interview material.

BU may have physical consequences such as extensive ulcers, unpleasant smell, disabilities visible scars and/ or deformities, which may reveal people as being affected by the disease (Aujoulat et al., 2003, Stienstra et al., 2002). These features may cause social exclusion of BU affected people (Aujoulat et al., 2003, Stienstra et al., 2002): *"The stench from the wound* *is so strong that it is very difficult for relatives and spouses to get close to the patients"* (Renzaho et al., 2007). Depending on the size and location of scars and lesions the BU affected person may feel ashamed and try to hide these scars (Aujoulat et al., 2003, Stienstra et al., 2002). An ulcer on a visible part of the body may be more stigmatizing than an ulcer on a hidden or less sensitive place (Stienstra et al., 2002).

Overall, the people in endemic communities seem to accept their BU affected neighbours (Renzaho et al., 2007): In Ga West it was found that the majority of the interviewees would interact with BU affected people themselves, welcome them in their households, allow their children to play or interact with BU affected people, and accept them as a teacher (Renzaho et al., 2007). But the feelings of shame and/ or embarrassment amongst BU affected people may not be unfounded: A study in Ghana found that 62% of the interviewed BU affected people experienced a negative change in attitude (e.g. gossip, being avoided, loss of respect, job loss etc.) towards them (Adamba and Owusu, 2011). Non-affected people may be afraid of social exclusion as a result of the financial burden of the disease (Stienstra et al., 2002). In Cameroon BU affected households try to avoid impoverishment by socially excluding their affected household member (Grietens et al., 2008).

An important factor for avoiding a BU affected person is the fear of getting infected (Stienstra et al., 2002). Due to this misperception BU affected people were sometimes not accepted or hindered in functioning as a leader (Renzaho et al., 2007, Stienstra et al., 2002). Another argument was the fact that leaders should display an undamaged and ideal performance (Stienstra et al., 2002). Sometimes the stigmatization even goes so far as to directly impact on the patient‘s closest relationships. Sexual performance was perceived to be limited due to BU (Stienstra et al., 2002). Some patients even stated that they encountered problems of getting married, of continuing their marriage (Stienstra et al., 2002) or of getting divorced due to the partner's fear of getting infected (Stienstra et al., 2002).

Several studies found that BU affected people experience stigma, shame, embarrassment, suffer from a low self-esteem and avoid to attend public meetings or even try to hide themselves or their disease from others (Adamba and Owusu, 2011, Stienstra et al., 2002). Other adopted strategies to cope with the stigma are praying or ignoring how others behave towards them (Adamba and Owusu, 2011). But not all BU affected people seem to hide themselves and their disease: Some prefer that their community members are aware that they are affected by BU. Help seeking was considered to be one of the reasons for this behaviour (Stienstra et al., 2002). The fact that some BU patients leave their community for a longer time due to stigmatisation may reduce the ability to mobilize communal labour[25] within the home community (Adamba and Owusu, 2011) (compare with *'Costs'*).

5.1.4 Enabling Factors (Health Service Characteristics)

'Health Service Characteristics' such as the aspects *'Accessibility'*, *'Appeal of Treatment'*, *'Acceptability, Quality, Communication'* as well as *'Costs'* were assessed in 19 studies (see Table 14, Annex A).

Accessibility

The aspect of *'Accessibility'* of health facilities was assessed in ten publications: BU affected people usually reside in remote communities with limited road access and transportation (Agbenorku et al., 2011) so that the distance between care provider and the patients'

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[25] Communal labour is periodic work, which is carried out by the communities to assist individuals in carrying out specific tasks (e.g. land clearing, harvest or construction work).

residences are commonly perceived as obstacles to early reporting (Ackumey et al., 2011a, Renzaho et al., 2007, Aujoulat et al., 2003, Mulder et al., 2008, Agbenorku and Kporku, 2001). However the significance of this factor could not be identified satisfactorily yet: Assessments in Benin revealed that participants who mentioned distance to the health centre or the costs for transportation as an obstacle to reporting did not have a longer patient delay than others who were living close by (Kibadi et al., 2009, Mulder et al., 2008). Distance also poses a selective factor with regard to the choice between traditional treatment and treatment in hospital: In case traditional treatment is offered in the vicinity of the patient the person seems very likely to prefer traditional treatment over going to the hospital (Ackumey et al., 2011a, Mulder et al., 2008, Grietens et al., 2008).

Appeal – Opinions and Attitudes towards the Treatment

Information about the *'Appeal of Treatment'* was found in 16 of the included publications: Here it was found that opinions and attitudes towards the kind of treatment might vary significantly. Although many people see the advantages of medical treatment many still associate it with various negative aspects: Qualitative interviews in Ga West district (Ghana) have shown that medical treatment was valued for the fact that it cleaned the sore (Ackumey et al., 2011a). A study conducted in the Democratic Republic of the Congo found that the therapy with Streptomycin and Rifampicin was perceived as acceptable, but the knowledge about effects of Streptomycin appeared to be rather poor (Kibadi, 2007).

Yet perceived obstacles to medical treatment exist, with the major one being the duration of admission – interviewees mentioned a range between 45 and 645 days (Ackumey et al., 2011a, Mulder et al., 2008, Grietens et al., 2008, Renzaho et al., 2007, Phanzu et al., 2006, Johnson et al., 2004, Asiedu and Etuaful, 1998, Ackumey, 2002). Further obstacles to medical treatment are fear of diagnosis and the treatment itself. The diagnosis is often associated with social consequences/ isolation such as loss of work, divorce, and abandonment or scarring (Grietens et al., 2008, Johnson et al., 2004). The treatment itself is associated with the fear of injections or the fear of amputation (Mulder et al., 2008, Stienstra et al., 2002) as well as other constraints involved in surgical treatment (Johnson et al., 2004) and its outcome. The avoidance of surgery and an all-oral treatment is preferable (Kibadi, 2007).

Traditional treatment still resembles a significant alternative to medical treatment: Especially in the early stages of the disease many BU affected people apparently prefer traditional herbal treatment (Ackumey et al., 2011a). Perceived advantages of traditional treatment are a quick treatment, that witches' attacks are taken into account, that children may be admitted at the healer's site and that agricultural work can be pursued due to the short distances between the BU affected person's and the healer's residence (Adamba and Owusu, 2011)). It was also stated that the treatment is supposed to be "free" of charge (Kibadi et al., 2009) (compare with section about *'Treatment Costs'*). Some herbalists have the reputation to have successfully treated BU (Ackumey et al., 2011a, Guédénom et al., 1995). In case the traditional herbal treatment alone does not lead to the anticipated healing of the lesion some people use a combination of traditional herbal and western (medical) treatment (Ackumey, 2002).

Acceptability, Quality, Communication

The aspect *'Acceptability, Quality and Communication'* of BU treatment were assessed in 14 of the included publications. It does not come as a surprise that the severity of the disease affects the duration of the treatment: As a consequence BU affected people reporting for treatment with nodules may lose 78 days, while a patient with an ulcer may lose 301 days of productive work time (Adamba and Owusu, 2011) – or even more, which has also a great impact on the costs of BU treatment (see also section *'Costs'*).

In one study, the quality of the health services was assessed as being quite bad. An overall *"poor functioning"* of health services as well as a lack of skilled health personnel within the health system were mentioned (Kibadi et al., 2009), which may impede the diagnosis and laboratory confirmation (Ackumey et al., 2011a, Asiedu and Etuaful, 1998) and lead to affected people's help-seeking outside the health system (Kibadi et al., 2009). Some of the diagnosis related challenges might be triggered by limited resources at the hospital (Asiedu and Etuaful, 1998), difficulties with obtaining primary cultures or samples/ as well as logistics. This leads to low percentages of confirmed cases (e.g. only 70% of suspected patients in a study in the DRC were confirmed) (Phanzu et al., 2006). Other aspects are delay and waiting lists at the hospital (Renzaho et al., 2007) which are not in favour of the patients.

People in BU endemic communities most commonly hear about the disease from peers, community leaders and health workers, or through the radio (Agbenorku and Kporku, 2001). Another access to information about BU is the commonly practiced method of awareness raising by NGOs, who present a BU documentary (night show) in endemic communities (Kibadi, Boelaert et al. 2009).

Costs

Information about the cost aspect of BU treatment were found in eleven of the included publications: Costs may incur both directly (i.e. expenditures during the course of the treatment) and indirectly (i.e. loss of productivity) and pose major obstacles to the treatment of the disease (Aujoulat et al., 2003). Yet detailed data on this factor is fairly limited, and most of the published literature deals with treatment costs for hospitalized BU patients, which involves surgical treatment. The total costs of hospital treatment for BU in Cameroon in 2006 calculated a median of 126.7€ (US$167.2) per patient (Grietens et al., 2008). One of the first studies on health-seeking behaviour for BU conducted in Ghana reported that 30% of the patients reported late due to financial difficulties (family had to gather money before reporting) (Stienstra et al., 2002).

In 2005 antibiotic treatment for BU (Streptomycin and Rifampicin) was introduced, which may avoid surgical interventions. In addition to that the respective drugs are supposed to be provided free of charge (Adamba and Owusu, 2011, Grietens et al., 2008). Until now no study has assessed the cost burden for BU patients receiving antibiotic treatment only.

Direct Costs of 'Modern Treatment'

Grietens et al. (2008) showed that among hospitalized BU patients in Cameroon the median cost burden of BU amounted to 25% of a household's annual earnings (31% direct costs, 69% indirect costs) (Grietens et al., 2008). In that study direct costs were defined as the expenditures incurred by the patient or the household during the course of the treatment. Direct costs included transportation costs (transportation for patient and caretaker(s) and other household members), irregular medical expenses and hygiene costs (e.g. bleach and soap to wash bandages and clothes), irregular expenses for extra medication (e.g. pain killer), feeding costs, as well as miscellaneous costs (e.g. extra rent in the vicinity of the hospital, extra phone calls, gifts etc.). The study reported direct costs of an equivalent of some 59 €/ patient (equals US$ 78) (Grietens et al., 2008). Travel costs of the patient to the hospital and the cost of visiting the patient by friends and relatives (29% of median direct costs) were commonly mentioned as financial obstacles (compare with *'Accessibility'*) (Grietens et al., 2008).

Indirect Costs

The loss of productivity are probably the major obstacle to the treatment of a BU affected person (Renzaho et al., 2007). Not only does the patient's loss of both time (Agbenorku and Kporku, 2001) and productivity play a role but also the productivity of the caregiver: If the patient is a child, a caregiver may have to stay along to provide basic needs for the patient. The fact that some caregivers have other social obligations (i.e. other children) may render further challenges to the caregiver (Grietens et al., 2008, Asiedu and Etuaful, 1998). A study conducted in Ghana found that caregivers lost on average four days of a week for taking care of the patient at the hospital (Adamba and Owusu, 2011). The median of lost earnings during a patient's care for an adult in Cameroon accounted for an equivalent of some 220 € (US$ 291) (Grietens et al., 2008). Another aspect is that BU patients often stop schooling (88% in Cameroon) or abandon school (22% in Cameroon) due to their disease (Grietens et al., 2008). This effect may lead to a lower educational status of the people and may therefore have an impact on the people's income in later life.

Coping with Treatment Costs

According to the assessed literature the commonly used strategies to cope with BU are the reduction of expenses for non-essentials and essentials, making claims from their social networks, supply of provisions from family members, borrowing, informal employment of the caregiver, use of savings, informal employment of the patient and the sale of assets (Adamba and Owusu, 2011, Grietens et al., 2008). Coping with loss of labour was associated with family support, reduction of farm size or hiring labour (Adamba and Owusu, 2011). In a study in Cameroon 63% of households socially isolated their hospitalized members to avoid expenses. This behaviour was triggered by the fact that treatment costs for hospitalized patients who received regular care and attendance from their family members were reported to be 8.6 times higher than for isolated patients who did not receive any attendance from their household or family members (an equivalent of some 106 € vs. 12 € (US$ 140 vs. US$16). According to Grietens et al. (2008) the fear of social isolation is one major reason for postponing or avoiding hospital treatment and for the preference of traditional herbal treatment (Grietens et al., 2008).

Costs of Traditional Treatment

Contrary to frequent expectations by people in endemic communities that traditional treatment is free of charge (compare with section *'Appeal of Treatment'*) two studies in Benin showed that the costs for traditional treatment were quite high (for the entire course an equivalent of some 18 – 91 €, US$ 24 –120) (2004) (Johnson et al., 2004) and US$ 11, 9 € (1992) respectively (Guédénom et al., 1995). Payment may not only made in currency but also in alternative ways such as livestock or land (Johnson et al., 2004). A possible explanation for the local perception that traditional treatment is cheaper than medical treatment may be cases where a relative or a friend is a herbalist who provides the services free of charge (Ackumey et al., 2011a). Furthermore, traditional treatment is mostly not associated with additional feeding costs or loss of productivity (Ackumey et al., 2011a, Grietens et al., 2008).

5.1.5 Choice of Health Care Resource

12 different publications described the choice of the different available health care resources (*'Self Treatment/ No Treatment'*, *'Drug Seller'*, *'Traditional Treatment'*, *'Modern Healer'* and the *'Church'*) (see Table 15, Annex A).

Choice of Treatment Option

Seven publications assessed the choice of the health care resources by BU affected people: Mulder et al. (2008) identified three stages of health-seeking behaviour: (1) self-medication, (2) failure of self-medication and (3) reconsideration of the health-seeking factors (Mulder et al., 2008). After failure of self-medication traditional treatment is most relevant in the early stages of BU: 40 to 75% of BU affected people use traditional treatment before they present to the hospital (Ackumey et al., 2011a, Mulder et al., 2008, Renzaho et al., 2007, Ackumey, 2002, Stienstra et al., 2002). After failure of herbal/ traditional treatment there is a tendency amongst the affected people to go to the local doctor or to seek help from the hospital (Mulder et al., 2008, Renzaho et al., 2007, Stienstra et al., 2002). The median delay for BU affected people to present at the hospital in order to receive treatment (regardless of the stage) varied between 60 days and 6 months (Kibadi et al., 2009, Mulder et al., 2008, Phanzu et al., 2006). It should not go unmentioned that BU affected people who report to the health centre may go to a traditional healer or practice self-medication at the same time (Ackumey et al., 2011a, Kibadi et al., 2009, Ackumey, 2002).

As opposed to the above-mentioned findings late reporting by BU affected people could not only be observed for medical treatment but also for traditional treatment options in a study conducted in Benin (Johnson et al., 2004). To sum it up the concurrent or serial use of different healing systems may be observed – especially if no success can be observed for one single treatment option (Ackumey, 2002).

Traditional Healer (Herbalist, Spiritualist etc.)

Nine of the included publications included information about traditional treatment practices. Here it was emphasized that the treatment is supposed to be provided by a *'gifted person'* (Guédénom et al., 1995). Traditional BU treatment involves poultices or cataplasms of herbs or leaves that are stuck on the wound. Another mentioned method is the treatment of the wounds with salted water or palm oil. After usage the leftovers of cataplasms and daily bandages are deposited ceremonially in a specially prepared deep hole in the ground (Guédénom et al., 1995) (compare with Johnson et al., 2004). Sometimes traditional therapy is also associated with food taboos (i.e. pork meat is not allowed (Guédénom et al., 1995)). In some African countries (e.g. Democratic Republic of Congo) people buy fetishes from witch doctors and use it to cure the disease (Kibadi et al., 2007).

The efficacy of traditional treatment was described in one single case study (one healer in Benin): It was reported that the healer treated more than 50 patients effectively (no failures or relapses reported). According to this study traditional methods may be effective and can lead to satisfactory results but debilitating contractures may not be avoided (Guédénom et al., 1995). Yet other authors mention that traditional treatment presents a number of risks (Johnson et al., 2004) and caution against the use of herbs to expose necrotic tissue, which may lead to co-infections (Ackumey et al., 2011a).

Modern Healer

Only one of the included publications included concrete descriptions about the treatment practices in governmental health facilities (clinics, community-based health planning services (CHPS)-compounds, health posts and hospitals), which are supposed to provide the WHO-recommended antibiotic therapy. In that publication it was also mentioned that private health practitioners seem to be a further relevant health provider for BU affected people: In Ga West (Ghana) 27% of the respondents with ulcers and 12% of the respondents with pre-ulcers used these services for pain relief or to receive injections (e.g. tetanus vaccine or unspecified injections to *“stop the spread of the disease”*) (Ackumey et al., 2011a).

Self-Treatment/ No Treatment

Five publications included information about the aspect *‘Self-Treatment/ No Treatment’*. The findings are that about half of the BU affected people do not use any treatment or make use of home remedies to treat their lesion (pre-ulcers) (Stienstra et al., 2002, Ackumey et al., 2011a). Common reported practices are the use of non-specific antibiotics, anti-inflammatory and topical antiseptics (Ackumey et al., 2011a, Kibadi et al., 2009), analgesics (Ackumey et al., 2011a), hot water/ bandages (Stienstra et al., 2002), blood tonics (Ackumey et al., 2011a), as well as traditional methods such as herbal dressings and the intake of herbal concoctions (Ackumey et al., 2011a, see also MULDER et al. 2008). Most drugs may be purchased on street markets or from patent medicine dealers (without prescription) (Ackumey et al., 2011a, Kibadi et al., 2009).

Church

Two of the included publications included information about the role of the church (Kibadi et al., 2009) or prayer camps (Ackumey et al., 2011a) for the health-seeking behaviour of BU affected people so that this aspect was added to the framework: It was found that BU affected people choose these institutions to seek relief as they believe that this practice should reveal the cause of the disease or *“stash the lesion away”*. This option may be taken by both patients and family members at the same time (Kibadi et al., 2009).

5.2 Results – Expert Interviews

The aim of the interviews among 33 BU experts was to explore the local disease perception, the respective treatment practices in the given circumstances as well as to modify the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I, see Figure 17) accordingly. The interview material was analysed by using quantitative content analysis (see chapter 4.2.4) and the categories of the framework were used as codes for this process. In case the answers of the experts led to conflicts with the adapted framework the necessary changes in the respective categories were done and led to the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 18). Some of the variables of the precedent framework were differentiated (e.g. *'Acceptability, Quality, Communication'*) or their chronology was changed (e.g. *'No Treatment'* etc.). These changes are described accordingly together with the following results. This version of the framework represents the final disease and setting specific framework which accounts for local and cultural characteristics.

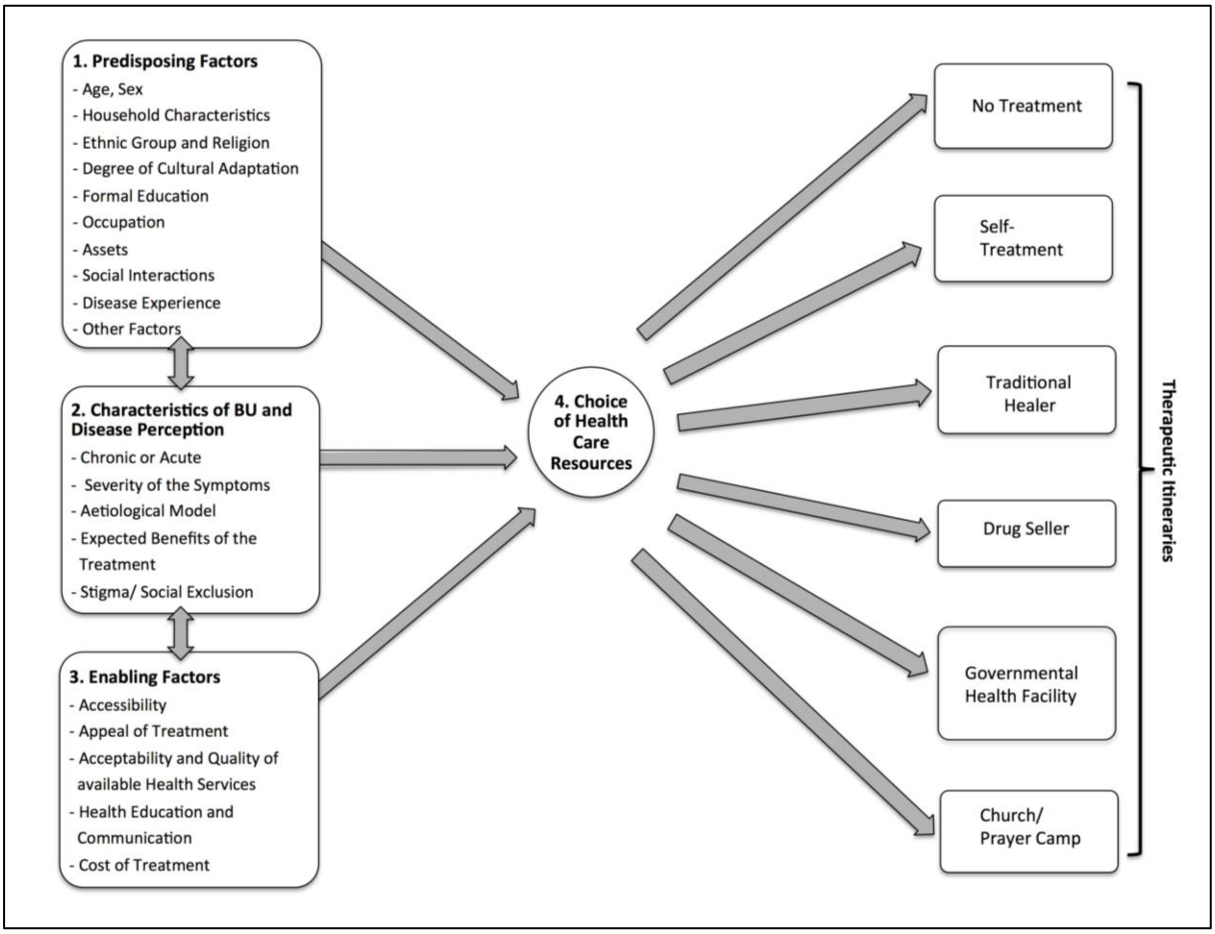

FIGURE 18: Modified BU specific Framework for Health-Seeking Behaviour (Version II)
Source: Author's own

5.2.1 Predisposing Factors (Social and Cultural Background)

This section summarizes the social background and interactions of BU affected people as reported by the interviewed experts.

Age, Sex

The interviewees explained that predominantly school-aged children (six to 15 years) are BU affected, which makes the disease even more challenging as these children fully depend on the care of their families. A mother may not realize that her child is BU infected, and children usually only start complaining as soon as the lesion ulcerates or becomes painful. The interviewed clinician reported that mothers might need some time to gather resources before they take their child for treatment: Parents do not *"feel the disease themselves"*[26] and may therefore not feel the urge for professional treatment. They may have other duties, needs or worries and might not realize that a delay in treatment may cause a severe condition. Those who have been searching for adequate treatment of their child may also get tired after some time and resign.

Women were reported to be a further vulnerable population group: Those who are not economically independent rely on their husband or other family members for financial support. This may also cause delay in case of an infection or prevent them from seeking health care at the appropriate time.

Ethnic Group and Religion

The research area domiciled mainly people from the Akwapim, Ewe and Krobo tribe so that different local disease names may be encountered[27]: Local health workers stated that people from the Ewe tribe normally seek herbal or traditional treatment before they report to a governmental health facility. The interviewees were divided over the question, whether the perception of the disease differs by ethnic group: One medical doctor stated that the perception of the cause of BU is not associated with any specific ethnic group but a belief system. According to her understanding people from the Ewe tribe tend to live in small and remote communities so that the distance and the poor infrastructure has led to the development of their own local health system. Another interviewee (health official) objected to the assumption that different Ghanaian tribes had varying kinds of understanding of physiological and pathological processes but did not specify his perception.

Most of the interviewed experts stated that religion plays a supportive role amongst BU affected people (e.g. *"Patients are sure that God takes care of them."*[28] or that *'only God'* has healed them). Some Ghanaians even believe that it is helpful if in case of a disease a religious person prays for them, or they go to prayer camps (compare with section *'Church/ Prayer Camps'*) instead of reporting to a health facility.

One of the interviewed medical doctors said that she had the impression that religion was perceived to be more relevant for the perception of BU than ethnicity. But besides this the interviewee stated that she was not able to clearly observe different kinds of behaviour among the specific religious groups. Some NGO staff members had observed that traditional religion is generally associated with traditional medicine and traditional belief and explained that traditional believers usually think that *"a curse is the cause of disease and therefore they*

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[26] Expert Interview No. 24: 160-171

[27] People from the Akwapim tribe usually call the disease *'Dufunu'*, which signifies that the disease causes a swelling. Interviewees from the Ewe tribe mentioned *'Pompo bone'* [bad boil] for the pre-ulcerative nodule as well as *'Detsifudor'* [*'cotton disease'*], *'Korkuram'* and *'Ekuro'* [sore] for the ulcerative stage.

[28] Expert Interview No. 5: 52-56

try to exorcise it from the patient"[29]. However, according to their observations traditional religion is no longer very prominent in the research area[30]. Furthermore some of the interviewed patients as well as one of the medical doctors stated that Christians usually do not use spiritual or traditional treatment to heal a disease, but that some of them seek help from a healer despite being Christian.

Degree of Cultural Adaptation

According to the interviewed experts local traditions and culture are important factors for the choice of treatment. The two most prominent factors why people do not report for medical treatment are that people are not used to interact with the staff at the governmental health facilities and that they hold on to local traditions.

Interviewees from different professional backgrounds confirmed that the nodular stage of BU is considered to be a *'boil'* and that Ghanaians *"are not supposed to take a boil to the hospital"*[31]. According to the reports of the experts a traditional saying does not permit them to consult a doctor in case of a *'boil'* so that they use herbal medicine instead:

> "*If you take a boil to the hospital, they will cut it. And as soon as they cut it you will die"*[32].

The people in the rural communities firmly believe in herbs and traditional treatment and prefer traditional healers to governmental health facilities. The general opinion among the interviewees seems to be that Ghanaians from rural communities consult herbalists and hold on to the traditions of their forefathers, who have never been exposed to medical treatment. Encountered explanations were that the people have a great respect for the knowledge of their ancestors or that they stick to this practice because *"they did not receive the appropriate education"*[33]. But even nowadays people with formal education say: *"When we were a kid, we did that"*[34] and wait for a long time before they report for treatment of their disease.

The reluctance to report to report to governmental health facilities may also be rooted in the difficult relationship between both affected people and medical practitioners as it was mentioned by a local nurse, a teacher, and an NGO staff member: They said that they have the feeling that the *"gap between medical practitioners and patients in Ghana is very wide"*[35]. One of the interviewed teacher reported that many people in his neighbourhood do not accept medical treatment and that health workers *"have to talk a lot"* before the people accept it. One explanation was that this treatment might be *"too distant in their imagination"*[36]. According to these reports patients in the study area usually do not mention if they experience any side effects while receiving medical treatment. If the doctor prescribes a drug

> *"the patient will see the doctor or health worker as a saviour and not scrutinize the treatment"*[37].
>
> A patient *"would never complain about pain because the medical staff would get angry: Doctors, nurses and health workers are believed to be on a higher level"*[38].

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[29] Expert Interview No. 13: 608-646

[30] One of the NGO staff members explained that the charismatic movement (Christian renewal movement in adopting beliefs and practices similar to Pentecostals) in Ghana has a strong influence on the decline of traditional religion.

[31] Expert Interview No. 9: 27-28; Expert Interview No. 13: 323-331; Expert Interview No. 17: 37-39; Expert Interview No. 29: 221-238

[32] Expert Interview No. 29: 242-243

[33] Expert Interview No. 20: 119-131

[34] Expert Interview No. 13: 143-160

[35] Expert Interview No. 11: 273-275

[36] Expert Interview No. 24: 198-201

[37] Expert Interview No. 13: 501-504

[38] Expert Interview No. 7: 239-243

Due to this gap between patients and the medical staff people do not report for medical check-ups but wait until the disease is severe. One national health representative explained that although Ghanaians nowadays have access to physical realms they still believe in the spiritual aspects and highly appreciate the spiritual remedies: He was convinced that in cases where first attempts with orthodox medicine have not been successful, the people *"move to the spiritual side"*[39].

Another phenomenon, which was mentioned by several Ghanaians was that people do not report for medical treatment because they generally do not take care of their health (no self-responsibility) or because they assumed that the people do not prioritize health (e.g. only few people in the rural communities have a health insurance; most people find the necessary financial means and transportation to attend the funeral of a family member or friend – no matter where it is – but do not provide any support for the treatment of this person).

Yet the reluctance to report to the health facilities is ascribed to the health facilities or the health system itself.

Formal Education

There was no doubt among the interviewees that a large percentage of the rural population is illiterate and that many people *"take education as a secondary affair"*[40]. The interviewed teachers complained that parents do not care for their children and consider education not to be important. They had the feeling that many of their pupils do not like to go to school. A further mentioned challenge was the fact that BU usually has a negative influence both on school attendance and the educational career of previously affected children: It was reported that only a few of them continue to go to school after they have been healed.

Occupation

In the rural surroundings of the research area most adults are either small-scale or peasant farmers[41]. Others are petty traders, service providers or have no specific occupation. Several people have a few jobs beyond their major occupation to sustain their family.

Children above the age of six usually go to school. In their leisure times they tend to go swimming in rivers, streams and swamps and catch crabs or fish to complement the family meals.

Assets

The people's standard of living in the research area is generally very low (e.g. no toilet facilities, difficult access to safe drinking water[42] etc.). The average family lives in one or two rooms and uses the limited array of farming products/ food items – only a small part is sold to buy further essentials. The interviewed teachers complained that many children and their families eat the same food every day: '*Agbele*'[43] and *'Koobi'*[44].

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[39] Expert Interview No. 23: 594-600

[40] Expert Interview No. 11: 41-51

[41] According to reports of the interviewed teachers parents who are farmers leave their children at home while farming or *"dump the children to the school and then neglect the child"* (Expert Interview No: 11:41-51).

[42] Some communities have a borehole but *"they are few and they are salty"*; some of them were broken down. Therefore many people still depended on the river/ stream or dugouts, ponds and stagnant water. In one community there was a *'water health centre'* to provide drinkable water: People could fetch a bucket of water for ten Pesewas (0.05 €, $ 0.07). But most people did not have the money and still fetched water from the stream, pond or stagnant water.

[43] *Agbele* is a locally prepared dish made from dried and ground corn.

[44] *Koobi* is the local term for salted and dried tilapia fish.

Due to the above-mentioned circumstances the income of households with BU affected people is often low and unstable. Many BU affected people do not have any money to access medical treatment so that the disease poses further financial constraints on them. Most households are unable to support any other person because they struggle to take care of themselves.

Social Interactions

'Social Interactions' were considered to be important for the detection, recognition and labelling of probable BU symptoms by the interviewed experts: Community members, fellow students or friends usually make recommendations or call somebody they know (e.g. the CBSV) for further referral. In this context it was mentioned that CBSVs do have the official order to actively search, assist or refer suspected BU affected people to report to the health facility. In addition to that advice from educated family members or foreigners may be taken more seriously than from others. Observant teachers were reported to be another important group of informants: if they realize that a particular child does not attend school they may try to find out the reason and report to the health post. Furthermore, doctors, nurses or health workers refer BU affected people from other clinics to the BU treatment centre or specialized health post. The interviewed health worker reported that sometimes the people in the communities inform him about other suspected BU cases.

Some of the interviewed patients reported that they had heard other people talk about the disease, had seen that other patients reported for treatment or stated that they knew other people who were affected. But not all of the interviewed patients had contact with other BU affected people within their community and only recognized some of them when they reported for treatment.

Some of the non-affected interviewees reported that the people in the communities talk about BU and that community members commonly recognize usual skin diseases because they know each other:

> *"If somebody's skin starts changing the people in the community suspect that the person has a skin problem"*[45].

However, one of the NGO workers explained that most of the people do not have time to talk about the disease and how one may identify the disease in the early stages. The interviewed experts reported that BU affected adults usually decide to report for treatment on their own and that only some seek a second opinion before they decide to report for treatment from a governmental health facility. Amongst the experts there was no doubt that for BU affected children usually their caregivers take the initial decision about the treatment. If the family is scattered or the head of the family is not around they gather and discuss the situation, which may cause further delay for the treatment. Yet the family members may also assist their BU affected relative to report for treatment and accompany or take them to the health facility.

Disease Experience

Nurses and NGO workers explained that previous BU patients play an important role with regard to the identification of the disease, the labelling of the respective symptoms and the possible referral for treatment. Patients who have received antibiotic treatment and got healed were considered as a great resource in the communities as they may serve as a first contact person. Those patients may educate their community members and spread this information among their peers, which may motivate and encourage other BU affected people

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[45] Expert Interview No. 30: 340-354

not to give up. One of the interviewed health officials explained that they might demonstrate that the nodule dissolves with early antibiotic treatment and thereby improve the awareness within their community:

> *"You should take the drugs. When you take the drugs you will become a healthy person"*[46].

One interviewed medical doctor and one researcher explained that family or community members who had already had a BU case among them were more likely to report earlier for medical treatment in case of a new skin lesion. Then again, a community member who had BU and gained some negative experience with medical treatment may be less likely to report for treatment in case of a new BU infection. One of the CSBVs reported on a patient who knew somebody with good experience in treating *'boils'* with herbs. According to this CSBV the people in the villages are likely to take these reports for granted:

> *"When I used this herbs on my wound, it went off. So when you use it, it will go away"*[47].

Some of the interviewed patients reported that they sought medical treatment because it was their habit to seek care from a governmental health facility, because they were aware of BU or had already experience with the antibiotic treatment.

It was explained that BU affected people themselves usually do not talk about the disease when they have an active ulcer, but that they may tell their story and report about their experience when they are healed or already receive effective treatment. Furthermore it was reported that patients know each other and share their experiences (e.g. about symptoms and preventive measures) among them.

Other Factors

Some of the interviewees mentioned that they encountered people who used *'excuses'* for not reporting to governmental health facilities (e.g. *"We were travelling."* "*My father or mother is travelling.*" *"We don't have money."*[48]). Some BU suspected people expected that a relative or CBSV would take them to the health facility. One of the interviewed teachers reported that some people refuse free medical treatment and transportation just because they are afraid that their herbalist would not accept it if they reported to a governmental health facility.

Other people wait for counselling and stay in their community until somebody calls a health worker (e.g. *"Come, come, come, come, there is someone lying in a room!"*[49]). Reported reasons for this behaviour were that the people might want to carry on their work/ duties before reporting for treatment; or they have to gather resources. One of the interviewed experts had the feeling that *"some of the patients are just ignorant"*[50] or *"do not want to report for treatment"*[51]. In contrast to the mentioned obstacles certain events (e.g. a family member comes back home from a journey or the family received some money) may motivate patients to report for treatment.

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[46] Expert Interview No. 32: 378-381
[47] Expert Interview No. 26: 270-275, 287-298
[48] Expert Interview No. 29: 277-286
[49] Expert Interview No. 29: 277-286
[50] Expert Interview No. 16:139-142
[51] Expert Interview No. 27:512-515

5.2.2 Characteristics of BU and Disease Perception

This section summarizes both the general features of BU as well as its perceptions including information about the *'Chronic or Acute'* symptoms of the disease, the perceived *'Severity of the Symptoms'*, the *'Aetiological Model'*, the *'Expected Benefits of the Treatment'* as well as the social aspects of BU (*'Stigma/ Social Exclusion'*).

Chronic or Acute

BU usually starts with mild and unspecific symptoms (see section *'Severity of the Symptoms'*) but may turn into a severe ulceration, which may affect the people for a long-time – especially larger wounds do not heal fast. One medical doctor explained that some of the people realize their infection only after they have already been affected for a long time (e.g. one interviewed patient got infected 13 years ago before he finally received medical treatment).

Some of the interviewed patients had been infected before the introduction of the antibiotic therapy (in 2005) so that their lesions were already *"burnt out"* and may not be infected with mycobacteria any longer – but their wounds were still not healed or the people suffered from deformities. These chronic wounds or scars were itching from time to time or reopened/ recurred whenever the person *"does some strong things"*[52].

Severity of the Symptoms

The range of BU symptoms is considerably wide, starting with pre-ulcerative stages that are very hard to ascribe to a severe disease. With regard to the early (pre-ulcerative) disease symptoms it was frequently stated that BU *"starts from a very simple point"*[53]*.* Furthermore it was explained that most people are not aware of the specific pre-ulcerative symptoms as they are very difficult to identify. It was said that most of the affected people were neither able to name the BU specific symptoms nor to recognize these conditions. Several interviewees confirmed that the knowledge of the people was limited to the fact that the disease starts as a *'boil'*, which bursts and turns into a sore. Some of the BU affected interviewees claimed that they wanted to know more about the initial symptoms of the disease; others thought that it was not so important as long as they get healed or that they had enough information. It was also reported that even health workers and doctors might have difficulties to differentiate between BU nodules and ordinary *'boils'*.

In fact, most of the pre-ulcerative BU symptoms were described as painless or only minimally painful and were perceived as mild or non-serious as they may look like an insect bite, a *'boil'*, an ordinary sore or a blister on the skin. Only few of the interviewed patients reported an itching sensation or spoke of a painful *'boil'*. Another mentioned aspect was that patients think their nodule will vanish or that sores heal on their own.

It was recognized that BU progresses in a relatively short period of time: Many of the affected interviewees stated that the nodule *"did not stay for a long time until it burst and became an open sore"*[54]. The interviewees described that – without early antibiotic treatment – the nodule starts to swell, becomes big and may be painful. Then it bursts and becomes a small sore, which may increase to a big ulcer within two months: *"The sore keeps on spreading and eating deep into the skin"*[55]. Clinicians gained the experience that the oedema-type develops even quicker and reported that it may be even more distressing than a nodule or a

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[52] Expert Interview No. 17: 52-56
[53] Expert Interview No. 23: 13-18
[54] Expert Interview No. 10: 19
[55] Expert Interview No. 11: 111-118

plaque. Lesions, which *“get out of control”,* usually become very extensive, often develop a bad odour, attract secondary infections or start to be painful.

Usually BU affected people recognize their condition only when they realize that their local medicine does not help to heal the lesion or when the *‘boil’* bursts and develops into an ulcer. Consequently attention for medical assistance was only drawn when the symptoms got severe and the lesion started to hurt. Furthermore, the people may not realize that a treatment delay may cause a severe condition but *“move around seeking for treatments elsewhere*[56]*”* until they realize that the disease condition is not improving. According to one of the interviewed researchers most people in the villages only recognize the ulcerative stage with the *“cotton wool swell”* of the ulcer as BU. Then the people realize that they have this *“special sore known as Buruli ulcer”*[57]. A challenge to the medical personnel may be the fact that BU is not a pleasant disease to manage, as the wound demands a lot of care before it heals. One of the disease control officers in the district summarized:

> *“The people do not take it serious when they see the disease because it does not come in any hard form. It comes slowly and ends bigly”*[58].

BU is associated with a high disease burden and is commonly perceived as “*a very, very, very dangerous disease”*[59]. One of the municipal health officials explained that BU is more disastrous than Leprosy: *“Both diseases may look like cousins but BU is more disabling than Leprosy.”*[60] His explanation was that *“BU spreads faster”*[61] so that BU affected people may develop deformities and disabilities within only one year. The interviewed experts reported that many BU affected people are scared because they are afraid of amputation and disabilities. Furthermore they explained that the disease goes along with many difficulties as it destroys the skin and deforms or disables. When the skin *“is worn away”*[62] only the bones are left over. BU causes a lot of incapacitation and is associated with a high disease burden. Some patients have even amputated body parts (e.g. arms, legs, organs etc.). Others have maimed hands or feet and cannot use their limbs any more or the affected body part *“will never be so strong again”*[63]. Untreated lesions may turn into cancer.

In addition to the clinical aspects many of the BU affected people experience social difficulties due to the disease (compare with section *‘Stigma/ Social Exclusion’*): The infection may be painful so that the people are not able to work as usual (e.g. they are not able to pound ‘*fufu’*[64], to lift heavy things, do their laundry etc.). Some of the BU affected people reported that they had to interrupt their farming activities, or that they suffered from insomnia, or that they were not able to use their arms, or could not eat alone, and lost weight. So it does not come as a surprise that the interviewed clinician knew that BU patients pass through *“a very unpleasant period of time”*[65]*.*

The interviewed experts also reported that school-aged children often interrupt their school attendance for a long time, as they had to spend a lot of time at the clinic while receiving

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[56] Expert Interview No. 27: 467-470
[57] Expert Interview No. 11: 217-218
[58] Expert Interview No. 30: 375-388
[59] Expert Interview No. 22: 148-149
[60] Expert Interview No. 30: 402-407
[61] Expert Interview No. 30: 417-418
[62] Expert Interview No. 12: 63-67
[63] Expert Interview No. 18: 101-102
[64] *Fufu* is a staple food of Ghana, which is made from boiled starchy food crops (e.g. cassava, yams or plantains), which are pounded into a dough-like consistency.
[65] Expert Interview No. 24: 901-903

treatment. Furthermore, it was mentioned that some patients were fully dependent on their family so that their mothers or other caregivers were not able to sustain their daily business. Consequently the disease may not only impoverish the sufferers but the whole family and their communities (see section *'Cost of Treatment'*). Only few patients were able to continue their daily life despite being affected.

Aetiological Model

Most of the affected people had no explanation how they had actually contracted BU; some had different views about the aetiology or thought that BU has various means of contraction.

During the interviews the experts mentioned several natural explanations for the aetiology of BU: Most of the interviewees in the communities believed that it is a water-borne disease. And the local health staff explained that this perception was associated with the fact that most BU affected people who report for treatment stay around river boundaries (*"People living along the banks of river normally have BU."*[66]) or come from communities without pipe water. One CBSV explained: *"According to the doctors BU derives from water"*[67] so that some few people started to boil their drinking water to prevent the disease. The interviewed herbalist also reported that he advises his clients to drink *"good water"*[68].

Another locally encountered explanation was that BU is caused by *'bacteria, which stay around wet and muddy places'*, or places with stagnant water (e.g. lagoons). Some people related BU to harsh environmental and sanitation conditions, which apply to most of the rural communities within the district. It was also reported that some people have moved to other places because they believed that the *"dirt from the ground"* might cause BU[69]. Quite a number of people stated that they were afraid that BU is contagious or that they believed in person-to-person transmission. Even some of the nurses in hospital reported that they wore a mask to prevent an infection. Others said that they do not believe in transmission from person-to-person as nobody in their house got infected. The interviewed herbalist had observed that BU occurs in certain years or times of the year, and one of the interviewed patients had a more detailed explanation:

> *"The situation gets worse during the Harmattan[70] when wells dry up so that dirt and other impurities may pollute the water"[71].*

Only few people considered insects or infected skin cuts which got swollen to be the cause of the disease.

Most of the interviewed researchers and national health staff stated that supernatural explanations among the people dominate the perception of the cause of the disease. The interviewed clinician reported that severe diseases – or diseases which cause deformities – are traditionally related to supernatural forces so that people think: *"Oh, this is not just an illness, you know, this has some root cause"*[72]. The reported reason was that patients ask themselves why they get a *'boil'*, which does not heal but rather develops into an ulcer, while everyone else with a *'boil'* gets healed. Therefore – according to some of the experts – the people believe: *"This disease is more than hospital",* and do not consider BU as a *"hospital*

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[66] Expert Interview No. 28: 770-773
[67] Expert Interview No. 1: 82-84
[68] Expert Interview No. 33: 204-208
[69] Expert Interview No. 9: 79-80
[70] The Harmattan is a dry and dusty West African trade wind, which blows south from the Sahara desert into the Gulf of Guinea (end of November until mid March).
[71] Expert Interview No. 12: 54-58
[72] Expert Interview No. 24: 508-523

disease"[73]; but think that it has a magical dimension. The perception of the local people as well as the district health staff was similar: They explained that some people think that someone *"does the disease to them"*[74]; others have even identified other community or family members as being the cause of their disease. Some CSBVs reported that BU affected people, who did not receive any health education, thought that they have been bewitched, that evil spirits were put on them or they associated the disease with some evil forces. One of the disease control officers speculated that some traditional healers might have told them that a witch or a wizard has caused BU and that the disease is spiritual. Another group of people attributed BU to superstitious beliefs like *'juju'*[75] or a taboo. It was reported that some people believing in *'juju'* think they might have touched somebody's personal belongings, asked somebody or attempted to cut the leaves or the branches of a protected palm tree and got the disease:

> *"In the juju, you may think that if you step or touch on the juju, you can develop ulcers. When you touch it the ulcer can come on the hand. So when you have this mind-set, you are not thinking about mycobacterium ulcerans. No, that's not what you are thinking of! You are thinking of the witchcraft and the juju"*[76].

Further supernatural explanations were that Gods had been offended or simply bad luck.

As opposed to what the above cited experts thought about the local perception some NGO workers had the impression that the people in the research area do not believe so much in myths and misconceptions any more. The interviewed patients or caretakers within the communities usually did also not voice out any of the above-mentioned supernatural explanations: Only one hospitalized interviewee stated he believed that a witch had sent and caused his disease. All other interviewees said that they did not really believe that witches cause BU. However, they explained that *"witches are powerful"*[77] and that they *"cannot be too sure"*[78] or that the disease might *"just happen"*[79].

In case the commonly known symptoms did not apply to their condition the interviewed BU affected people reported confusion about the symptoms they had observed (e.g. the disease did not start as a *'boil'*, no offensive smell from the sore, painful *'boil'*).

There were some instances when the people seem to tend ascribing the causes of BU to supernatural causes as well. This was particularly the case when commonly propagated health messages obviously did not hold for everybody (e.g. someone believing in the assumption that BU originates from water, yet not everybody who had drunk from that water got infected; people who previously had drunk river water but changed to water from the borehole – believing in the probability of contracting BU from the river – still were infected; people, who did not live along the river but were infected nevertheless; a caretaker believing in contracting BU from dirt from the ground, so not allowing his child to play in the dirt – yet his child contracted BU nevertheless). In these cases it was reported that people believed that someone had cursed them:

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[73] Expert Interview No. 19: 364-370

[74] Expert Interview No. 4: 126

[75] *Juju* refers to the use of certain objects to perform a form of witchcraft: *„An object of any kind superstitiously venerated by West African native tribes, and used as a charm, amulet, or means of protection; a fetish. Also the supernatural or magical power attributed to such objects, or the system of observances connected therewith; also a ban or interdiction effected by means of such an object (corresponding to the Polynesian taboo)"* (N.N. 1971. Juju. *Oxford English Dictionary.* Oxford University Press).

[76] Expert Interview No. 16: 145-162

[77] Expert Interview No. 9: 88-89

[78] Expert Interview No. 9: 88-89

[79] Expert Interview No. 8: 49

> *'Yaree weyi dee eye abonsam yaree'* [as for this illness, it is an evil illness][80].

Furthermore it was also reported that some people believe in a combination of different causes for BU: On the one hand they may complain that the cattle pollutes their water source; but in the same breath they attribute the disease to some evil spirits.

Based on these statements the interviewees claimed that information on the mode of transmission and preventive measures should be covered by health education and communication programmes.

Expected Benefits of the Treatment

The analysis of the interviews revealed that the people expect different benefits from traditional treatment (both herbal and spiritual treatment) and from medical treatment: One of the interviewed hospital nurses elucidated that most BU patients report for medical treatment because they want to get healed quickly or expect *"that the antibiotic treatment may do some magic"*[81] and heal the lesion within the eight weeks of antibiotic treatment. Another nurse illustrated that most of the people report to the health facility only after receiving traditional treatment for a long time without any improvement.

Yet some reservations about the antibiotic treatment could be detected: according to the interviewed nurses some of the patients do not continue the treatment in case they do not see an immediate improvement in the healing process due to the antibiotics. The health worker from the health post had the feeling that some of his patients do not appreciate the treatment with Streptomycin and Rifampicin because it is provided for free.

The information about herbal treatment was mainly provided by two herbalists who explained that herbs are usually applied on the *'boil'* until it bursts. According to their reports the main aim of this practice is to remove the necrotic tissue (*'the cotton'*) from the lesion, which is believed to increase the healing process. One of the interviewed herbalists explained that the herbal treatment itself needs to be combined with a strong alcoholic beverage, which is mixed with certain herbal essences *('bitters'): "Bitters will kill the bacteria from the body"*[82]. According to his understanding the disease may *"germinate from other places"*[83] and recur if '*bitters'* are not part of the treatment. The additional application of palm oil was supposed to reduce pain and inflammation of BU sores.

One of the interviewed disease control officers explained that the people in the communities commonly believe that the treatment with antibiotics may *"eliminate the bacteria within the body"* but that the lesions will not disappear:

> *"They are chemically but not spiritually healed and seek help from the herbalist or occultist"*[84].

Therefore – according to him – the people consult a spiritualist for treatment. A doctor may cure the patient chemically but only a spiritualist is able to heal them spiritually.

Stigma/ Social Exclusion

The interviewees' perception of possible stigmatization and or social exclusion of BU affected people is considerably mixed. According to some interviewees stigmatization and social exclusion are not prominent in the study area any more, whereas others think that many BU affected people are still subjected to social exclusion.

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[80] Expert Interview No. 26: 303-309

[81] Expert Interview No. 20: 165-179

[82] Expert Interview No. 33: 936-939

[83] Expert Interview No. 33: 943-946

[84] Expert Interview No. 30: 268-274

Some of the interviewed patients stated that they did not experience any social problems (e.g. going to church or attending funerals) and said that BU patients may live *"just normally"* and are not neglected due to the disease. Some also added that their community members did not mind to get closer to them and were not afraid of the disease. Other interviewed experts had gained the same impression – yet attributed this behaviour to the possibility that some of them might not even be aware of the disease. The caretaker of a small BU affected child reported that other children came around to play with his daughter or to see how she was doing. One of the interviewed researchers got the impression that stigmatization had decreased due to educational activities and explained that the people in the past were silent about BU due to their beliefs in witchcraft and the associated fear. On the whole it seemed that the *"rural folks are very united"*[85] and that the people in the communities care for the patients (e.g. sick people are exempted from communal labour activities) but that there are rumours about them in the communities: *"Oh in this house, there is someone who has a sore that doesn't heal"*[86].

Social exclusion such as neglect by the affected person's family and/or friends as a consequence of a BU infection was mentioned by several experts. One hospitalized patient complained that other family or community members neglected and visited him rarely. Another patient was even rejected by his own parents and siblings, who did not want to get close to him or talk about the disease.

The intense smell of the lesion seems to be a major reason for the social exclusion – in particular among the health staff. One nurse explained that as long as BU lesions do not smell the people in her community see them as an ordinary wound. But when it starts smelling the people may cover their nose, avoid getting closer or shun and isolate the BU affected people. In these severe cases no driver may be willing to allow BU affected people inside their car; other BU affected people were given a room on their own and were restricted to stay indoors. One previously affected interviewee even reported that his food was not brought into the room but left at his doorstep. Besides the stench, which hinders the people to get in close contact with the affected people, several people (including health workers) are afraid to catch the disease (compare with *'Aetiological Model'*). Even health workers reported difficulties in dealing with BU:

> *"It is not easy oh. The last time when I finished dressing the wound, I couldn't even eat"*[87].

Another mentioned reason for the social exclusion of the BU affected people was the perception that the BU infection was triggered by a curse and any mingling with or talking to the affected person might pose the danger of being cursed as well. One of the interviewed CSBVs explained that about ten years ago the people on the market even rejected products from BU affected traders.

A further challenge for BU affected people was partnership and marriage: It was reported that some of the BU affected people (or the mothers of BU affected children, who have to leave their husband to stay with the child) get divorced or that those who intend to marry have difficulties to find a partner because an ulcer or deformity is not attractive to many people. Not surprisingly several experts pointed out that the self-esteem of the BU affected people tends to be low, and that many of them are shy and therefore do not socialize with other people.

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[85] Expert Interview No. 20: 203-217

[86] Expert Interview No. 29: 616-624

[87] Expert Interview No. 26: 601-616

With regard to the still existing stigmatization and social exclusion, the interviewees observed various strategies by the affected people: One researcher had the impression that the people nowadays dare to speak about their BU infection, go to governmental health facilities, and tell others about it: *"I'm going to hospital for my Buruli ulcer"*[88]. Other interviewees stated that BU affected people usually only start to speak about the disease when the wound is almost healed (compare with section *'Social Interactions'*). According to some interviewees some of the affected people did not see any point in hiding the disease, were not shy of talking about their infection and showed their lesion to other people in order to confer about the symptoms. Those interviewees who did not want *"to make the disease public"* tried to hide it[89] or bandaged their wounds and avoided to talk about it. It was reported that the preferred strategy of people with extensive ulcers was to hide or cover their wound in public (e.g. wear trousers and long sleeves) and put herbal remedies on it. Others stay in their homes and do not mingle with friends, avoid attending gatherings approaching the community so that other people may not smell their lesion. One of the CSBVs was sure that people who report early for treatment usually get better and do not feel ashamed and therefore may continue their job without any problem in joining the community life.

For BU affected school children it was reported that they are also kept indoors and stop schooling as they are afraid that the other children may laugh at them or that the teacher may be afraid of the disease. According to the data some of the children are even too shy to play with their friends. One of the teachers reported that BU affected children might avoid to inform their parents about their symptoms but rather try to find a treatment themselves. And last but not least it was mentioned that sometimes BU affected people from the cities come to stay in the village to hide their disease.

5.2.3 Enabling Factors (Health Service Characteristics)

The following section covers the results with respect to the health service characteristics and includes the aspects of *'Accessibility'*, the *'Appeal of Treatment'* (both traditional and modern options), acceptability and quality of the offered services as well as health communication. The question of cost is a further topic, which was assessed during the interviews.

Accessibility

All interviewed experts agreed that BU affected people who live in remote communities have difficulties with receiving regular antibiotic treatment. The health worker from the health post argued that not all villages within the sub district may be reached by public transport: some communities have only irregular public transport (e.g. during market days) or the available public transport is very expensive so that many people have to walk to reach the health facility. Patients who cannot walk or live far away and do not see any improvement in the healing process may not report regularly for treatment but stay in their village. One caretaker mentioned further challenges: first he had to walk a long distance and carry his BU affected child on his back to reach public transport, then he needed to pay for the fare but did not have any money available. One of the NGO staff argued that the fact that the medical treatment for BU is facility based makes access to the treatment extremely difficult: daily visits to a health facility to receive the Streptomycin injection for two months might be a challenge for every patient – no matter if they have a nodule or a big ulcer. A few patients who lived in remote communities reported that the health worker from the health post used his motorbike to come to their house and provide treatment.

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[88] Expert Interview No. 21: 364-370

[89] Expert Interview No. 8: 135

As opposed to medical treatment traditional and herbal treatment have the significant advantage of proximity to the people as various experts pointed out to: Usually BU affected people resort to what is available first so that the people in some remote places have developed their own local community health system to care for their illnesses. But in contrast it was also reported that some people came from very distant places (e.g. Central Region) to receive treatment from one specific herbalist in the research area because they had heard of his treatment practice. The interviewed herbalist confirmed this. He also explained that he makes home visits if the patients are not able to come: *"When it is severe I have to be attending them at their place"*[90]. Another mentioned option was that the patients stay with the herbalist to receive treatment for some time.

Appeal of Treatment

Opinions and attitudes of the interviewees towards medical and herbal treatment, which were mentioned during the interviews, were quite diverse: One of the most important arguments for the antibiotic treatment for BU as mentioned by the health staff was the fact that surgery is not required if patients report in the *'early stages'*[91]. The people do not need to be scared of the treatment any longer (*"The moment where surgery is not required any more speaks for itself"*[92]), and the health officials were convinced that people would report for antibiotic treatment as soon as they know that it may prevent surgery.

Another advantage according to the health officials and health workers was the fact that the treatment with Streptomycin and Rifampicin reduces the treatment duration significantly: Before its introduction it took one to two years, or even more to heal the disease. Nowadays BU lesions treated with antibiotics may heal completely after four or five months. So it does not come as a surprise that most of the patients receiving Streptomycin and Rifampicin were quite satisfied and said that they liked it as they had the impression that *"the drugs are working"*[93]. Some of the interviewed patients reported that the treatment also eased the pain and therefore alleviated sleeping. Health workers and CBSVs had also noted that the patients appreciated the antibiotic treatment and *"like it very well"*[94]:

In addition to the advantages mentioned above some experts said that Streptomycin and Rifampicin are not commonly used so that the resistances have not often been observed yet. Even the herbalist had the perception that the antibiotic treatment is effective and reported that he sometimes refers BU affected people for antibiotic treatment from the health post in case he is not available. Another positive mentioned issue was the fact that the antibiotics may heal the disease without deformities, scars or contractures. Last but not least the NBUCP manager explained that the antibiotic treatment saves money: The drug treatment usually shrinks the lesion to a small level so that wide incisions and skin grafting may often be avoided. In 2003 non-surgical (antibiotic) treatment cost less than 20 US $ per person; but the cost for surgical treatment amounted 980 US $ per person.

Nevertheless many interviewees mentioned reservations about reporting to a governmental health facility: First, there is fear of surgery and of pain due to various reasons such as injections amongst the patients as the experts said: before the introduction of the treatment

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[90] Expert Interview No. 33: 150-155

[91] One of the interviewed doctors reported that most often category 1 and part of category 2 lesions get healed without surgery and that some category 2 lesions heal one or two weeks after the antibiotic treatment so that they do not require surgery (see chapter *'Background'*).

[92] Expert Interview No. 23: 346-353

[93] Expert Interview No. 9: 119

[94] Expert Interview No. 4: 158

with Streptomycin and Rifampicin BU patients were likely to be subjected to amputation, extensive scars and restriction of movement so that some people still mentioned they were afraid of the hospital as they perceived that they had to undergo surgery/ would be amputated: *"I am afraid of surgery. I better not go"*[95]. Obviously this fear cannot be considered to be illegitimate for large ulcers: One of the interviewed clinicians argued that adequate wound care/ cleaning is still essential:

> *"The antibiotics alone, would not be adequate to cater for – the wounds need to be cleaned, and the skin to be grafted. And if it is not done, all the focus is on the antibiotics then it is not adequate. If this would be done alongside the antibiotics then the total care would – then the people would fare better"*[96].

According to her many of the reported lesions are still too big to be treated with antibiotics alone and therefore still require surgical interventions (e.g. excision, skin grafting). Apparently some people are also afraid of injections and believe that everybody who comes to the health facility will be given an injection. Those interviewees who had received injections complained about pain. NGO staff and some health workers explained that Streptomycin injections are known to be painful and be followed by abscesses. Moreover, regular dressings – as explained by one of the disease control officers – may also be painful.

Secondly, probable side effects of the treatment with Streptomycin and Rifampicin are known: Sometimes the patients' urine may turn brown and if they do not eat before receiving the antibiotics they may feel dizzy. Furthermore the patients' immune system may be weakened if their diet is not adequate. Some nurses explained that children are not able to swallow the Rifampicin tablets, as they are too big for some of them. Another raised issue was that the antibiotics alone do not relieve the patients from pain so that anti-inflammatory drugs are necessary for pain relief.

Thirdly, the time which the treatment and its supervision through the health staff consumes keeps patients from the medical treatment: Several interviewees mentioned that some patients do not like going to health facilities as it may consume a lot of time: *"When I go there, I won't come back early"*[97]. Furthermore it was reported that the daily injections at the health facility for two months were not acceptable for the patients: *"The injections used to be plenty"*[98].

Fourthly, a lack of knowledge and wrong expectations with regard to the antibiotic treatment is immanent amongst the people: Before the BU treatment program was established and the health insurance scheme was introduced Ghanaians had to pay before receiving medical treatment (*'cash and carry system'*) so that the costs for medical treatment were perceived as high (see section *'Cost of Treatment'*). Nowadays many people still do not know that the antibiotic treatment for BU is free of charge but think they need money or a health insurance to receive treatment. According to one of the interviewed nurses and a teacher especially people without health insurance prefer herbal or traditional treatment. Then again the health worker from the health post had the impression that free treatment was not so much valued by the people.

Besides this, there is the common belief that people get cured as soon as they take the antibiotics (see section *'Expected Benefits of the Treatment'*). It was reported that some

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[95] Expert Interview No. 24: 311-314
[96] Expert Interview No. 24: 798-801
[97] Expert Interview No. 26: 113-120
[98] Expert Interview No. 32: 424-429

affected people who do not see an immediate improvement may lose confidence in the antibiotics, get discouraged and think that the drugs cannot help them:

> *"No, no, no. I don't think this a disease that requires treatment from the hospital. If the hospital had something better for you, they could have done it in your earlier this things, attempts you made. But all the treatment they gave you couldn't work. I don't think so. Besides I don't have the money to pay for all this long hospitalization"*[99].

The following statements by one of the disease control officers and one of the interviewed researcher illustrate the arguments why people seek assistance from traditional healers instead of governmental health facilities:

> *"Oh, I know this herbalist in that corner, who can do it very fast, and within some weeks she will be fine"*[100].

> *"So even at times, when they come to the clinic and you want to treat them on scientific drugs you see them going back to the spiritualist and they will come back in the worst stage"*[101].

One of the researchers explained that people were previously thinking that BU has no medical remedy and must have a magical cause; therefore they were reluctant to report for medical treatment.

Sixthly, health infrastructure related problems were mentioned: Among the health workers, health officials and NGO staff it was commonly known that Streptomycin and Rifampicin are occasionally out of stock and that the health facilities sometimes receive patients without having sufficient drugs.

In addition to that, only professionally trained health staff may provide the treatment, and – depending on the size of the ulcer – it may not be managed within all settings. Therefore health workers, NGO staff and CBSVs argued that a home-based and all-oral treatment would help to sustain regular treatment as it might even be supported and ensured by the CBSVs.

The medical treatment as described above is always in competition with the traditional herbal treatment with its distinctive features: It was widely acknowledged by the interviewed experts that the most important feature of herbal and traditional treatment is the fact that it is community-based and close to the village, which allows the people to conveniently and easily access the provider. A treatment provider who lives next door makes the treatment cheaper for the patients; the people may go there any time (without need of transportation) and usually continue their daily activities (no waiting time). Furthermore, herbalists provide treatment in an environment, which is familiar to the people. It was reported that they consider the provision of treatment as a business, present themselves nice, are easy to contact and wish the patients to feel comfortable.

Apart from the pragmatic reasons for making use of traditional healers Ghanaians prefer traditional herbal treatment for two major reasons: there is the spiritual aspect and the strong belief in the potential of herbs as herbs are considered as a part of the things that are *"provided by God"*[102]. Due to the fact that some people ascribe the disease to supernatural sources, there are some of the affected people who believe that they have been bewitched (compare with section *'Aetiological Model'*). Those are most commonly the group of people who prefer seeking care from traditional healers. Descriptions about these aspects were mainly provided by the professional experts and not by affected people themselves.

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[99] Expert Interview No. 28: 256-266

[100] Expert Interview No. 20: 165-179

[101] Expert Interview No. 30: 238-245

[102] Expert Interview No. 19: 581-583

Another important factor for preferring traditional treatment over medical treatment is the fact that BU affected people usually draw on the experience that their social environment has gained with this method (see section *'Degree of Cultural Adaptation'*): The interviewees stated that it is very likely that grandmothers or grandfathers recommend traditional treatment because they have experience in using herbs and are familiar with it: *"Oh I have used a herbal medicine and it will go it will go"*[103]. People who have received or used herbal treatment were considered to recommend this practice often to other patients as well. One of the interviewed herbalists stated: *"Everywhere you pass here, they know me, they have heard of me"*[104]. So it was reported that a good reputation of a herbalist may attract people from distant places. Some of them have passed their occupation on from generation to generation and may therefore say: *"I have this one from my grandfather"*[105].

Several interviewees, including the herbalist, explained that people think herbal treatment may heal the wound if the necrotic tissue is removed completely (see section *'Expected Benefits of the Treatment'*). According to this belief the disease will *"heal completely"*[106] and not recur if the patients take the treatment regularly because the *"herbs help to heal the disease internally"*[107]*.* Along with this explanation in favour of traditional treatment some experts mentioned that herbal treatment is less invasive (e.g. no use of scalpels).

Apart from identifying aspects that make people feel attracted by traditional treatment the experts also outlined reservations about this treatment approach: Several interviewees argued that traditional or herbal treatment is often associated with scars and disabilities, and that BU affected people are left with contractures. The interviewed health workers explained that the risk of further complications is higher when traditional herbal treatment is practiced. According to their observations it may only heal the visible surface but the undermined skin might still be infected so that the disease may recur. Another reported risk was secondary wound infections (e.g. increased risk of tetanus infection).

Furthermore some of the interviewed health workers and the NGO staff argued that herbal medicines have not been tested yet and therefore suggested assessing its efficacy. Another group of interviewees thought that *"the efficacy of the herbal medicine is not 100%"*[108] and that it may worsen the state of the lesion (e.g. bigger swelling/ sore or disabilities). Even one of the interviewed herbalists stated that some of his colleagues do not have enough experience to treat BU and do not work neatly (e.g. use of outmoded treatment, or leaves that are not fresh): According to his reports decayed herbs cannot heal the lesion but *"keep trouble to the patient"*. He claimed that all herbalists should get a license to treat their patients properly and practice in hygienic conditions. He even recommended reporting to governmental health facilities for BU treatment:

> *"It's more advisable to go to the hospital than to rely on inexperienced people"*[109] [i.e. herbalists].

In general traditional and herbal treatment was known to take even longer than medical treatment (three to four years) and – similar to medical treatment – BU affected people receiving herbal treatment have to report frequently, which may also be a challenge for them. Furthermore community based health staffs complained traditional healers may *"entice them*

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[103] Expert Interview No. 26: 524-529
[104] Expert Interview No. 33: 143-145
[105] Expert Interview No. 13: 335-346
[106] Expert Interview No. 33: 381-396
[107] Expert Interview No. 33: 176-179
[108] Expert Interview No. 15: 13-14, 22
[109] Expert Interview No. 33: 362-370

[the patients] *with trickery into believing they can help them"*[110] or do not even allow them to report to other places for treatment. As a consequence it may take a long time until BU affected people realize that herbal treatment does not heal the disease.

Despite the conviction and efforts of the local health staff, teachers and CBSVs who favoured the antibiotic treatment for BU, the interviewed patients had the overall perception that both treatment options (herbal and medical treatment) might be useful to get healed. The researchers', clinicians', health officials' and NGO staff's assessment of the general population's preferences would even go further: *"Most people place their beliefs in the herbalist rather than coming to the clinic"*[111].

Acceptability and Quality of available Health Services

Interviewees, who were working professionally with BU affected people commonly complained about the quality of the available health services. Non-professional interviewees (e.g. BU affected people and caretakers) did not mention this aspect independently.

Overall Perception of Governmental Health Services

The overall perception of the available governmental health services (namely the health post, the small community clinics as well as the Government Hospital in the next city) were both positive and negative: there was a tendency amongst the affected people to be less critical about the provided services than the other interviewed experts, but the general appeal of the governmental health facilities among them was more or less positive: One patient who had been hospitalised for more than two years thought that his *"time in hospital was good"*[112]. Interviewees who had received daily BU treatment from the health post said: *"The services at the health post are OK"*[113] as *"they take good care of general ailments"*[114].

As opposed to that the small *'community clinics'* in the remote communities were reported to be still in bad condition (e.g. not even a blood pressure meter available) so that only outreach services were provided.

The experts with a professional view complained that the available services from the hospitals are insufficient: One interviewed nurse deplored a lack of dressing equipment (e.g. no adjustable beds and stools), and the researchers and clinicians explained that most district health facilities have no specialized rooms to provide surgical care (e.g. no surgical equipment or specialized unit for skin-grafting and not enough beds for BU care) so that the facilities are not prepared to provide BU treatment in the advanced stage of the disease: *"Buruli is – they take up all our space – bed space, they take up all our time"*[115]). It was reported that these challenges also apply to the local Government Hospital.

Professional Skills of Health Staff

None of the BU affected interviewees explicitly complained about the professional competences of the local health staff; one of them even assumed that: *"the health worker knows everything"*[116]. In contrast to the BU affected people several other interviewees deplored that the capacity and training of staff is insufficient. It was said that the facilities do not have enough staff to treat the high number of patients and that there was no medical

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[110] Expert Interview No. 12: 40-45
[111] Expert Interview No. 12: 54-59
[112] Expert Interview No. 5: 89
[113] Expert Interview No. 10: 113
[114] Expert Interview No. 8: 205
[115] Expert Interview No. 24: 239-247
[116] Expert Interview No. 12: 90-91

assistant at the health post within the research area: The health officials remembered that the trained staff had left the facility due to career development and said that they had the impression that the other health workers *"lost the spirit to work"*[117]. Furthermore they thought that the health staff has a lack of adequate knowledge and sufficient skills/ expertise to care for BU patients (e.g. one health worker remembered that he had received only little training on BU care management and some booklets before he started treating BU affected people). Other reasons for the apparent insufficient skills of the staff are that usually the senior nurse (*'in charge'*) attends the offered trainings, and those who usually provide the services do not participate. As a consequence the array of offered services in the Government Hospital was limited so that patients who required skin grafting had to be referred to the adjoining district. Whereas the NGO staff could confirm the lack of knowledge amongst the health staff – it was mentioned that some health workers do not know much about side effects related to the treatment with Streptomycin and Rifampicin and do not have enough time to explain it to the patient – they also pointed out that they had the perception that most health workers are overworked and therefore have not enough time for physiotherapy or prevention of disabilities (POD).

Behaviour of Health Staff

The behaviour of the health staffs was perceived and experienced differently among the affected people: One hospitalized patient thought that the attitude of the nurses was friendly and described the atmosphere in hospital as *"cordial and relaxed"*[118]. The health worker from the health post who explained that some people came from far away to receive treatment confirmed that he has a good relationship with his patients. One of the interviewed CBSV agreed that *"everybody likes the staff from the health post"*[119]. In contrast to these statements one of the affected people complained that the health worker was unreliable and unfriendly because he stopped his home visits to provide her with treatment.

Opposed to the predominantly positive statements of the affected people most of the interviewed researchers, health workers and officials, NGO staff and teachers explained that the attitude of the health workers towards the patients is often a problem. They knew that some of the affected people (especially those with big ulcers) are not well treated by the staff so that treatment might be delayed or interrupted. It was reported that some health workers even blame BU affected people for not coming early, insult them or shout at them:

> *"We the health workers we misbehave towards the patient. When the patient comes we shout on him. Maybe a patient, you know* [name of a very remote community]*, yaa? So they don't have access to a vehicle, you see. So when a person was referred to the hospital here, when you report at the hospital here, around 11 or 12. You have to ask him the reason why he or she is late. Look at the terrain from* [name of a very remote community] *to* [name of another community within the research area] *but some of the workers say: 'You are now coming! Why do you delay like this? You are now coming!'"*[120].

Some of the explanations for this behaviour were that the health workers themselves are scared of BU and have a *"take it or leave it attitude"* or *"do not put themselves in the position of the patients"*[121]. The nurses from the health post said that they usually did not shout at the patients but agreed that they sometimes might get a little bit angry (e.g. when patients do not

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[117] Expert Interview No. 16: 413-418
[118] Expert Interview No. 5: 18-21
[119] Expert Interview No. 22: 278
[120] Expert Interview No. 32: 308-324
[121] Expert Interview No. 19: 334-362

comply with the treatment) but *"come back to themselves"*[122] very soon. They explained that some of the patients feel insulted when they advise them. Usually

> *"it is nice to work with them* [the patients] *because their understanding sometimes is difficult. It is different from yours, but if you are able to understand them or persuade them, or convince them, they cope with you. But if you cope with them, if you love them, if you take them as your sisters or your brothers, they also accept you"*[123].

The nurses said that they try to

> *"make* [their] *best possible to give them the correct treatment, so they* [the patients] *appreciate it"*[124]

and try to encourage the patients in their behaviour and say: *'thank you'* or *'you are welcome'*. According to their perception the attendance of patients has increased due to their behaviour.

BU Diagnosis

A further issue which was raised by the interviewed health workers and officials, NGO staff and researchers was that a BU diagnosis based on the laboratory confirmation is a major challenge for the health workers: The experts deplored that pre-ulcerative BU lesions may only be judged clinically so that the health workers have to wait until it ulcerates before they may take a sample (swab) for confirmation. In addition to that remote health facilities do not have the necessary facilities (e.g. reagents and equipment) for on-site diagnosis and therefore have to send their samples to an institute for confirmation: After the *"BU clinic day*[125]*"* a driver has to collect the specimen from the community and take it to the laboratory. Usually it should only take two more days until the results are ready. But according to the reports of one researcher some clinicians or health workers send the samples for laboratory confirmation but do not follow-up the results. In contrast to these reports the health worker from the health post stated that it sometimes took so long to get the results that – in practice[126] – every person who reports with a suspected BU nodule is examined and – in case of being diagnosed positively under the given conditions – immediately treated with antibiotics – without having taken a swab:

> *"There are some* [patients] *who have even finished treatment, but the results have not even yet come. So, that you don't know whether this is Buruli ulcer or not Buruli ulcer. But all the same they get healed. So, what you can't even tell if it is Buruli ulcer or it is not Buruli ulcer. So that* [the provision of treatment with Streptomycin and Rifampicin without laboratory confirmation] is *what we do"*[127].

Two of the affected people confirmed this challenge and complained about the uncertainty and inconsistency of the diagnosis[128].

Logistics (Supply of Drugs and Dressing Material)

In addition to that the interviewed experts deplored significant problems in the logistics of the health sector: Some health facilities have a lack of the necessary resources (e.g. drugs and dressing material) and do not have access to the full complement of materials. The interviewed health staff as well as the officials explained that – in theory – the BU cases have to report, be diagnosed and confirmed first, before the facility receives the drugs.

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[122] Expert Interview No. 27: 512-515

[123] Expert Interview No. 27: 91-95

[124] Expert Interview No. 27: 320-323

[125] Health facilities usually establish one fixed BU clinic day during the week. On this day they clean the lesions, change bandages and take swabs for laboratory confirmation.

[126] In July 2011 the health worker complained that he may only retrieve the results from the internet, but has no facilities to do that.

[127] Expert Interview No. 2a: 150-156

[128] A female patient was told at the hospital that she may have multiple ulcers (without laboratory confirmation), an herbalist had told her that she had BU until finally a health worker took a swab to test whether she has BU. By the time of the interview she was still waiting for the results and was not sure whether she had BU or not.

Consequently, the supply was officially based on the numbers of BU patients, who were supposed to receive treatment. Then the facilities had to request the drugs through the Regional Health Directorate before they may receive them. In practice WHO supplies the NBUCP with Streptomycin and Rifampicin, who then distributes the drugs to the endemic regions. Unfortunately the deliveries are often not regularly except for some (e.g. Ashanti Region) who received frequent supplies.

A further reported obstacle was that the storekeeper at the Regional Health Directorate has to sign the requisition before delivery of the drugs to the district. In practice the NGO staff had observed that the health workers started providing BU treatment to suspected patients without having the full complement for all of them. Then they run out of medicine so that finally some of the BU affected people cannot complete their treatment. One of the interviewed NGO staffs suggested to packing and labelling the medicine for each patient to ensure uninterrupted treatment.

The health worker from the health post explained he may request some drugs from a Catholic sister to sustain regular treatment. The DHMT in the research area admitted to have *“a slight problem with the supply of BU antibiotics”* and to sometimes face difficulties to get the whole amount of drugs[129]. Similar challenges were reported for the supply with bandages, dressing material and lotions so that the health workers have to use the same bandage several times, or the same gloves for the whole day and do not have normal saline for wound cleaning and use normal water. It was also reported that that patients commonly have to buy their own bandages for dressing.

Financial Resources

Another reported challenge (by researchers, NGO staff, health providers and officials) was that it is the duty of the NBUCP to strengthen the health facilities (e.g. provision of equipment and basic tools for surgeries), to organize and coordinate health education activities and to ensure the national policy (*“free treatment for BU patients”*), which includes the supply of logistics and equipment to the respective levels but that the financial resources are insufficient in general. At district level funds were *“basically not existent”*[130]. Some health officials deplored that this was also the reason why it was sometimes not possible to provide enough education and that funds were mainly provided for diseases such as Malaria, HIV and TB:

> *“BU affects mainly children and these children are our future leaders. If the future leaders come out with these deformities and disabilities: where is the country heading to? It should be possible to do monitoring like in Malaria to control these people from dying and to disabilities/ deformities”*[131].

Even funding for the NBUCP was said to be unreliable: WHO provides funds for their office, vehicles, medicine and trainings and NBUCP 20,000 GHC[132]/ year for further activities (as from 2010). According to health officials this budget does only allow to cooperate with NGOs or research institutes to organize trainings (no individual activities). Some other health officials deplored that for other diseases (e.g. TB[133]) more resources were available.

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[129] Usually they project the number of cases they may have in a year but nevertheless do not get the full quantity (e.g. they ask for drugs for 20 people but provide only for 15).

[130] Expert Interview No. 13: 123-141

[131] Expert Interview No. 30: 453-458

[132] 20,000 GHC equalled (11,000€, 14,520$)

[133] The Global Fund pays the treatment supporters and even the patients receive money to buy food and further supplies.

Health Education and Communication

Further important aspects of the health service characteristics are the disease specific *'Health Education and Communication'* activities: According to the narratives of the interviewees several institutions (i.e. NBUCP, DHMT, and NGO) as well as professions (i.e. health workers, CSBVs and teachers) play a role in the BU specific health education.

National BU Control Program (NBUCP) and District Health Management Team (DHMT)

The NBUCP controls and coordinates national BU activities, provides technical and material support for all treatment centres and is responsible for capacity building (e.g. training of staff to improve skills and case management). Besides this the NBUCP staff cooperates with NGOs, which organize trainings for health workers to reduce the burden of the disease. The responsibility of the DHMT is to provide community education about the disease. Sometimes their staffs (disease control officers) educate the people (e.g. in prayer camps etc.) to report early to the hospital.

NGOs

In consultation with the NBUCP and the DHMT a local NGO supports the district[134] with BU control activities: Their main focus is to train CBSVs in endemic areas. In 2010 they provided a one-day training on recognizing BU symptoms and registration of suspected cases[135]. Furthermore they have organized trainings of health workers (i.e. non-surgical treatment aspects of BU, BU surveillance and behaviour towards BU patients). Besides this they have organized BU trainings for teachers and for school health education program (SHEP)-coordinators (i.e. recognizing BU in the communities as well as provision of IEC materials (e.g. posters and T-Shirts) for advocacy). Furthermore they have organized evening film shows[136] in selected endemic communities to educate the people about BU.

Some of the interviewed patients indicated that they had attended a film show and saw some posters displaying the disease. According to observations of the interviewed health workers the number of affected people, who reported for treatment with pre-ulcerative lesions, had increased after these evening events.

Local Health Workers

The local health workers are the first point of contact for BU affected people within the governmental health system. Their main duties are to provide care and information about BU and to guarantee informed consent amongst the affected people (e.g. information about BU infection, explanation of treatment procedures and translation of health messages in understandable (local) language). Furthermore the health workers were involved in the above mentioned film events and provided information to CBSVs or accompanied them into their communities. The health worker from the health post explained that he provides

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[134] The district was supported because they had no funding for BU specific trainings.

[135] In addition to that the NGO supplied the health post with consumables (e.g. gauze, bandages, and cotton wool) as well as basic equipment to manage BU cases (e.g. autoclaves, trolleys etc.).

[136] First they start playing some music for the children or show a local comedy movie, which is meant to attract as many people as possible from the village. Then they show the WHO documentary and give them commentaries in the local language. During this session they teach the people that there is antibiotic treatment available (instead of surgery). According to the experience of the NGO they use the pictures of severely affected patients to deter people from reaching this stage. The next day they go back to the community for a skin screening of the community members, check every person for suspected skin diseases, collect specimen and take them to the lab for case confirmation. For those who are tested positive for BU they make sure that the people receive treatment, refer them to the health facility and inform the CBSVs to follow them up. For pupils the SHEP-coordinators are informed to follow-up the cases.

education about BU with the hope to change the behaviour of the people[137]. In addition to that he pays visits to BU affected people who default reporting for treatment. The affected people confirmed that they had received most BU specific information from local health staff. According to their narratives health workers mainly informed them about the mode of transmission and had said that:

> *"The germs that cause the disease live in water so it's most likely contracted when you go for a swim in the river or when children play on the ground"*[138].

In addition to that the affected people attributed further advice to the health workers: one should avoid walking in the drain and avoid swimming/ bathing in streams. Children should not play in the dirt and the people should only drink pipe water.

Community-based Surveillance Volunteers (CSBVs)

Every community is supposed to have a community-based surveillance volunteer (CBSV) [139], who receives trainings in surveillance and reporting and get an update before every health event/ campaign by the DHMT or local NGOs. During these campaigns they are supposed to go from village to village and educate the people about health issues or assist the health workers. Furthermore they actively search for BU affected people, inform them about the disease (e.g. cause of the disease, preventive measures, early symptoms, antibiotic treatment) before reporting for treatment and are supposed to accompany them to the health facility. From time to time they are also involved in supporting the film shows of the NGOs.

Schools/ Teachers

Some of the teachers of the local schools have been trained to screen children with BU suspected nodules. They are supposed to educate their children about the disease as well as to look for early lesions to be diagnosed and managed at the health post. The NGO had linked the teachers with the coordinators of the SHEP-Programme as well as the health workers, so that they may talk to the pupils or advise them on preventive measures of BU. The interviewed teachers were certain that educating children is effective as they may pass this information on to their parents and families.

BU Awareness

The experts perceived the BU awareness among the people differently: One group stated that there is no awareness at all. Another group thought that the people are generally aware of BU and that it may be treated – but that they are not aware of the antibiotic treatment and its drugs in specific. A third group of experts stated that the people are aware of the antibiotic treatment with Streptomycin and Rifampicin.

The first group of interviewees who thought that the people in the villages did not have any idea of BU and its treatment or that they have not been educated argued that BU affected people would come earlier if they had known that there is treatment available – which is even free of charge. Some of them explained: *"It is only when they come to the facility that they get to know about it"*[140]. It was also said that some of the affected people neither know that BU may cause severe deformities, nor are aware of the consequences of a treatment delay. Therefore they wait until the lesion has developed into a big ulcer: *"They think try and come"*[141]. The interviewed clinician summed the thoughts of affected people up as follows:

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[137] Usually he tells the people that BU is not an evil disease and not caused by witchcraft, that it may not be transmitted from human to human and that they should report for early treatment.

[138] Expert Interview No. 9: 73-75

[139] Expert Interview No. 16: 193-204

[140] Expert Interview No. 19: 410-415

[141] Expert Interview No. 24: 635-646

> *"Once you can get the necrotic tissue out of the lesion, they are on their way to healing"*[142].

The second group of experts who thought that the people were generally aware of BU ascribed this to an increase in knowledge (e.g. early signs and symptoms) due to better information and awareness programmes: The people should know that they must not wait before reporting for treatment but still report to the herbalist for treatment instead of medical care because "*some may still do not believe what they have heard"*[143]. Due to the fear of surgery some of them still think: *"Surgery is the first recourse – when you go, it's operation"*[144] (compare with section *'Appeal of Treatment'*). It was said that there was a general awareness of some kind of medical treatment but no awareness of the specific kind of treatment: The people in the communities have no information how the treatment and which specific drugs are provided until they report to the health facility (e.g. CBSVs only tell the people to report to the health post; people who attended the film shows were likely to know that they have to take a certain medicine for 56 days but do not know the name of the drugs). Even some of the patients receiving treatment from the health post stated that they did not know the names of the respective *"drugs and injections"*. According to NGO staff the people were not yet aware to a level where they are explicitly aware of the drugs:

> *"Oh the national Buruli ulcer, you treat it with Rifampicin and Streptomycin. Make sure that when you go to the facility they continue the dose all that"*[145].

Only a few health workers and officials (third group) were certain that the awareness of the treatment for BU has been raised to a state where people know about Streptomycin and Rifampicin as they had organized durbars and sensitization activities in the communities of the research area.

All the other interviewees claimed that it should be promoted that people should report to the nearest health facility when they observe anything on their skin as the governmental health facilities provide antibiotic treatment free of charge: *"The earlier the people come the better"*[146]. The interviewed clinicians also felt the need to inform the people that not only the visible part but also the undermined skin is infected and that traditional care might go along with severe implications (e.g. tetanus infection, loss of a body part).

Cost of Treatment

The following sections summarize all narratives of the interviewees concerning the question of cost of BU treatment (cost of medical treatment vs. cost of traditional herbal treatment).

Cost of Medical Treatment

As was outlined in the interviews that in former times patients were supposed to pay for any kind of medical treatment (*'cash and carry system'*) so that even today statements such as *"medical treatment is sometimes attributed to the cost"*[147] are still prevalent conventional wisdom amongst the people in the research area, which refrains them from seeking early care (compare with *'Appeal of Treatment'*). This wisdom was also reflected in some observations by the experts (e.g. one of the CSBVs confirmed that one of the first questions of BU affected people is whether they have to pay for the antibiotic treatment). At the same time Ghanaians generally say that they are poor and therefore do not accept to pay for medical treatment as one of the interviewed teachers explained.

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[142] Expert Interview No. 24: 635-646
[143] Expert Interview No. 27: 461-465
[144] Expert Interview No. 13: 431-451
[145] Expert Interview No. 29: 518-542
[146] Expert interview No. 24: 675-679
[147] Expert Interview No. 11: 241-244

Although the antibiotics to treat BU are provided free of charge those patients who do not have a health insurance have to pay for any additional item (e.g. bandages and vitamins or *"iron drugs to boost up their immune system"*[148]) so that they may feel disappointed to buy their own bandages or normal saline:

> *"When they are coming you have to bring normal saline, and you have to bring your own bandage. You have to bring your own this and your own all that. So, that is one of the disincentives why people won't go to the facility"*[149].

Apart from the direct treatment costs itself the patients receiving treatment from a governmental health facility have to face a lot of inconvenience and opportunity costs (e.g. business or farming activities slow down). The interviewed clinician explained that loss of working time is a big problem: If BU affected people are unable to find the necessary resources to care for their condition they may abstain from seeking care. One of the nurses explained that BU affected people therefore often depend on their family (compare with section *'Age and Sex'*) and *"if they are not lucky they even die of hunger"*[150]. A further mentioned obstacle were the daily transportation fares to the health facility. The health providers reported that many of their patients complain that they do not have money for their transportation and therefore discontinue or interrupt their treatment:

> *"OK, I know I have to go. But then I haven't got the money now for the lorry fare"*[151].

For some patients, who were not able to sustain the regular antibiotic treatment on their own a Catholic sister or some nurses supported them with money for transportation. Some of the affected people also reported that either family or church members provide them support (e.g. provision of money, farm work etc.) Furthermore it was reported that hospitalized BU patients are confronted with another cost factor: additional feeding costs[152].

Cost of Traditional Herbal Treatment

The cost of traditional treatment was reported to vary from one healer to another and was considered to be untransparent: The interviewees explained that herbal doctors usually charge for their consultation. One of the interviewed herbalists explained that the payment depends on the severity of the disease:

> *"When you come with a sore like this it takes a longer time. But if it is getting earlier time then it is easy"*[153].

Some herbalists charge their patients before the provision of treatment to buy the necessary items. Others request regular instalments. Several interviewees mentioned costs between 50 pesewas (0.28€; US$ 0.37) for the treatment of a nodule and 30 to 200 GHC (€ 8,35 to 55,67; US$ 11 to 73.48) to heal a big ulcer (because it takes a long time to heal). It was reported that other healers or herbalists do not necessarily demand money for their consultation, but charge in kind (e.g. goats, sheep, chicken and all other sorts of animals):

"What I'll need maybe is a fowl. I'll treat you, but when you get treated you may come and thank me"[154].

The interviewed health workers explained that many BU affected people go to the herbalist because they think that it is *"cheaper"* to receive herbal treatment. In case a family member provides the herbal treatment it is mostly free of charge. One of the interviewed researchers

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[148] Expert Interview No. 2a: 124-130; Expert Interview No. 27: 686-693, 700

[149] Expert Interview No. 13: 360-384

[150] Expert Interview No. 27: 707-709

[151] Expert Interview No. 24: 305-309

[152] If a patient is hospitalised usually a family member stays in hospital to feed, clean, and wash the patient and his or her bed sheets and bandages. Most of the time the mother stays with a child in the hospital, which has a great impact on the family: These mothers may have to leave other children behind when she stays with the sick child and finds it difficult to feed both the child and herself.

[153] Expert Interview No. 33: 265-266

[154] Expert Interview No. 13: 348-358

explained that the opportunity costs of herbal treatment are often lower than for treatment from a governmental health facility and provided an example:

> *"If a Kenkey[155] seller has to leave the business and go and stay in hospital it will cost more than the payment to the traditional healer. Besides that the business may go on. In the end traditional treatment is far cheaper than going to the hospital for treatment"[156].*

5.2.4 Choice of Health Care Resources

The majority of the interviewed experts stated that the vast majority of BU affected people who report to the health post have tried other treatment options before without success and therefore consider the health post to be *'the last resort'*: In most cases the BU affected people register at the health post in a bad state. According to one of the health officials the same pattern of behaviour may be observed among Leprosy patients. He said: *"As long as their hands or feet are not deformed they consult a priest[157] or go to the herbalist"*[158]. Most narratives of the affected people confirmed this behaviour.

Nevertheless one of the health officials was optimistic and reported that nowadays some of the affected people report already in the pre-ulcerative stage. She believed that the people are now aware of BU and the fact that there is medical treatment available.

Therapeutic Itineraries

Most of the BU affected people use all kinds of herbal medicines or consult traditional or spiritual healers before they report to the health post. According to the experts, the *'typical course of a BU patient'* starts with self-medication, and only when the lesion gets worse and *"everything is getting out of hand"[159]* they report to a herbalist or traditional healer. Some of these people are taken to many different healers or facilities to have the disease cured. Some of them also combine herbal with medical treatment or use both options at the same time.

The interviewed experts explained that the exact patient delay may be very difficult or even impossible to assess as the affected people usually do not have a very precise perception of time and decide already at home what they will tell the health worker:

> *"When you go, tell them it is only three days"/ "When you go don't tell them it is four weeks, tell them it is only three days"*[160].

The interviewed clinician complained that the patients usually do not tell their *"real story"* to the health worker. The first story may differ from the one that they will tell when they are interviewed again. In the end they may tell a different version so that the health worker may only estimate the duration of delay.

No Treatment

Some of the BU affected people explained that they waited until the pre-ulcerative lesion had turned into a sore before they reported for treatment (compare with section *'Severity of the Symptoms'*). Other people simply thought that the lesion may heal by itself or stop using treatment in case the treatment is not successful after a long time so that the mother of an affected child may decide that: *"I have had enough of this treatment. Let's try something*

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[155] *Kenkey* is a staple dish of the Akan, Ga and Ewe tribes and a sourdough dumpling made from ground maize. Usually it is wrapped in banana leaves, cornhusks, or foil, and served with soup, stew, or sauce.

[156] Expert Interview No. 19: 380-386

[157] Expert Interview No. 30: 184-189

[158] Expert Interview No. 30: 332-335

[159] Expert Interview No. 11: 244-249

[160] Expert Interview No. 24: 368-373

else!"[161]. The interviewed clinician explained that this does not mean that the parents do not want to care for their children (compare with section *'Other Reasons'*):

> *"Probably they are just exhausted or out of resources and do not have the ability to carry on"*[162].

Self-Treatment

A further and very common scenario is that pre-ulcerative BU lesions are treated as a usual *'boil',* which people might have got through a bacterial infection. In this case the people use local preparations such as '*Tinkalo'*[163], which is commonly sold by traders who come to the villages or stay on markets:

> *"Tinkalo, Tinkalo, weyi eye ma pompo. Wode sra pompo noso pe oh three days na pompo no ahye"* [*Tinkalo, Tinkalo*, this is good for boils. When you smear it over a boil, oh just three days and the boil will vanish][164].

Further *'boil medicines'* were reported to be the bark of a tree, an ointment, or hot water. One of the teachers reported that some of the affected children hide their sore and avoid informing their parents. He said that they try to treat it by themselves and put a leave or smear saliva on it to protect the sore from flies until it develops into an ulcer and the parents recognize it. Another way how people treat their own lesion is to use medical drugs such as Chloramphenicol, Flucoxacillin, and Penicillin V, as was observed by one of the local health workers [165] or Ampicillin, as one of the interviewed patients stated. Painkillers such as Paracetamol were apparently also used, as one of the BU affected people stated (see section *'Drug Seller'*). According to a health worker people try these remedies and usually after two or three weeks the *'boil'* turns into an ulcer. After that the affected people either seek help from a spiritualist or a herbalist.

Traditional Healer

According to one of the interviewed researchers one may observe four different types of traditional BU treatment in Ghana: Some healers use pure herbs, others use other applications (e.g. grinded turtle shell, palm oil, *'bitters'* etc.); then there are those who use a mixture of herbal and other applications (*'herbalists'*). The fourth group uses spiritual rituals or other practices *"that are meant to appease, clean or do something spiritual"* [166] (*'spiritualists'*).

Three out of the four BU affected interviewees who had received herbal treatment at some point had received treatment through a family member. These *'healers'* had used (a mixture) of grinded herbs, which they applied on the lesion. In one case the herbalist had used a blade to cut the leg so that the herbs could easily penetrate into the body. Another affected person reported that the herbs were not only used to dress the wound but that they were also used to prepare a drink.

One interviewee stated that he had consulted a spiritualist, who bandaged the *'boil'* until it burst. Another interviewee knew from the hearsay that some people indulge the powers of the gods they believe in.

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[161] Expert Interview No. 24: 210-214

[162] Expert Interview No. 24: 160-171

[163] *,Tinkalo'* is moulded into a ball, will be grinded on a stone, then mixed with lemon juice and applied on the swelling. If it is a *"real boil"* it is supposed to burst within three days to one week.

[164] Expert Interview No. 2a: 235-239

[165] Some people use these drugs orally; others grind it and apply the powdered drug on the open sore.

[166] Expert Interview No. 24: 443-482

Governmental Health Facility

People who nowadays report to a governmental health facility and have a suspected BU lesion will receive Streptomycin and Rifampicin for 56 days. The health workers are requested *"not to rush into surgery"*[167] but try to give the antibiotics a chance to see whether the lesion heals without surgery. All BU affected interviewees had received antibiotic treatment for BU for some time, but not all of them reported with a pre-ulcerative lesion or completed the full course of 56 Streptomycin injections and Rifampicin capsules.

In case the health workers are not aware of BU or not able to diagnose it they may provide several injections or different kinds of drugs with the hope that the lesion heals. This practice was confirmed by some of the affected interviewees.

Drug Seller

Some people in the communities prefer buying some of the above-mentioned drugs from the chemical shop as it requires less time than reporting to a health facility. Here they may also receive basic recommendations from the drug-seller. Sometimes even the CBSVs recommend buying certain drugs from the chemical shop.

Church/ Prayer Camp

Some BU affected people attend prayer camps or consult spiritualists and churches for prayers rather than to report to a governmental health facility. The health worker from the health post deplored that the people have a strong belief in priests and prayer camps because some pastors have claimed that they may cure any disease through prayers and fasting. He knew that the people are put in a small tent are and then told to fast. Usually these priests usually charge their patients by collecting certain items (e.g. goats, chicken, and clothes) or money from them. It was said that the patients stay in the camp until the sickness is getting better. One of the research assistants explained that some pastors even preach beliefs, practices and doctrines, which restrain people from reporting for medical treatment.

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[167] Expert Interview No. 23:111-112

5.3 Results – KAP Survey

The KAP survey allows quantifying the information on the different aspects of health-seeking behaviour, which were assessed and described during the expert interviews. Furthermore the specific objectives of this survey were (1) to assess socio-demographic characteristics of (previously) BU affected people, (2) to understand knowledge, attitude and practice of (previously) BU affected people with regard to the disease and to assess heterogeneity within the sample of (previously) BU affected people in terms of background characteristics. Two individual characteristics may be particularly relevant in this regard: (3) gender and (4) age. Whereas no remarkable differences between male and female participants could be observed (see Annex C), for some questions age did matter. The analysis of certain characteristics will therefore differentiate between respondents up to and above the age of 15. Furthermore the survey aimed at (5) determining characteristics of (previously) BU affected people who delayed medical treatment and reported only when the lesion was already ulcerated and therefore might be considered as *'Late Care-Seekers'*. And last but not least the study was designed to (6) determine differences between (previously) BU affected people and matched non-affected community members.

In total 244 people (122 (previously, N = 77) BU affected and 122 non-affected participants who were matched for age[168] and sex) were included in the analysis of this study. The data was analysed according to the evaluation plan (see Annex C), and the respective results are described according to the specific objectives (1) to (6). Tables displaying the results (characteristics of the study population) of the analysed data – including a list of the variables – are located in Annex C.

5.3.1 Characteristics of (previously) BU affected People (objectives 1 to 4)

The results with regard to the specific objectives 1 to 4 are presented according to the structure of Kroeger's framework. In case significant differences were assessed for age these findings are included into the results.

Predisposing Factors (Social and Cultural Background)

The *'Predisposing Factors'* include information about *'Age and Sex'*, *'Household Characteristics'*, *'Ethnic Group and Religion'*, *'Formal Education'*, *'Occupation'*, *'Assets'* as well as *'Social Interactions'*. These were found to be as follows:

By the time of infection the BU affected study participants were on average 27.7 years old (SD = 22.0 years; min: 3 years; max: 102 years) (see Figure 19).

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[168] Study participants up to the age of 18 years were matched with a non-affected person within an age range of maximum two years. Study participants who were older than 18 years were matched with a non-affected person within an age range of maximum five years.

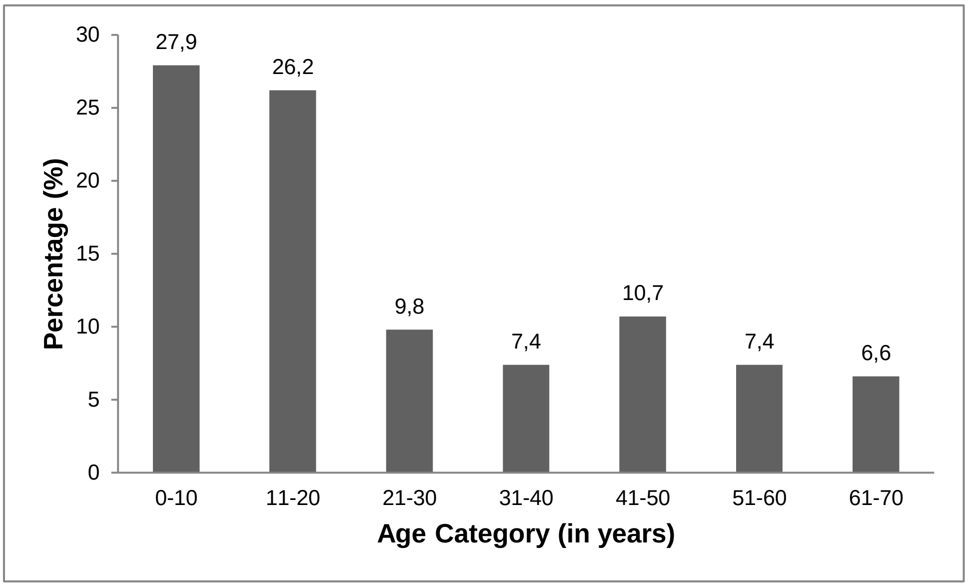

FIGURE 19: Age Distribution of (previously) BU affected People in the Study Area (by Time of Infection); rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants (several options permitted)
Source: own Data

The following table (Table 11) summarizes the distribution of *'Predisposing Factors'* among the (previously) BU affected study participants.

TABLE 11: Distribution of Predisposing Factors among (previously) BU affected People in a rural Sub District of the Eastern Region, 2010, N = 122

Characteristic	(Previously) BU affected in No.	(Previously) BU affected in %
Sex		
Male	59	48.4
Female	63	51.6
Number of People in Household		
1-5	38	31.1
6-10	61	50.0
11-15	12	9.8
16-20	4	3.3
21-25	1	0.8
"Many"	6	4.9
Marital Status of Study Participants * **≥ 18 years, N = 67**		
Single	27	40.3
Married	40	59.7
Divorced	3	4.5
Widowed	9	13.4

* several options permitted

TABLE 11: Distribution of Predisposing Factors (continued)

Characteristic	(Previously) BU affected in No.	(Previously) BU affected in %
Number of Children in Household		
No children	9	7.4
1-2	29	23.8
3-4	40	32.8
5-6	28	23.0
7-8	12	9.8
9-10	3	2.5
> 10	1	0.8
Mother Tongue		
Twi (Akan) [169]	54	44.3
Ewe [170]	52	42.6
Other	16	13.1
Religion		
Christian	106	86.9
Muslim	4	3.3
None	11	9.0
Traditional	1	0.8
Highest attained Education Level (participants ≥ 6 years), **N = 116**		
No formal education	39	33.6
Primary school	37	31.9
Junior Secondary School (JSS)	32	27.6
Senior Secondary School (SSS)	7	6.0
Post-Secondary	1	0.9
Occupation (participants > 15 years), **N = 75**		
Student/ pupil	13	17.3
Farming	40	53.3
Unemployed	8	10.7
Trade and commerce	6	8.0
Other	8	10.7

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[169] People from the Akan tribe commonly used expressions such as *Dufunu* [cut down near rotten tree], *Kissikru* [sore that never heals] *and Kukuram* [dangerous sore – cancer] as local names for BU.

[170] The Ewe speaking population mentioned *Detifudɔ* [cotton disease], *Abi vɔdi* [bad sore], and *Dɔgbara* [bad disease].

TABLE 11: Distribution of Predisposing Factors (continued)

Characteristic	(Previously) BU affected in No.	(Previously) BU affected in %
Money for Food, Water and Transportation per day and household		
1-5 GHC	57	46.7
6-10 GHC	45	36.9
11-15 GHC	6	4.9
> 15 GHC	3	2.4
Don't know	10	8.2
No answer	1	0.8
Mean 7.17 GHC; SD= SD = 4.20 GHC		
Main Source of Income of Household *		
Farming	103	84.4
Trade and Commerce	38	31.1
Other	14	11.5
Don't know	4	3.3
Frequent Means of Transport *		
Trotro (local bus)	105	86.1
Taxi	59	48.4
Walking	60	49.2
Treatment Recommendation		
Nodule (N = 94)	38	40.4
Plaque (N = 7)	7	100.0
Oedema (N = 20)	14	70.0
Ulcer (N = 100)	61	61.0

Source: own Data

* several options permitted

The importance of social interaction for the choice of the respective health care resource was acknowledged by the (formerly) BU affected study participants: The majority of those who reported that they had an ulcer on their skin had received treatment recommendations by family members, friends, colleagues, herbalists, CSBVs, health personnel, foreigners, assemblymen or teachers.

Characteristics of BU and Disease Perception

This section describes the characteristics of BU lesions, which were encountered among the 122 (previously) BU affected study participants (*'Severity of the Symptoms'*). Furthermore, the *'Aetiological Model'* of the study participants as well as psychosocial aspects of the disease (*'Stigma/ Social Exclusion'*) are illustrated.

Chronic or Acute

By the time of research the most prominent type of lesion in the study area were old healed lesions (63%), followed by active (pre-ulcerative or ulcerative) lesions (26%) and chronic lesions (11%). About 15% of the study participants had pre-ulcerative lesions (nodule, oedema or plaque). 23% reported that they had multiple lesions; most prominent lesion sites were lower limbs, followed by the upper limbs (see Annex C).

Aetiological Model

The people's perception of the aetiology was assessed by asking questions on the knowledge of the onset of the disease, the knowledge of BU specific symptoms, the perceived cause of the disease as well as the perception of preventive measures.

88% of the (previously) BU affected study participants stated that they are aware of the symptoms of the disease: Almost 80% were aware that nodules are an initial and specific symptom of BU; 11% knew about the oedema, 7% mentioned the plaque and 3% thought that the ulcer was the initial form of the disease.

More than 40% of the study participants were not able to ascribe the origin of their infection to a specific cause. Besides this the major perceived causes of the disease were *"drinking water from lakes and rivers"*, *"swimming and wading in rivers or stagnant water"*, *"rainwater"* or a *"lack of personal hygiene"* (compare with Figure 20).

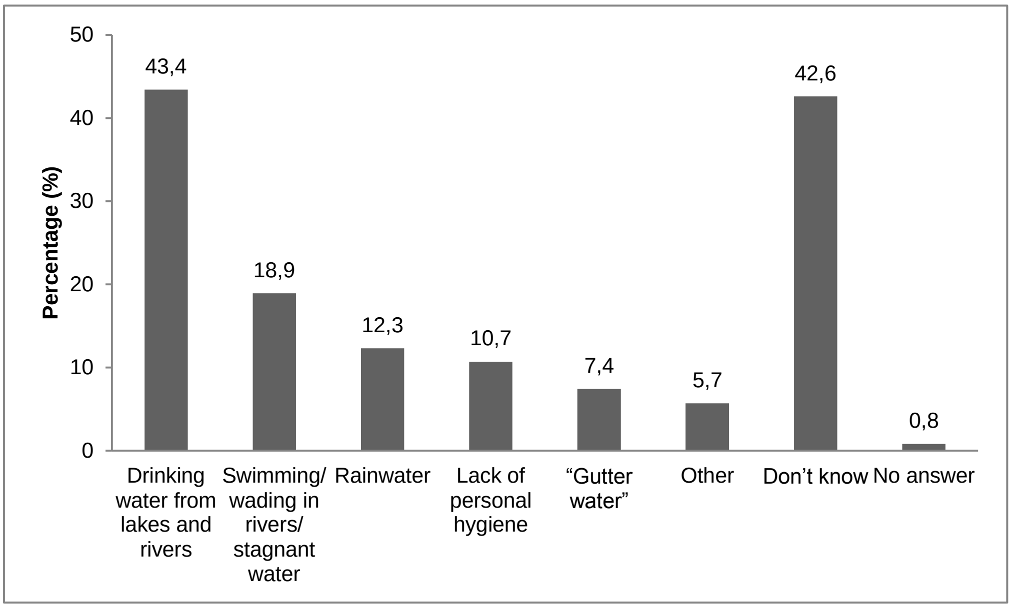

FIGURE 20: Perceived Causes of BU among (previously) affected People in the Study Area (Rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants (several options permitted))
Source: own Data

Differences by generation (people up to 15 years and those above 15 years) were assessed using Chi-square tests, which allowed to assess significant differences in the perception of the cause of the disease ($p < 0.05$) between the generations (several options permitted): The study participants up to 15 years were more likely to believe that *"drinking water from lakes and rivers"* (55% vs. 36%; $p = 0.036$), *"swimming/ wading in rivers and stagnant water"* (32% vs. 11%; $p = 0.003$), *"rainwater"* (21% vs. 7%; $p = 0.023$) as well as a *"lack of personal hygiene"* (21% vs. 4%; $p = 0.005$) might cause BU than people from the older generation, who more often stated that they *"don't know the cause of the disease"* (53% vs. 26% $p = 0.003$) (for more details see Annex C).

Almost 55% of the 122 (previously) BU affected participants stated that they knew at least one way to prevent BU; 38% were not sure (*"don't know"*) and 7% did not know any means. Most commonly mentioned preventive measures were to avoid wading in rivers/mud or dirty *"gutter water"* (25%). Others thought that drinking clean or purified water (14%) helped to prevent BU, that cleanliness of the environment (6%) or observing hygiene and covering food (4%) helps to prevent BU. In this context it was found that the younger generation was more likely to believe that they knew preventive measures to protect themselves against BU (p = 0.002; see Figure 21).

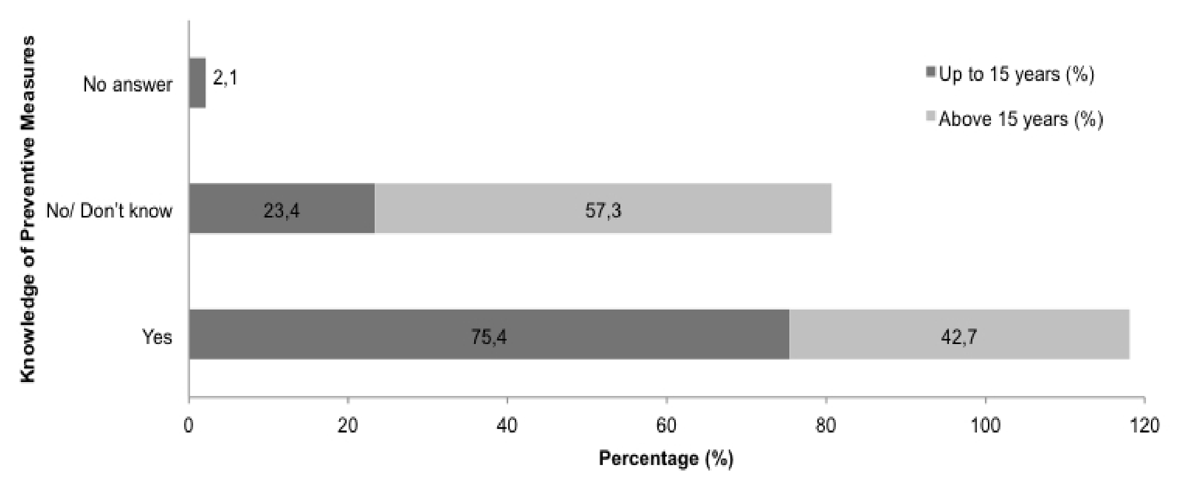

FIGURE 21: Knowledge of preventive Measures for BU by Generation in the Study Area (rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants)
Source: own Data

Stigma/ Social Exclusion

Probable *'Stigma/ Social Exclusion'* of BU affected people within the study area as perceived by the (previously) affected study participants was assessed with five questions: The majority (62%) of the study participants had the impression that they were encountered with full sympathy. 24% stated that they were partially treated with sympathy, 7% with unsure sympathy, and 5% with no sympathy (see Annex C).

Regarding the question whether BU patients are welcome to attend social functions the majority agreed that they were accepted (75%). Most important reasons for being welcome (N = 91) were: *"everybody is welcome to attend"* (22 (24%)), *"it depends on the patient him-/ herself and on the severity"* (21 (23%)), the fact that *"people do not want to exclude them"* (12 (13%)) as well as that *"they may attend if they are able to walk"* (8 (9%)). Those, who thought that BU affected people are not welcome (N = 24) argued (open text field): *"BU smells"* (5 (22%)), *"BU is a severe disease"* (5 (22%)) or mentioned circumstances that *"BU patients cannot walk"* (3 (13%)) and *"suffer from pain"* (3 (13%)).

The majority (63%) of the interviewees answered that BU affected children do not attend school. Only 31% stated that children should be allowed to do so, and about 6% were not sure whether it is possible. Given comments for an interruption of school attendance (N = 77) were (open text field) that the children *"may only continue schooling after the lesion is healed"* (34 (44%)), *"BU affected children may not be able to walk."* (12 (16%)), *"BU affected children suffer from pain."* (11 (14%)) and the assumption that *"BU is a severe disease."* (7 (9%)). Those who thought that BU does not hinder pupils from attending school (N = 38) stated (open text field) that pupils continue schooling *"if the disease is not so serious"* (10 (26%)), and *"when it is treated easily"* (7 (18%)). Some simply stated that *"education is important and children need to study"* (4 (11%)). Others said that *"some children attend school"* (4 (11%)) despite being affected, or that *"children attend school if they are not deformed or disabled"* (4 (11%)). For this question it was found that the study participants above 15 years were more likely to believe that BU affected children do not have to interrupt their education (39% vs. 19%; p = 0.003).

The interviewees were divided over the question, whether BU patients may be accepted as a leader: 44% of the BU affected respondents believed that it was not possible and 43% stated that they were not sure about that. Only 12% said that they believed that a BU patient may be a leader. These statements were based on the background (N = 54, open text field) that *"A sick/ deformed person cannot become a leader."* (13 (25%)), or *"cannot lead healthy people"* (11 (21%)). *"Tradition doesn't allow"* (8 (15%)). *"Sick people cannot work well"* (5 (9%)). *"BU has to heal completely"* (4 (8%)); as well as the fact that *"BU patients won't be elected."* (3 (6%)).

About half of the study participants who were 18 years or older (N = 85) thought that BU might have an impact on sexuality: 34% were not sure and only 13% stated that BU would not influence this aspect of the life.

Enabling Factors (Health System Characteristics)

In order to assess the local infrastructure (*'Accessibility'*) as well as the performance (*'Appeal of Treatment'* as well as *'Acceptability and Quality of the available Health Services'*, *'Health Education and Communication'*) of the existing health system several questions were posed to the (previously) BU affected people.

Accessibility

The majority of the (previously) BU affected respondents stated that they either walked (57%) or used local transport (64%) (several options permitted) and needed 29 min on average (SD = 23 min, min: 0 min; max: 120 min) to reach the nearest health facility.

Appeal of Treatment

The perception of antibiotic treatment was elicited with an open question. 19% of the previously BU affected people stated that they did not know about the antibiotic treatment; 23% gave no answer to this question. The other interviewed people answered: *"It heals the ulcer"* (18%), *"It is very good"* (14%), *"It includes too many injections"* (16%), or *"It has side-effects"* (9%).

Acceptability and Quality of available Health Services

The general satisfaction of the (previously) BU affected study participants with the local health care facilities was considerably high (71%). Only 12% stated that they were not satisfied. Most important reasons for their satisfaction (N = 87, open text field) were that the health workers *"take good care"* of the patients (40 (46%)), that *"they receive patients well/ do their best"* (30 (34%)), that they got healed (6 (7%)) or that the health workers *"are very patient"* (4 (5%)). Mentioned reasons for dissatisfaction (N = 15, open text field) were that *"the nurses/ health workers are impatient/ do not take particular attention"* (5 (29%)), *"the provided medicine does not serve the people"* (3 (18%)), *"health workers don't have time for patients"* (2 (12%)), the fact that there were *"drug shortages"* at the facility (1 (6%)) or that the participants were generally reluctant to report to hospital (1 (6%)).

Health Education and Communication

The results of the survey show that the majority of the (previously) BU affected study participants had heard about BU (71%); but still 29% stated that they had never received any official or specific information about the disease. Most of the (previously) affected people only got to know about the disease through their personal infection (69%), through friends and neighbours (34%), or through family members (27%) (several options permitted). The analysis revealed that (previously) BU affected study participants above 15 years were more likely to only hear about the disease due to their own infection (79% vs. 53%; p = 0.003). The younger generation was more likely to get to know about BU from friends and neighbours (45% vs. 28%; p = 0.059) as well as from their family members (43% vs. 16%; p = 0.001) (for more details see Annex C).

About 75% of the (previously) BU affected study participants were aware that hospitals/ clinics provide antibiotic treatment for BU, 62% mentioned wound care and 6% surgery as being the respective provided treatment.

A further question assessed whether the (previously) BU affected study participants had lately received BU specific information: 43% of them had received information about the disease within the last six months but 56% had received no information. Those who were lately informed (N = 52 (previously) BU affected study participants) attended a video show in the village (organised by a local NGO; 21 (40%)), were informed by health workers and nurses (20 (39%)), saw respective posters or pamphlets (9 (17%)) or heard about it via radio (4 (8%)). Study participants up to 15 years stated more often that they had lately (within the last six months) received information about the disease (55% vs. 35%; p = 0.033).

Only 13% of the (previously) BU affected study participants were satisfied with the specific health information they had received. Most desired topics (open text field) were information about preventive measures/ mode of transmission (29%); an efficient treatment/ permanent cure (10%), and early symptoms/ disease progression (6%). Study participants older than 15 years were less likely to state that they had not sufficient information about BU (56% vs. 38%; p = 0.018; see Figure 22).

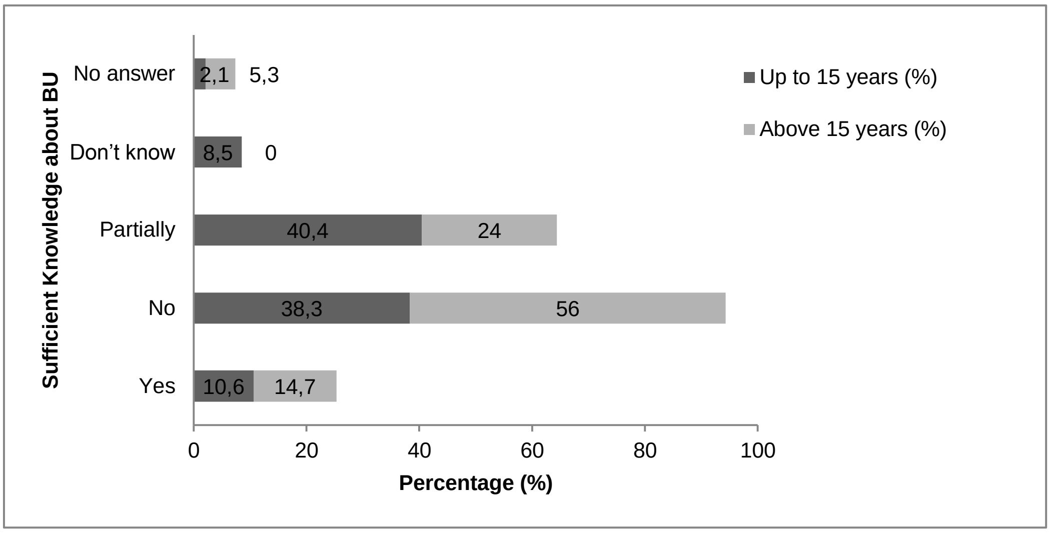

FIGURE 22: Perception of sufficient Knowledge about BU by Generation in the Study Area (Rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants)
Source: own Data

Cost of Treatment

The perception of how the cost of medical treatment for BU is taken care of was assessed with an open question: The answers ranged from *“medical treatment is provided for free”* and *“payment for treatment”* to partly free treatment (i.e. *“some people pay – others not”*, *“payment for transportation, additional drugs/ medicine or dressing material”*). About 15% had no idea whether one has to pay for the treatment or not.

The most important aspect of indirect costs for medical treatment are the travel costs to the facility to regularly receive the antibiotic therapy. About 40% of the (previously) BU affected study participants reported that they had no travel costs when they sought medical care because it was only a walking distance away from their home. The average travel costs of the people who could not walk to the health facility (N = 73) were 38 Pesewas (0.20€, $0.27) (SD = 0.44 GHC; min: 0 Pesewas; max: 3 GHC).

By the time of research only 34% of the (previously) BU affected people reported that they had a valid health insurance, which would cover the provision of additional drugs and bandages[171]. Most commonly mentioned reasons for not having a valid insurance card were (several options permitted): *“No money”* (51%), *“too expensive”* (44%), *“never used it”* (29%), and *“expired/ forgot to renew”* (11%).

Choice of Health Care Resources

Not all of the (previously) BU affected people reported to a health post/ hospital for treatment: some did not use any treatment option; others had tried to treat the disease themselves, reported to an herbalist, a spiritualist or sought help in a church/ prayer camp. All these health care resources are not necessarily accessed exclusively but sometimes at the same time.

Therapeutic Itineraries

After displaying the respective WHO pictures to the study participants 77% of the (previously) BU affected study participants (N = 94) were able to recall that they had observed a nodule on their skin and remembered which kind of treatment they had used (see Figure 22). The remaining 26 participants did not encounter a nodule on their skin or were not able to recall this situation. Only seven of the (previously) BU affected study participants were able to recall that they had observed a plaque and 20 an oedema. 100 study participants had observed ulcers on their body and reported which treatment option they had chosen (see Figure 23).

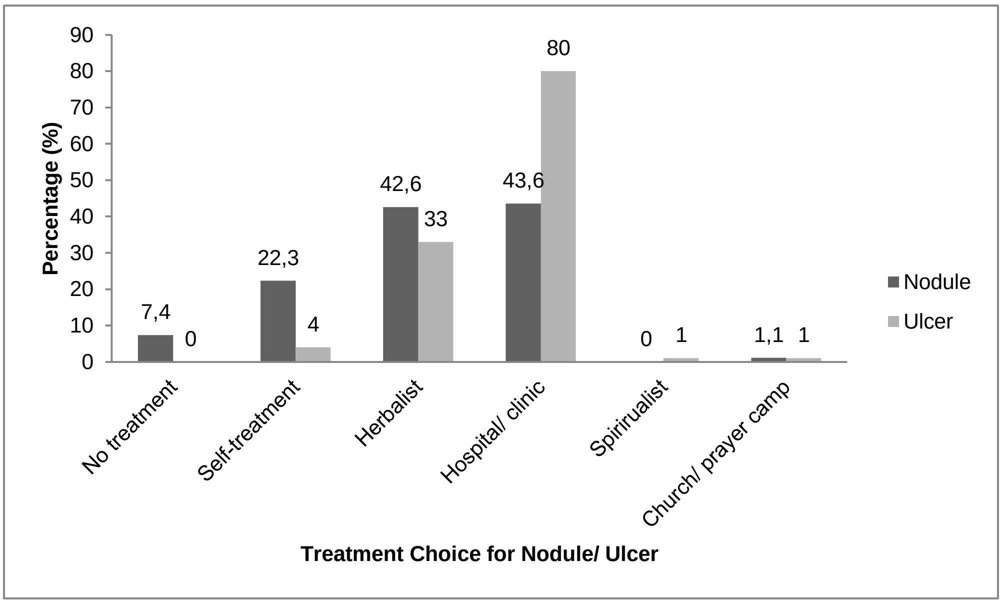

FIGURE 23: Choice of Treatment for BU suspected Nodules (N = 94) / Ulcers (N = 100) among BU affected People (several options permitted)
(Rural Sub District of the Eastern Region, 2010; (previously) BU affected Study Participants)
Source: own Data

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[171] The possession of a health insurance would reduce the costs of BU treatment on the travel aspect.

Self-Treatment

For the treatment of nodules several self-treatment techniques were described: either the placement of a towel, which was soaked in hot water, or the application of *“boil medicine”*/ the content of penicillin capsules/ shea butter mixed with ash. One interviewee had used *‘Ekuro Bewu’* [a locally sold ointment] to treat a plaque. For the ulcer the interviewees reported that they had used hot water for the treatment.

Traditional Healer

Some interviewees explained the practice of traditional herbal treatment for the respective stages of their disease in detail (open text field): It was described that a herb or a mixture of herbs[172] was applied on nodules until they burst and the *“cotton wool”* (necrotic tissue) came out. Other ways of treating nodules by herbalists were to *“cut it through”* or to apply a mixture of tortoise and snail shell.

For the treatment of plaques it was reported that some herbs were mixed and applied on the lesion and then tied with a bandage. Alternatively an unspecified herbal medicine from the local market was ground with water and then applied on the plaque.

For oedemas three different techniques of herbal treatment were described: Either the application of a mixture of herbs (e.g. *‘Dufani’*) on the *“swell”*, or bathing the oedema in an infusion of herbs. The third reported technique was to pound *‘Nyamedua’* root, mix it with water and then apply it on the lesion.

For the treatment of ulcers the study participants described four different techniques: Some people applied a mixture of herbs until it healed. Others cleaned the lesion with an herbal infusion; a further group smeared a herbal mixture on the sides of the wound or spread boiled leaves over the ulcer.

Governmental Health Facility

The specific treatment in governmental health facilities was known and described respectively by some of the interviewees: For nodules it was reported that some patients underwent an unspecific antibiotic treatment, some the BU specific treatment with *“pills and injections”* (Streptomycin and Rifampicin); others were in need of a surgical intervention. Those who were able to give a specific report about the treatment of their plaque recalled *“pills and injections”* (Streptomycin and Rifampicin) as well as skin grafting.

For oedemas antibiotic treatment with Streptomycin and Rifampicin as well as dressing were reported.

For the treatment of ulcers not only the treatment with Streptomycin and Rifampicin – combined with dressing – was described, but also surgery as well as amputation.

Church/ Prayer-Camp

The consultation of a pastor for the treatment of oedemas as well as well as ulcers was mentioned: the interviewees reported that the pastor prayed for the patient and also provided an unspecified treatment.

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[172] Specific names of these herbs were: *'Megbezzli', ‘Aflaki’, ‘Gboti', ‘Afideme’, 'Akidi/ Kpanukeke’, ‘Agalagbe',* pawpaw leaves, *‘Ahame’, ‘Tweenteen’* root, *'Atsiakyrnakpa', 'Danumegbe'* and *‘Duasudua’.*

5.3.2 Characteristics of Late Care-Seekers (objective 5)

The characteristics of *'Late Care-Seekers'* ((previously) BU affected study participants who sought medical care only for ulcerated BU lesions, N = 63) were tabulated by cross-tables and assessed by using Chi-square test respectively. Furthermore the odds-ratio (OR) and the respective p-value were calculated. The results according to the evaluation plan (see Annex C) are described in the following sections.

Predisposing Factors

The *'Late Care-Seekers'* did not differ significantly for age (28.8 years vs. 26 years on average). They were living in households with fewer members (6.9 vs. 8.3 on average) and had fewer children (3.4 vs. 4.2 on average; no significant difference). Nevertheless 37% of the *'Early Care-Seekers'* lived in households with more than four children and had a 39% lower odds of late reporting, compared to the *'Late Care-Seekers' where* 35% of the households had more than four children (OR 0.391; 95% CI 0.189-0.812; P = 0.012).

A significantly different characteristic of *'Late Care-Seekers'* as opposed to *'Early Care-Seekers'* was that the former more often considered walking as their common mean of transport (60% vs. 37%). A higher likelihood of late reporting could be identified (OR 2.1; 95% CI 1.232-5.036) for those who consider walking as a common mean of transport.

Another significant characteristic was the social interaction of *'Late Care-Seekers'*: 30% of them who had observed a nodule sought advice/ received recommendations from other people. Yet 50% of the study participants who sought early medical advice had received recommendations. This proportion was opposite for those who reported for treatment with an ulcer (see Figure 5.14; OR 18.6; 95% CI 6.265-55.432 P < 0.001), where 42% of those who sought early medical care had received recommendations (71% of the *'Late Care-Seekers'*). *'Late Care-Seekers'* were also found to more often decide on their own about treatment for general conditions (49%; OR 2.4; 95% CI 1.131-5.063; P = 0.022) than those who sought early medical care (29%).

Characteristics of BU and Disease Perception

There was no significant characteristic regarding the knowledge of BU symptoms or the perceived cause of the disease between *'Late'* and *'Early Care-Seekers'*. Nevertheless *'Late Care-Seekers'* were less likely (43% vs. 68%) to state that they knew preventive measures to protect themselves against BU (see Figure 24 and Annex C).

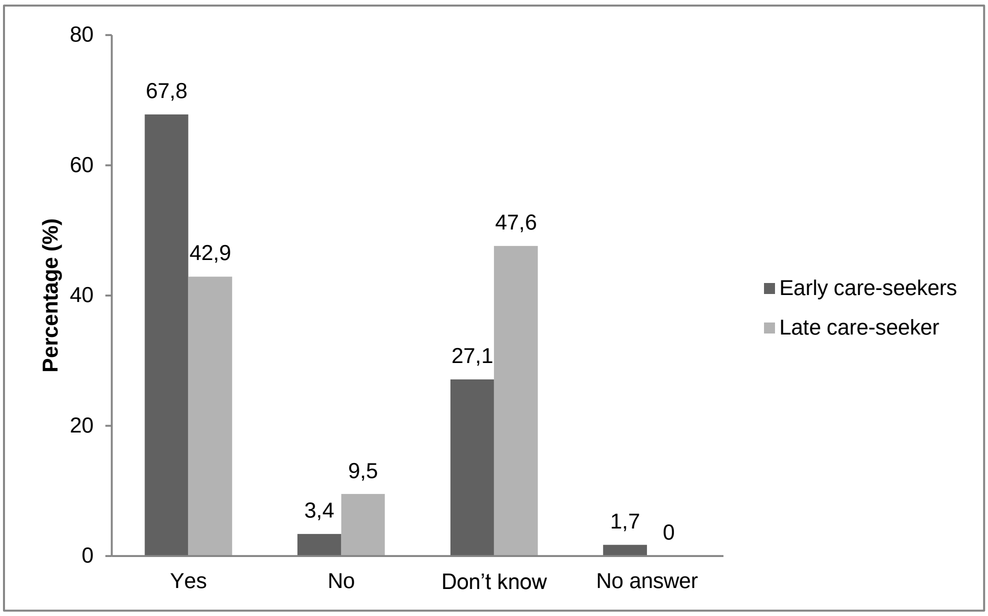

FIGURE 24: Knowledge of preventive Measures – 'Early Care-Seeker' vs. 'Late Care-Seeker' (rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants)
Source: own Data

The aspect *'Stigma/ Social Isolation'* was a further characteristic which differed between *'Early'* and *'Late Care-Seekers'*: Although 87% of the *'Late Care-Seekers'* stated that they were welcome to attend social functions while being BU affected (*'Early Care-Seekers'* 70%) they had a 2.9 times higher probability of late reporting (95% CI 1.028-5.081; P = 0.027) (see Figure 25).

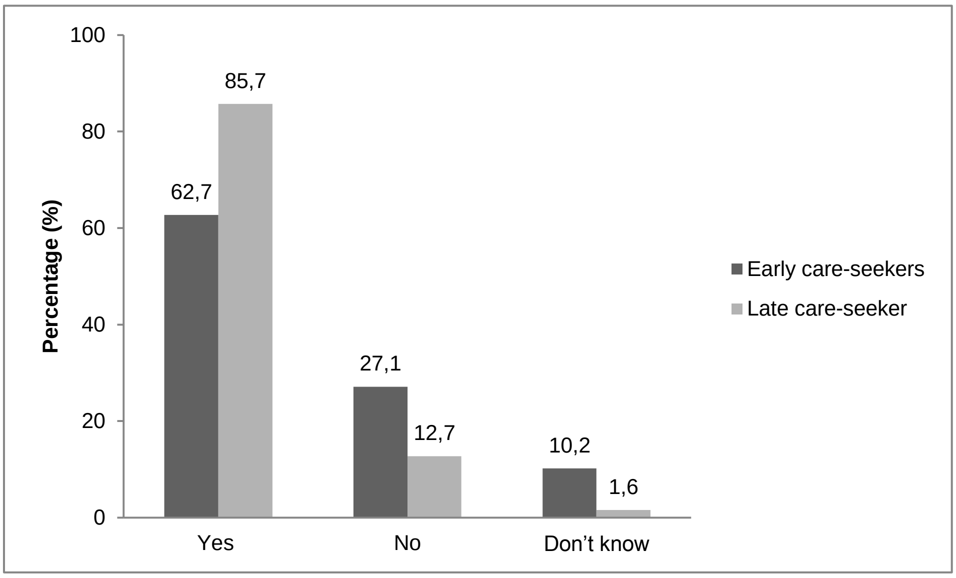

FIGURE 25: Perception of BU Patients' Welcome at social Functions by *'Early Care-Seekers'* and *'Late Care-Seekers'*; (rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants)
Source: own Data

For the question whether BU affected children continue schooling 76% of the *'Late Care-Seekers'* thought that these children were not able to further their education (*'Early Care-Seekers'* 58%) so that they had a 2.3 times higher probability of late reporting (95% CI 1.028-5.081; P = 0.043).

Enabling Factors (Health Service Characteristics)

For the aspect *'Accessibility'* it was found that *'Late Care-Seekers'* had to use public transport more often to reach the health facility (65%) than those who reported early (48%): Therefore (previously) BU affected people who had to use public transport to access medical treatment had a 2.1 times higher probability of late reporting (95% CI 0.997-4.271; P = 0.051). Significant differences were also found for the aspect *'Health Education and Communication'* (see Figure 26):

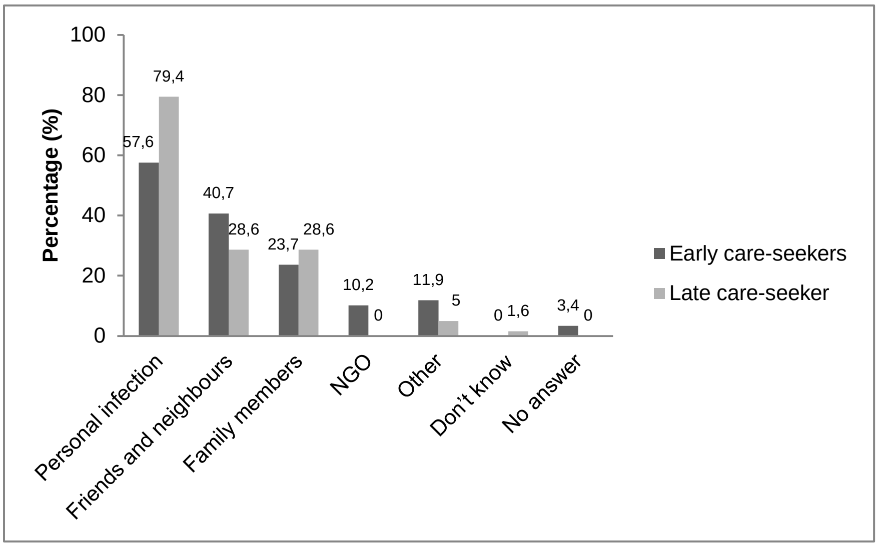

FIGURE 26: Source of Information regarding BU – Early Care-Seeker vs. Late Care-Seeker; (rural Sub District of the Eastern Region, 2010; N = 122 (previously) BU affected Study Participants (several options permitted))
Source: own Data

'Late Care-Seekers' more often got to know about BU through their own infection than *'Early Care-Seekers'*, which was associated with a 2.8 times higher probability of late reporting (95% CI 1.272-6.290; P = 0.011). None of them had received information by the local NGO.

The perception about the local health facilities was better among *'Early Care-Seekers'* with 96% being satisfied (*'Late Care-Seekers*' 74%; OR 0.1; 95% CI 0.023-0.511; P = 0.005).

A further assessed aspect was the perception of *'Cost of Treatment'* for BU: While 80% of the *'Early Care-Seekers'* thought that the antibiotic treatment is *"provided for free"* only 67% of the *'Late Care-Seekers'* agreed with this statement (OR 0.315; 95% CI 0.134-0.742; P = 0.008).

Choice of Health Care Resources

The *'Therapeutic Itineraries'* of *'Early Care-Seekers'* differed significantly from those who sought late care. *'Early Care-Seekers'* generally used less self-treatment (6% vs. 39%) and herbal treatment (33% vs. 52%) for nodules than *'Late Care-Seekers'* (several options possible).

5.3.3 Differences between (previously) BU affected People and the matched non-affected Population (objective 6)

The results with regard to differences between (previously) BU affected (N = 122) and the matched non-affected study participants (N = 122) were tabulated by cross-tables and assessed by using Chi-square tests respectively. The results according to the evaluation plan (see Annex C) are presented below.

Predisposing Factors (Social and Cultural Background)

The two groups did not differ significantly (p > 0.05) with regard to the socio-demographic background/ predisposing factors (number of children, marital status, ethnic background, religion, education, occupation and assets).

Characteristics of BU and Disease Perception

The perception of the *'Aetiological Model'* differed significantly between (previously) BU affected participants and the non-affected ones: The non-affected study participants were less likely to be aware of the initial symptoms than the (previously) affected people (60% vs. 88%; p = < 0.001) (see Figure 27). Furthermore they were less informed about specific BU symptoms (i.e. nodule and oedema) than (previously) infected study participants (see Annex C).

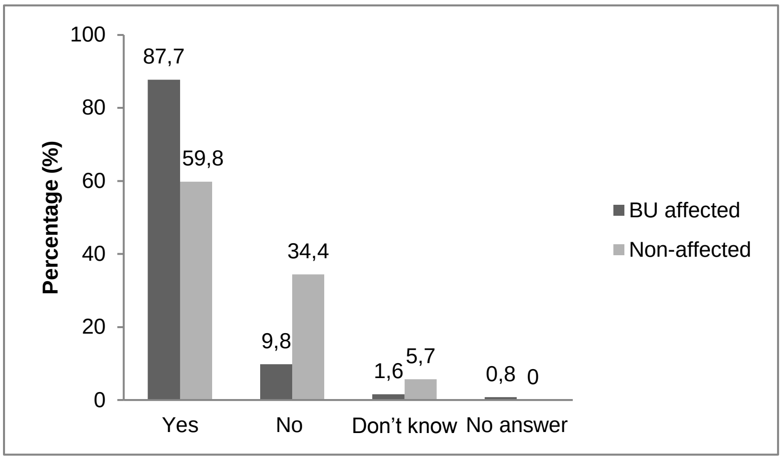

FIGURE 27: Knowledge of initial Symptoms of BU – BU affected vs. non-affected people; rural Sub District of the Eastern Region, 2010; N = 244 Study Participants)
Source: own Data

The perception of the cause of the disease and probable preventive measures did not differ significantly between the groups. Yet significant differences were found for the aspect *'Stigma/ Social Isolation'* (p = 0.024): Here the (previously) BU affected participants stated more often that BU affected people were welcome to attend social events than the non-affected ones (see Figure 28).

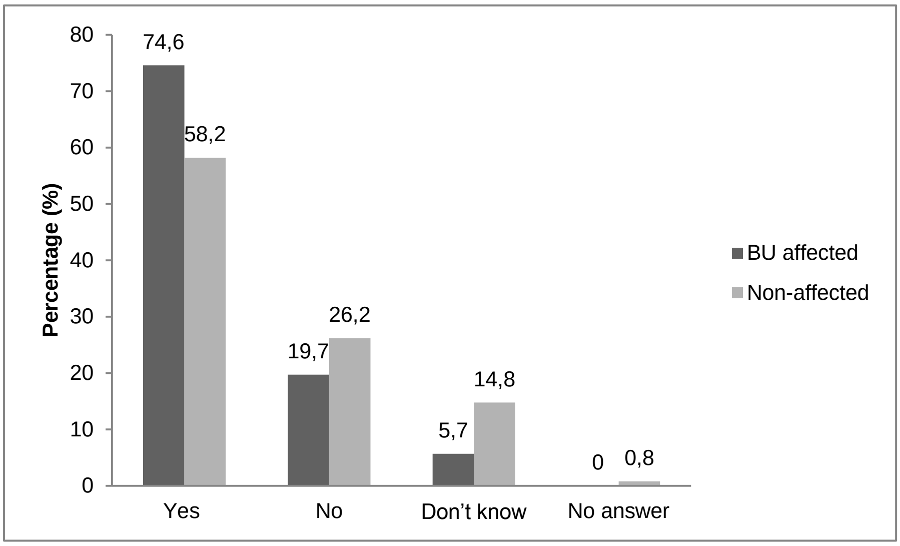

FIGURE 28: Perception of BU affected People's welcome at social Functions – BU affected vs. non-affected People (rural Sub District of the Eastern Region, 2010; N = 244 Study Participants)
Source: own Data

Enabling Factors (Health Service Characteristics)
Significant differences between (previously) BU affected participants and the non-affected participants could be identified for *'Appeal of Treatment'*: (Previously) BU affected study participants were more likely to state that they do not seek medical care for general diseases (e.g. because *„Herbalists know the right treatment."*) than the non-affected study participants (6% vs. 2%; p = 0.034).

An open question was used to gather the perception of antibiotic treatment for BU. (Previously) affected study participants were better informed and more likely to give both positive (*"It heals the ulcer." "It is very good."*) and negative reasons for a treatment (*"It includes too many injections." "It has side-effects"*). More than half of the non-affected study participants gave no answer ((previously) BU affected 23%); one third stated that they did not know anything about the antibiotic treatment for BU ((previously) BU affected 19%; for more details see Annex C).

(Previously) BU affected study participants were generally better informed about the respective treatment in a governmental health facility and were more often able to name the different medical treatment options (see Figure 29).

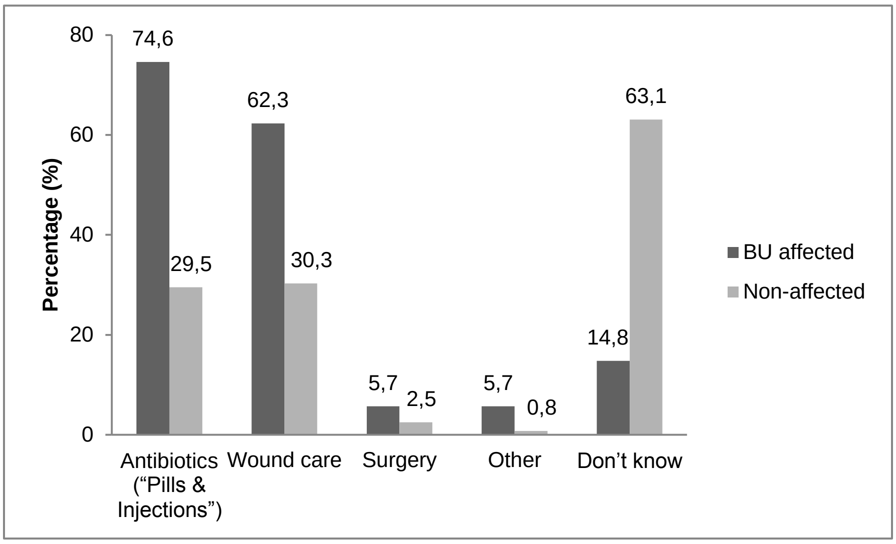

FIGURE 29: Understanding of how BU is treated in a Governmental Health Facility – BU affected vs. non-affected People; rural sub district of the Eastern Region, 2010; N = 244 Study Participants (several options permitted))
Source: own Data

The fact that BU may be treated with antibiotics (Streptomycin and Rifampicin) was not known by all study participants, and the understanding of how BU is treated in a governmental health facility differed significantly between (previously) BU affected people and the non-affected ones: 63% of the non-affected respondents stated that they were not aware of the available treatment options for BU in the health facilities (affected: 15%; p = < 0.001). Only some 30% of the non-affected study participants were aware of the antibiotic treatment and the respective wound care for BU in the health facilities (p = < 0.001; see Annex C).

The analysis of the data about the perception of *'Cost of Treatment'* (open question) showed that it differed significantly between the two groups of interviewees (p = < 0.001): (Previously) BU affected people were obviously more likely to state that *"medical treatment is provided for free"* (61% vs. 34%) or explain for which services they had to pay (e.g. for transportation, bandages, additional drugs etc.) than the non-affected people (14% vs. 7%). Almost half of the non-affected interviewees (48%) stated that they did not know how the medical costs for BU treatment are taken care of. This was only the case for 15% of the (previously) BU affected participants (see Annex C).

5.4 Results – FGDs

The objectives of the 12 FGDs conducted in six different communities were (1) to answer questions, which could not be sufficiently answered through the expert interviews and/ or the KAP survey, (2) to identify differences in the perception of the disease between BU affected people and non-affected people as well as (3) to assess differences in the disease perception between three communities with a high number (more than five) of BU affected people as compared to three communities with only few (up to five) BU affected people.

In the following chapter the answers to the questions concerning the second (*'Severity of the Symptoms'*, *'Aetiological Model'*, *'Expected Benefits of the Treatment'* as well as the aspect *'Stigma/ Social Exclusion'*), the third (*'Appeal of Treatment'* as well as *'Acceptability, Quality and Health Communication'*) and the fourth framework element (*'Choice of Health Care Resources'*) will be answered and elaborated according to the specific objectives of the study.

5.4.1 Severity of the Symptoms
– *"What do you think about Buruli ulcer?"*

The question *"What do you think about Buruli ulcer?"* provoked several general statements among the FGD participants: BU was unanimously considered to be a very *'dangerous'* and *'disgraceful disease'*. Some interviewees also stated that it *"is a very bad disease"*[173], which destroys and deforms its patients and *"the wonderful way God created them"*[174]. Other common statements were that *"BU is not a good disease"*[175] so that *"one has to do everything to avoid being affected and act quickly in case one is affected"*[176]. In other discussion groups the participants mentioned that it is a *'deadly disease'* as it may kill people physically as well as socially.

The most common statement about the physical consequences was that *'BU destroys'*, which according to the FGD participants meant that the body of the affected person will be deformed or disabled so that people who do not seek early care may even have to undergo amputation of body parts (e.g. leg, hand etc.) or lose organs (e.g. eyes):

> *"Even when it comes, you might not notice it early. So if you don't see it early to seek treatment, then it means it will destroy you"*[177].

The participants explained that BU affected people might become *"cripples"*, that the infection would *"leave a mark on the body"*[178] and may even affect the *"private parts"* of the body: *"Affected people will no longer look nice and change their look"*[179]. They reported that BU affected people often depend on the assistance of other people as they may be unable to walk or use their hands properly (e.g. BU affected people may not be able to eat, bath or go to the toilet on their own). Furthermore the FGD participants mentioned that BU inflicts pain and bitterness so that the affected person may grow lean or even die untimely. Another reported challenge was that BU – even with medical treatment – takes a long time to cure.

The social and economic challenges of the disease did also play an important role in how BU was judged by the FGD participants.

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[173] FGD1-2/ R4: 126-128 & FGD6-2/ R2: 230
[174] FGD1-2/ R4: 140-141
[175] FGD1-1/ R2: 88-89 & FGD2-2/ R3: 143-144
[176] FGD2-2/ R3: 143-144
[177] FGD1-2/ R3: 120-121
[178] FGD4-1/ R5: 204-205
[179] FGD3-2/ R4: 203-204

The statement

> *"One may want to cast oneself into the sea and die if one considers how badly BU may affect a person. People do not even want to hear the name"*[180]

underlines the severe impact of BU on the affected person's life as attributed by one participant of the fact that the affected people may not be able to work or continue their education (cost issue) as well as the characteristic that severe BU lesions may smell badly. The mentioned aspects will not be elaborated in this section as they are also covered by other questions (see section *'Stigma/ Social Exclusion'*). The most obvious difference regarding the perception of the *'Severity of the Disease'* between BU affected people and the non-affected study participants was the way the narratives about BU were told: the anecdotes of non-affected people were much more elaborate and well founded than the ones by previously BU affected people.

A characteristic difference in the perception of the severity of BU between the communities with many previously BU affected people and those with only a few victims could not be observed for this question.

5.4.2 Aetiological Model
– *"In which way do you believe that somebody can contract this disease?"*

The question of how one may contract BU revealed that the participants in the different communities had many differing explanations for the underlying mechanism. Not only natural but also supernatural/ spiritual aspects played a role in their perception.

The most commonly encountered explanation was that *'one may contract BU through water'* (water-borne disease): Especially walking, bathing and wading in dirty rivers, stagnant water, gutter water or muddy places as well as walking and playing in rainwater were perceived to cause the disease. However, some people had reservations about that explanation. They reported that they had heard that BU is acquired through contact with dirty water but that they knew about people who *"never played in the mud"*[181], *"had no contact with dirty water"*[182], *"took regular bathes"*[183] or *"lived in good and tidy conditions"*[184] but got infected. Other people stated: *"If BU is water-borne the whole town should have contracted it as everybody depends on the same water bodies"*[185]. Or that: *"If BU is in the drinking water everybody should have got it and nobody would remain alive"*[186].

As opposed to the thesis of the transmission through water several FGD participants believed that *'BU must be air borne'* and that BU affected people *"generate air, which may affect somebody else"*[187] as every community member walks in water, goes farming and/ or is involved in other activities when it rains. One participant said: *"You stand a high chance of contracting it if you're not lucky"*[188]. Another explanation as to how BU is transmitted through the air was given from a participant in a severely affected community:

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[180] FGD4-1/ R2: 217-220
[181] FDG 1-1/ R1: 98-100
[182] FGD 1-1/ R2: 104-107
[183] FGD 5-2/ R3: 415-416
[184] FGD 1-2/ R1: 332-335
[185] FGD 1-2/ R4: 337-338
[186] FGD 6-1/ R4: 302-304
[187] FGD 3-1/ R4: 213-214
[188] FGD 1-1/ R6: 109-118

> *“The wind which blows in the community is not favourable to everyone: It is just like the weather and the farmers: if one is a farmer the weather may be favourable for farmers but not favourable to others”*[189].

Further explanations for the transmission of BU were *‘unhygienic conditions’* (i.e. an untidy body or people who do not bath regularly) as well as *‘walking in bushy areas’*. Quite many of the FGD participants explained that they were *‘not sure about the origin of the disease’*. Even some of those who had heard different explanations and/ or were themselves affected with the disease had no clear idea of its mode of transmission: *“One will just be there and feel some itches. Then it explodes and some liquid will come out of it.”*[190]

In contrast with the natural explanations for the mode of transmission some of the people (in five out of the six communities) mentioned that spiritual aspects play a role in the development of the disease or that many people – especially old people – perceive BU to be a spiritual disease which is caused by witches and wizards. Mentioned reasons for this belief were various: Some believed that the serious consequences of BU on the affected person could not be of natural origin (e.g. *“it is a bad and some kind of evil disease”*[191], *“it took a long time to cure it and they have tried many different treatment options”*[192], *“the body may be damaged”*[193]*.* Others considered God to permeate all areas of one’s life so that the disease is God’s will: *“If it had not been the will of God the disease would not have come to the world”*[194]. Another mentioned reason for considering BU to be of spiritual origin is that the participants could not think of a natural explanation: They did not understand why they got affected despite taking care of the propagated risk factors (i.e. walking or playing in water bodies) or vice versa – that only some of the community members got affected although they all live in the same surroundings (i.e. depend on the same water source). Last but not least human failure such as greed could be a reason for punishment through spiritual figures as some participants in one community deplored:

> *“Witches send the disease to this person when they realize that somebody tries to do something great”*[195]

or something profitable and that *“one will lose everything”*[196] in case one is affected. One of the FGD participants reported that he got to know that the disease is spiritual because he went to a spiritualist after his father’s funeral, who then told him that he would contract BU. As a consequence of their believe that BU is a spiritual disease many people report to idol worshippers for treatment instead of reporting to a governmental health facility.

Those FGD participants who stated that they do not believe in a spiritual origin of the disease explained that they got to know that BU is a water- or air borne disease. Others said that it is just a disease like malaria or any other disease:

> *“Some people blame it on witchcraft but this is not the case as they* [the people who believe BU to be of spiritual origin| *tend to blame any evil thing that happens around them on witchcraft. Satan may even send malaria”*[197].

A further explanation was that *“if BU is spiritual disease it would have affected all the people in town”*[198]. A third group of people was not sure whether BU is a spiritual disease or not as some encountered statements show:

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[189] FGD 4-1/ R1: 281-284
[190] FGD 6-1/ R1: 324-328
[191] FGD 2-2/ R4: 191
[192] FGD 2-1/ R4: 137-139
[193] FGD 2-1/ R2: 234-238
[194] FGD 1-2/ R3: 173-175
[195] FGD 4-1/ R1: 250-253
[196] FGD 4-1/ R1: 199-202
[197] FGD 4-1/ R5: 275-265
[198] FGD 5-1/ R1: 252

> *"Some people say that BU is a spiritual disease, others will say this, and other will say something different. But if one is affected one may know whether it is a spiritual disease or not"*[199].

"One cannot tell where BU is coming from but only God knows it"[200].

As it turned out one could observe significant differences regarding the mentioned prevention strategies amongst the participants: Most of the people who considered BU to be water borne consequently thought that it is possible to prevent it. They most often mentioned that *'avoiding contact with water'* in many different ways (*'stop walking in stagnant, muddy or filthy water'*, *'children should not play in the mud'*, *'avoid bathing in the river'*, *'avoid rainwater'*, *'wearing shoes* (i.e. sandals, wellington boots) *when walking or working in wet and muddy areas'*, *'using and drinking clean water'* (i.e. water from the borehole and not stagnant water or from the river)) are effective means. Another commonly mentioned prevention strategy was to *'observe hygiene', which* – according to their perception – involved staying away from rubbish, consuming good and clean food and water, covering food after it is cooked as well as cleaning oneself and one's kitchen belongings regularly as one participant stated:

> *"You can abstain by keeping a good personal hygiene. This can be done by bathing regularly, avoid walking in the mud, regularly washing cooking utensils and cleaning my room regularly and stay away from any dirt"*[201].

The study participants summarized this behaviour with the term *"the people have to take care of themselves"*[202].

Those participants who believed that BU is air-borne stated that it may not be prevented and *"before one knows one is affected"*[203]. Something unexpected may always happen so that a person contracts BU. Some very faithful participants considered themselves to be at the mercy of God and would only consider protection strategies if *"it is the will of God to help them"*[204] as *"one cannot live without using water or walking through the bush in this surrounding"*[205]. According to their beliefs *"one has to trust oneself and the Lord since he created us. The Lord will care for us"*[206]. Other mentioned prevention strategies were to *'avoid sand winning areas'.* Two different discussion participants reported that they avoid food they are not used to or *'avoid buying food outside'* [readymade food from the market] as they think that it may cause BU. One of them added that he only eats carrots when he travels.

Those who thought that BU is unpreventable argued that *"one may take care of oneself but one may get it"*[207] as nobody knows exactly how the disease is transmitted and even people who drink clean water contract BU.

People in the FGDs who had never been affected with BU had a tendency to ascribe the mode of transmission to water and were more inclined to say that the disease is common among people who suffer from unhygienic living conditions. Those, who had previously been confronted with the disease (previously affected person, family member of a (previously) affected person etc.), reported more detailed explanations for both the transmission and prevention of BU as well as paradoxes (e.g. never played in the mud, took regular bathes

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[199] FGD 5-2/ R5: 358-362
[200] FGD 6-2/ R5: 275-276
[201] FGD 4-2/ R3: 171-173
[202] FGD 5-2/ R6: 360-361
[203] FGD 4-1/ R2: 290-293
[204] FGD 1-1/ R3: 202
[205] FGD 5-1/ R5: 274-275
[206] FGD 5-1/ R6: 277-278
[207] FGD 6-2/ R2: 337

etc. – yet contracted the disease) and were more likely to think that spiritual aspects are involved. Furthermore they stated more often that they were not sure about the origin/ cause of the disease than the ones who had not been affected yet. Probable preventive measures were discussed in more detail among the non-affected FGD participants. They mainly propagated hygienic conditions but were also more likely to admit that they have no idea how to prevent themselves from the disease.

In discussion rounds with previously affected people the participants were more likely to state that *'safe water'* is an adequate preventive measure as well as the fact that *'God may protect'* them.

A characteristic difference in the perception of the aetiology of BU between the communities with many previously BU affected people and those with only a few victims could not be observed for this question.

5.4.3 Expected Benefits of the Treatment

– "What motivates the people to visit the traditional herbalist or any other place?"

The FDG participants' presented motivations and expectations with regard to the different treatment options explain why the people in the communities usually use traditional herbal treatment first and in which case they opt to report for medical treatment.

The analysis of the FGD transcripts showed that the people tend to use traditional herbal treatment for BU before seeking care from a governmental health facility predominantly for two reasons: First, there are practical reasons: the people see it as an *'easy treatment'*, which most of them use at the onset of any symptoms, without knowing what disease they have actually got or not being aware of possibly having contracted BU. In addition to that, the people pointed out that practical reasons play a role and that herbalists live close by[208] so that one may receive treatment while staying at home:

> *"A BU affected person may never seek medical attention in the early stages but prefer to stay at home and use herbs of their own knowledge for curing the disease until somebody else shares a bad experience"[209].*

Second, there is the belief in the potential of traditional herbal treatment: some FGD participants stated that *"herbs may cure BU"[210]*. Another reason for this treatment was the fact that people think that they have contracted a spiritual disease and that traditional treatment methods involving herbs may also cure the spiritual aspect of the disease.

Third, some people also stated that herbal treatment had avoided amputation (e.g. in some cases some doctors wanted to amputate a BU affected leg but the people did not agree, went to a herbalist instead and got healed).

According to the FDG participants some people also tend to ask for herbal treatment in case the medical treatment failed to heal the wounds. In contrast to this some of the interviewees explained that traditional herbal treatment was preferably used in the past, as they were not aware of the fact that an effective medical treatment is available but that they have learnt that they must report to a governmental health facility in case they observe any BU symptoms:

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[208] *"The herbalist is closer to them and one can easily obtain treatment from there. In case there is no herbalist they* [the patients] *have to go to hospital"* FGD 4-1/ R1: 387-390.

[209] FGD 4-2/ R3: 263-266

[210] FGD 1-1/ R5: 201; FGD 5-1/ R5: 346

> *"We are old enough to know that we should go to the health post for treatment and I believe that most people go for treatment from this health post"*[211].

The most important motivation of the people to report to a governmental health facility for BU treatment was that they see the medical treatment as a *'final resort'* and that *"only the injections from the hospital may treat the disease"*[212] – especially when herbal treatment had not been successful, *"they realize that it is not a herbal disease"*[213] or they believe that the herbalist only tried to cheat them. Another important motivation was the expectation of a correct *'diagnosis'* of their disease and its symptoms.

> *"The initial symptoms are not easy to identify so that it is better to first seek treatment from the hospital for clarification"*[214].

One participant stated:

> *"People have to take it to hospital for diagnosis instead of using herbal medicine until the leg or hand rots. In the long run it will be too late to take it to hospital"*[215].

And last but not least they thought that the health workers are able to provide an *'instant cure'* and that medical treatment is faster than traditional herbal treatment. One of the statements from a discussion round in a remote and severely BU affected community underlined this perception:

> *"It is true that the treatment from the hospital is faster than the traditional herbal medicine: With the traditional treatment the wound keeps expanding and becomes severe. But when the person goes to hospital it does not take long to heal"*[216].

The differences regarding *'Expected Benefits of the Treatment'* did not differ with regard to the specification of the different aspects of the discussion but with regard to the fact that the non-affected participants explained more often the benefits of medical treatment and that *"one can only take it to the hospital"*[217] [medical treatment is the adequate treatment option]. Previously affected people took both options into consideration and were more open for herbal treatment (*"Herbal treatment is good and is used to cure BU"*[218]) than the non-affected FGD participants.

No specific pattern could be observed for the perception of treatment benefits between the different communities.

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[211] FGD 4-2/ R2: 268-274
[212] FGD 1-2/ R4: 282-286
[213] FGD 5-2/ R5: 744-746
[214] FGD 2-1/ R5: 354-355
[215] FGD 6-2/ R4: 549-551
[216] FGD6-1/ R2: 562-565
[217] FGD6-2/ R2: 545
[218] FGD5-1/ R5: 346

5.4.4 Stigma/ Social Exclusion

– "What do people who are not affected with Buruli ulcer think about those affected by the disease?"

The aspect *'Stigma/ Social Exclusion'* due to BU was discussed by asking several questions: The initial question was whether BU affected people involve themselves in the community life, and the following one assessed what non-affected people think about those who have the disease. Then the discussions also focused on probable solutions to include BU affected people into the community.

Most of the FGD participants assumed that BU affected people do not involve themselves in community life as they *"do not have the strength"*[219], are not able to walk and therefore *"stay in their room"*[220]. Some participants knew both BU affected people who would participate in the community life as well as BU affected people who would refrain from that. Only a few stated that BU affected people generally go farming or to school and pound *fufu*[221] either because they are not so severely affected or because they have no other choice.

Many participants mentioned that they sympathize with or feel compassionate and sad for BU affected people because *"BU patients suffer a lot and go through a lot of pains"*[222]. According to the discussions, the sympathy of some people even manifested itself in taking action by directing BU affected people to report for early treatment from a governmental health facility. Some explained that they *"pray and ask for God's healing mercies over them"*[223].

Nevertheless the majority of the FGD participants explained that other people (who are *"narrow-minded"*[224], *"do not have a good heart"*[225] or *"are not courageous"*[226]) try to avoid contact with BU affected people and see the cause of the disease in the people's misbehaviour in the past or a curse. According to the FDG participants the most important aspect why people would avoid contact with BU affected people is that they are afraid to contract BU and that they try to be careful *"not to stain their white shirt"*[227]:

> *"BU affected people are not neat or do not take proper care of themselves so that a lot of people do not go nearer to them – some people do not even go closer to their own child"*[228].

Another commonly mentioned reason why people would avoid BU affected people is the severe smell of BU lesions. Other FGD participants explained that some people believe that BU affected people have insulted elderly people and therefore got infected:

> *"It serves them, they don't respect. They have gone to insult someone and cast a spell on them"*[229].

A further prejudice is that BU affected people have stolen something and then got cursed by the owner:

> *"They will not sit quiet, their hands are fast, they have gone to steal something and the owner has cursed them"*[230].

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[219] FGD 6-1/ R2: 592
[220] FGD 6-1/ R6: 624-625
[221] *Fufu* is a staple food of Ghana, which is made from boiled starchy food crops (e.g. cassava, yams or plantains), which are pounded into a dough-like consistency.
[222] FGD 2-2/ R3: 350-353
[223] FGD 6-2/ R5: 698-699
[224] FGD 5-2/ R6: 895-902
[225] FGD 3-2/ R3: 577-578
[226] FGD 3-2/ R4: 572-573
[227] FGD 1-1: R4: 340-345
[228] FGD 5-2/ R6: 860-864
[229] FGD 5-2/ R6: 895-902
[230] FGD 5-2/ R5: 906-908

According to some interviewees social exclusion also occurs because BU patients who might feel fine may be confronted with the prejudice that they are unable to work or do anything so that *"nobody will grant them a job"*[231].

Against the background of the aforementioned problems of the BU affected people's integration into the community, the FDG participants suggested various ideas: First, raising awareness for the affected people as well as providing information and education about BU were considered to be a suitable approach, as one participant summarized:

> *"One should meet the people, provide education and explain them that BU is not a disease that kills and that they must respect anyone who is infected"*[232].

The FDG participants also pointed out to the problem of communicating to the people that *"it* [BU] *is a disease and not a curse"*[233] as well as the fact that it does not kill: Furthermore it was claimed that *"BU victims should feel love and being cared so that the person's soul will be happy in health."*[234]*.* Community and family members should allow social contact and support, visit BU patients once in a while and *"relate to the patient as if there is no difference between them to offer inner joy to the patient"*[235].

Quite a few of the participants suggested that they would direct BU affected people for (early) treatment so that they may get healed and stated that BU lesions have to be treated as this minimizes the bad odour of the wounds and they may not infect anybody else:

> *"Only treatment can solve the problem. If the people are not treating it, it may infect other people but if the person treats it, it cannot infect anybody else"*[236].

Some of the FGD participants simply said that *"one has to be brave and take the mind off"*[237] if one deals with BU affected people. In conclusion the participants did not have a common solution for a better integration of the BU affected people so that *"it will be very difficult to unite with BU patients"*[238].

For the question if BU affected people involve themselves in community activities the discussion rounds revealed certain differences in the perception between previously affected and the non-affected people: Non-affected people were obviously more sceptical that BU affected people participate in the community life than those who had had BU. The main reason the previously affected people gave for participating in community life was that they had had no other choice than to work (to sustain their living) or go to school while they were infected. Yet, the previously affected people agreed that severely BU affected people are not able to participate in any work/ activities and that *"BU brings shame on the affected people as they cannot even get in the midst of the people"*[239].

Over the course of the discussions it also turned out that the FDG participants' attitude towards BU patients differed according to their former experience with the disease: non-affected people often show compassion and sympathy for them but still avoid contact (i.e. due to the apparent smell of the lesion or because they are afraid to contract the disease), have prejudices (e.g. *'BU affected people are not neat'*, *'… have stolen something'* or *'… have insulted someone'* and *'… have been cursed'*) and discriminate against them. The

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[231] FGD 6-2/ R6: 705-706
[232] FGD 4-1/ R2: 514-516
[233] FGD 4-1/ R5: 518-523
[234] FGD5-2/ R6: 1059-1063
[235] FGD 2-2/ R3: 443-447
[236] FGD 6-2/ R6: 841-843
[237] FGD 1-2: R4: 462-471
[238] FGD1-2/ R3,4: 483
[239] FGD 4-1/ R1: 440-442

previously affected people mentioned way less of the raised prejudices (e.g. smell of the lesion) and misperceptions (i.e. *'BU is communicable'*, *'BU affected people have been cursed'*). Both the previously affected as well as the non-affected FGD participants suggested organizing awareness campaigns to publicize the latest information about BU as well as to improve social contacts and support to better integrate affected people into the community. In addition to that the non-affected study participants mentioned that early and regular treatment – to avoid a smell of the lesion and to get healed – is necessary and that the wound needs to be healed first before they may get closer to them.

No specific pattern could be observed for the perception of stigmatization/ social exclusion between the different communities.

5.4.5 Appeal of Treatment

– *"What is the difference between the treatment at the hospital* [governmental health facilities] *and the traditional herbal medicine?"*

The general perception of the available treatment options differed considerably amongst the FGD participants: Some of them stated that *'there is a difference'* between the treatment at governmental health facilities (e.g. diagnosis, equipment, treatment with injections etc.) and traditional herbal medicine. Others were not able to describe the difference between the two options or stated that both work well:

> *"There are diseases which are best cured by a doctor, and other diseases are best cured by an herbalist"*[240].

A third group thought that one does not have a guarantee that either the medical or the traditional treatment helps to heal the disease as one member of this group explained:

> *"Everything about BU is about luck: If you are lucky you may be cured at the hospital but if you are not lucky it will destroy you. You could be well treated by a doctor* [i.e. medical treatment]*, but it may still destroy you"*[241].

The overall appeal of medical treatment was predominantly positive: Some people knew that *"people, who go to hospital* [i.e. governmental health facility] *will receive medicine, get their sore washed and given an injection"*[242]. The majority of the participants was convinced that it is better than herbal treatment and that *"hospital medicines* are the ones that cure the disease"[243] or *"work faster"*[244]. The mentioned explanation for this perception was that medical treatment

> *"kills the things, which are alive in the person. The bacteria will die and wash the things out of the system"*[245].

Those study participants who stated that the health post is the *'first point of call'*, explained that *"everybody goes for medical treatment"*[246] at the health post in the study area as the people get healed there.

Nevertheless traditional herbal treatment is the first treatment choice for many people. Obviously there is a tendency that *"people prepare herbal medicine before reporting to hospital"*[247] (see also the section *'Choice of Health Care Resources'*). People who reported that herbal treatment practices are favoured, justified this choice by saying that they have always used traditional herbal treatment and have had positive experience with it, that many

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[240] FGD 4-2/ R2: 282-287
[241] FGD 1-1/ R6: 167-172
[242] FGD 5-2/ R1: 739-740
[243] FGD5-2/ R1: 766-767
[244] FGD 3-2/ R7: 505
[245] FGD 5-2/ R6: 791-797
[246] FGD 2-1/ R3: 331
[247] FGD 3-2/ R3: 486-487

people consult herbal doctors and that there are a lot of different traditional medicines. Furthermore, it was explained that they were not aware of the disease:

> *"In the beginning they* [the people] *say it is a 'boil' and 'boils are not taken to hospital'. Later on people realize that it is too late"*[248].

Others reported that herbal treatment was used in case medical treatment had failed:

> *"One should preferably go to hospital for treatment, but if the disease persists one may try some herbal medicine"*[249].

The same applies to those people who use herbal treatment, which fails to cure BU lesions: It was reported that they end up in a governmental health facility/ hospital where they are finally healed, as *"the doctor knows the right thing"*[250].

Differences between traditional and medical treatment as outlined by the study participants included diagnosis and equipment. Several FDG participants stated that one will be examined and receive a diagnosis at the hospital – which according to them does not necessarily happen at the traditional healers[251] – so that the patients are aware of which disease they are suffering from. Furthermore the people in the communities explained that

> *"Hospitals have machines for weighing, detecting or diagnosing people. In addition medicines are available and they inject people. They may also take a sample to test whether it is BU or not"*[252].

The fact that BU *'patients will receive drugs and injections'* was not only known among the previously BU affected FGD participants, but also among the non-affected community members and was an aspect which was perceived as an obstacle to report for treatment at a governmental health facility. Another point which seemed to frighten the participants about the medical treatment was that severe cases have to undergo an operation: *"If nothing can be done about the disease they will cut it open and take out the bacteria"*[253]. The fact that *"one may lose some own flesh"*[254] was a further issue, which was perceived as negative. This was also the reason why one of the previously affected FGD participants did not report to a governmental health facility for treatment: He said: *"In hospital they would have cut off the hand"*[255].

The traditional herbal medicine was discussed as being both positive and negative: Some of the FGD participants explained that they prefer traditional treatment as they were convinced that *'it works better than the orthodox medicine'*. It was even reported that some people had received treatment from the hospital but that their wounds did not heal so that they later reported to the herbalist. Another group of FGD participants thought that herbal doctors might treat some diseases but not all of them. A third group stated that herbal treatment does not cure BU patients:

> "*It will rather destroy people; the wound will heal but your whole body would have been destroyed"*[256].

Some of them thought that herbalists deceive BU patients and tell their patients *"to bring a fowl and a goat"*[257] but that the wound will not heal and rather become severe. Another

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[248] FGD 6-2/ R6: 481-482
[249] FGD2-1/ R6: 244-345
[250] FGD 6-2/ 572-573
[251] In one community the FGD participants reported that herbalists/ spiritualist apply dust on the BU suspected lesion to diagnose the disease.
[252] FGD 3-1/ R1: 277-283
[253] FGD 2-2/ R2: 284-290
[254] FGD 4-1/ R5: 409-420
[255] FGD 4-1/ R5: 409-420
[256] FGD 1-1/ R1: 156-159
[257] FGD 6-2/ R5: 596-599

mentioned risk was that herbal medicine is not tested or standardized and that the people *"may receive some drips and cannot tell whether they got medicine or something else"*[258].

The difference between herbal medicine and the antibiotic treatment was explained with the facts that *"traditional herbalists do not have any machines for diagnosis"*[259] but that they *"consult the dwarfs to find a solution"*[260]. It was also reported that the patients usually *"do not receive anything to drink to kill the germs in the stomach"*[261], but that *"the herbalist will only boil herbs"*[262] and *"apply them on the affected part of the body"*[263]. The mentioned advantages of this treatment option were that *'the people are familiar with it'*, that it is usually *'provided at home'* and that *'traditional herbalists neither give injections nor do surgeries'* but provide a medicine, which *"will block all the bacteria, which work against the immune system"*[264].

The perception of available treatment options between BU affected people and the non-affected study participants did not differ to a great extent. As to the differences between the treatment at governmental health facilities and the traditional herbal medicine the non-affected people could only mention more arguments speaking for a treatment at a governmental health facility than from a traditional healer as the previously affected people.

It could be observed that several study participants in the two remote communities with more than five BU patients preferred traditional to medical treatment and argued that they have *"more knowledge about traditional medicine"*[265] or that they went to hospital but that their wounds did still not heal so that they would still prefer to go to the herbalist.

5.4.6 Acceptability and Quality of available Health Services – *"What is your perception of the health facilities around you?"*

The general perception of the *'Acceptability and Quality of the available Health Services'* was predominantly positive. Most of the participants of the discussion rounds reported about their experience with the health post and mentioned that they *"like the facilities a lot"* and are satisfied or appreciate them. There were various aspects that saw them appreciate these services:

One important reason for being happy about the available health facilities was the newly constructed health post:

> *"The new health facility is well kept; but this was not the case some time ago. Just recently they got a new building and the patients are now well treated"*[266].

Some people mentioned the proximity of the health facilities:

> *"Nowadays the facilities are closer to them* [the people in the communities]: *When something occurs they may quickly rush the person to the hospital"*[267].

They also added that in the past people often died on their way to hospital. Furthermore they explained that the establishment of the health post reduced the costs of transportation as the

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[258] FGD 6-2/ R6: 601-603
[259] FGD 3-1/ R1: 277-283
[260] FGD 2-2/ R3: 294-295
[261] FGD 2-1/ R2: 397-399
[262] FGD 5-2/ R3: 776-777
[263] FGD 2-1/ R4: 384-389
[264] FGD 4-1/ R5: 409-420
[265] FGD 5-1/ R5: 364
[266] FGD 1-1/ R1: 332-333
[267] FGD 1-2/ R3: 518-522

people may now easily access medical treatment by walking there and by not having to take a vehicle to hospital.

Apart from practical reasons some people pointed out to the good treatment at the health post, in terms of both treatment results and the way the staff handled the patients. Many of the FGD participants reported that they had received treatment at the health post, got healed and therefore appreciated the services there:

> *"If BU affected people go to hospital* [i.e. the health post in the study area] *we surely see something. The health workers prepare some medicine to see whether the person will be all right. This is why we think that the healing centres are good"*[268].

In addition, participants reported that the patients may receive quick medical attention from the health post in the study area and that they do not have to wait for a long time before receiving treatment.

Other participants' acceptance of and respect for the staff at the health facilities even went further. They liked the staff *"because they are the people who give us strength. Our strength depends on them, which is the reason why we accept them"*[269].

Those who said that they were dissatisfied with the health facilities complained about the behaviour of the health workers and nurses (see section about the attitude of the health workers below) or the fact that a doctor in hospital was not able to diagnose the disease correctly.

One single participant had not formed a final opinion about the health facilities and stated:

> *"If one goes to hospital and it happens that one will die right now one will die. It is God who gives life and if God wants the person to die, the person will die"*[270].

Another FGD participant stated that she did not report to the health post when she had an ulcer. She thought that she would be amputated and therefore was scared to go there. She did not explicitly mention, however, what she did to receive treatment.

The attitude of the health workers was explicitly assessed with the question *"What do you think about the attitude of the people working in the health facilities?".* The answers revealed that the attitude of the health workers from the nearby health post was generally perceived as being more positive (especially after they have changed the personnel) than the behaviour of nurses and health workers in hospital (i.e. *'Government Hospital'*).

Those FGD participants who were satisfied with the attitude of the health workers explained their positive perception by giving examples such as: the health workers attended well to them, they were patient when treating them, and they took good care of them, observed their medication and did not insult them:

> *"The health workers receive people well. They do not lazy around me and receive me well so that I get happy about it"*[271].

Another mentioned aspect was that they were warmly received and treated with a smile despite their wound, which sometimes smelt. Some of the previously affected people also reported that the health worker from the health post greeted them whenever they met him, that he was sociable and encouraged the patients to be hopeful.

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[268] FGD 3-1/ R2: 384-386
[269] FGD 6-2/ R3: 889-890
[270] FGD 5-2/ R6: 1085-1089
[271] FGD 6-1/ R4: 749-750

In two out of the six communities some participants complained about the hostile behaviour of the health workers. In one community it was reported that

> *"there are times at certain health facilities that the nurses tell them stories or that the doctor is not available. At other times they are not even able to recognize the disease. But immediately they get to the hospital they will hear the nurses shouting: "Why did you spend so much time in the house before coming here?" (…) The manner they speak to them is too bad and people who find themselves in this situation promise to never go to hospital again"*[272].

Others explained that the attitude of the health workers gets worse throughout the day or that they have observed that

> *"not all of the health workers smile: Only those who are patient and have given birth before have a feeling for the people and take care of them"*[273].

One of the participants added to the discussion that the behaviour of the health workers might also be triggered by the improper way some of the patients report to hospital:

> *"If one comes to hospital with dirty clothes and improper dressing – would one talk to the person?"*[274].

Some of the FGD participants had a more or less neutral perception and stated:

> *"Every hospital has nurses with different characters. A particular nurse may treat the patients so and another may treat them differently"*[275].

In another community some people complained that the nurses in hospital shared the food, which was supposed for the patients, among themselves and did not care whether the patients had enough or not.

If the people were given the chance to advice the health workers in the local health facilities many of those former patients complaining about the health staff's behaviour would tell them to exercise patience, *"cool their temper"* and show sympathy for the patients:

> *"The advice is that BU is painful: If a BU patient comes to them they should be patient in treating everyone as no one contracts the disease voluntarily"*[276].

Another group of participants tried to explain the way the health workers do their job, not without giving some piece of advice:

> *"Something shows that they have love for their neighbours. If you don't have love for fellow human beings, you cannot do this work but sometimes they become too proud. Their work is appreciated but they should always remember to do it the way they have been doing it all the time"*[277].

Furthermore, the health workers should behave responsibly, and have in mind that their behaviour may both positively (e.g. *"the way the doctor speaks may heal the person"*[278]) as well as negatively (e.g. *"patients may die out of frustration"*[279]) contribute to the healing process of the patient.

Some of the participants of the discussion rounds stated that they would not like to advice the health workers but just wanted to thank them for the work they do and encourage them to continue doing it:

> *"Health workers need to be encouraged but not advised because they do well. One may advice the people but the people cannot advice health workers because they are doing well"*[280].

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[272] FGD 4-1/ R5: 534-541
[273] FGD 5-2/ R3: 1126-1127
[274] FGD 4-2/ R1: 452-455
[275] FGD 2-1/ R6: 624-625
[276] FGD 4-2/ R2: 583-585
[277] FGD 1-2/ R3: 564-568
[278] FGD 3-1/ R1: 412-416
[279] FGD 2-1/ R5: 666
[280] FGD 4-2/ R3: 472-474

Others said that they would like to pray for the health workers so *"that God should grant them courage to be able to cater for the patients"*[281] and that *"the Lord may bless the health workers"*[282] and reward them for their efforts so that their work prospers.

The perception of the *'Acceptability and Quality of the available Health Services'* differed between previously BU affected people and the non-affected study participants: Some of the previously affected people reported negative experiences in seeking treatment from governmental health facilities while none of the non-affected participants in the discussion rounds either reported corresponding experiences when treated for other diseases in hospital or mentioned to have heard of any similar experiences from others.

There were only two communities where people complained about the available health services and the behaviour of the health workers. These communities were the ones that are nearer to the next town than to the health post in the study area so that the people sometimes report to the *'Government Hospital'*. In one of the two remote communities one FGD participant stated that she did not report to a health facility as she was afraid to go there.

5.4.7 Health Education and Communication

– *"How did you hear about the disease?"*

During the interviews it turned out that the FDG participants got to know about the disease via various ways: many explained that they were either informed through their (BU affected) family members or that they had observed other BU affected people in their own community. In four out of the six communities the participants stated that they had received BU specific health education *"from people, who made announcements"*[283], by attending a video show, from health workers, at school, via radio or TV. Yet some of the previously affected people reported that they only got to know about BU when they got affected themselves – or only after the treatment had already been finished.

In three out of the six communities the people reported that *BU "exists already for a long time and is nothing new"*[284]. Yet they had only known the disease as *'Dufunu'*, *'Detifudɔ'* or *'cotton disease'* due to *"the cotton-like substance on the surface"*[285] until they were told otherwise when being treated or during awareness campaigns. They also admitted to not having had any proper knowledge and were not familiar with the name *'Buruli ulcer'* until the time of treatment or treatment campaigns.

The study participants requested for information from *"somebody, who knows something about the disease"*[286]. These people *"should pass this information to them so that they are prepared for future infections"*[287]. Most of them wanted to receive this information from doctors, health workers or nurses and perceived that *"they are the right people"*[288] or that *"there is nobody apart from the doctors"* [289], [290] as *"they are the ones who are*

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[281] FGD 1-1/ R1: 549-550
[282] FGD 6-2/ R1: 968
[283] FGD 1-2/ R3: 82
[284] FGD 4-1/ R2: 116-124
[285] FGD 5-2/ R4: 160-163
[286] FGD 1-2/ R4: 70
[287] FGD 2-2/ R2: 83-85
[288] FGD 5-2/ R6: 197-198
[289] FGD 6-1/ R4: 213-214
[290] The interviewees did not differentiate between medical doctors, health workers or nurses and called all of them *'doctors'*.

knowledgeable"[291] and therefore *"are supposed to educate them"*[292]. Apart from the groups mentioned above herbalists, spiritualists as well as the research team were considered to have this knowledge. Furthermore, some study participants claimed:

> *"The government and the health and information ministries are responsible for providing understandable information to everyone"*[293].

Yet, a few of the interviewed people doubted the professionals' competence and said that more research about BU was needed before the professionals know how to prevent the disease properly.

It cannot go unmentioned that some people demanded more initiative from the people themselves to acquire some knowledge about BU. So one group explained that the doctors cannot make home visits to everyone to inform them about BU but that the people themselves have to report to the health facilities. Some people said that the challenge is that some of the communities are very remote and *"the doctors are in town, which is sometimes far away"*[294].

Even though many possible sources for information were mentioned only few of the FGD participants were satisfied with the information they had received about the disease. All the others requested for details about the mode of transmission (e.g. *"Is it true that it is water-borne?"*[295]), the specific symptoms and how to recognize it as well as its treatment.

Given reasons for the supposed lack of information about BU were that *"the government did not take its responsibility and had not yet appointed people for this task"*[296] and that those who are responsible do not care. Due to the fact that not all communities have access to electricity some people it was pointed out that some people may not benefit from radio and TV presentations. By sending somebody to the people's houses to publicize information about BU this problem could be tackled as was brought up.

It could be observed that several of the previously BU affected people only got to know about the disease when they were themselves affected but that the non-affected study participants had observed some BU affected people before. Besides this there was no characteristic difference in the perception of the disease specific health communication between previously affected and the non-affected study participants.

The discussions in the different communities showed that especially the people in one remote community got to know about BU only when they got affected themselves and were then respectively informed by the health worker. Furthermore, the analysis of the discussion data revealed that in three of the six communities (which are located along the main street) the participants mentioned that they got to know about the disease by attending a video show or via radio/ TV.

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[291] FGD 5-2/ R3: 170-172; FGD 6-1/ R6: 230-231

[292] FGD 6-1/ R3: 186-187

[293] FGD 4-1/ R1: 79-86

[294] FGD 5-2/ R1: 246-248

[295] FGD 2-1/ R4: 92

[296] FGD 2-2/ R1: 122-124

5.4.8 Choice of Health Care Resources

– "If people are affected with Buruli ulcer, which kind of treatment options will they use?"

The general perception of the available health care resources to treat BU suspected symptoms differed between the participants of the discussion rounds as well as the different communities. The most common described treatment practice was to *'use herbal medicine first and use medical treatment as a last resort'* as the patients were not aware that they had BU (compare with section *'Appeal of Treatment'*) or due to practical reasons (compare with section *'Expected Benefits of the Treatment'*). A further reported reason was that people say they do not have sufficient money to seek treatment from a governmental health facility.

Those who gave other general statements about the choice of treatment explained that the people in the communities have a diverse perception of probable treatment options (antibiotic treatment or herbal treatment): Some of them try many different treatment options, others trust their own knowledge about herbs, and a further group of people prefers medical treatment (compare with section *'Appeal of Treatment'*). One person suggested that *"whilst in hospital one should support the treatment with prayers"*[297].

The discussion about the choice of the respective health care resources for BU showed that most of the non-affected people know that *'BU affected people usually use herbal treatment first and seek medical treatment only as a last resort'* because the people are not able to identify the disease in the early stages or have other reasons to avoid medical treatment (e.g. no money available). Many of them also argued that people in former times used herbal treatment but that they nowadays know that they should report to a governmental health facility. In contrast to the perception of the non-affected study participants the previously affected people themselves gave reasons why they had used herbal treatment and would still use it again.

Furthermore it could also be noted that in two remote communities with more than five previously BU affected people the former victims explained that they had used traditional herbal treatment. Some also mentioned that they would use it again in case of a BU infection.

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[297] FGD 2-1/ R6: 360-363

6. Discussion

The discussion chapter is structured into five sections: In the first section the adaptation of Kroeger's framework (Kroeger, 1983) will be discussed and evaluated along with the results according to the different elements of the '*Modified BU specific Framework for Health-Seeking Behaviour'* (version II) as well as the available research literature (specific research question (1)). Furthermore, the relevance of the framework elements (i.e. *'Predisposing Factors'*, *'Characteristics of BU and Disease Perception'*, *'Enabling Factors'* as well as *'Choice of Health Care Resources'*) will be evaluated and compared with the model proposed by Mulder (2008) as well as with two other models which were published after the systematic literature search was conducted (December 2011) (see section 6.1).

Secondly, the results with respect to the specific research questions (2) to (6) will be discussed (see section 6.2). Furthermore, they will be embedded into the findings provided by the available research literature.

In the third section the methodological approach of the different research steps will be judged – differences across the applied methods will be described accordingly. In this flow an interpretation of the reasons for the differing results and an overview of the research methods that serve best to assess the different aspects of the '*Modified BU specific Framework for Health-Seeking Behaviour'* (version II) will be given. In addition to that the limitations of the applied methods will be discussed (specific research question (7), see section 6.3).

In the fourth section of this chapter ethical aspects related to the study will be discussed (see section 6.4).

And last but not least the value of this study for both the scientific community and the local disease control and management activities will be elucidated and compared with other studies which have proposed similar models to explain health-seeking behaviour (see section 6.5).

6.1 Discussion of the Validity of the Modified BU specific Framework for Health-Seeking Behaviour (Version II)

The following subsections evaluate the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) according to its four elements: *'Predisposing Factors'*, *'Characteristics of BU and Disease Perception'*, *'Enabling Factors'* and *'Choice of Health Care Resources'* (see Figure 30). The relevance of the different variables related to these elements is outlined at the end of each subsection.

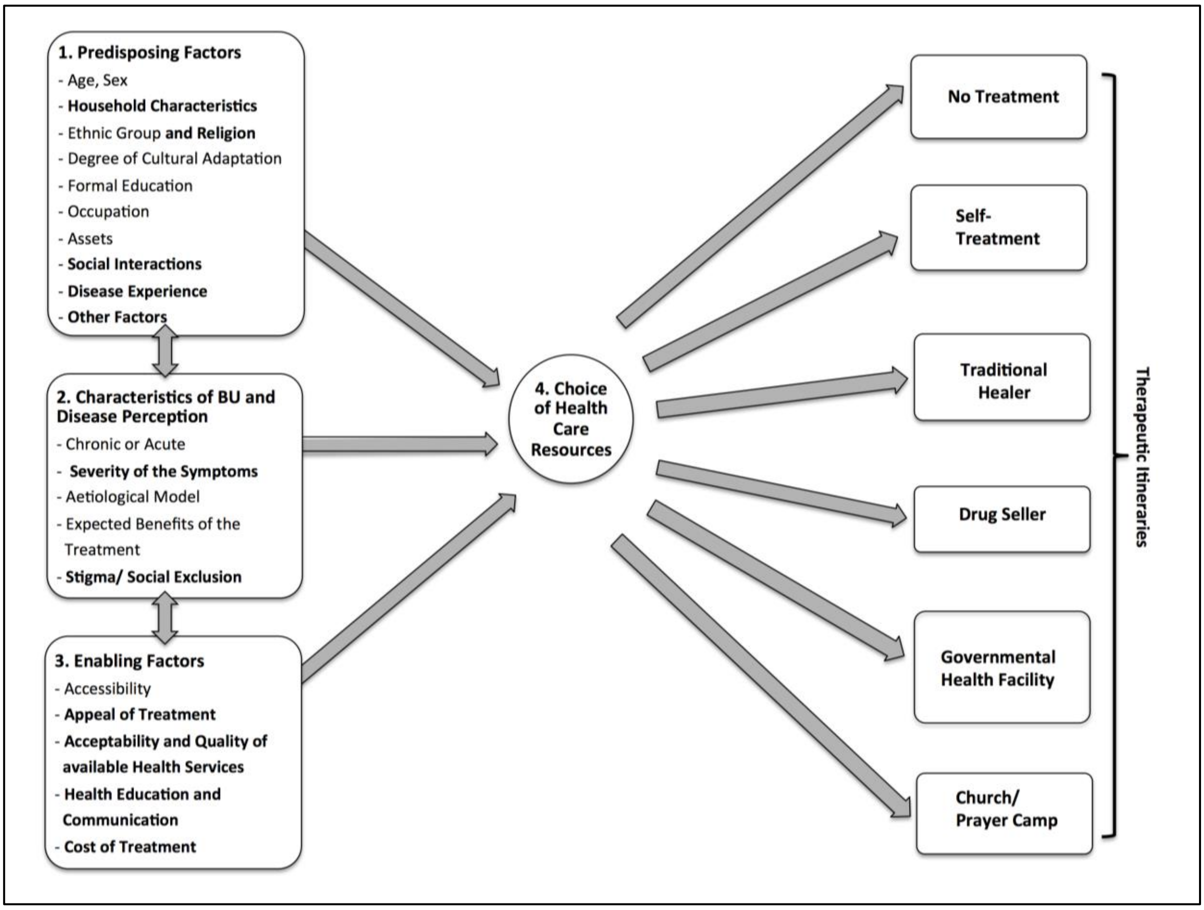

FIGURE 30: Modified BU specific Framework for Health-Seeking Behaviour (Version II), Overview of Modifications
Variables/ aspects differing from Kroeger's Framework are bolded
Source: Author's own

6.1.1 Predisposing Factors (Social and Cultural Background)

The original set of *'Predisposing Factors'* of Kroeger's framework (see Figure 6) was slightly modified for the *'Modified BU specific framework for Health-Seeking Behaviour'* (version II) (i.e. redefinition of the variable *'Interaction with family, neighbours, community etc.'*, replacement of the variable *'Innovators'* by the variable *'Disease Experience'* and introduction of the variable *'Other Factors'*).

Age, Sex

Age and sex often have a discriminatory function for the choice between traditional and modern health care: According to Kroeger especially elderly people in transitional countries prefer the consultation of traditional practitioners. Apart from that he suggests that the choice of modern treatment options depends less often upon the age of the affected people (Kroeger, 1983). In the context of this specific research, interviewed experts considered school-aged children as the most disadvantaged group in terms of receiving medical care as they depend on the support of their caregivers who are not personally suffering from the disease and may have further duties. The findings of the KAP survey have confirmed that the affected people are rather young with the majority being less than 18 years old. This is in line with the findings of the research literature which suggests that about half of the BU affected people in Africa are younger than 15 years (Ackumey et al., 2011a, Adamba and Owusu, 2011, Agbenorku et al., 2011, Kibadi et al., 2009, Grietens et al., 2008, Phanzu et al., 2006, Johnson et al., 2004, Asiedu and Etuaful, 1998).

A survey conducted among 48,962 individuals in Cameroon identified a further vulnerable age group for BU: According to that survey not only children between 12 and 14 years were the most affected cohort but also people older than 50 years (Bratschi et al., 2013). A similar pattern was observed in this study: by the time of infection the affected people were either up to 20 years old (54%) or above 40 years (28%). These findings underline that BU control and health education activities in the research area should pay special attention to these two age cohorts (as also highlighted by Debacker et al., 2004).

Kroeger's framework suggests sex-specific utilization patterns particularly for societies with strictly defined sex roles as it is the case for Islamic societies, for example (Kroeger, 1983). The experts interviewed in this study described a gender specific challenge and explained that women are generally more vulnerable to delay in seeking appropriate health care as many of them are not economically independent and therefore rely on the support of others (e.g. husbands or families). The analysis of the KAP data did neither reveal sex-specific disease patterns (49% male; 51% female) nor the respective behaviour. In a similar vein, most of the literature does not identify any sex-specific differences for either disease patterns or a sex-specific health-seeking behaviour (Ackumey et al., 2011a, Adamba and Owusu, 2011, Agbenorku et al., 2011, Kibadi et al., 2009, Grietens et al., 2008, Phanzu et al., 2006, Stienstra et al., 2002, Johnson et al., 2004, Asiedu and Etuaful, 1998). Nevertheless socially constructed gender roles are described by Ackumey et al. (2012a), who found that mothers are more likely to miss work for caretaking of their BU affected child than fathers (52% compared to 6%). Furthermore sisters more often stay at home (8.4%) than brothers (1.2%) to care for their sick relatives (Ackumey et al., 2012a). These findings were confirmed by own observations within the study area, where most of the BU affected children receiving treatment from the health post were accompanied by their mother or their older sister. Against this background the specific role of women with respect to health care should always be kept in mind during the development of health education and promotion interventions.

Household Characteristics

According to the framework by Kroeger, extended families behave more traditionally than nuclear families as the social interaction in large families and the interaction with the corresponding network may be more intensive (Kroeger, 1983). The head of household, for example, can act differently from the rest of the family and warrant special attention. The survey data indicates that there is no significant difference in the composition of BU affected and non-BU affected households in terms of household size, marital status, and number of children. Only the assessment of differences between *'Early Care-Seekers'* and *'Late Care-Seekers'* revealed significant differences between households with up to four children and households with more than four children (see section 6.2.2). The analysis of the research literature and the survey data showed that most of the BU affected people are singles (Ackumey et al., 2011a, Agbenorku et al., 2011) – a fact, which may solely be explained by the young age structure of the affected people. Marital problems of BU affected people – as reported by Stienstra (2002) – could not be quantitatively confirmed for the study area.

Ethnic Group and Religion

Kroeger's framework suggests that the disease perception and the resulting patient itineraries usually differ across ethnic and religious groups (see Kroeger, 1983): The results of the KAP survey show that the study area is clearly dominated by the Akan (44%) and the Ewe tribe (43%), but that clear differences in BU specific health-seeking behaviour across these two major ethnicities could not be revealed. Whether there are differences between the locally encountered minorities (i.e. Ga, Krobo, Hausa etc.) may not be clearly stated. These findings were more or less confirmed during the expert interviews within this study. Nevertheless the interviewees mentioned that the different ethnicities have different local disease names and that they may have a different understanding of physiological and pathological processes. The analysis of the research literature did also reveal many different local disease names for BU (see Kibadi et al., 2007) but provided no information about ethnic differences in the health-seeking behaviour. Against this background one may suggest that BU specific health information and education campaigns should consider using local disease names to address the specific ethnicities more appropriately and to avoid misunderstandings.

The analysis of the survey data showed that about 86% of the (currently or previously) BU affected people are Christian; only a small proportion is Muslim (3%) or follows traditional religion (1%). These small proportions of other believers did not allow for a reasonable comparison between the different religious groups. The interviewed experts were not able to observe clear differences for the different groups either, but explained that religion plays a supportive role for the respective health-seeking behaviour. Furthermore they added that the influence of religious beliefs on the health-seeking behaviour might be stronger than ethnicity in the study area. The analysed literature suggests that specific religious groups have their own preferences for the choice of the adequate health care resource: Renzaho et al. (2007) found that Muslims in the Ga District (Ghana) consider BU more often as a sign of being plagued with evil forces than other groups, whereas Animists and Catholics in a study in Benin were more likely to rely on traditional treatment than Protestant Christians (Johnson et al., 2004). Even though interviewed experts pointed out that religious belief may play an important role in the study area as well, the collected data could not confirm such patterns. Against this background, the influence of religious aspects on the health-seeking process of BU affected people seems to be insufficiently examined yet and it should in general be considered that religious aspects might promote or hinder the access to medical care (see also section *'Church/ Prayer Camp'*).

Degree of Cultural Adaptation

Kroeger's framework underlines that the exposure to another culture and the acceptance of associated attitudes and behaviour allows for implications whether people are familiar with seeking medical care (Kroeger, 1983). This coincides with the narratives of the interviewed experts, who highlighted that a lack of education along with the exposure to medical treatment and Western practices are challenges for a cultural change so that the people rather stick to traditional treatment practices. Moreover, the experts provided several reasonable examples and explanations why medical treatment is not yet the favoured treatment option; e.g. *"Ghanaians are not supposed to take a boil to hospital"*[298], show *'no self-responsibility with respect to health'*, or that the *'social gap between medical practitioners and patients'* is a challenge. Only one publication within the analysed research literature

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[298] Expert Interview No. 9: 27-28; Expert Interview No. 13: 323-331; Expert Interview No. 17: 37-39; Expert Interview 29: 221-238

pointed out that *'community habits'* influenced the choice of the respective health care resource (Mulder et al., 2008). This research gap might be explained by the fact that cultural aspects are difficult to operationalize and may only be explored by research involving qualitative methods.

Against the background that most of the people in the research area are not familiar with the governmental health system – including reservations about communicating with the staffs – some of the findings of this research may not only be applied to BU affected people but also to people with other diseases (i.e. chronic diseases; diseases, which are perceived as non-severe or stigmatising diseases). In addition to that further research should assess these cultural phenomena so that they may be considered when designing and implementing health education and promotion campaigns (e.g. in BU endemic areas *'every boil should be taken to hospital* [i.e. governmental health facility] *for diagnosis'*).

Formal Education
According to Kroeger's framework *'Formal Education'* may be one of the severest exposures to Western culture and thereby influence the health behaviour of the people (compare with Kroeger, 1983): Due to the fact that BU occurs predominantly in rural settings, where the people generally have a lower degree of education, it does not come as a surprise that the majority of the affected individuals have attained only primary education or no formal education at all (66% in the study area). According to the survey data the educational status does not differ significantly between BU affected people and the non-affected population. As long as there are no great differences in the educational status, this variable is not an essential element of the framework. Nevertheless it should not go without notice that BU often impedes the educational attainment and thereby influences the economic independence and future development of the affected people, so that disrupted education represents one of the major social problems of a BU contraction (compare with Ackumey et al., 2012a) (see also section *'Stigma/ Social Exclusion'*).

Occupation
Kroeger included the aspect of *'Occupation'* in his framework as it may be a valid indicator for social and cultural change and thereby have an influence on the health-seeking behaviour of the people (see Kroeger, 1983): According to the KAP survey in the study area 85% of the (previously) BU affected children up to 15 years of age attend school; people of more than 15 years of age are mainly engaged in agriculture, petty trading or unskilled labour. Due to the limited array of job opportunities and the predominance of subsistence farming in the study area it does not come as a surprise that no significant difference between (previously) BU affected people and the non-affected population could be identified in terms of occupation. The analysed research literature does not provide any further information with respect to occupation and its influence on the BU specific health-seeking behaviour. Hence, BU control and health promotion activities should be tailored to reach and support pupils as well as small-scale farmers/ traders.

Assets
The socio-economic status is difficult to analyse in rural African societies. Nevertheless Kroeger has integrated this aspect into his framework as it may have a reasonable impact on the health behaviour of the people (see Kroeger, 1983). The analysis of the KAP data shows that the standard of living among the (previously) BU affected households in the study area is very low (average daily expenditure of BU affected households for food, water and transportation was about 7 GHC per household (about 3.80€/ 5 US$): Most of the families depend on a limited array of farming products or the unstable income through trade or

service related activities. Although the analysis of the KAP data could not identify a significant difference between the households with (previously) BU affected and non-affected members it is obvious that even small treatment associated expenses (i.e. for transportation, food, bandages, pain killers) have a significant impact on the budget of BU affected households. Apart from this the applied research measure is not very sensitive so that there may still be a difference between the two different groups of households. The BU specific research literature does not assume any socio-economic differences between BU affected and non-affected people either, but Ackumey et al. (2012b) have found that the socio-economic status of families worsens if the main income-earner is BU affected. Health interventions that provide support for BU affected individuals and their families may be an adequate means to tackle this challenge (compare with Ahorlu et al., 2013b).

Social Interactions

Kroeger has highlighted that relatives and friends are usually consulted first in a case of illness (see Kroeger, 1983). The original framework variable was called *'Interaction with family, neighbours, community etc.',* and during the BU specific adaptation process it was redefined as *'Social Interactions'* as it is more open for further interaction partners. The importance of this extension of interactions for the referral of BU affected people was confirmed by the interviewed experts, who elucidated that community members commonly recognize skin diseases among their peers, because they know each other and are exposed to each other intensively. Furthermore the interviewed experts pointed out that the local CSBVs are important stakeholders for the referral of BU affected people: It was explained that these volunteers have the official order to assist suspected BU patients to report to a governmental health facility. The results of the survey point in the same direction: The majority of the (previously) BU affected study participants who reported that they had an ulcer on their skin had received treatment recommendations from their fellows (i.e. family members, friends, colleagues, health workers, herbalists etc.). Nevertheless some of the interviewed experts within this study thought that the majority of BU affected adults usually take the decision about the respective treatment on their own and do not follow any recommendation. The truth may be that people consider the advice from others in case they classify the symptom as being severe or strange; but as long as they consider it to be an ordinary swelling they may follow their own practice.

The phenomenon of patient referral by peers to respective health care providers is also mentioned in the BU specific literature (Ackumey et al., 2011a, Agbenorku et al., 2011, Kibadi et al., 2009, Mulder et al., 2008, Phanzu et al., 2006, Aujoulat et al., 2003, Agbenorku and Kporku, 2001, Ackumey et al., 2012b, Ahorlu et al., 2013a): There it is highlighted that the *'advice from health workers/ peers'* is an important aspect in the BU specific health-seeking process as it allows for a better labelling of the symptoms (Kibadi et al., 2009). Obviously, both the use of medical and other treatment options may be advised (Ackumey et al., 2012b). Ahorlu et al. (2013a) have found that the advice from peers may be even more important than *'financial considerations'* – especially for category one and two lesions.

Disease Experience

Kroeger's framework operates with the term *'innovators'*, which refers to individuals who choose new alternatives first and then may influence other members of their community (see Kroeger, 1983). Due to the fact that this phenomenon may also work in the opposite way (i.e. people use traditional treatment and promote this option) this framework aspect was redefined as *'Disease Experience'*.

Several of the interviewed experts within this study highlighted that successfully treated BU patients are a great resource to improve the BU specific awareness in the communities. They explained that people with prior BU experience may serve as contact person in the endemic communities, may inform about and clarify suspected symptoms as well as the respective treatment. The most convincing argument is probably the fact that these people – apart from the CSBVs – stay permanently in their communities – other than the BU specific health education events, which rather take place once a year. The analysis of the retrieved literature underlines that BU affected adults rely on their prior disease experience to make their choice (Ackumey et al., 2011a, Phanzu et al., 2006) and that people with *'general confidence in hospitals'* report earlier to a facility of the formal health system than those without confidence (Mulder et al., 2008).

Experiences that saw people struggle under the governmental health system or confirmed that traditional/ herbal remedies helped to cure their disease worked into the other direction: People who have gained such experiences may weaken the choice of a governmental health facility. These findings underline that the aspect of *'Disease Experience'* is an important element of the framework to explain the BU specific health-seeking behaviour. Furthermore, previously BU affected people, who were effectively treated with antibiotics, should be included into health promotion activities.

Other Factors

Aspects which could not be classified under the existing elements of Kroeger's framework were assigned to the newly introduced category *'Other Factors'*: This was information about a seasonal or time-related influence of the treatment choice (compare with Mulder et al., 2008) or narratives that people reported late for medical treatment due to ignorance or that no apparent reason could be observed (see Agbenorku and Kporku, 2001). The interviewed experts confirmed these phenomena: Some of them argued that Ghanaians *'use excuses why they were not able to report for medical treatment'*. These aspects could not be assigned to the existing variables of Kroeger's framework. Furthermore, they were not comprehensive enough to represent an individual variable so that the aspect *'Other Factors'* of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) serves as an open variable which may promote further research in this field.

Relevance of Predisposing Factors for BU related Health-Seeking Behaviour

Most variables of the *'Predisposing Factors'* are not very specific for the BU related health-seeking behaviour but rather describe the social and cultural characteristics of the people in the concrete setting. Consequently, this information might be considered as background information and being generic for the research area.

As opposed to that *'Degree of Cultural Adaptation'*, *'Social Interactions'* as well as *'Disease Experience'* are variables, which are more or less disease specific. Data could not be collected for all of them over the course of the KAP survey so that most of them were only assessed qualitatively.

Mulder et al. (2008) did only assess age and educational background of their study participants but did not include these aspects in their model (no significant differences identified). Nevertheless they have also identified and described the relevance of the aspect *'Social Interactions'* (here: *'advice of others'*) as well as *'Other Factors'* (here: *'other external influences'*) for the therapy choice of BU affected people. Grietens et al. (2012) did not include any information on *'Predisposing Factors'* in their results. Alferink et al. (2013) provided information on *'Age, Sex'*, *'Ethnic Group and Religion'*, *'Formal Education'*, *'Occupation'* as well as *'Assets'* but did not find any correlation with hospital delay. These findings support the assumption that – compared to non-affected people in the endemic areas –*'Predisposing Factors'* are not characteristic of BU affected people.

6.1.2 Discussion of Characteristics of BU and Disease Perception

The framework element *'Characteristics of BU and Disease Perception'* includes the most individual characteristics of the BU specific health-seeking process: The condition can be acute or chronic and may therefore be perceived as being trivial or severe. A further role does the perceived aetiology of the disease play – particularly in settings in which *"anthropology enters the medical field"* (Kroeger, 1983). As a consequence, this set of variables needed the most disease specific revisions and adaptations. The development of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) involved the introduction of the variable *'Stigma/ Social Exclusion',* deletion of the variable *'Psychosomatic vs. Somatic Disorders'* and modification of the variable *'Severe or Trivial'* to *'Severity of the Symptoms'*.

Chronic or Acute

According to Kroeger's framework the choice of the health care resource is influenced by the nature of the disease (i.e. *'Chronic or Acute'*), with chronic diseases being more likely to be treated by traditional methods (Kroeger, 1983). BU research mainly focuses on acute conditions (or the status of a lesion presented to a health facility) and usually does not assess the actual situation in the communities, so that the aspect *'Chronic or Acute'* is not properly covered by the existing research literature. As opposed to this the interviewed experts outlined that chronic BU lesions are frequently encountered in BU endemic communities and pose a special burden to the health system. The active community case search in the study area revealed a *'natural distribution'* of BU affected people with about 70% of them being active cases (that may be treated with Streptomycin and Rifampicin) and about 30% of them being chronic lesions.

People with chronic lesions are not only personally challenged but also pose a special burden on the district health management as antibiotic treatment may not be effective. These people require individual and specific attention with relatively expensive clinical interventions (e.g. surgery, skin grafting etc.). A further difficulty may be the fact that most of the people with chronic lesions in the study area were not under medical surveillance as they may have gained some negative experiences with the formal health system (see section *'Disease Experience'*). A study conducted in Benin found that people who believed that BU is a chronic disease were more likely to report late for treatment (Alferink et al., 2013). Due to these experiences or perceptions they may already have accepted their situation and may therefore not try to seek medical care at an early stage of the disease.

The presented findings show that the health facilities in the study area are not sufficient to fully care for BU affected people. Further resources such as staff with surgical skills are needed to treat chronically BU affected people.

Severity of the Symptoms

According to Kroeger (1983) for diseases which are perceived as severe, the affected people seek predominantly treatment from a *'modern healer'* (i.e. governmental health facility). Due to the fact that the severity of BU progresses over time, Kroeger's framework aspect *'severe or trivial'* was renamed into *'Severity of the Symptoms'.* This allows for differentiating the stages/ distinct features of the disease and for relating them to the perception of the disease.

The narratives of the interviewed experts illustrated and pointed out that BU *"starts from a very simple point"*[299] and that the disease is mostly painless in the beginning. Due to these features especially the pre-ulcerative symptoms are not exactly known and difficult to identify by patients and even by local health staff. These findings coincide with the reports in the literature (Kibadi et al., 2009, Stienstra et al., 2002, Ackumey et al., 2011a), which may also explain the delayed health-seeking behaviour: About 90% of the affected people wait until their lesion develops into an ulcer (Agbenorku et al., 2011, Phanzu et al., 2006) before they report to a governmental health facility for treatment.

In contrast to the early lesion features, the ulcerative stage is commonly recognized as a severe health problem: This was confirmed by the interviewed experts, who explained that extensive ulcers often develop a bad odour, may attract secondary infections, and are painful and thereby be difficult to manage. Due to these features BU may disrupt the affected person's daily life activities (e.g. inability to work; cooking and farming activities and even personal hygiene may be impaired) so that the whole family may suffer from a lack of income (see also Ackumey et al., 2012a). During the FGDs in the communities it was added that *'one may think to kill oneself if one realizes being BU affected'*, which underlines the severe impact of the disease on the affected person's life. These findings represent one important reason why the majority of the BU affected people only report in the advanced stage of the disease. Information about the influence of the *'Severity of the Symptoms'* on the health-seeking behaviour was mainly encountered in research involving qualitative methods (see Aujoulat et al., 2003, Ackumey et al., 2012a).

A specific training in diagnostics (i.e. clinical features and differential diagnoses) of BU seems to be essential for health workers being in contact with suspected BU affected people. Furthermore, BU specific health education should promote knowledge about the pre-ulcerative stage of the disease. Most of the people in the endemic communities may have heard that *'BU starts as a boil, which bursts and turns into a sore'* but are only able to identify the ulcer with its *'cotton wool'*-like appearance as being BU.

Aetiological Model

The aspect *'Aetiological Model'* as part of Kroeger's framework was not modified during the research process and assessed in all research steps: For supposedly magical or supernatural diseases traditional treatment and self-treatment are predominantly observed as preferred choice of treatment in rural settings. For physical diseases (i.e. infectious or digestive conditions) the popular strategy of treatment is *'modern medicine'* (see Kroeger, 1983).

There is no doubt that the fact that the mode of transmission of MU is still under investigation represents the essential challenge to both BU control and health education activities: The BU affected interviewees (expert interviews) either stated that they had heard that BU is water-borne, caused by *'bacteria that stay around wet and muddy places'*, the *'dirt from the ground'* or that *'BU is contagious'* (person-to-person transmission). Some of them also said that they were not sure about the specific cause or that they were confused as the commonly known and propagated risk factors and symptoms did not apply to their condition. Furthermore, they stated that everybody lived in the same conditions so that they started to doubt or question why they got infected and others did not, or they took several explanations into account (see also Ackumey et al., 2012b).

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[299] Expert Interview No 23: 13-18

As opposed to the statements from the affected people the interviewed researchers and national health staffs were convinced that supernatural or spiritual explanations dominate the disease perception of the people. One clinician explained that people relate severe diseases or diseases that cause deformities to supernatural forces. A further interpretation was that the people believe in a *'root-cause'* as soon as the medical treatment fails or is prolonged. These differences in the reported perceptions may either be attributed to the affected people's aversion to mentioning their true perception or to the interviewed researchers' and health staff's bias or even arrogant view on the perception of the rural people.

According to the results of the KAP survey in the study area the majority of the (previously) BU affected people thought that they contracted the disease through contact with non-purified water, and more than 40% were not able to ascribe the origin of their infection to any specific cause. Supernatural explanations were not among the determining ones (less than 1%) so that no significant differences could be identified between *'Late'* and *'Early Care-Seekers'* for the perceived cause of the disease (see section 6.2.2).

Further local explanations for the cause of the disease were encountered during the FGDs in the selected communities. There it was revealed that the supernatural explanations were definitively (still) part of the explanatory model of the people. According to the narratives of the participants especially *'older people'* tend to believe in supernatural forces. Whether the participants themselves did not believe this way or whether they avoided confessing this belief lies beyond the borders of this study. Apart from this controversially discussed aspect the most commonly encountered explanation was that *'BU is water-related'*. Another explanation that accounts for the perception that one may not effectively prevent the disease was that *'BU must be air-borne'*.

According to several authors of the BU specific research literature the unknown cause may explain the *'Therapeutic Itineraries'* of the people (Kibadi et al., 2009, Mulder et al., 2008, Renzaho et al., 2007, Aujoulat et al., 2003) as the uncertainty supports the belief in supernatural causes. In contrast to this commonly cited explanation the authors of a study conducted in Benin revealed that this explanation may over-simplify the health-seeking process but that structural elements are more determining, for example the perception of the effectiveness of the treatment, the availability of traditional treatment to reduce costs and the relationship between health care provider and patient (Grietens et al., 2012). Similar findings were reported in a study conducted in Ga West and Ga South (Ghana) (Ackumey et al., 2012b). These findings underline that the *'Aetiological Model'* represents probably the most controversial aspect of the discussions on the health-seeking behaviour of BU affected people.

The above-mentioned findings show that the answers of the study participants differ from one research method to another (compare with Renzaho et al., 2007), so that the real perception of the cause of the disease in the study area may lie somewhere in between: Most of the people have somehow encountered the over-simplified or misinterpreted health education message that *'BU is water-related'*, so that they were most likely to report this socially accepted answer (although the scientific evidence is weak for the assertion that ingestion of unclean water may be a possible mode of transmission (Duker et al., 2004)). Their perception depends upon their own experience: They have realized that they are not the only ones, who live in this harsh setting – but not everybody in their community is affected with BU. This is the point where the people start doubting and either believe in different causes (i.e. BU is transmitted through contact with water but a supernatural force determines who gets infected or not) or they believe in supernatural causes so that their disease may only be cured by traditional treatment. As a consequence of these findings a better evidence on risk factors for BU combined with as well considered health education messages may help the people to adapt these explanations into their life world.

Expected Benefits of the Treatment

According to Kroeger's framework the expected outcome of a therapy is the basic determinant for the choice of a specific treatment option. Furthermore its choice is closely linked to the perceived aetiology and/ or the satisfaction with former therapies (see Kroeger, 1983).

Due to the fact that information about the expected benefits of BU treatment are mainly encountered in research settings involving qualitative methods (compare with Alferink et al., 2013, Grietens et al., 2012, Ackumey et al., 2012b, Ackumey et al., 2011a, Johnson et al., 2004, Stienstra et al., 2002) this aspect was assessed during the expert interviews as well as during the FGDs: The most important argument for seeking care from a governmental health facility among the interviewed experts was that the people expect fast and effective healing of their lesion (faster than herbal treatment –*'something magic'*). A commonly encountered assumption amongst the expert interviews was that the disease must be completely healed after 56 days of antibiotic treatment. Furthermore, the people perceive the antibiotic treatment to be the *'final resort'*: When herbal treatment has failed they expect a correct diagnosis as well as fast and effective treatment from a governmental health facility (compare with Ackumey et al., 2012b).

In reality the expectations of the people for the treatment from a governmental health facility are hard to reach – either due to the fact that the people report too late, so that antibiotic treatment alone may not be effective, or due to the fact that the treatment is interrupted. Reasons for treatment interruptions are manifold: There may be a non-sustained supply of Streptomycin and Rifampicin at the health facilities, or the affected people have no money for transportation. Another commonly mentioned reason for treatment interruptions is the fact that the patients do not report regularly to the health facility when they do not observe an immediate improvement. Reasons for not observing the anticipated improvement may be a *'paradoxical reaction'* (see section 2.1.7)*:* In case of a paradoxical reaction the treatment should be different from treatment failures so that clinicians require respective information and training about the incidence, risk factors, clinical features, and respective treatment (O'Brien et al., 2014). In a study that was conducted in Benin it was found that people who were convinced of the effectiveness of BU treatment were more likely to report early for treatment (Alferink et al., 2013). According to Grietens et al. (2012) the perceived effectiveness was even more prominent for the treatment choice than beliefs. These findings underline the importance of adequate health education among the people in BU endemic communities and the fact that specific counselling of the affected patients is essential.

The expected benefits of traditional herbal treatment that were reported in this study were the acceleration of the healing process through the removal of the necrotic tissue (*'cotton wool'*) from the BU suspected lesion (compare with Ackumey et al., 2012b). Some traditional healers also use a combination therapy, which involves the consumption of strong alcohol flavoured with herbal essences (*'bitters'*) to *'eliminate the bacteria from the system'*. But the most important characteristic of traditional herbal treatment is that it may heal the patient spiritually – a feature which does not apply to the antibiotic treatment.

Stigma/ Social Exclusion

The newly introduced variable *'Stigma/ Social Exclusion'* (no variable of Kroeger's framework) accounts for both the physical consequences (i.e. scars and deformities) (Aujoulat et al., 2003, Stienstra et al., 2002) and unpleasant features of BU lesions as well as the social aspects (i.e. prejudices of the society and feelings of the affected people), which are mentioned in the literature (Adamba and Owusu, 2011, Grietens et al., 2008, Renzaho et al., 2007, Aujoulat et al., 2003, Stienstra et al., 2002): Due to the specific features of BU lesions the affected people may not be able to hide or deny their infection. These characteristic attributes may evoke reservations and social exclusion of BU affected people.

Although the overall perception of the interviewed experts was that *'rural folks are united'* and care for each other or do not exclude BU affected people from social events, it was found that the affected people in the study may suffer from on-going rumours about them. This may not apply to people with pre-ulcerative lesions that may be covered: However, patients with severe and smelling lesions (compare with Adamba and Owusu, 2011, Renzaho et al., 2007) often find that people cover their nose or avoid getting closer to them as some of the non-affected community members still believe in the misperception that BU may be transmitted from one person to another, that the disease is caused by a curse or just because they think that BU lesions are disgusting. These findings explain why people who experience such behaviour are often shy, have a low self-esteem and therefore hide their lesion, stop schooling, stay in their homes and avoid approaching the community (see also Adamba and Owusu, 2011, Aujoulat et al., 2003).

The answers provided by the participants of the KAP survey show that the majority of the (previously) BU affected people state that they had the feeling that the people showed sympathy for them and that were welcome to attend social functions while the disease affected them. Yet, the majority of the (currently or previously) BU affected study participants also stated that affected children interrupt their education. Furthermore, only 12% of the (currently or previously) affected study participants believed that a BU patient may be a leader. The findings from the qualitative interviews and discussions suggest that some of the (previously) affected people may have been too uptight to report that they were excluded from their peers when suffering from the disease. Findings from the literature support this observation and suggest that the majority of the affected people experience a negative change in the attitude towards them (Adamba and Owusu, 2011) or even social exclusion (Grietens et al., 2008).

Probable solutions to promote the social inclusion of BU affected people in the community were discussed and proposed by the FGD participants: They emphasised that there needs to be more awareness of the disease (i.e. BU is a curable disease, not caused by a curse and may not be transmitted from one person to another) and the fact that there is medical treatment available. Similar findings are reported about people being affected by Leprosy: In that case a lack of knowledge and wrong perceptions of the disease as well as the presence of visible deformities and disabilities are assumed to contribute to a higher perceived stigma (Adhikari et al., 2014). Overall it seems that knowledge, timely treatment and adequate disease management have the potential not only to lower the physical disease burden but also to reduce the social and psychological disadvantages of the disease in the study area so that people may be more self-confident and less stigmatised.

Relevance of the Framework Element Characteristics of BU and Disease Perception for respective Health-Seeking Behaviour

All variables of the framework element *'Characteristics of BU and Disease Perception'* are valid and relevant to describe/ assess the respective health-seeking behaviour and are more or less BU specific.

The obtained findings for the different variables coincide with the results of the other studies conducted in Ghana and Benin (Grietens et al., 2012, Ackumey et al., 2012a, Ackumey et al., 2012b, Alferink et al., 2013), which have discovered that the expected benefits as well as the perceived seriousness of the disease play a dominating role in the health-seeking behaviour of BU affected people.

Some of the aspects, which were mentioned as *'internal factors'* in Mulder's model (i.e. *'perceived seriousness'*, *'cause of the disease is witchcraft'*) (see Mulder et al., 2008) may be summarized under the variables of the aspect *'Characteristics of BU and Disease Perception'* of the *'Modified BU specific Framework for Health-Seeking Behaviour'*. Only the phenomenon *'confidence in hospital'* falls into another category (i.e. *'Disease Experience'*) but is also a valid aspect of the BU specific framework. Grietens et al. (2012) assessed similar aspects and included them in their model (*'difficulties of symptom recognition'*, *'perceived aetiology'*, *'effectiveness of treatment'*). The aspect of stigmatization was not covered. As mentioned in section *'Expected Benefits of the Treatment'* the perceived effectiveness of a treatment option was found to be more determinant for the treatment choice than beliefs. Alferink et al. (2013) collected data on aspects which are comparable or could be matched with the aspects included under the element *'Characteristics of BU and Disease Perception'* (*'illness perception', 'cause', 'consequences', effectiveness of treatment', 'stigma'*). In addition to that Alferink and colleagues have assessed emotional representations as an additional aspect. But it was not found to be important for the BU specific health-seeking behaviour.

These findings support the assumption that this framework element includes aspects with a strong influence on the *'Choice of Health Care Resources'*.

6.1.3 Discussion of Enabling Factors (Health Service Characteristics)

Kroeger identified geographical accessibility, communication between healers and patients, quality of care and costs as being factors which facilitate the use of particular health services (Kroeger, 1983). These aspects were also found to be determinants for the BU specific health-seeking process even though three of the original four variables have been slightly adapted in this study: two variables were renamed (*'Appeal of Treatment'* and *'Cost of Treatment'*) and the original variable *'Acceptability, quality, communication'* was split into *'Acceptability and Quality of available Health Services'* and *'Health Education and Communication'.*

Accessibility

Kroeger argued that the low degree of *'Accessibility'* to governmental health facilities is a major argument for the use of traditional treatment options (Kroeger, 1983). According to the interviewed experts in this research there is no doubt that most BU affected people live in remote communities with irregular access to public transportation, so that people may struggle to find their way to governmental health facilities. Looking at the research literature the significance of *'Accessibility'* to health care resources could not yet be satisfactorily identified: Studies conducted in DRC and Benin did not observe a longer patient delay of those patients who reported that the distance to the health facility or transportation costs were obstacles for reporting to a governmental health facility (see Kibadi et al., 2009, Mulder et al., 2008).

The results of the KAP survey may not fully explain the real challenges in the study area: 64% of the (previously) affected people used local transport and/ or walked (57%) to the health facility. The average duration to reach the health facility was 29 minutes, and the vast majority of the study participants may reach the health facility within 30 minutes. Then again more than half of the (previously) BU affected people need more than 25 minutes – one of them even had to walk for two hours. Furthermore, these figures do not give sufficient insight into the affected people's possibility to report for daily treatment for 56 Streptomycin injections: Only the combination of distance to the facility with the challenges encountered at the health facility and the period of time required for diagnosis may somehow reveal the full picture of *'Accessibility'* to the antibiotic treatment.

Similar to the reports in previous studies (Ackumey et al., 2011a, Mulder et al., 2008, Grietens et al., 2008) and the accounts by Kroeger (1993) the traditional herbal treatment in the study area was closely available to the people. These are strong arguments for its use. It was also reported that people travel long distances to seek help from one specific herbalist from whom they have heard providing effective BU treatment. These narratives underline that at least some people do not mind travelling long distances if they expect to be healed.

To what degree the BU affected people need to live close by the governmental health facilities to benefit from their supply or not may not be clearly identified given the current status of knowledge. Nevertheless, a further decentralization of the governmental health facilities (see Grietens et al., 2012), incentives for CSBVs supporting early case detection and reimbursement of travel costs (compare with Ahorlu et al., 2013b) combined with valid health information about the potential and effectiveness of the antibiotic treatment may be helpful interventions to promote early reporting as well as treatment adherence. The prospects for an all-oral treatment may further promote early treatment (compare with O'Brien et al., 2014).

Appeal of Treatment

Information on people's attitude towards the different health care resources is not easy to assess and retrieve in transitional societies (Kroeger, 1983). Nevertheless quite a few studies have assessed opinions and attitudes of the people towards traditional herbal treatment and/ or the treatment provided by governmental health facilities (Ackumey et al., 2011a, Kibadi, 2007, Mulder et al., 2008, Grietens et al., 2008, Renzaho et al., 2007, Phanzu et al., 2006, Johnson et al., 2004, Asiedu and Etuaful, 1998, Ackumey, 2002, Stienstra et al., 2002, Adamba and Owusu, 2011) so that one may summarize the major advantages and disadvantages of those two treatment options for BU as perceived by the people:

It is known that traditional herbal treatment is preferably used in the pre-ulcerative stage of the disease (Ackumey et al., 2012b, Ackumey et al., 2012a, Ackumey et al., 2011a) or before reporting to a governmental health facility. The main reason for its choice is that patients are used to it and treated in their natural environment (i.e. their community) so that they may easily access the provider and thereby save both time and money (compare with Adamba and Owusu, 2011). Furthermore, the experts interviewed within this research explained that the people consider the herbs as part of the things *"provided by God"*[300], which may *"help to*

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[300] Expert Interview No. 19: 581-583

cure the disease internally'[301]*;* traditional treatment is not invasive and may also cure the spiritual aspect of the disease. Reports from the research literature, about certain herbalists having the reputation of being able to effectively treat BU cases (see Ackumey et al., 2011a, Guédénom et al., 1995), could be confirmed in this study: Some of the interviewed experts (i.e. health staff) have reported that there was at least one herbalist in the study area with the ascribed expertise.

The interviewed experts explained that traditional herbal treatment is also known for being associated with higher risks of complications (i.e. secondary wound infections, scars, contractures and disabilities) and higher probability of recurrence. Usually traditional treatment for BU requires a longer duration of treatment than treatment from a governmental health facility. And last but not least the provided therapy and its quality may differ more strongly among healers than among health facilities as most of the traditional herbal remedies have not yet been tested and their quality is not monitored. An overall valid evaluation is therefore not yet possible. Due to the strong belief of the people into herbs and traditional treatment research into its remedies and the related effectiveness seems to be recommendable.

In the KAP survey about 40% of the (previously) affected people stated that they did not know anything about the antibiotic treatment for BU (including those who provided no answer). These findings show that even many of those who are or were BU affected are or were not familiar with the available treatment (compare with Kibadi, 2007). At the same time, the missing answers may be triggered by the fact that the people are not used to evaluate the treatment provided by someone with a higher degree of formal education. In the KAP survey (previously) BU affected people who provided an answer thought that the antibiotic drugs are effective (i.e. faster than treatment with herbs, clean and heal the lesion without deformities, alleviate sleeping and ease the pain) (compare with Ackumey et al., 2011a). The interviewed experts confirmed the above-mentioned findings. In addition to that the experts argued that the treatment with Streptomycin and Rifampicin does not only significantly reduce the duration of treatment but also the cost of treatment. Despite the predominantly good experiences with this regimen there are still BU affected people with lesions that are too big to heal with antibiotics alone, or where the effectiveness of the drugs may not meet the expectations of the people (i.e. *'paradoxical reactions'*, see O'Brien et al., 2014).

Due to the fact that the people in the research area are usually treated on outpatient basis long duration of admission (Ackumey et al., 2011a, Mulder et al., 2008, Grietens et al., 2008, Renzaho et al., 2007, Phanzu et al., 2006, Johnson et al., 2004, Asiedu and Etuaful, 1998, Ackumey, 2002) did not apply to them (compare with Ahorlu et al., 2013b). But other known disincentives – fear of diagnosis and fear of the treatment itself – were reported in the study area: many people are afraid of injections (see also Mulder et al., 2008) and the necessary dressing/ wound care. Although there is no longer a well-founded reason for the fear of amputation (compare with Mulder et al., 2008, Stienstra et al., 2002) or surgical intervention in case the people report for early treatment, there were still some people not being aware of the drug based treatment and the fact that it may prevent surgery. Another raised issue was the time spent while travelling to and waiting at the health facility (see also section *'Accessibility'*) as well as the fact that the number of injections is not acceptable. Grietens et al. (2012) highlighted that local treatment is an important aspect for the treatment choice so that decentralization of the health system could constitute a key element to reduce delay and

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[301] Expert Interview No. 33: 176-179

increase adherence to biomedical treatment. The before-mentioned all-oral treatment which was also suggested by the interviewed experts seems to be the most preferred medical treatment option (see also Kibadi, 2007). This would allow for an independent and more or less home based therapy without the need to receive daily treatment from professionally trained health staff (compare with O'Brien et al., 2014).

Acceptability and Quality of available Health Services

During the systematic literature search a lot of information was retrieved for the original aspect *‚Acceptability, quality, communication'* of Kroeger's framework. The expert interviews provided even more extensive information so that the differentiation/ split into two aspects seemed to be reasonable: *'Acceptability and Quality of the Health Services'* and *'Health Education and Communication'* (see Figure 30).

The assessment of most answers with respect to *'Acceptability and Quality of the Health Services'* provided different information by (previously) BU affected people and the interviewed experts with a professional background. More than 70% of the (previously) BU affected people in the study area stated that they were satisfied with the services of the accessible infrastructure. The interviewed experts held the view that the health facilities are insufficient in terms of lacking dressing equipment and facilities for surgical care to provide treatment in the advanced stage of the disease, which includes a lack of hospital beds. The same pattern was found for the perception of the professional skills of the health staff: Some of the affected interviewees assumed that the health workers are omniscient, but the interviewees with a professional background and perspective judged that the number and capacity of the staff is insufficient (i.e. lack of professional training and knowledge) (compare with Kibadi et al., 2009). The differing perception of the quality and acceptability of the governmental health services may be caused by mainly two reasons: First, the patients are not used to evaluate these services and therefore do not dare to criticize them as the health personnel has a higher professional qualification. Second, they may not have the insights to evaluate whether the skills of the health worker are adequate or whether the facilities meet the necessary standards. Third, they are probably too courteous to talk bad about the health workers.

A similar pattern can be observed for the doctor-patient relationship: individually interviewed patients predominantly perceived the friendliness of the health staff as positive, but the interviewed health workers and officials, NGO staff and teachers considered the attitude of the health workers towards the patients as challenging (i.e. shouting, blaming and insulting patients – especially if people report late or interrupted their treatment). Grietens et al. (2012) reported similar findings from their field research in a hospital in Cameroon: The lack of respect by medical staff led to treatment abandonment of the patients.

As opposed to the above-mentioned patients the participants of the FGD rounds explained that they had experienced misbehaviour of health staff and that the staff in the small community-based facilities were perceived to be friendlier than the personnel of the local *'Government Hospital'*, which was the adjacent hospital for the people in the study area. These findings show that the individual judgement of the patients regarding the *'Acceptability and Quality of available Health Services'* differed across the different research methods; probably because the individually interviewed patients did not dare to criticize the health personnel.

A further aspect criticized by the interviewed experts was the BU specific diagnosis (see also Ackumey et al., 2011a, Asiedu and Etuaful, 1998). Due to several constraints some of the BU suspected patients in the study area never received a definite diagnosis (see also

Phanzu et al., 2006) – others did not receive it before they were already receiving treatment or had been already healed. Reasons for this were manifold: BU suspected pre-ulcerative lesions in rural facilities may only be judged clinically, many other diseases disguise BU and false diagnoses occur (compare with O'Brien et al., 2014). Therefore the health workers may either wait until the lesion ulcerates and then take a swab for confirmation, try other drugs first and see whether the lesion heals or immediately start with the Streptymycin/ Rifampicin-treatment. In case the swab is being taken the challenges are different as only few laboratories within Ghana can do the confirmation. Due to a lack of communication between the different institutions the results sometimes do not reach the patient.

A further constraint in the rural facilities were the lack of drugs (i.e. Streptomycin and Rifampicin) and dressing materials, which occurred from time to time: The respective logistics were depending on some few people, who were not permanently present and the patient-based requirements for the necessary drug supply (i.e. laboratory confirmation) could usually not be met. The bereaved are the patients: some of them may receive delayed and interrupted treatment, or the accepted hygienic standards may not be maintained in that bandages and gloves are not changed or normal water instead of normal saline is used.

Another constraint was the low budget for BU specific health education and training, supplies as well as the poorly managed activities, which did not even allow the NBUCP to organize individual activities (i.e. health education and trainings or research and control activities). Reasons for this situation reported by the interviewed experts were that BU belongs to the neglected tropical diseases with limited international interest (see also Hotez et al., 2009).

Health Education and Communication

The interviewed experts had a very diverse perception of the BU specific knowledge and awareness status of the people in the study area: Researchers and clinicians stated that there is no awareness at all whereas nurses and NGO staff thought that the people are generally aware but not familiar with the antibiotic treatment and its drugs in specific. A third group of experts, health workers and officials stated that the people are aware of the antibiotic treatment with Streptomycin and Rifampicin.

The KAP survey in the study area allowed for quantifying the BU specific knowledge: about 30% of (previously) BU affected people maintained that they had never received any official disease specific information. This may be driven by the fact that the 60% of the surveyed people with an old healed BU lesion may not necessarily have received antibiotic treatment and respective health information from the health post or any other institution. Another explanation could be that they had never received a proper diagnosis or disease specific counselling or considered the information they received as being *'non-official'*. This would be in line with the finding that only three out of four of the (previously) BU affected people stated that they are aware that governmental health facilities provide antibiotic treatment (*'pills and injections'*) for BU.

The fact that the majority of the (previously) BU affected people (69%) did not get to know about the disease before they were affected themselves underpins the assumption that BU specific health education campaigns in the research area have either been insufficient or ineffective. Commonly reported information sources were friends and neighbours or family members. These findings go in line with information from the research literature (compare with Agbenorku and Kporku, 2001). Only 43% of the people declared that they had received BU specific information within the last six months either by attending a video show (organized by a local NGO) in the village or by some of the health workers, that they had seen posters or had heard about it on the radio. Against this background it does not come as a surprise that only 13% of the (previously) BU affected study participants (KAP survey) were satisfied with the information they had received and therefore claimed for information about the mode of transmission (e.g. *"Is it true that BU is water-borne?"*[302]) and respective preventive measures, information about an efficient treatment to cure the disease as well as particulars about early symptoms.

The FGD participants explained that they preferably wish to receive information about BU from doctors, health workers or nurses. Furthermore, they underscored that they considered the government and the respective ministries to be responsible for providing understandable information to all of them. In this respect findings from the FGDs have shown that especially people in remote communities have a particular need for BU specific education, so that respective campaigns should focus on these settings.

Cost of Treatment

Kroeger's framework includes the aspect *'costs'*, which represents another frequently mentioned obstacle to access governmental health facilities. Besides this, it is mentioned that traditional treatments are often perceived to be cheaper (see Kroeger, 1983). During the adaptation process the variable was redefined as *'Cost of Treatment'* to describe this aspect more specifically.

The analysed research literature confirms that *'Cost of Treatment'* represents an important obstacle to the treatment of BU (Aujoulat et al., 2003). Due to the fact that antibiotic treatment was not introduced before 2005 most of the published literature deals with treatment associated costs for hospitalized BU patients involving surgical treatment so that detailed information on BU treatment based on antibiotics and provided on an outpatient basis is fairly limited. Furthermore, it needs to be differentiated between direct (i.e. expenditures during the course of the treatment) and indirect cost of treatment (i.e. loss of productivity).

Although Streptomycin and Rifampicin for BU treatment are provided free of charge any further item (i.e. bandages, normal saline, painkiller, etc.) may fall beyond. In reality only people with a health insurance (34% of the (previously) BU affected people in the study area) are treated entirely for free, so that patients without a valid insurance card may have to provide for these items on their own. This may be the reason for the observation that about 15% of the (previously) BU affected people were unable to tell whether one had to pay for the treatment or not. Although this study did not assess the actual costs of individual treatment, the findings substantiate claims for the establishment of a health insurance support scheme for BU patients. This could help to sustain an uninterrupted and adequate treatment with the necessary supplies. In the study area with about 25 newly affected BU patients per year this would amount to 350 GHC[303] (about $ 260/ 150 €) annually.

Probably even more important are the high treatment related costs (costs which are related to the treatment but not covered by the national health system or insurance: i.e. transportation costs, etc.): About 60% of the (previously) BU affected people reported that they had to use public transportation to reach the nearest health facility to receive the daily injection. Further consequences and costs of the disease were not assessed in this study, but the study by Grietens et al. (2008) give valuable insights into the financial and social burden of hospitalized BU patients. In their study hospitalisation accounted for 25% of a

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[302] FGD 2-1/ R4: 92

[303] In the year 2010 the costs of a health insurance were 14 GHC per person and year ($10.16; 7.70€).

households' yearly earnings on average so that some families isolated their hospitalized family members as a coping strategy.

In this context, findings from a social intervention in Obom (Ghana) have shown that the provision of transportation and breakfast for BU affected patients could be another meaningful investment to significantly reduce default and dropout of patients as well as to increase case detection in the study area (Ahorlu et al., 2013b). Considering the costs of 85 US$ per patient and treatment course determined in that study, which also include an incentive for the referring CSBV, this intervention would save a considerable amount of money for the health system as it could prevent a lot of disabilities (see Ahorlu et al., 2013b). This intervention could also counteract the arguments of many people claiming that herbal treatment is cheaper for the individual patient than reporting to a governmental health facility. Yet, a study conducted in Ga West and South Municipalities (Ghana) has found that other social factors (e.g. *'Social Interactions'*) may be even more important than financial considerations (Ahorlu et al., 2013a), so that social interventions should aim to be holistic.

Relevance of Enabling Factors for BU related Health-Seeking Behaviour

The findings regarding the health system related variables show that several aspects need to be improved to allow for an easy access to governmental health facilities. Points of intervention may range from improvements in *'Accessibility'* to health facilities and of the *'Acceptability and Quality of available Health Services'* as well as *'Appeal of Treatment'* to adequate *'Health Education and Communication'* and an establishment of a social and financial support system. All included variables and the respective phenomena are essential to explain and assess the BU specific health-seeking behaviour; hence, they should be considered when designing health promotion campaigns.

Theoretically, the set of *'Enabling Factors'* may be compared with the *'external factors'* as described by Mulder et al. (2008) (i.e. *'advice of community and family'*, *'cost of treatment'*, *'community habits'*, *'season'* and *'admission time to hospital'*). Mulder's aspects *'costs'* and *'admission time to hospital'* correspond with the element *'Cost of Treatment'* of the *'Modified BU specific Framework for Health-Seeking Behaviour'*. The other phenomena of Mulder's model (i.e. *'advice of community and family'*, *'community habits'* and *'season'*) were also included in the framework but shoud be subsumed under the *'Predisposing Factors'.*

Grietens et al. (2012) as well as Alferink et al. (2013) assessed aspects which could all be subsumed under the framework's element *'Enabling Factors'*. As highlighted by Grietens et al. (2012) local treatment as a *'cost prevention strategy'* and the characteristics of the *'doctor-patient relationship'* are important aspects for the treatment choice. Alferink et al. (2013) added that (apart from the perceived *'effectiveness of treatment'*) the *'timeline acute-chronic'*, which could be matched with the framework aspect *‚Acceptability and Quality of the available Health Services'* of the *'Modified BU specific Framework for Health-Seeking Behaviour'*) showed the strongest association with delayed health-seeking behaviour.

These details underline that not only the perception of the disease but also the local health infrastructure – including the performance of the health staffs – are most important aspects that need to be improved to promote early treatment from a governmental health facility.

6.1.4 Discussion of the Framework Element Choice of Health Care Resources

The original set of variables of *'Choice of Health Care Resource'* as suggested by Kroeger consists of four different options/ resources. During the research process two specific elements (*'Therapeutic Itineraries'* and *'Church/ Prayer Camp'*) were added, and two elements were split (*'Self-Treatment'* and *'No Treatment'* instead of *'Self-Treatment + No Treatment'*) or modified (*'Governmental Health Facilities'* instead of *'Modern healer'*) to give a detailed and more specific overview of the available treatment options in the study area (see *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II), Figure 30).

Therapeutic Itineraries

The embracing element *'Therapeutic Itineraries'* was newly included to the framework to allow for an overall summary of the treatment courses of BU affected people and account for the alteration/ choice of different options at the same time (i.e. *'healer-shopping'*).

Looking at the research literature the majority of the BU affected people either try self-treatment and/ or traditional herbal treatment before they report to a governmental health facility (see Ackumey et al., 2011a, Mulder et al., 2008, Renzaho et al., 2007, Ackumey, 2002, Stienstra et al., 2002, Ackumey et al., 2012b). Although the findings from the FGDs have confirmed this practice ('*herbal treatment was used first and medical treatment as the last resort*') the results of the KAP survey provided another picture of the behaviour in the study area: According to the reports of the (previously) BU affected people there was almost no difference in their frequency of consultation between the herbalist (43%) and the governmental health facility (44%) for treating nodules. Comparing these results with the research literature it seems to be most likely that the participants had provided socially accepted answers (i.e. consultation of a governmental health facility in the pre-ulcerative stage). A further element of uncertainty is the fact that the results of the survey are solely based upon the reports and the personal memory of the (previously) BU affected people (after a maximum of three years after the lesion healed) and not on clinical reports so that these answers may be imprecise and even more biased by social acceptance.

The KAP questionnaire did not assess which treatment option was used first for the specific characteristics of the lesion, or whether several options were combined at the same time. Therefore it may be assumed that the question about the choice of the respective treatment option was not precise enough. The phenomenon of compatibility and inter-changeability of different treatment options at the same time – commonly known as *'healer-shopping'* (compare with Aikins, 2005) – was also reported by the study participants (see also Ackumey, 2002) but was not quantitatively assessed during the survey. Another associated limitation for this aspect is the fact that only 94 of the (previously) BU affected people reported about their treatment choice for a nodule. It is also not possible to differentiate whether the remaining 28 study participants did not have a nodule, did not observe it or were not able to recall this stage of the disease.

The aspect of patient delay was not directly assessed as the interviewed experts had reported that the BU affected people might not be able to provide the real picture (see also section 6.2.2).

No Treatment

7% of the (previously) BU affected survey participants stated that they did not use any treatment option. This behaviour may have been determined by a lack of awareness of the disease as suggested by the interviewed experts. Another incidence, where people do not use any treatment, may be the fact when they have the feeling that they have already tried everything that is in their hands and did not succeed (i.e. *'paradoxical reaction'*). This behaviour was also reported by the interviewed experts and described in the literature (see Ackumey et al., 2011a, Stienstra et al., 2002) so that the variable *'No Treatment'* needs to be included within the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 30).

Self-Treatment

Corresponding to the findings on the option *'No Treatment'* more than one fifth of the (previously) BU affected study participants in the study area reported that they used several home remedies (i.e. hot water, *'blood tonics'*, herbal preparations, analgesics or unspecific antibiotics) to treat their pre-ulcerative lesion or combined several remedies to complement another health care resource. These findings were confirmed by the available research literature (Stienstra et al., 2002, Ackumey et al., 2011a, Mulder et al., 2008, Alferink et al., 2013), so that this phenomenon also needs to be considered as an essential variable of the framework.

Drug Seller

The aspect *'Drug Seller'* was not specifically assessed during the survey, but the literature (see Ackumey et al., 2011a, Kibadi et al., 2009) and the expert interviews have confirmed that some people prefer buying unspecific antibiotics and analgesics to treat their lesion or the associated symptoms instead of reporting to a governmental health facility. This seems to be a common practice among those who cannot or do not want to cope with the waiting time at the facility to clarify the symptoms and to receive a diagnosis: waiting time at governmental health facilities may run up to several hours.

Drug sellers in BU endemic communities may be considered as kiosk owners without any special education on the drugs they offer. This aspect is not necessarily an individual variable of the framework but may also be subsumed under the variable *'Self-Treatment'*. Nevertheless, these stakeholders need to be taken into consideration when designing BU specific health education and promotion activities.

Traditional Healer

The results of the expert interviews, the KAP survey as well as the FGDs have shown that the majority of the people in the study area highly value traditional treatment: Major reported reasons for the preference of traditional herbal treatment – especially in the pre-ulcerative stages – over medical treatment were culture and tradition (see section *'Degree of Cultural Adaptation'*), convenient accessibility and thereby low transportation costs (see sections *'Accessibility'* and *'Cost of Treatment'*), the perception that herbs may effectively remove the *'cotton wool'* from the lesion to increase the healing process (see section *'Expected Benefits of the Treatment'*), the fact that it is not invasive (see section *'Appeal of Treatment'*) as well as the perception that traditional treatment may also cure the spiritual aspects of BU (see sections *'Aetiological Model'* and *'Expected Benefits of the Treatment'*).

Although findings on herbal treatment practices have increased within the last years (see Guédénom et al., 1995, Ackumey et al., 2011a, Johnson et al., 2004, Kibadi et al., 2009, Ackumey et al., 2012b, Grietens et al., 2012, Yemoa et al., 2011) concrete treatment details and its probable effectiveness as well as respective techniques of diagnoses are still not sufficient – either because it is not on the research agenda, the traditional healers do not want to share their knowledge or the medical personnel avoids contact with traditional healers. Opposed to the statements by the interviewed health personnel and researchers, the interviews with the herbalists/ traditional healers of this research were very open-minded and detailed and did not confirm the common prejudice that they would not share their knowledge.

Governmental Health Facility

The narratives of the experts are particularly helpful to understand the local circumstances since descriptions of concrete BU treatment practices in governmental health facilities are rarely encountered in the literature. As mentioned before the diagnoses may be delayed so that the specific treatment might also be unpunctual. As long as the responsible health worker is not aware of BU or does not receive the results from the laboratory the patients may receive an unspecific multi-drug treatment. Due to this practice some of the patients may perceive the treatment provided from the governmental health facility as being non-effective (see section *'Appeal of Treatment'*).

Nevertheless more than 40% of the (previously) BU affected study participants stated that they reported for medical treatment when they had a pre-ulcerative lesion; 80% reported that they went to a governmental health facility when they had an ulcer. Whether these statements reflect the true behaviour of the people may only be presumed. The narratives of the expert interviews suggest that these results of the KAP survey are biased by social desirability or the fact that these results are based on personal reports of the study participants (in some cases three years after the lesion healed).

Church/ Prayer Camp

The phenomenon of seeking relief from priests rather than reporting to a governmental health facility or a traditional healer was mentioned by the interviewed experts as well as in the literature (see Ackumey et al., 2011a, Kibadi et al., 2009). Yet, the KAP survey in the research area has shown that this option does not play a major role: Only about 1% of the (previously) affected people in the research area reported that they sought relief for a nodule or an ulcer from a church or prayer camp. Nevertheless, religion and church attendance play an important role in the rural communities so that priests and church events should be considered as relevant stakeholders in educating the people on BU. Priests may strongly influence the health-seeking behaviour as some people *"have a greater faith in God than in doctors"* (Edwards, 2014).

Relevance of the Framework Element Choice of Health Care Resources

The evaluation of this set of variables has shown that all treatment options are valid in the study area but have a different relevance. Notably *'Traditional Healer'*, is more relevant than others (i.e. *'Church/ Prayer Camp', 'Drug Seller'*), which play an inferior role. These aspects are not necessarily an essential aspect of the framework for the study area but should be considered when assessing the BU specific health-seeking behaviour.

Furthermore, it can be summarized that the choice of the respective health care resource differs between the stages of the disease: During the pre-ulcerative stage, when some of the affected people may not be aware of the disease, they are more likely to practice *'No Treatment'*, *'Self-Treatment'* or *'Traditional Treatment'*. During the ulcerative stage – after the people have probably tried other options and remedies – they tend to use *'Traditional Treatment'* or seek care from a *'Governmental Health Facility'* as they may have gained the experience that the previously used options or remedies did not succeed to heal their lesion.

The three other models that try to explain the BU specific health-seeking behaviour subsume more or less the same variables/ health care resources: Mulder et al. (2008) provide a good overview of exemplary patient itineraries as it also includes the timely alteration as well as the choice of different options over time but does not consider the phenomenon of *'healer-shopping'*, which refers to the compatibility and inter-changeability of different treatment options at the same time. Grietens et al. (2012) assessed *'number of health encounters'* as well as *'alternation of treatment'* and thereby describe similar aspects as the variable *'Patient Itineraries'*. Due to the fact that Alferink et al. (2013) assessed pre-hospital delay only among healthy individuals – and not amongst BU affected people – they did not gain information on this variable.

All researchers aimed to assess patient delay: Mulder et al. (2008) and Grietens et al. (2012) requested this information from both BU affected and non-affected study participants; Alferink et al. (2013) included estimations by skin pictures presented to healthy individuals. The findings of the present study suggest that this aspect is very sensitive since the influence of social acceptance may play a dominant role (see section 6.2.2).

None of the other models included the aspect *'No Treatment'*. The observations of the present study suggest that this variable should be subsumed under the framework.

The aspects *'Self-Treatment'* and *'Traditional Healer'* are also part of Mulder's (2008) and Grientens (2012) model. Alferink et al. (2013) did not assess these aspects but focused only on the use of governmental health facilities.

The aspects *'Drug Seller'* and *'Church/ Prayer Camp'* are unique in the developed framework. The research findings suggest that these variables are valid but do not play a major role for the BU specific health-seeking behaviour in the study area.

6.2 Discussion of Results with Respect to the Specific Research Questions (2) to (6)

The following section provides the answers to the specific research questions (2) to (6). The first subsection addresses research question (2) by discussing observed differences in knowledge, attitudes and practice between (previously) BU affected and the non-affected study participants (see section 6.2.1) in the study area. Then the determinants for seeking care from a governmental health facility as assessed in the study area will be discussed in section 6.2.2. There the characteristics of *'Early Care-Seekers'* and *'Late Care-Seekers'* will be provided (research question 3).

Section 6.2.3 discusses whether there are any age-related differences with respect to the BU specific health-seeking behaviour (research question 4) before section 6.2.4 debates potential gender-related differences with respect to the BU specific health-seeking behaviour (research question 5). Local or cultural related differences in terms of BU specific health-seeking behaviour (research question 6) will be discussed in section 6.2.5.

6.2.1 (Previously) BU affected vs. Non-affected People

This section compiles and discusses the differences of the results between the (previously) BU affected people and the non-affected community members as encountered during the KAP survey as well as during the FGDs (specific research question 2).

Predisposing Factors (Social and Cultural Background)

The KAP survey has shown that the (previously) BU affected people and the non-affected population (matched comparison group) did not differ significantly with regard to the assessed *'Predisposing Factors'*. This finding underlines the assumption that the social and cultural background of the affected people is not very specific for BU but rather reflects the local circumstances.

Characteristics of BU and Disease Perception

The knowledge about the initial disease symptoms (aspect *'Severity of the Symptoms'*) differed significantly between the two survey groups with the non-affected people being less informed. These results do not come as a surprise and may be explained by the fact that the (previously) BU affected people may not only have received specific information from the local CSBVs, health workers/ staffs or through conversations with other people. (Previously) BU affected people have also personally observed and experienced these symptoms so that they are more likely to recall them.

The difference in the perception of the cause of the disease (aspect *'Aetiological Model'*) between the two groups was assessed during the KAP survey as well as during the FGDs: The survey results of the perception of the cause of the disease and probable preventive measures did not differ significantly. Another – but not representative – picture was revealed over the course of the discussion rounds: The hitherto non-affected people showed a tendency to ascribe the transmission of BU to water and unhygienic conditions, so that they either reported respective preventive measures (*'hygienic conditions'*) or incertitude. Those who had the BU related disease experience reported more different and specific explanations (i.e. uncertainly about the cause, perceived paradoxes as well as spiritual aspects).

The previously affected FGD participants seemed to be more likely to be convinced that *'safe water'* and *'the protection of God'* may prevent an MU infection. These findings are another example of study participants providing different answers when different research methods are applied (compare with Renzaho et al., 2007). A further explanation may be the fact that the composition of the FGD rounds was not representative for the whole research area.

Further significant differences were found for the perception whether BU affected people are welcome to attend social functions (aspect *'Stigma/ Social Exclusion'*): Here the (previously) BU affected survey participants were more likely to state that they had the feeling to be welcome than it was described by the non-affected community members (86% vs. 63%). A similar picture of the perceived stigma was encountered during the FGDs, where non-affected people were more sceptical that BU affected people participate in the community life than those who had been affected. Reasons given by the previously BU affected FGD participants were that they had no other choice as they had to work or go to school despite being affected. These findings suggest that this question does not apply to the rough and pragmatic everyday life of the people. As discussed above particularly BU affected people with severe and/ or smelling lesions gain the experience that people cover their nose, avoid getting closer to them or even isolate them in an individual room. People with small and inconspicuous lesions may not experience any discrimination as their community members may not be aware that a BU affected person is living among them. The fact that the majority of the study participants were already healed did not allow to further differentiate the survey results between the severity of the BU related symptoms and the associated stigma.

Enabling Factors (Health Service Characteristics)

For the aspect *'Appeal of Treatment',* different perceptions were assessed between (previously) BU affected survey participants and matched community members. People with BU experience were found to be less likely to seek medical care for general diseases than the non-affected ones. Probable reasons for this behaviour are likely to be triggered either by their good experiences with traditional treatment methods or by rather bad experiences with governmental health facilities (aspect *'Disease Experience'*). During FGDs, non-affected community members brought up more arguments for treatment from a governmental health facility, while many of the people with BU experience provided more reasons and details why traditional treatment was their first treatment choice. On the one hand these results suggest that non-affected people may be more rational about the specific features of the available treatment. On the other hand these differences in the perception may also be caused by the fact that non-affected people have not yet experienced any of the treatment options for BU and therefore provided socially preferred arguments.

Nevertheless the non-affected people were less informed about the antibiotic treatment so that more than half of them gave no answer to the question on their perception of the *'treatment with pills and injections'.* One third stated that they did not know anything about this treatment regimen. 63% of them were also not aware of the different components of BU treatment in a governmental health facility (i.e. antibiotics, wound care); almost 50% did not know how the cost of medical treatment is being taken care of (aspect *'Cost of Treatment'*). These results underline that there is a general need for health education promoting the free antibiotic treatment for BU which is available from the governmental health facilities. Raising people's awareness on this treatment option even before a probable infection may have the potential to promote early reporting.

6.2.2 Early vs. Late Care-Seekers

This section compiles and discusses the differences of the results between *'Early Care-'* and *'Late Care-Seekers'* as assessed during the KAP survey (research question 3).

One challenge that became apparent during this research was the fact that the exact patient delay may not be thoroughly assessed: Although some studies (Kibadi et al., 2009, Mulder et al., 2008, Phanzu et al., 2006, Grietens et al., 2012) tried to concretely assess BU specific patient delay (variation of the median delay between three weeks and six months), the narratives of the interviewed experts and the experiences of the research team in the study area have shown that the value of this information may be limited: Most of the people in BU endemic settings in Africa do not have a very precise perception of time or may not be willing to report the truth.

Due to this fact (previously) BU affected people were put into the categories *'Late Care-Seekers'* and *'Early Care-Seekers'* only, with the former one consisting of care-seekers who reported to a governmental health facility only after the lesion had been ulcerated according to own reports and the latter one consisting of *'Early Care-Seekers'* who reported to a governmental health facility in the pre-ulcerative stage. Consequently this research defined *'Late Care-Seekers'* and *'Early Care-Seekers'* as proxies for patient delay and evaluated the characteristic differences of these two groups.

Predisposing Factors (Social and Cultural Background)

Among the *'Predisposing Factors'* only few differences were identified between *'Early Care-'* and *'Late Care-Seekers':* The analysis showed that those who already reported for medical treatment with a pre-ulcerative lesion, lived significantly more often in households with more than four children (37%) than those who did not report before the lesion had developed into an ulcer (35%) (aspect *'Household Characteristics'*). This suggests that larger households/ households with a traditional family system are in a better position to cope with a situation when one member needs medical attention. Although the applied method (cross-sectional survey) may not identify whether there is a causal relationship between households with more than four children and early reporting one may speak of indications for a contributing cause.

Furthermore, it was found that *'Social Interactions'* play an important role: in the choice of the respective health care resource *'Late Care-Seekers'* took recommendations on nodules significantly less (30%) into account than *'Early Care-Seekers'* (50%). These proportions were converse in the advanced stage of the disease: 71% of the *'Late Care-Seekers'* reported that they made use of recommendations from other people when their lesion was already ulcerated. *'Late Care-Seekers'* take the decision on the treatment for general conditions on their own without consulting anybody 2.4 times more often than *'Early Care-Seekers'*. This underlines that *'Social Interactions'* are an important aspect of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II): Consequently, *'Social Interactions'* among the people within BU endemic communities (i.e. referral of people with BU suspected symptoms by experienced community or family members) should be born in mind when planning BU specific health interventions. This means in practice that the role of people with BU specific disease and treatment experience should be highlighted in specific health communication programs and their reputation within the communities needs to be strengthened.

Characteristics of BU and Disease Perception

Although the perception of the disease (aspect *'Aetiological Model'*) did not differ between the two groups it was found that *'Late Care-Seekers'* were less likely to express that they knew any preventive measures against the disease. This difference may be caused by the fact that *'Late Care-Seekers'* were probably undecided regarding any of the commonly propagated risk factors: for instance a BU affected person might have been told that the major reason for contracting the disease is to wade in stagnant water – with him/ her not having done this ever before (compare with Ackumey et al., 2012b). Another possibility might be the belief in a spiritual cause or a curse so that the affected people may not be able to protect themselves.

An interesting finding is the aspect that *'Late Care-Seekers'* stated more often that they had the feeling to be welcome to attend social events (87%) than those who reported early for medical treatment (70%) (aspect *'Stigma/ Social Exclusion'*). Several possibilities may explain why *'Late Care-Seekers'* did not report any social exclusion: either they were too shy or their lesions were not apparent (i.e. no odour of the lesion and/ or no visible deformities) and could be covered or hidden (compare with Adhikari et al., 2014). BU affected people with small and/ or non-smelling lesions may not be identified as being affected and therefore not be stigmatized by their peers due to their infection. Finally, *'Late Care-Seekers'* reported more often that BU did not allow for continuously attending school which is likely related to the fact that BU affected people who report late and receive delayed medical treatment need a longer time to recover and are often stigmatised. This finding underlines the before mentioned possibility that *'Late Care-Seekers'* were too shy to speak about their social exclusion/ isolation.

Enabling Factors (Health Service Characteristics)

Among the *'Enabling Factors'* it was found that *'Late Care-Seekers'* had a 2.1 times higher probability to depend on transportation to access a governmental health facility (aspect *'Accessibility'*). Hence, people who need to cover transportation costs to regularly report to the governmental health facility are less likely to report early. Reimbursement for transportation costs of affected people therefore seems to be a useful intervention (see Ahorlu et al., 2013b).

'Late Care-Seekers' furthermore differed in that they were more likely not to have heard of BU before their treatment than *'Early Care-Seekers'* (79% vs. 58%) and were less satisfied with the local health facilities (74% vs. 96%) (aspect *'Acceptability and Quality of available Health Services'*). This group of (previously) BU affected people was also less likely to state and believe that the medical treatment for BU is provided for free (aspect *'Health Education and Communication'*). Although this cross-sectional survey cannot provide strong evidence of cause and effect, these findings support the assumption that the awareness of BU and its treatment options as well as a general satisfaction with the available governmental health facilities may increase the probability of early reporting (see also Grietens et al., 2012).

6.2.3 Age-related Differences

This section discusses age-related characteristics with respect to health-seeking behaviour for BU (specific research question 4). Only few significant differences between (previously) BU affected people below and above the age of 15 years (compare with ILO definition on labour force status (International Labour Office (ILO), 1990)) were identified during the analysis of the KAP data. A further age categorization was not useful due to the small sample size. The age of 15 seemed to be the average age of graduation from school so that this age categorization seems to be justifiable.

Characteristics of BU and Disease Perception

According to the survey data (previously) BU affected study participants up to 15 years were more likely to believe in the communicated health messages (i.e. *'BU derives from water'*, *'drinking clean water prevents BU'*) than the study participants who were older than 15. Consequently the former were also more likely to believe in knowing preventive measures against BU (aspect *'Aetiological Model'*). These findings suggest that study participants being older than 15 years and therefore more likely to have made their own experiences with a BU infection, were less likely to believe in the health messages and therefore stated that they did not know the cause of the disease. Probable reasons why the results for children up to 15 years were different from those being older are that children up to 10 years were not interviewed on their own but were accompanied by their caretakers.

Children up to 15 years were more likely to state that BU affected children interrupt their education due to the disease than the older study participants (aspect *'Stigma/ Social Exclusion'*). Naturally, pupils still attending school stand a higher chance of experiencing such incidents than those outside the system. Although the older people may have been to school as well they did not make this experience on their own. This finding leads to the assumption that those who were personally confronted with this situation are more sceptical.

Enabling Factors (Health Service Characteristics)

With respect to the health education aspect it was found that study participants above the age of 15 were more likely to hear about BU for the first time when they report for treatment (79%) than the younger generation (53%). Furthermore, they were less likely to have received information about BU within the last six months (35% vs. 55%) and were more dissatisfied with the information they had yet received (aspect *'Health Education and Communication'*). These findings show that children/ pupils have a higher chance to hear about the disease – probably because they have been confronted with BU affected peers or they may have received some health education at school.

6.2.4 Sex-related Differences

Although several of the interviewed experts had explained that women are more vulnerable to report late to a governmental health facility no remarkable differences in health-seeking behaviour of the study participants could be observed during the KAP survey across the genders (specific research question 5). This may in parts be explained by the fact that 39% of the study participants were children up to 15 years, who do not decide about the treatment on their own but fully depend on their parents.

6.2.5 Differences in Disease Perception and Choice of Health Care Resources between the Communities

Differences in the disease perception and the choice of treatment options for BU were assessed in six selected communities during the FGDs (research question 6). Due to the applied research design the findings may not be representative for the research area but allow for an insight into the array of differences with respect to disease perception and the preferred health care resources between the communities. Renzaho et al.'s (2007) finding, according to which people in less endemic locations mention stronger stigmas than people in communities with more BU affected people, could not be confirmed for the research area. One probable reason may be the fact that the research area itself was relatively small and that the differences in endemicity were too small to observe differences. Apparent differences were encountered for the elements *'Enabling Factors'* as well as *'Choice of Health Care Resources'*.

Enabling Factors (Health Service Characteristics)

With respect to the *'Appeal of Treatment'* it was found that previously BU affected study participants in remote communities argued that they prefer traditional herbal treatment to heal their ulcer. The justifications they provided were that the people have *'more knowledge about herbs'* and are disappointed by the effectiveness of medical treatment. This reasoning may be explained by the fact that the people in remote communities receive less information about BU than people in communities along the road (i.e. no video events and screening activities organized by the local NGO). Furthermore, they have no access to transportation so that they may either have to walk long distances or have to hire a taxi, which makes it difficult to report early and regularly for treatment from a governmental health facility.

The overall perception of the available health services and the behaviour of the health workers were quite positive. Only the people in two communities, which were closer to the *'Government Hospital'* in town than to the local health post, reported negative experiences with respect to the friendliness of the staff (variable *'Acceptability and Quality of available Health Services'*). Two scenarios seem to be reasonable to explain this experience: First, the staff at the hospital may have to deal with more patients per day than the staff from the rural health post, which may lead to stressful situations. Second, the staff from the hospital may not be as familiar with the living conditions of the people in the villages as the health worker in the rural community, who is personally known by many of the people in the BU endemic communities. Most of the local health staff is involved in BU specific health promotion and education activities such as the evening video shows organized by the local NGO or the national immunization campaigns. These experiences in general allow for a more personal communication between treatment providers and their patients.

BU specific health education appears to be a special challenge in remote communities, so that the people living there are more prone to only get to know about BU when they are treated themselves and receive respective information from the local health worker. FGD participants of communities which are located along the main street, for example, reported that they have attended one of the video events or had received respective details via radio/ TV (aspect *'Health Education and Communication'*). These findings underline the need to put a stronger focus on communities which are inaccessible by local transport and are not yet connected to the electricity grid.

Choice of Health Care Resources

The findings of the FGDs show that traditional herbal treatment (aspect *'Traditional Healer'*) has a higher value among the people and is therefore more commonly used in remote communities than medical treatment: These findings correspond with the previously mentioned aspects that people in these settings have difficulties with accessing transportation and abovementioned health education and therefore prefer traditional herbal treatment.

6.3 Discussion of the applied Research Steps and Methods (specific Research Question 7)

This section evaluates the four methodological approaches applied in this study: the systematic literature search, the expert interviews, the KAP survey as well as the FGDs in six selected communities within the research area (specific research question 7). At the end of each section the benefits as well as probable limitations of the respective methods or research steps are provided.

6.3.1 Methodological Approach via a Systematic Literature Search

According to the knowledge of the principal investigator of this study only one comprehensive literature review gives an overview of the different health-seeking related aspects of BU, which is the one by Webb et al. (2009). This review came to the conclusion that the awareness of BU is generally good in endemic regions but that the perception of the cause of the disease – including the role of supernatural powers – varies among the people (Webb et al., 2009).

The findings about the awareness could only be partly confirmed in this study: the analysis of differences between (previously) BU affected people and the non-affected population has shown that the non-affected study participants had less knowledge about the disease and its initial symptoms than those who were personally affected or confronted with it. According to the results of the KAP survey almost 70% of the (previously) BU affected study participants only got to know about the disease when they received respective treatment. Furthermore, the findings about the cause of the disease in this study correspond with the findings of the review by Webb et al. (2009) with respect to the perception of the cause of the disease – although supernatural powers seemed to play a less important role in the study area.

Moreover, the authors of the aforementioned review highlight that the use of traditional treatment, a general lack of awareness of the availability of effective medical treatment as well as financial concerns contribute to a delay of accessing care from a governmental health facility (Webb et al., 2009). Compared with the findings of the systematic literature search the review by Webb and colleagues provides important aspects for treatment delay but omits the analysis why the people in BU endemic settings first seek treatment from a traditional healer. Furthermore, the systematic literature search could show that only one model on health-seeking behaviour for BU had been published (until December 2011), namely the one by Mulder et al. (2008)[304].

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[304] Further studies which either proposed or applied an existing model to systematically assess and explain BU specific health-seeking behaviour were conducted in Benin (Grietens et al., 2012, Alferink et al., 2013) and were published after the fieldwork of this research (see section *'Value of the Study for both the Scientific Community as well as Local Disease Control and Management Activities'*).

Adaptation of Kroeger’s Framework for BU

The 22 identified publications were assessed and analysed by using the variables of Kroeger’s framework as codes for the qualitative content analysis. Most variables of this framework appeared to be useful for this procedure as they could be identified within the published literature. For 13 aspects the principal investigator changed, simplified or added some specifications to the original denomination (compare with Tables 12 to 15). Two aspects (*‘Chronic or Acute’* and *‘Psychosomatic vs. Somatic Disorders’*) were not covered by the BU specific literature. The aspect *‘Chronic or Acute’* is clinically relevant for BU so that it was included into the *‘Adapted BU specific Framework’* (version I); but the aspect *‘Psychosomatic vs. Somatic Disorders’* does not apply to the symptoms of BU and was therefore not included into the disease specific framework. Furthermore, two aspects (‘*Other Factors’* and *‘Stigma/ Social Exclusion’*) were newly introduced. Evidently, the aspect *‘Stigma/ Social Exclusion’* plays an important role for both the perception of the disease as well as the BU specific research: Six of the retrieved publications point out the relevance of this aspect.

Validity and Limitations of the Findings of the Systematic Literature Search

The systematic literature search provided an overview of the published evidence. The retrieved results were matched with the aspects of Kroeger’s framework and thereby allowed to identify research gaps and needs. These were mainly related to the *‘Degree of Cultural Adaptation’* and details about traditional treatment practices. Furthermore, this systematic overview considered studies of all possible research designs, i.e. quantitative surveys, qualitative case studies, qualitative interviews and FGDs as well as mixed-methods studies. This allowed for new insights into which aspect might be best assessed by which method.

Nevertheless, the applied systematic literature review had some limitations: The primary limitation concerns the approach of the review according to which the majority of the selected publications was retrieved through a free text search limited to the term “Buruli ulcer treatment”, which was followed by a screening of abstracts of the retrieved results. Due to limited time and resources, no peer assessment was done and the verification and quality control process had to be focused on the aspects of the framework. A second limitation – or better qualification – is the heterogeneity of the research settings and, hence, the context-specificity of some of the results: Although all studies were conducted in the African setting not all of them may be completely comparable among each other for both cultural as well as socio-economic circumstances. The situation in the selected research area may be completely different. Furthermore, the researchers have used different questionnaires and interview guidelines which make it difficult to overall summarize and interpret the respective results. Nevertheless, it may be concluded that this systematic literature search delivered a comprehensive overview of the available literature and represents a good starting point for this research. Furthermore, this conducted research step shows that most of the aspects of Kroeger’s framework could be matched with the findings from the literature so that an adapted version of this framework is suitable to explain the BU specific health-seeking behaviour (specific research question (1)).

6.3.2 Methodological Approach of the Expert Interviews

This section discusses the key methodological aspects of the Expert Interview Approach, i.e. the recruitment of the experts, the mode and completeness of the questions of the guidelines, the characteristics of the interview process as well as the specific answer characteristics of the different groups of interviewees. Finally the validity of the results of the expert interviews with respect to the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 30) will be judged.

Selection and Recruitment of the Interviewees

All designated experts were people with a considerable knowledge about the BU specific health-seeking behaviour (compare with Table 7). Based on an analysis of the BU specific research literature, the people with the most important and acknowledged backgrounds were identified in the study area. At the end of each interview the interviewee was asked to suggest or recommend another expert who could provide further details about BU specific treatment and disease perceptions. By using this snowball sampling approach via liaison persons, the different stakeholders could be accessed in a smooth and culturally appropriate way. As opposed to medical staff herbalists, who were not yet included in the BU specific health promotion activities and not part of the different personal networks of the majority of the interviewed experts, were relatively difficult to approach. As a consequence interviews which provided in-depth information about herbal treatment practices were only possible after a few months of fieldwork and after the people in the villages got used to interact with the research team.

All in all the interviews were stopped after saturation for the majority of the relevant aspects had been reached. Although the interviews with two herbalists delivered in-depth information about their treatment practices further interviews with herbalists and spiritualists could have possibly helped to get a better overview of the array of different practices. Yet, the focus of the research on the behaviour of BU affected people made it reasonable to stop the research process at that point.

The relatively high number of expert interviews delivered rich and in-depth information on the various treatment techniques and the BU specific disease perception in the study area. Since the choice of interviewees did not follow a representative sampling technique, not all aspects may have been covered in a representative way. It is, though, relatively unlikely that major aspects were not considered due to the fact that a certain point of saturation was reached and no new aspects arose. Therefore it may be concluded that this research step delivered a comprehensive but not fully quantifiable overview of the different aspects of people's behaviour in relation to BU.

Completeness and Quality of the Interview Guidelines/ Questions

The interview guidelines were developed after the analysis of the BU specific research literature so that the major aspects were structured according to the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I) and then included into the respective guidelines. They were not used as a fixed catalogue of questions in order to allow the interviewees to talk openly and to give them the chance to add further aspects or to highlight specific characteristics they considered to have an impact on the health-seeking behaviour of the people. The guidelines were tailored to the specific groups of interviewees so that they were only requested to answer those questions which fell into their field of work or experience.

Interviews with BU affected people were mainly conducted in the local language and therefore done by research assistants. To ensure the validity of the questions they used translated versions of the guidelines. Another trained research assistant directly translated and transcribed the recorded interviews into English. To ensure the validity of these translations the transcripts were crosschecked by the research assistants, who had conducted the respective interviews. Nevertheless this step was difficult to supervise by the principal investigator as the research assistants may have used their own translations or interpretations without discussing them in every detail with the principal investigator.

Characteristics of the Interview Process

The principal investigator tried to conduct the interviews in an enclosed interview setting to avoid disturbances. Yet, she decided not to strictly insist on the enclosed interview atmosphere in cases where it would conflict with the natural behaviour of the interviewees. One interview with a CSBV as well as two interviews with patients were therefore conducted on the open veranda of the health post so that disturbances of the interview could not be avoided. Furthermore, several of the interviewed health professionals received phone calls during the interviews so that the interview as well as the recording had to be paused for the duration of the call. These incidents can be considered as natural circumstances in this research setting and may be considered to have no negative influence on the interviewees' answers. All interviewees agreed to the audio recording, which ensured a natural conversation as well as a detailed documentation and transcription of the provided information.

Characteristics of the Interviewees

Apparent differences in the duration and elaborateness of the interviews were noticed between interviews with patients or their caregivers and interviews with the other interviewees (i.e. professional experts): The major difference between the professional experts and the patients or caretakers was the duration and consequently the elaborateness of the provided narratives. The BU affected interviewees provided short but concrete answers. This fact may possibly be explained by the different educational backgrounds and professional experiences of the interviewees.

Health staff and officials provided very detailed answers. They were also able to provide narratives from their vast experiences and could thereby explain changes in the perception of the disease over the time. Furthermore, they were familiar with all structural challenges within the research area. The interviewed scientists had the advantage of being able to draw comparisons to other endemic regions, had a good overview of the published evidence and were able to combine this with their own experiences in the field. Almost all professional experts were convinced of the fact that the people in the endemic communities still strongly believe in supernatural powers and traditional aspects. Opposed to that the NGO staff reported that these perceptions are on decline.

The interviews with the herbalists/ traditional healers were characterized by openness and detailedness and did not confirm the common prejudice that they would not share their knowledge. Most helpful for the exploration of social aspects regarding BU were the interviewed teachers as their professional background allowed them to share both life worlds: They were familiar with the life of the people and were self-confident enough to give non courtesy-biased answers and provide reflected thoughts about the local disease perception and treatment challenges.

Validity of the Modified BU specific Framework for Health-Seeking Behaviour (Version II) and the Findings of the Expert Interviews

The *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I) (see Figure 17) was used as a reference for the development of the interview guidelines. Only after the analysis of the interview material the framework was differentiated and modified: Among the *'Enabling Factors'* the variable *'Acceptability, Quality and Communication'* was subdivided into *'Acceptability and Quality of available Health Services'* and *'Health Education and Communication'*. Among the depending variables the original variable *'Self-Treatment/ No*

Treatment' was subdivided in two separate ones. The original variable *'Modern Healer'* was redefined as *'Governmental Health Facility'*. Furthermore, the embracing aspect *'Therapeutic Itineraries'* was added to include the sequence and/ or the parallel use of different health care resources; the order of some of the variables was changed according to the commonly therapeutic itinerary by BU affected people. For example, in the early stage of the disease the people usually opt for *'No Treatment'* or *'Self-Treatment'*, which is then usually followed by *'Traditional Treatment'*. All of the modifications allow for a more detailed analysis and description of the BU specific health-seeking behaviour in the study area (*'Modified BU specific Framework for Health-Seeking Behaviour'*). For an overview of all respective changes/ modifications see Figure 30.

The expert interviews provided detailed explanations for local and cultural characteristics, namely *'Degree of Cultural Adaptation', 'Aetiological Model', 'Appeal of Treatment' and 'Health Education and Communication'* as well as expectations of the people reflected in *‚Expected Benefits of the Treatment'*. Furthermore the interviews allowed assessing personal reports and estimations (i.e. *'Disease Experience', 'Chronic or Acute', 'Severity of the Symptoms', 'Cost of Treatment'* and *'Therapeutic Itineraries'*).

Sensitive and delicate topics such as spiritual aspects, *'Stigma/ Social Exclusion'* as well as *'Acceptability of the available Health Services'* were elicited among the interviewees but especially the BU affected interviewees seemed too shy to report misbehaviour or deficits within the health system. For these aspects, the principal investigator instead relied upon the detailed descriptions by the non-affected experts, i.e. researchers, health staff or teachers. This research step provided unique insights into the study setting even though it did not allow for quantifying socio-demographic background characteristics of the study population and the status of the knowledge of the affected people.

In conclusion, the expert interviews were useful to understand the local disease concept and respective treatment practices and served to answer the specific research questions (1) and (3) of this study.

6.3.3 Methodological Approach of the KAP Survey

This section discusses the selection procedure of the survey participants, the questionnaire, the training of the research assistants as well as the advantages and limitations of the quantitative KAP survey.

Selection Procedure and Representativeness of the Results

This study was conducted among more or less all people affected by BU within the previous three years (2007 to 2010) in a rural sub district in Ghana. Nevertheless it has to be admitted that not all of them may have been encountered during the active community case-search (among others due to the unavailability of centralized information on affected people or because some people may simply not be aware of carrying the disease). Whether or not this picture truly reflects the actual distribution of cases lies beyond the knowledge of the author: There is a chance that some people in the communities may not have been aware of further cases, or that they may have concealed their existence or the field workers/ CSBVs may have decided to skip one of the cases – due to whatever personal reason. All in all it can be expected that a large share of (previously) BU affected people in the study area could be surveyed. In consequence, the study allows for fairly representative conclusions about the disease perception and the corresponding health-seeking behaviour in the study area. Most of these characteristics may also apply to other BU endemic areas in the African region (i.e. rural settings with poor hygiene conditions and limited health and travel infrastructure).

A comparison group consisting of non-affected people of the same sex and similar age was additionally sampled in the same village which the (previously) BU affected person was from in order to elicit whether the knowledge and perception differed between the affected and the non-affected population. Considering that the two compared groups had the same sex ratio and age structure and lived in the same villages, basic comparability between the two groups can be assumed. A caveat of this cross-sectional setup is that findings on relationships between the various factors and the resulting health-seeking behaviour may be more biased than results derived from larger and more sophisticated studies so that they may not necessarily be interpreted as causal. Statements about the temporal evolution of the studied population are furthermore less feasible. In the light of the available resources, having information on virtually all people affected with BU between 2007 and 2010 and of a matched comparison group at hand, nevertheless, provided for a decent basis to derive valuable and reliable insights into BU related health-seeking behaviour.

Review of the Research Manoeuvre

In the course of the development of a questionnaire it should be thoroughly tested whether the questions are valid, which means to assess, whether the questionnaire measures what it is supposed to measure. The questionnaire used in this study was not subjected to a specific validation process as only the data from the pilot-phase were assessed in a rapid pre-analysis to see whether the answer options were selected adequately. This must be considered when interpreting the results and the further use of the questionnaire. Due to the fact that most of the findings may be compared with those gained through other methods, a detailed assessment seems legitimate.

In the course of the study it turned out that it would have been an interesting detail to find out whether specific treatment options were used for specific disease symptoms (i.e. nodule, plaque, oedema, and ulcer) at one point or one after another (quantitative assessment of the phenomenon of *'healer-shopping'*). This aspect is a relevant detail for further studies to understand the patient itineraries of BU affected people in more detail (e.g. Grietens et al. (2012) have recorded the number of health encounters of BU affected people).

The principal investigator was able to identify *'critical questions'* and modification needs through the back translation of the questionnaire as well as during the pre-test. However, it cannot go unmentioned that the principal investigator does not speak any of the local languages so that she was not able to control whether the research assistants strictly followed the translation of the questionnaire when administering the questions to the people.

Although the training of the research assistants who conducted the interviews in the local languages took only one day the principal investigator was convinced that they were well informed about the study subject and the focus of the research. Especially those assistants who participated in the research already during the pre-test phase or had conducted expert interviews in the local language before the start of the survey seemed to be well prepared and according to the principal investigator's observation connected well with the interviewees.

A critical constellation arose when one of these well-trained assistants was sick or started a new appointment, so that a new assistant had to take over. Nevertheless the principal investigator followed every interview, provided the assistants with a fieldworker manual (see Appendix C) and checked every questionnaire after completion of the interview, so that there was always the chance for questions and clarification. At the end of each day in the field the research team sat down to discuss the interview experience and performance in order to clarify possible gaps or misunderstandings.

Response Rates

All (previously) BU affected people who were encountered during the active community case search agreed to participate in the survey.

Among the non-affected people there was only one person who was selected as a matched community member but refused to participate. Due to traditional beliefs she wanted to avoid that anything about her would be written down. In this case the research team was able to identify another person in the same neighbourhood with the same sex and of similar age.

Validity and Limitations of the Results of the KAP Survey

The *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (see Figure 30) served as a background for the construction of the KAP questionnaire. This research tool was applied to all (previously) BU affected people within the study area who may have had the chance to receive antibiotic treatment as well as to the matched comparison group.

The fact that the inclusion of (previously) BU affected people was only based on clinical diagnosis and personal reports of the interviewees does not represent a limitation to the results of this research: All study participants who either had the knowledge or perception of being BU affected would behave as being (previously) BU affected.

The KAP data provide percentage frequencies of the elicited aspects and thereby a tool to describe the relevance of the respective aspect for the BU specific health-seeking behaviour. This allowed for the analysis of probable associations between the different subgroups (age, sex, *'Early Care-Seekers'* etc.). The evaluation of the retrieved data showed that socio-demographic aspects as well as knowledge-based variables (i.e. *'Severity of the Symptoms'*, *'Health Education and Communication'* etc.) provide valid results.

A limitation of the survey was the relatively small sample size for each of the survey groups with 122 (previously) BU affected and 122 non-affected people. On the one hand this may have contributed to a lack of statistical power for some of the analyses. On the other hand the results show the natural distribution of cases in one BU endemic sub district with 48 communities in the Eastern Region. Similar studies on health-seeking behaviour (i.e. Mulder et al. (2008), Grietens et al. (2012) and Alferink et al. (2013)) operated with alike numbers of study participants). To enrol more cases it would have been necessary to extend the research area or to move to another district, which would have also been associated with changes in the local circumstances.

A further limitation is the fact that some of the interviewees have been affected by the disease three years before the interview was conducted so that the results of this research may be prone to recall bias. Furthermore, it is not possible to quantify if people, who did not provide any information about their choice of treatment for a nodule, actually did not have a nodule, or were not aware of having a nodule or did not want to provide this information.

The design of KAP surveys has been criticized by social scientists as being not appropriate for exploring health-seeking practices (see Launiala, 2009). A main point of critique is that these surveys fail to explain the reason and the conditions for choosing a specific treatment option and thereby *"fail to explain the logic behind people's behaviour"* (Launiala, 2009). Furthermore, it may be difficult to obtain sensitive information about traditional treatment practices or sexuality as the short period of the interview with a structured questionnaire does not allow to build a trustful situation (Launiala, 2009). This phenomenon was observed in the context of the reports about the *'Choice of Health Care Resources',* which seems to be influenced by courtesy bias. This aspect may be compensated by the methodological approach according to which one may draw from the findings of the other research steps involving qualitative methods.

Due to the fact that some of the aspects have a rather qualitative character (i.e. *'Degree of Cultural Adaptation'*, *'Expected Benefits of the Treatment'* and the phenomenon of *'healer-shopping'*) they were not assessed by the KAP questionnaire. Furthermore some aspects provide different results than the findings which were gained from qualitative methods (i.e. supernatural explanations for the *'Aetiological Model'*, *'Stigma/ Social Exclusion'*). A further constraint may have been that some of the interviewed BU affected people had already overcome the disease within the last three years. This may go along with some unavoidable recall bias in terms of therapy choice for the respective stages of the disease. Moreover, clinical data (information on the aspect *'Severity of the Symptoms'*) could provide further insights into the aspect *‚Stigma/ Social Exclusion'* (e.g. people with specific lesion features are more stigmatized than others). This aspect should be considered when planning further research on this topic.

Keeping these constraints in mind the survey was combined with other research methods, so that the contextualisation of the answers was given to understand the logic behind treatment-seeking practices (compare with Launiala, 2009). In a nutshell, the KAP survey seems to be a valid tool to assess and quantify the BU specific health-seeking behaviour according to the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (Figure 30): A high validity of the findings may be assumed for the *'Predisposing Factors'* as well as the knowledge-based aspects variables (i.e. *'Severity of the Symptoms'*, *'Health Education and Communication'* etc.). Therefore, one can assume that the survey results allows for answering the specific research questions (2) to (5) as well as (7).

6.3.4 Methodological Approach of the FGDs

This section discusses the representativeness of the FGD results, the selection procedure of its participants, the quality of the question route, the performance of the two moderators, the characteristics of the different discussion groups (i.e. previously BU affected vs. non-affected participants) as well as the validity of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) (Figure 30).

Representativeness and Limitations of the FGD Results

FGDs provide detailed findings on public experience and understanding of illness in a form of communication which is similar to the day-to-day interaction and thereby allow for answers that would not be easily accessible through one-to-one interviews (compare with Wong, 2008). One major advantage within this study was that the moderators were able to clarify responses to receive detailed explanations for relevant phenomena (i.e. *'Aetiological Model'* and *'Stigma/ Social Exclusion'*), which could neither be gained nor explained through the expert interviews and the KAP survey alone.

Due to the fact that this method draws only from the experiences of a few community members within six selected communities the findings may not be considered as being representative for the whole study area. Furthermore, FGDs are in general less likely to achieve the level of representativeness and precision of (semi-)structured individual household or expert surveys, among others, since they are susceptible to bias with respect to dominating opinions or participants, which may control the group. This phenomenon was observed in one community, where the local CSBV was among the previously affected participants so that the other members of the group were under-confident to contradict his narratives or avoided to provide reports about their own experiences and perceptions.

Selection and Recruitment of the FGD Participants

The previously BU affected people living in the study area were already known through the KAP survey. They were informed about the FGD and invited by the local CBSV, who received a small incentive for each participant he was able to recruit. The participants themselves also received a small incentive. This seemed to be successful in that all invited patients joined the discussions except for one mother of a previously affected girl who disagreed to participate. In addition, one of the previously BU affected people had died and another person had moved away. The venue for all discussions was located within the respective community and arranged by the local CSBV so that it was also comfortable and suitable for everyone to attend. The high number of participants as well as their punctuality confirmed this.

Quality of the Question Route

The question route was built upon the theoretical guideline provided by Krueger and Casey (2009) and the practical experiences gained through the expert interviews and the KAP survey. The suggestions from local experts as well as the pre-tests with the moderators in the local school helped to finalize the route in the local language. It seems that the questions evoked answers and narratives with a high grade of nativeness. This impression was confirmed by the research assistants who crosschecked the translations of the transcripts and assisted already during the KAP survey.

Performance of the FGD Facilitators

The fact that the FGD facilitators were teachers in one of the local primary schools assured that they were familiar with the local dialect and knew about the social background of the participants. Due to their profession they were already used to act as a moderator and to interact in groups with different personalities. These advantages more or less counterbalanced the challenge that the participants may have been too shy to provide unbiased answers to somebody with a higher educational background.

Characteristics of the Discussion Groups

In line with best practice in the implementation of FGD, all groups were composed of four to six participants. This composition allowed for inviting only previously affected people who got healed between 2007 to 2010. At the same time this limited number of participants made it possible to capture the order of the people who spoke without the participants' need to mention their names each and every time they gave a comment. This also allowed for a more natural conversation/ communication. The fact that the narratives of the non-affected participants were more detailed and sophisticated points to the matter of records that even the previously BU affected people still felt inclined to provide all details of their disease experience.

Validity of the FGD Data in the Context of the Modified BU specific Framework for Health-Seeking Behaviour (Version II)

All aspects that were elicited during the discussions fitted into the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) and provided explanation about ambiguous details. The FGDs focused on phenomena, which could not readily be explained in the course of the other research steps, i.e. *'Aetiological Model', 'Expected Benefits of the Treatment', 'Stigma/ Social Exclusion'* etc.. For that reason not all aspects of the framework were discussed. Among others, no details on *'Predisposing Factors'* or on the knowledge about disease symptoms have been elicited.

In conclusion, the FGDs confirmed or clarified the elicited aspects of the *'Modified BU specific Framework for Health-Seeking Behaviour'* but are not suitable to provide quantifiable details (i.e. socio-demographic information, knowledge status etc.). Thereby the specific research questions (1) to (3) and (7) could be answered.

6.4 Discussion of Ethical Issues

This section discusses the ethical issues of the study and lines out potential barriers which were encountered while conducting field research.

The review and approval of the proposal for this study was done by the Institutional Review Board of the Noguchi Memorial Institute for Medical Research at the University of Ghana (NMIMR-IRB CPN 041/09-10) as well as the Ghana Health Service Ethical Review Committee (GHS-ERC: 01/4/10). The approval was renewed yearly during the study period.

Before the start of the study, permission was sought both from the NBUCP Manager, the Regional Director of Health Services of the Eastern Region as well as the Municipal Health Director. After ethical clearance the final research plan was introduced to the institutions for information and support of the case search.

With respect to the involvement of individuals under the age of 18, parents or caretakers consented on behalf of the child to participate in the study and provided respective details. The participation in this study drew back on the local knowledge of the people and consumed time of the participants. Taking part in this study was voluntary and the participants could withdraw at any time they wished. No particular health risks were associated with the participation in a discussion or in giving an interview. Those participants who were BU affected received free medical treatment and counselling from the local health facility within the study area – supported by the treatment component of the ACBridge Project. The other volunteers, who all were non-affected community members, did not benefit directly; but results of the study may help to assess causes of delay in health-seeking behaviour and are intended to improve the medical treatment of BU affected people. Information on the health-seeking behaviour of BU affected people can be of value for the regional and national health institutions and strengthen further research in this area.

The objectives and procedures of the study were fully explained to all study participants before the start of any interview. The agency of all potential and enrolled subjects in the study was respected by permitting to withdraw from the research. Despite these practices the principal investigator was not able to judge whether all study participants made use of this right. The privacy was protected through confidentiality at any time (no personally identifiable information in resulting publications) and informing subjects of the results of the study. Informed consent forms (see Appendix B-D) were administered to patients or their parents/ caretakers. Those who agreed to participate provided their consent by signing or thumb printing. The document with the name and unique case ID was always kept separate from the questionnaire, which did not record the name of the participant. Due to the fact that it was obvious to other community members when the research team interviewed one of their members it may have not been avoided that they had to give reports about these interviews.

Besides these relatively inferior limitations some of the study participants may have had the hope to receive better treatment through their participation in the study. Even though it has been made explicit to study participants that they were supposed not to expect better treatment, some have done so and requested for free additional medications (e.g. pain killers). Others may have been a bit irritated by the questions they were confronted with. In a similar vein, interviewers tried to explain the reasoning behind certain questions if study participants appeared to be irritated by them.

6.5 Value of the Study for both the Scientific Community as well as Local Disease Control and Management Activities

This section discusses the value of the study for the scientific communities – namely other researchers aiming to understand the BU specific health-seeking behaviour – as well as for district health managements, NGOs or the NBUCP.

The study gives a systematic overview of the published evidence on health-seeking behaviour (until December 2011). To the knowledge of the author only one further systematic literature was published before (see Webb et al., 2009).

The developed and applied *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II, see Figure 30) was found to be valid to explain and assess the BU specific health-seeking behaviour in the study area (see section 6.1). It captures all aspects that were identified during a systematic literature search. Furthermore, it allowed for identifying the major fields for future health intervention and promotion campaigns (i.e. campaigns reaching remote communities as well as adult education – besides school-based health education). The study identified research needs (i.e. all-oral antibiotic treatment, differential diagnosis and modes of transmission) and provided evidence for necessary interventions to improve the access as well as the compliance of BU affected people (i.e. BU specific health education, training of local health personnel, incentives for CSBVs, reimbursement of travel costs for patients receiving treatment).

The majority of the different framework aspects are also part of the models by Mulder (2008), Grietens (2012) and Alferink (2013). The framework proposed by Mulder et al. (2008) as described in section 2.2.2 may be useful to give an overview of the itineraries of BU affected people and gain a rapid overview of some disease-specific phenomena that are involved in the health-seeking process – but it does not consider any existing conceptual model or describe the development of the model in detail. Furthermore, Mulder and her co-authors assessed the specific duration of patient delay, which is difficult to examine in a rural African setting (compare with section 6.2.2).

Grietens et al. (2012) proposed a model, which was developed after extensive anthropological fieldwork involving 152 BU affected people in a mixed methods study in Cameroon. With the primary aim to elicit the role of beliefs for the choice of the treatment and patient delay they used a quantitative survey and triangulated ethnographic research in both community and clinical settings. Their findings describe complex patient itineraries, involving both elements of traditional and biomedical treatment – including its alternation and combination (*'healer-shopping'*). Moreover, they found that the perceptions of the effectiveness of the treatment, the possibility of a local treatment (to reduce costs) and a good doctor-patient relationship were more important for the treatment choice than the beliefs. Their model displays the determinant factors for the treatment choice of BU affected people through a ranking of the specific aspects according to their importance: (1) *'Effectiveness of Treatment'*, (2) *'Place of Treatment'*, (3) *'Doctor-Patient Relationship'*, (4) *'Causality: Mystical/ Natural'*. Grietens' model (2012) is also based on results involving both qualitative and quantitative methods, and the phenomena they described could also be matched with the BU specific framework (Figure 30). The major difference to the *'Modified BU specific Framework for Health-Seeking Behaviour'* is that it is defined ad hoc and not based upon an existing model or framework but only on the author's own research findings (similar to Mulder et al., 2008). In comparison the framework proposed by the principal investigator of the present study provides a more structural approach to explain the respective health-seeking behaviour. Furthermore, it includes the views of professional experts as well as the non-affected population which does not hold for the abovementioned studies.

The group of Alferink et al. (2013) applied the existing model of *'Leventhal's Commonsense Model of Illness Representations'* to examine the perception of the effectiveness of the treatment and its influence on pre-hospital delay in Benin. This research group aimed at determining predictors for pre-hospital delay and explored whether the type of available treatment modality influenced (whether surgery or antibiotic treatment) the individual's perceptions of BU and thereby the pre-hospital delay. For this reason they adapted Leventhal's Model for BU. This model aims at describing a process where cognitive and emotional responses to an illness occur in parallel: Knowledge about symptoms as well as cultural factors such as stigma influence the illness perception in terms of identity, timeline, cause, consequences, cure/ control and emotional representations. Apart from practical aspects ranging from socio-demographic characteristics to financial as well as transportation barriers, the illness perceptions influence the pre-hospital delay on the individual level. According to the model the illness perceptions are in turn supposed to be influenced by whether the standard treatment available on village level is surgery or antibiotics. Alferink et al. (2013) applied this model to 130 healthy individuals living in BU endemic areas in Benin: According to the authors 64 came from areas where surgery was the dominant treatment; 66 from areas where antibiotic treatment was the dominant treatment modality. The individual characteristics *'effectiveness of treatment'* and *'timeline acute/ chronic'* showed the strongest associations with pre-hospital delay. No differences were identified between the different regions of surgery vs. antibiotic treatment. The applied model of *'Illness Representations'* by Alferink et al. (2013) does not include traditional or any other treatment options but focuses only on the available treatment from governmental health facilities. Furthermore, the study only involved people without a history of BU. Against this background it is not appropriately comparable with the *'Modified BU specific Framework for Health-Seeking Behaviour'* (Figure 30).

One may conclude that the proposed *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) covers almost all aspects which are included in the other models. Some aspects are solely covered in the newly developed framework (e.g. *'Degree of formal Adaptation'*, *'Disease Experience'* etc.). Only the model by Alferink et al. (2013) has two features (*'emotional representations'* and *'Level 1: Individuals/ Level 2: Villages'*) which may not be exactly matched with the proposed framework of the principal investigator. The aspect considering both the individual as well as the village perspective seems to be an important and worthwhile aspect. Future research should try to include this aspect in the *'Modified BU specific Framework for Health-Seeking Behaviour'*. For further specific details on the different models/ frameworks see Annex E: Table 103.

These findings underline that the full array of probable aspects influencing the health-seeking behaviour of BU affected people was considered. It may be assumed that most of the assessed aspects apply to other rural African settings as well so that the framework may also be used as a starting point for the assessment of BU specific health-seeking behaviour as well as the planning of respective health promotion in other endemic regions.

The study deduces measures to improve the treatment and control of BU as well as specific need for education in the study area. These findings and recommendations could be used and implemented by the local health authorities. In addition to the current state of research on BU specific health-seeking behaviour this thesis provides interpretations of at first sometimes contradictory sounding results and statements. The *'Modified BU specific Framework for Health-Seeking Behaviour'* is a suitable instrument, which may be used for future surveys and for the evaluation/ quality control of BU specific campaigns and interventions. The developed guidelines and questionnaires can be adapted with little effort to other settings or other target groups. The detailed descriptions of the methods and research procedures in the field are also available as orientation.

Researchers with the aim to capture BU specific health-seeking behaviour in a similar manner may use the *'Modified BU specific Framework for Health-Seeking Behaviour'* as starting point for further studies and research questions. In principle, the use of the framework in other BU endemic areas of Ghana and the corresponding adaptation for its use in other areas within Africa (e. g. Benin, Cameroon and the Ivory Coast) appears possible. Based on the experience of this study, the specific adaptation and use for other medical conditions could be considered. In this regard research could contribute to the evaluation and further development and optimization of the instrument.

7. Conclusions and Recommendations

The final chapter of this thesis concludes on the specific research questions (1) to (7) and provides recommendations on actions and interventions.

7.1 Conclusions

On the basis of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) and the detailed findings from the different research steps the following conclusions can be drawn:

(1) The proposed framework is a valid tool to assess and describe the BU specific health-seeking behaviour. The set of *'Characteristics of BU and Perception of the Disease'* as well as the *'Enabling Factors'* were shown to be most relevant to explain the BU specific health-seeking process which leads to the *'Choice of Health Care Resources'*: initially affected people often rely on self-treatment and only later on traditional herbal treatment or biomedical treatment provided by a governmental health facility as a *'final resort'*. Due to the detailed variables of the framework it may also be adapted for the assessment of BU specific health-seeking behaviour in other endemic regions in Africa. The specific adaptation and use for other medical conditions could be considered.

(2) The triangulation of results (KAP survey and FGDs) has shown that there are some differences in the perception of the disease between the (previously and presently) BU affected and the non-affected population: Non-affected participants were less informed about initial disease symptoms, not sufficiently informed about the antibiotic treatment for BU and not aware that it is provided free of charge. Moreover they were more likely to believe in the oversimplified health message that *'dirty water and unhygienic conditions'* are the cause of the disease and a bit more sceptical that BU affected people participate in the community life than the affected people themselves. And last but not least study participants without any BU related experience were more convinced of the quality of BU treatment provided at governmental health facilities than their BU affected peers.

(3) The assessment of the characteristics of *'Late Care-Seekers'* (KAP survey) has shown that BU affected people who delay medical treatment reported less often that they had received treatment recommendations for their pre-ulcerative nodule. They were less likely to express that they know any preventive measure against BU but more likely to state that they had the feeling to be welcome to attend to social events. Furthermore, BU affected people who needed to cover transportation costs to report to the governmental health facility regularly were less likely to report in the pre-ulcerative stage. A last difference between *'Early'* and *'Late Care-Seekers'* were that delayers more often only got to know about BU when they were themselves receiving treatment and were in general less satisfied with the provided health-services and facilities

(4) Findings from the expert interviews and the analyses of the KAP data showed that BU affected children depend on the support and decision of their parents or caretakers. On the other hand BU affected study participants up to 15 years were less sceptical but more likely to believe in the communicated health messages. Study participants above the age of 15 years were found to be more likely to only hear about the disease when they were already receiving treatment and more often dissatisfied with the information they had yet received.

(5) Although the KAP survey did not reveal any sex-related differences among the BU affected study participants the interviewed experts explained that women are more likely to delay medical treatment. Therefore it should be kept in mind that women are generally more vulnerable to report to for treatment a governmental health facility than men.

(6) The assessment of differences in the perception of the disease and the available treatment options between the communities in the FGDs has shown that BU affected people in remote communities prefer traditional treatment over medical treatment. Furthermore these people were more prone to be informed about BU only when they were themselves affected and mentioned difficulties to access local transportation. Study participants in communities, which were closer to the *'Government Hospital'* seemed to be less satisfied with the health services. Those who were living in communities along the main street indicated more often that they had attended video events or had received information about BU via radio or TV.

(7) The study has shown that a combination of different research methods is necessary to assess all relevant aspects, which have an influence on the health-seeking process of BU affected people:

The systematic literature search allowed for an overview on the available evidence and identified research gaps and needs. These results made it possible to develop the *'Adapted BU specific Framework for Health-Seeking Behaviour'* (version I). Thereby it allowed answering research question (1).

The expert interviews provided detailed explanations for local and cultural characteristics as well as expectations of the people. Furthermore the interviews allowed assessing personal reports and estimations. Details about sensitive and delicate topics such as spiritual aspects were best provided by the non-affected experts – as some of the BU affected interviewees seemed to be too shy to report about respective experiences and perceptions. This research step provided unique insights into the study setting and allowed to develop the *'Modified BU specific Framework for Health-Seeking Behaviour'* (version II) even though it did not allow quantifying socio-demographic background characteristics of the study population and the status of knowledge of the affected people. This research step served to answer the specific research questions (1) and (3).

The KAP survey appeared to be a valid research method to assess and quantify the BU specific health-seeking behaviour: High validity of the findings may be assumed for the *'Predisposing Factors'* as well as the knowledge-based aspects variables. It allowed answering the specific research questions (2) to (5) as well as (7).

The FGDs confirmed or clarified the aspects of the *'Modified BU specific Framework for Health-Seeking Behaviour'* (i.e. *'Aetiological Model', 'Expected Benefits of the Treatment', 'Stigma/ Social Exclusion'* etc.) but were not suitable to assess quantifiable details (i.e. socio-demographic information, knowledge status etc.). Thereby the specific research questions (1) to (3) and (7) could be answered.

7.2 Recommendations

This research has shown that especially in remote communities of the study area the awareness about BU and its yet unknown cause is not sufficient. To avoid misperceptions, to eradicate over-simplified health messages and to reduce stigmatization among the people specific education programmes should be organized to target for the most important age groups (pupils/ students up to 20 years as well as people above 40 years). Based on the findings according to the *'Modified BU specific Framework for Health-Seeking Behaviour'* the following topics should be covered by understandable health-messages:

- The initial BU symptoms should be displayed and explained to the people in endemic regions.
- BU may affect everybody who lives in an endemic area.
- The mode of transmission is not yet identified but certain risk factors as well as some protective factors have been identified in the study area[305].
- It is important to report to the nearest governmental health facility when any of the initial symptoms are observed (i.e. *'Every boil should be taken to hospital* [governmental health facility] *for diagnosis.').*
- Governmental health facilities provide effective antibiotic treatment free of charge – irrespective of the availability of a health insurance.
- BU may lead to the development of deformities or even disabilities. Early antibiotic treatment is effective and may thereby prevent deformities and disabilities.
- Not only the visible part of BU lesions but also the undermined skin is infected. For this reason traditional treatment methods should be avoided, as they may not be effective but cause secondary infections of the wound.

To publicize this information all available means should be employed (i.e. posters and provision of pamphlets in the communities, TV, radio, newspapers, phone-ins, presentation of WHO-BU documentary during a night-show, drama sessions, and multipliers such as NGOs, health workers, teachers as well as community organizations).

Besides the need for education to improve the BU specific perception and awareness the findings of the study revealed certain weaknesses of the local health system so that it should be strengthened in the following areas:

- Provision of funds for both BU specific education as well as improvement of the health and treatment facilities, including the inclusion of BU under the National Health Insurance program
- Training of health workers (i.e. BU treatment and management as well as doctor-patient communication) to increase the likelihood that antibiotic treatment is attractive for BU affected people.
- Regular supply of drugs (i.e. packed and labelled medicine for each patient), bandages and other required materials would ensure uninterrupted treatment and adequate wound care.

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[305] The presence of wetland, an insect bite in water, the use of adhesive after an injury as well as washing in Densu river have been identified as risk factors for BU. On the other hand covering limbs during farming and the use of alcohol after insect bites occurred have been shown to protect against the disease (Kenu et al. 2014).

- Sustained logistics for transportation of BU samples to the reference laboratory and improved communication between the institutions would allow for early treatment based on a scientific diagnosis.
- More staff in the health facilities receiving BU affected people would allow that the health workers have sufficient time to adequate counsel and treat (including POD) their patients.
- The infrastructure of the *'Governmental Hospital'*, which is supposed to provide services for the district should provide surgical care and additional beds to integrate BU care (including corrective surgery for chronic BU cases).
- Provision of incentives (i.e. small amounts of food such as rice, soap etc.) as well as reimbursement of travel expenses to BU affected people could motivate the patients to report regularly.
- The public education programmes should be synchronized among the NBUCP, NGOs, the district health management as well as the SHEP, local health facilities, CSBVs and herbalists.

- The integration of the herbalists and traditional healers into the national health system seems to be necessary for a better acceptance of the services provided from governmental health facilities,

In addition to the practical recommendations more research is needed to identify the cause of the disease and to develop respective preventive measures. Until this is not the case research endeavour should aim to further understand the local beliefs, treatment practices and the underlying reasons for delayed medical treatment in more detail. Moreover research into traditional herbal medicine, differential diagnosis or further possibilities to allow for an on-site diagnosis as well as a home-based all-oral treatment is recommended.

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Annex A: Tables Systematic Literature Search

TABLE 12: Overview Systematic Literature Search - Predisposing Factors (1)

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect Assessed
Ackumey et al. 2011a	Help-seeking behaviour for Pre-Ulcer and Ulcer Conditions of *Mycobacterium ulcerans*	Examination of socio-cultural features of help-seeking for BU-affected persons	Ghana	Qualitative Study (Phenomenological analysis of help-seeking variables)	N = 181 BU Patient interviews	1. Household Characteristics 2. Formal Education 3. Occupation 4. Assets 5. Social Interactions 6. Disease Experience
Ackumey et al. 2011b	Health services for Buruli ulcer control: lessons from a field study in Ghana	Assessment of achievements of the BUPaT programme and lessons learnt Evaluation of programme impact on broader interests of the health system	Ghana	Mixed-Method Approach (Patients' records, review of programme records, stakeholder forum, key informant interviews, focus group discussions, clinic visits and observations)	N = 35 Participants in stakeholder forum Documents review N = 3 Key informant interviews N = 297 BU Patient records On-site clinic visits N = 3 (à 10 participants) FGDs	1. Age, Sex
Adamba & Owusu 2011	Burden of Buruli ulcer: how affected households in a Ghanaian district cope	Review of the burden of BU on households Discussion of household coping strategies to deal with the socioeconomic burden of BU (including stigma)	Ghana	Mixed-Method Approach (Semi-structured questionnaire, in-depth interviews to complement the data)	N = 86 BU affected households	1. Age, Sex 2. Formal Education 3. Occupation 4. Assets
Agbenorku et al. 2011	Factors enhancing the control of Buruli ulcer in the Bomfa communities,	Examination of factors that may enhance the control and holistic treatment	Ghana	Observational study (2005-2006)	N = 189 BU patients	1. Age, Sex 2. Household Characteristics 3. Occupation 4. Assets

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect Assessed
	Ghana					5. Social Interactions
Larbor 2010	Knowledge, Attitude and Practice of Buruli ulcer in Ga West District	Assessment of: Community perception Knowledge about BU Health seeking behaviour of BU cases	Ghana	Mixed-Method Approach (Quantitative survey, focus group discussions qualitative case studies)	N = 200 Community members	1. Ethnic Group and Religion
Kibadi et al. 2009	Therapeutic itineraries of patients with ulcerated forms of *Mycobacterium ulcerans* (Buruli ulcer) disease in a rural health zone in the Democratic Republic of Congo	Description of lay perceptions of the ulcerated forms of BU Description of therapeutic itineraries of BU patients	Democratic Republic of Congo	Qualitative Study (Semi-structured interviews with patients; in addition in-depth interviews with confirmed patients)	N = 19 Semi-structured Interviews N = 12 In-depth Interviews	1. Age, Sex 2. Occupation 3. Social Interactions
Grietens et al. 2008	*“It Is Me Who Endures but my Family That Suffers”:* Social Isolation as a Consequence of the Household Cost of Buruli Ulcer Free of Charge Hospital Treatment	Evaluation of the economic and social impact of hospital treatment for Buruli ulcer (medical costs for hospital treatment and supplementary aid were subsidized)	Central Cameroon	Mixed-Method Approach (Participant observation, in-depth interviews, focus group discussions, structured questionnaire)	N = 79 Questionnaires, clinically confirmed and hospitalized BU patients N = 73 Household Interviews	1. Age, Sex 2. Occupation 3. Assets
Mulder et al. 2008	Health care seeking behaviour for Buruli ulcer in Benin: a model to capture therapy choice of patients and healthy community	Description of the steps that BU patients go through before reporting to the hospital/ treatment centre Assessment of the influence of stigma and	Benin	Mixed-Method Approach (Structured questionnaire and qualitative in-depth interviews)	N = 107 BU Patients treated in hospital N = 46 BU Patients treated traditionally N = 107 Healthy community	1. Degree of Cultural Adaptation 2. Formal Education 3. Social Interactions 4. Disease Experience 5. Other Factors

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect Assessed
	members	distance to the treatment centre			members	
Kibadi et al. 2007	Study of names and folklore associated with *Mycobacterium ulcerans* infection in various endemic countries in Africa	Presentation of names used for *M. ulcerans* infection (Buruli ulcer) Explanation of their meanings in various African languages Study of the representations associated with the disease	Benin, Cameroon, Congo-Brazzaville, Cote d'Ivoire, Ghana, Uganda, Democratic Republic of Congo, Southern Sudan and Togo	Qualitative Study (Analysis of information from interviews and literature)	Interviews and Information from nine African countries	1. Ethnic Group and Religion
Renzaho et al. 2007	Community-based study on knowledge, attitude and practice on the mode of transmission, prevention and treatment of the Buruli ulcer in Ga West District, Ghana	Assessment of: Community perceptions Understanding of the BU aetiology Attitudes towards BU patients and Treatment seeking behaviours	Ghana	Mixed-Method Approach (Quantitative survey, focus group discussions)	N = 504 Households N = 7 FGDs (à 8-12 people)	1. Household Characteristics 2. Ethnic Group and Religion 3. Formal Education
Phanzu et al. 2006	*Mycobacterium ulcerans* disease (Buruli ulcer) in a rural hospital in Bas-Congo, Democratic Republic of Congo, 2002-2004	Review of the experience of IME/ Kimpese in the management of hospitalized laboratory-confirmed BU patients (May 2002 – August 2004)	Democratic Republic of the Congo	Clinical study (Socio-demographic characteristics, clinical features and management)	N = 51 suspected BU patients	1. Age, Sex 2. Social Interactions 3. Disease Experience
Stienstra et al. 2005	Factors associated with functional	Evaluation of former BU patients to assess the	Ghana, Benin	Mixed-Method Approach (Buruli	N = 638 BU patients, who	1. Age, Sex

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect Assessed
	limitations and subsequent employment or schooling in Buruli ulcer patients	factors associated with functional limitations and subsequent employment or schooling		ulcer functional limitation score (BUFLS) questionnaire and interviews about educational and professional consequences incurred by BU)	had finished treatment	
Johnson et al. 2004	Traditional treatment for Buruli ulcer in Benin	Tracking of the treatment itinerary of patients Main phases of traditional treatment Cost and efficacy of traditional treatment Knowledge and skills of traditional practitioners	Benin	Qualitative Study (Interviews with: patients who received traditional treatment, patients who received surgery, traditional practitioners)	N = 35 BU Patients N = 20 Practitioners	1. Age, Sex 2. Ethnic Group and Religion
Aujoulat et al. 2003	Psychological aspects of health seeking behaviours of patients with Buruli ulcer in southern Benin	Perception of BU and treatment facilities Obstacles causing patient delay Local names for BU Identification of most appropriate people for delivering health education messages	Benin	Qualitative Study (Focus group discussions)	N = 78 Adults N = 28 Children	1. Disease Experience 2. Social Interactions
Ackumey 2002	Local Perceptions of Buruli ulcer in the Ga district, Greater Accra Region	Assessment of socio-cultural perceptions of BU and how these perceptions affect the management of the disease:	Ghana	Mixed-Method Approach (Structured questionnaire, focus group discussions, case	N = 200 Questionnaires N = 4 FGDs N = 3 Case studies	1. Ethnic Group and Religion

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect Assessed
		Disease aetiology Health seeking behaviour Beliefs and practices governing BU Community reaction towards patients		studies)		
Stienstra et al. 2002	Beliefs and attitudes toward Buruli ulcer in Ghana	Exploration of: Beliefs and attitudes towards BU Ideas on the cause of BU Help-seeking behaviour Views on treatment and stigma	Ghana	(Qualitative and quantitative data from BU patients and control subjects)	N = 33 BU patients N = 33 Control Subjects	1. Formal Education
Agbenorku & Kporku 2001	Buruli Ulcer: A Poverty Disease	Assessing causes for late reporting	Ghana	Quantitative Survey	N = 50 (former) BU patients N = 30 Non-affected	1. Assets 2. Other Factors
Asiedu & Etuaful 1998	Socioeconomic implications of BU in Ghana: a three-year review	Estimation of short-term treatment costs of BU (1994 – 1996) in the Amansie West district, Ghana	Ghana	Retrospective study (Review of hospital records)	N = 102 hospitalized BU patients	1. Age, Sex 2. Ethnic Group and Religion 3. Assets

Source: Author’s own

TABLE 13: Overview Systematic Literature Search - Characteristics of BU and its Perception (2)

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
Ackumey et al. 2011a	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model 3. Expected Benefits of the Treatment
Ackumey et al. 2011b	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Expected Benefits of the Treatment
Adamba & Owusu 2011	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Stigma/ Social Exclusion
Agbenorku et al. 2011	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms
Larbor 2010	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model
Kibadi et al. 2009	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model 3. Expected Benefits of the Treatment
Grietens et al. 2008	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Stigma/ Social Exclusion
Mulder et al. 2008	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model 3. Stigma/ Social Exclusion
Kibadi 2007	Streptomycin injections for the treatment of *Mycobacterium ulcerans* (Buruli ulcer) in a rural health zone in the Democratic Republic of the Congo	Assessment of acceptability and efficiency of antibiotic treatment for BU in rural settings	Democratic Republic of the Congo	Qualitative Study (Guideline oriented interviews with BU patients)	N = 14 BU Patients receiving treatment N = 14 Patients awaiting onset of treatment	1. Aetiological Model 2. Expected Benefits of the Treatment
Kibadi et al. 2007	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Aetiological Model
Renzaho et al. 2007	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
						3. Stigma/ Social Exclusion
Phanzu et al. 2006	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms
Stienstra et al. 2005	Factors associated with functional limitations and subsequent employment or schooling in Buruli ulcer patients	Evaluation former BU patients to assess the factors associated with functional limitations and subsequent employment or schooling	Ghana, Benin	Mixed-Method Approach (Buruli ulcer functional limitation score (BUFLS) questionnaire and interviews about educational and professional consequences incurred by BU)	N = 638 BU patients, who had finished treatment	1. Severity of the Symptoms
Johnson et al. 2004	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Expected Benefits of the Treatment
Kapay 2004	Investigation Knowledge-attitude-practices of Songololo-population (D.R. Congo)	Provision of anthropological knowledge for better treatment of BU Confirmation of the presence of BU in that focus Description of general characteristics of the subjects	Democratic Republic of the Congo	Quantitative Survey	N = 51 confirmed BU patients N = 102 Matched control subjects	1. Aetiological Model
Aujoulat et al. 2003	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model 3. Expected Benefits from the Treatment 4. Stigma/ Social Exclusion
Ackumey 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Aetiological Model 2. Expected Benefits of the

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
						Treatment
Stienstra et al. 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Severity of the Symptoms 2. Aetiological Model 3. Expected Benefits of the Treatment 4. Stigma/ Social Exclusion
Agbenorku & Kporku 2001	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Aetiological Model
Guédénom et al. 1995	Traditional treatment of Buruli ulcer in Benin	Description of the aetiological model and traditional treatment of Buruli ulcer	Benin	Qualitative Study (Case study)	N = 1, Case study with one traditional practitioner	1. Severity of the Symptoms 2. Aetiological Model

Source: Author’s own

TABLE 14: Overview Systematic Literature Search - Enabling Factors (3)

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
Ackumey et al. 2011a	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of the Treatment 3. Acceptability, Quality, Communication 4. Costs
Ackumey et al. 2011b	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of the Treatment 2. Acceptability, Quality, Communication 3. Costs
Adamba & Owusu 2011	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of the Treatment 3. Acceptability, Quality, Communication 4. Costs
Agbenorku et al. 2011	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Acceptability, Quality, Communication
Larbor 2010	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment
Kibadi et al. 2009	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of the Treatment 3. Acceptability, Quality, Communication
Grietens et al. 2008	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of Treatment 3. Costs
Mulder et al. 2008	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of Treatment
Kibadi 2007	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment 2. Acceptability, Quality, Communication
Kanga et al. 2007	Impact of Buruli ulcer secondary prevention program in an endemic area	Assessment of the potential impact of a screening and treatment strategy for nodular forms of BU on	Côte d'Ivoire	Quantitative Survey (Before/ After: 1998 vs. 2002)	N = 781 BU patients	1. Acceptability, Quality, Communication

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
	in Côte d'Ivoire	ulceration rate decrease				
Renzaho et al. 2007	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of Treatment 3. Acceptability, Quality, Communication 4. Costs
Phanzu et al. 2006	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment 2. Acceptability, Quality, Communication
Johnson et al. 2004	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of Treatment 3. Acceptability, Quality, Communication 4. Costs
Aujoulat et al. 2003	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Appeal of Treatment 3. Acceptability, Quality, Communication 4. Costs
Ackumey 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment
Stienstra et al. 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment 2. Acceptability, Quality, Communication 3. Costs
Agbenorku & Kporku 2001	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Accessibility 2. Acceptability, Quality, Communication 3. Costs
Asiedu & Etuaful 1998	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Appeal of Treatment 2. Acceptability, Quality, Communication 3. Costs
Guédénom et al. 1995	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	1. Appeal of Treatment 2. Costs

Source: Author’s own

TABLE 15: Overview Systematic Literature Search - Choice of Health Care Resources (4)

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
Ackumey at al. 2011a	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource 2. Traditional Healer 3. Modern Healer 4. Drug Seller 5. Self-Treatment/ No Treatment 6. Church
Ackumey at al. 2011b	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource 2. Self-Treatment/ No Treatment
Kibadi et al. 2009	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource 2. Drug-Seller 3. Self-Treatment/ No Treatment 4. Church
Mulder et al. 2008	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource 2. Traditional Healer 3. Self-Treatment/ No Treatment
Kibadi et al. 2007	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Traditional Healer
Renzaho et al. 2007	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Traditional Healer
Phanzu et al. 2006	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource
Johnson et al. 2004	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Choice of Health Care Resource 2. Traditional Healer
Aujoulat et al. 2003	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	see TABLE 12	1. Traditional Healer

Citation	Title	Objective of the Study	Study Setting	Study Design/ Methods	Sample Size	Aspect assessed
Ackumey 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Choice of Health Care Resource 2. Traditional Healer
Stienstra et al. 2002	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	see **TABLE 12**	1. Traditional Healer 2. Self-Treatment/ No Treatment
Guédénom et al. 1995	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	see **TABLE 13**	1. Traditional Healer

Source: Author’s own

Annex B: Guideline for Expert Interviews

Example: Caretaker of a Patient

PHASE	TOPIC	QUESTION
Introduction	**Own Presentation**	Good morning Mr/ Mrs ____. My name is Linda Seefeld. I am a health scientist from the University of Bielefeld in Germany and I am working on my PhD with the aim to describe the local knowledge and the treatment practices of Buruli ulcer in your district. Do you have any questions on that? In the course of the interview I will ask you different open questions and I would like to ask you to basically tell me everything, which is relevant and important for YOU. I will not interrupt you; none of your answers can be “wrong”. There will be enough time to say everything that you like to tell me.
		Mr/ Mrs _________, I am very gracious that you have the time to give me an interview and tell me YOUR story about your experience with Buruli ulcer. The interview will take approximately 60 minutes. For a better analysis of the conversation I will record it with this MP3-recorder and transliterate it afterwards. This allows me to follow the conversation much better. Of course the interview material will be kept confidential and anonymous, ensuring that no one will be able to determine your identity based on the answers provided. We will also ask you to give informed consent at the end. Of course, the data will only be analysed when you agree after the interview that we may use your information for this research. Is this O.K. for you? In case you are interested I will provide you with the relevant passages for your personal use when the project is finished. Well, let’s start with the first question:
	Introduction to Family and Village Life	Mr/ Mrs _________, you are living here in _________. Could you please tell me how you live here in ______?
	Consumables/ Shopping	What are the items that you spend most of your income/money on? How often do you go to the next market centre?

		Where is it exactly? Which other villages do you visit on a regular basis? What do you do there? And how do you go there?
	Personal BU Affiliations/ Confirmation	As I told you in the beginning, I am here to talk with you about Buruli ulcer and the challenges that you and your family have to face due to the disease: How did you know that it was BU? How the reaction of your family when they saw the first symptoms of the disease? Were you sure that your ____ has the disease? How long did it take until you were sure about it? What was your reaction after confirmation?
	BU Knowledge	How did you get to know about BU? What did you hear about the symptoms of BU? What is the best treatment of BU according to your knowledge? **Personal Contact/ Sources:** Did you know somebody with BU before your _____ got the disease? Which sources of information do you use? **NGOs:** Do you know if there are any information campaigns on Buruli ulcer going on in Pakro/Dago Sun district? What are they doing? Do they distribute leaflets or posters?

		Request: Is there anything else that you would like to tell me about the symptoms of BU?
	Transmission	Can you tell me what you know about the transmission of BU? Does everybody have the same risk of getting BU? Why (not)? **Own Explanation:** What do you think, how did your child contracted with BU?
	Introduction to Local Perception/ BU Activities	Now, I would like to talk about your perception of the disease: **Perception:** If you compare Buruli ulcer with other diseases: how would you describe it? Is there any disease that causes more problems? **Local Names:** Do you know any local names for the disease? What do the stand for? **Need for further Information:** Do you think that you are well informed about BU or would you like to have more information on the disease?
	Treatment	What do you hear about the available treatment options for BU? Is your child already undergoing a therapy? What kind of therapy is it? Where do you get it?

	Traditional Treatment	Why do people seek traditional treatment? Can you tell me a little more about traditional treatment and its different approaches/ ways of treatment? Which treatment options do you know? **Religion:** Does religion play a role in treatment and healing of BU patients? **Culture:** Does the cultural background influence the treatment and your treatment-seeking behaviour? **Request:** Are there other practices for the treatment of BU?
	Antibiotic Treatment	What do you think about antibiotic treatment for BU? Is antibiotic treatment well known in the rural communities? What were the treatment practices like before antibiotic treatment was introduced? Why do you refuse this treatment? Do people refuse only to take antibiotics – or do they refuse medical treatment in general? Why?
	Treatment Challenges	Where do the people normally go to when they need treatment but do not have money for the transport to the next hospital? What are the biggest problems regarding the treatment of Buruli ulcer to your perception? Do you see differences, if you compare your village to other villages?
	Health Decision Making	Does your ______ take the same treatment as the others within the community? (Why/ why not?) Who told you how to deal with the disease and how to treat it? Who gave you this information?

		What did they tell you exactly? Which treatment did you finally choose for your child? Why? How many different treatments did you try? Who decided about the adequate treatment of your child?
	Structural Factors	Have there been some changes concerning the treatment over the years? …. Regarding medication? …. Regarding availability? …. Regarding the duration of treatment? …. Costs?
	Treatment Costs	What are the consequences of the BU infection on the income of your household? How did you pay for BU treatment? How long did he/she stay in hospital? How did you cope with that? How did the disease and its treatment influence the productivity of your household?
	Disabilities	Does your ______ have any disabilities due to BU? How does this influence the life? Do you think that BU may influence marriage/ sexual functioning? Does somebody help you with your daily activities/ do you need help due to the disease of your _____?

		What kind of help would you need? **Request:** Is there anything more that you would like to tell me?
	Introduction of the Health Topic/ Health Facilities	Now, I would like to talk about the quality of health care within your community! What do you think about the local health care facilities? **Request:** Are there any more things that you would like to tell me?
	Introduction to Consequences and Problems/ Social Exclusion	Let's talk about the consequences of the BU infection and problems that are connected with the disease: What were the consequences of the BU infection of your _____? How did it affect your life?
	Integration	Is a Buruli ulcer infection a common topic in your community? Can you speak freely about the disease? Does your _____ have any problems within the community due to BU? Do other community members treat him/ her well? Does he/ she feel equally integrated into the society as before the contraction of the disease? Do you see any differences? Can you see a difference over the time how the community deals with BU affected households? How do other communities deal with BU affected households?
Final Part		I am finished now with my questions that I had foreseen. Do you have anything else that you would like to add?

		Do you have any suggestions for my research? I would also be very pleased in case you have any suggestions at a later stage. Please feel free to contact me again.
End		Thank you very much for your time and the information! May I get back to you in case I have any more questions? Do you know a ___________ in Pakro/Dago Sub district or Akuapim South District who might also be willing to give me an interview? Thank you very much and Good Bye!

Annex C1: Evaluation Plan KAP Survey

Aim:

Understand Knowledge, Attitude and Practice of (previously) BU affected people (N = 122)

Specific Objectives:

(1) Assess socio-demographic characteristics of (previously) BU affected people

(2) Assess knowledge, attitude and practice of BU and its treatment of (previously) BU affected people

Method:

Descriptive analysis

Framework Element	Aspects and Variables	Justification/ Rationale
Predisposing Factors – Social and Cultural Background	***'Age, Sex'*** - Age (by time of infection) - Sex	Basic demographic information (element of Kroeger's framework)
	'Household Characteristics' 'Number of people in Household - Marital status - Number of children in household	Basic information about the constitution of the studied households (element of Kroeger's framework)
	'Ethnic Group and Religion' - Ethnic background of mother and father - Mother tongue - Religion	Information about ethnical background of the study participants (element of Kroeger's framework) Relevant research literature and expert interviews provide findings that religion may influence health behaviour of BU affected people
	'Formal Education' - Highest attained education level (participants, who are 6 years or older)	Information about formal education status of the study participants (element of Kroeger's framework)
	'Occupation' - Occupation	Information about occupation of study participants, who are older than 15 years ("working population") (element of Kroeger's framework)
	***'Assets'* (indicator for SES)** - Money for food, water and transportation (per day and household) - Main source of income of household - Frequent means of transport	Assets serve as indicators or proxies for SES (element of Kroeger's framework)
	'Social Interactions' - Treatment recommendation	Information about social interaction about disease symptoms (element of Kroeger's framework)
Characteristics of BU and Perception of the Disease	***'Severity of the Symptoms'*** - State of lesion - Year of healing - Multiple lesions - Location of the lesion - Type of lesion	Modified aspects of Kroeger's framework (initially 'severe or trivial' and 'chronic or acute')
	'Aetiological Model' - Knowledge of initial BU symptoms - Knowledge of specific BU	Information about the aetiological conception of the study participants (element of Kroeger's framework)

Framework Element	Aspects and Variables	Justification/ Rationale
	symptoms - Perceived cause of BU - Knowledge of preventive measures	
	'Stigma/ Social Exclusion' - How do community members treat BU patients? - Are BU patients welcome at social functions? - Do children with BU continue schooling? - Would other community members accept a BU patient as a leader? - May BU patients have to face difficulties with sexual functioning?	Information about stigmatization of BU patients (mentioned in the relevant research literature; newly included/ adapted to the framework)
Enabling Factors - Health System Characteristics	***'Accessibility'*** - Means of getting to the health facility - How long does it take to get there?	Information on the accessibility (travel distance) of available health services (element of Kroeger's framework)
	'Appeal of available Treatment' - Perception about antibiotic treatment for BU - General reasons not to seek medical treatment	Information on people's attitude towards antibiotic care for BU as well as reasons not to seek medical care (element of Kroeger's framework)
	'Acceptability and Quality of the available Health Services' - Satisfaction with local health facilities	Information on the attractiveness of the available health care services (element of Kroeger's framework)
	'Health Education and Communication' - Have you ever received information about BU? - Knowledge of treatment options for BU - How did you get to know about BU? - Information about BU within the last 6 months - Type of information within the last 6 months - Sufficient information about BU? - What would you like to know about BU? - How is BU treated in a hospital/ clinic?	Information on the provided health information (element of Kroeger's framework)
	'Costs' - How is the cost of medical treatment for BU taken care of? - Availability of a valid health insurance at the moment - Travel costs to the nearest health facility	Treatment costs are a frequently mentioned obstacle to access modern health facilities (element of Kroeger's framework)

Framework Element	Aspects and Variables	Justification/ Rationale
Choice of Health Care Resources	***'Therapeutic Itineraries of BU affected People'*** - Choice of treatment for nodule - Choice of treatment for plaque - Choice of treatment for oedema - Choice of treatment for ulcer ***'No Treatment'*** ***'Self-Treatment'*** - Specification of treatment practices for nodules, plaques, oedemas and ulcers ***'Herbal Treatment'*** - Specification of treatment practices for nodules, plaques, oedemas and ulcers ***'Governmental Health Facility'*** - Specification of treatment practices for nodules, plaques, oedemas and ulcers ***'Church/ Prayer-Camp'*** - Specification of treatment practices for nodules, plaques, oedemas and ulcers	The concurrent or serial use of different treatment options (healer-shopping) is a typical feature of transitional societies of the developing world. Common treatment options are traditional healer, modern healer, self-treatment and no treatment (elements of Kroeger's framework)

Aim:
Determine differences among (previously) BU affected people

Specific Objectives:
(3) Assess characteristic differences of (former) patients by gender (N = 122)
(4) Asses characteristic differences of (former) BU patients between the generations (up to 15 years and above 15 years) (N = 122)

Method:
→ Descriptive analysis, cross tables, Chi-square-test/ Fisher-exact-test

Framework Element	Aspects and Variables	Justification/ Rationale
Characteristics of BU and Perception of the Disease	***'Aetiological Model'*** - Knowledge of initial symptoms - Knowledge of specific symptoms - Perceived cause of the disease - Knowledge of preventive measures	Information about the aetiological conception of the study participants (element of Kroeger's framework); probable different perception of BU by gender and between the generations
	'Stigma/ Social Exclusion' - How do community members treat BU patients (with ulcers)? - Are BU patients welcome at social functions? - Do children with BU continue schooling? - Would other community members accept a BU patient as a leader? - May BU patients have to face difficulties with sexual functioning?	Information about stigmatization of BU patients (mentioned in the relevant research literature; newly included/ adapted to the framework); probable different perception of stigmatization/ social exclusion by gender and between the generations
Enabling Factors - Health System Characteristics	***'Appeal of available Treatment'*** - Perception about antibiotic treatment for BU - General reasons not to seek medical treatment	Information on people's attitude towards antibiotic care for BU as well as reasons not to seek medical care (element of Kroeger's framework); probable different status of information and perception by gender and between the generations
	'Acceptability and Quality of the available Health Services' - Satisfaction with local health facilities	Information on the attractiveness of the available health care services (element of Kroeger's framework) ; probable different status of information and perception by gender and between the generations
	'Health Education and Communication' - Have you ever received information about BU? - Knowledge of treatment options for BU - How did you get to know about BU? - Information about BU within the last 6 months - Type of information within the last 6 months - Sufficient information about BU?	Information on the provided health information (element of Kroeger's framework); probable different status of information and perception by gender and between the generations

Framework Element	**Aspects and Variables**	**Justification/ Rationale**
	- What would you like to know about BU? - How is BU treated in a hospital/ clinic?	
	'Costs' - How is the cost of medical treatment for BU taken care of? - Availability of a valid health insurance at the moment	Treatment costs are a frequently mentioned obstacle to access modern health facilities (element of Kroeger's framework); probable different status of information and perception by gender and between the generations
Choice of Health Care Resources	***'Therapeutic Itineraries'*** - Choice of treatment for nodule - Choice of treatment for plaque - Choice of treatment for oedema - Choice of treatment for ulcer	Preferred treatment options (elements of Kroeger's framework); probable difference in use by gender and between the generations

Aim:
Assess risk for late medical reporting

Specific Objective:
Determine risk for late medical reporting (e.g. self-treatment, herbal or spiritual treatment; N = 63). Comparison group is the group of *'Early Care-Seekers'* (medical treatment for pre-ulcerative lesions; N = 59).

Method:
→ Descriptive analysis of selected variables of the health seeking framework (see table below), cross tables, Chi-square test (for categorical variables) or Wilcoxon rank sum test (for metric variables)
→ Odds-ratios were calculated when $p < 0.25$
→ $P \leq 0.05$ was considered as statistically significant (→ see results table 47)

Framework Element	Aspects and Variables	Justification/ Rationale
Predisposing Factors – Social and Cultural Background	***'Age, Sex'*** - Age (by time of infection) - Sex	Young people (< 15 years) are dependent on the care/ observance of their parents Gender differences in health seeking (→ Elements of Kroeger's framework)
	'Household Characteristics' - Marital status - Number of children in household	Patients who are not married are less likely to report for treatment. Households with many children (above average (> 4) care less for the individual (→ Elements of Kroeger's framework)
	'Ethnic Group and Religion' - Mother tongue - Religion	People with different ethnic backgrounds have a different disease perception and a different health seeking behaviour (→ Expert interviews). People who follow traditional believes are more likely to practice traditional treatment and delay reporting for medical treatment (→ Expert interviews, elements of Kroeger's framework)
	'Formal Education' - Highest attained education level (of people, who are 6 years or older)	People with a low level of formal education have only limited possibilities to access information about available treatment options (→ Element of Kroeger's framework)
	'Occupation' - Occupation (of participants above 15 years)	Farmers are more likely to delay in reporting for treatment as they may have to continue farming. Students/ pupils may receive information about the disease through their teachers and peers (→ Expert interviews; element of Kroeger's framework)
	'Assets' - Money for food, water and transportation (per day and household) - Frequent means of transport	Money for food, water and transportation (proxy for SES); People, who do not frequently use a troto or taxi may have limited resources (proxy for SES) Assess whether 'assets' influence the treatment-seeking behaviour (→

Framework Element	**Aspects and Variables**	**Justification/ Rationale**
		Element of Kroeger's framework)
	'Social Interaction' - Treatment recommendation	Patients who do not talk about their disease with others have only limited information about the available treatment options and are therefore less likely to access medical treatment (→ BU literature, expert interviews; element of Kroeger's framework)
BU Characteristics and Perception of the Disease	***'Characteristics of encountered Lesions'*** - Type of lesion - Multiple lesions - Location of the lesion	People with old/ chronic lesions have more time to recourse different treatment options and are more likely to use traditional methods. Diseases, which are perceived to be acute/ severe are more often treated by modern health practitioners (→ modified element of Kroeger's framework) People with multiple lesions are more likely to be *'Late Care-Seekers'* than those with a single lesion. People with a lesion on a visible site of the body (upper/ lower limbs, face, neck) are more likely to report for medical treatment than those, who have a lesion on a hidden site (→ newly introduced into the framework)
	'Aetiological Model' - Knowledge of initial symptoms - Knowledge of specific symptoms - Perceived cause of the disease - Knowledge of preventive measures	People without information on the disease and its symptoms are more likely to delay medical treatment. The perceived cause of the disease/ preventive measures may influence the treatment seeking behaviour. Assess whether *'Early Care-Seekers*' have a different perception than *'Late Care-Seekers'* (→ BU literature, expert interviews; element of Kroeger's framework)
	'Stigma/ Social Exclusion' - How do community members treat BU patients (with ulcers)? - Are BU patients welcome at social functions? - Do children with BU continue schooling?	People who are stigmatized are less likely to report for treatment. Assess whether *'Early Care-Seekers'* have a different perception regarding stigma than '*Late Care-Seekers'* (→ BU literature; expert interviews, newly included/ adapted to the framework)
Enabling Factors - Health System Characteristics	***'Accessibility'*** - Means of getting to the health facility - How long does it take to get there?	Assess whether *'Early Care-Seekers'* may access health facilities easier than *'Late Care-Seekers'*. People with a short travel distance to the health facility may easier access medical treatment. People, who live within a short walking distance may report earlier for treatment (→ BU literature, expert interviews; element of Kroeger's framework)
	'Appeal of Treatment' - Perception about antibiotic treatment for BU	Assess whether the perception of the available treatment differs between '*Early Care-Seekers'* and *'Late Care-*

Framework Element	**Aspects and Variables**	**Justification/ Rationale**
		Seekers'. Patients with a negative perception of the antibiotic treatment for BU are less likely to report for medical treatment (→ Element of Kroeger's framework)
	'Acceptability and Quality of the available Health Services' - Satisfaction with local health facilities	Information on the attractiveness of the available health care services (element of Kroeger's framework); People with a positive perception of the local health services/ system report for early treatment (→ Expert interviews, element of Kroeger's framework)
	'Health Education and Communication' - Have you ever received information about BU? - Knowledge of treatment options for BU - How did you get to know about BU? - Information about BU within the last 6 months - Type of information within the last 6 months - Sufficient information about BU? - What would you like to know about BU? - How is BU treated in a hospital/ clinic?	Information on the provided health information (element of Kroeger's framework)
	'Costs' - How is the cost of medical treatment for BU taken care of? - Availability of a valid health insurance at the moment - Travel costs to the nearest health facility	Patients who consider the costs for antibiotic treatment of BU as being high are less likely to report for treatment. Patients, who do not have a valid health insurance card are less likely to report for medical treatment (→ Element of Kroeger's framework)
Choice of Health Care Resources	***'Patient Itineraries'*** - Choice of treatment for nodule - Choice of treatment for ulcer	Preferred treatment options of '*Early Care-Seekers*'/ '*Late Care-Seekers*' Assess whether '*Early Care-Seekers*' rely on medical ("modern") treatment only or whether they include traditional options (herbalist, spiritualist, prayers etc.) (→ Expert interviews, elements of Kroeger's framework)

Aim:
Determine differences between (previously) BU affected people and the non-affected population

Specific Objective:
(6) Determine characteristic differences between (previously) BU affected people (N = 122) and the non-affected population (N = 122)

Methods:
→ Descriptive analysis, cross tables, Chi-square-test (for categorical variables) or Wilcoxon rank sum test (for metric variables)

Framework Element	**Aspects and Variables**	**Justification/ Rationale**
Predisposing Factors – Social and Cultural Background	***'Household Characteristics'*** - Number of people in Household - Marital status - Number of children in household	Basic information about the constitution of the studied households (element of Kroeger's framework); probable difference between BU affected and non-affected households
	'Ethnic Group and Religion' - Ethnic background of mother and father - Mother tongue - Religion	Information about ethnical background of the study participants (element of Kroeger's framework); probable difference between BU affected and non-affected participants
	'Formal Education' - Highest attained education level (participants, who are 6 years or older)	Information about formal education status of the study participants (element of Kroeger's framework); according to the research literature BU influences the educational career of affected individuals
	'Occupation' - Occupation	Information about occupation of study participants, who are older than 15 years ("working population") (element of Kroeger's framework); according to the research literature BU influences the ability to work of affected individuals
	'Assets' - Money for food, water and transportation (per day and household) - Main source of income of household - Frequent means of transport	Assets serve as indicators or proxies for SES (element of Kroeger's framework); according to the research literature BU affected individuals are often deprived members of the society
Characteristics of BU and Disease Perception	***'Aetiological Model'*** - Knowledge of initial BU symptoms - Knowledge of specific BU symptoms - Perceived cause of BU - Knowledge of preventive measures	Information about the aetiological conception of the study participants (element of Kroeger's framework); probable different perception of BU between BU affected and non-affected individuals
	'Stigma/ Social Exclusion' - How do community members treat BU patients (with ulcers)? - Are BU patients welcome at social functions?	Information about stigmatization of BU patients (mentioned in the relevant research literature; newly included/ adapted to the framework); probable different perception of stigmatization/

Framework Element	Aspects and Variables	Justification/ Rationale
	- Do children with BU continue schooling? - Would other community members accept a BU patient as a leader? - May BU patients have to face difficulties with sexual functioning?	social exclusion between BU affected and non-affected individuals
Enabling Factors - Health System Characteristics	***'Appeal of available Treatment'*** - Perception about antibiotic treatment for BU - Reasons not to seek medical treatment	Information on people's attitude towards antibiotic care for BU as well as reasons not to seek medical care (element of Kroeger's framework); probable different status of information and perception between BU affected and non-affected individuals
	'Acceptability and Quality of the available Health Services' - Satisfaction with local health facilities	Information on the attractiveness of the available health care services (element of Kroeger's framework); probable different status of information and perception between BU affected and non-affected individuals
	'Health Education and Communication' - Have you ever received information about BU? - Knowledge of treatment options for BU - How did you get to know about BU? - Information about BU within the last 6 months - Type of information within the last 6 months - Sufficient information about BU? - What would you like to know about BU? - How is BU treated in a hospital/ clinic?	Information on the provided health information (element of Kroeger's framework); probable different status of information and perception between BU affected and non-affected individuals
	'Cost of Treatment' - How is the cost of medical treatment for BU taken care of? - Availability of a valid health insurance at the moment	Treatment costs are a frequently mentioned obstacle to access modern health facilities (element of Kroeger's framework); probable different status of information and perception between BU affected and non-affected individuals

Annex C2: Results KAP Survey

KAP of (previously) BU affected people (specific objective 1 + 2)

1. Predisposing Factors

TABLE 16: KAP of (previously) BU affected People: (1) - Age and Sex Distribution

Characteristic	BU Affected (%)
Age Category (by time of infection)	
0-10	34 (27.9)
11-20	32 (26.2)
21-30	12 (9.8)
31-40	9 (7.4)
41-50	13 (10.7)
51-60	9 (7.4)
61-70	8 (6.6)
71-80	2 (1.6)
81 and above	3 (2.5)
Sex	
Male	59 (48.4)
Female	63 (51.6)

Source: Author's own

The average age of the BU affected people was 27.7 years (min. = 3 years; max. = 102 years; SD = 22 years).

The overall average number of BU affected people in a household was 7.6 (SD = 3.8). About 65% of the BU affected study participants were either single or married. The average number of children of BU affected households was 4.8.

TABLE 17: KAP of (previously) BU affected People: (1) - Household Characteristics

Characteristic	BU Affected (%)
Number of People in Household	
1-5	38 (31.1)
6-10	61 (50.0)
11-15	12 (9.8)
16-20	4 (3.3)
21-25	1 (0.8)
"Many"	6 (4.9)

TABLE 17: KAP of (previously) BU affected People: (1) - Household Characteristics (continued)

Characteristic	BU Affected (%)
Marital Status of Study Participants[306] ≥ 18 years, N = 67	
Single	27 (40.3)
Married	40 (59.7)
Divorced	3 (4.5)
Widowed	9 (13.4)
Number of Children in Household	
No children	9 (7.4)
1-2	29 (23.8)
3-4	40 (32.8)
5-6	28 (23.0)
7-8	12 (9.8)
9-10	3 (2.5)
> 10	1 (0.8)

Source: Author’s own

TABLE 18: KAP of (previously) BU affected People: (1) - Ethnic Group, Religion

Characteristic	BU Affected (%)
Mother Tongue	
Twi (Akan)	54 (44.3)
Ewe	52 (42.6)
Other	16 (13.1)
Ethnic Background Mother	
Akan	54 (44.3)
Ewe	52 (42.6)
Other	16 (13.1)
Ethnic Background Father	
Akan	54 (44.3)
Ewe	52 (42.6)
Other	15 (12.3)
Don’t know	1 (0.8)
Religion	
Christian	106 (86.9)
Muslim	4 (3.3)
None	11 (9.0)
Other	1 (0.8)

Source: Author’s own

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[306] several options permitted

TABLE 19: KAP of (previously) BU affected People: (1) - Formal Education

Characteristic	BU Affected (%)
Highest attained Education Level (participants ≥ 6 years), **N = 116**	
No formal education	39 (33.6)
Primary school	37 (31.9)
Junior Secondary School (JSS)	32 (27.6)
Senior Secondary School (SSS)	7 (6.0)
Post-Secondary	1 (0.9)

Source: Author's own

TABLE 20: KAP of (previously) BU affected People: (1) - Occupation

Characteristic	BU Affected (%)
Occupation (participants > 15 years), **N = 75**	
Student/ pupil	13 (17.3)
Farming	40 (53.3)
Unemployed	8 (10.7)
Trade and commerce	6 (8.0)
Other	8 (10.7)

Source: Author's own

The interviewees reported that they cultivate cassava, maize, okro, tomatoes, pepper, plantain, garden eggs, oranges, sugar cane, palm trees/ palm nuts, pawpaw and cocoyam. On average the households spent 7.17 GHC/ day (SD = 4.23 GHC; min = 1 GHC; max. 30 GHC) for food, water and transportation.

TABLE 21: KAP of (previously) BU affected People: (1) - Assets

Characteristic	BU Affected (%)
Money for Food, Water and Transportation	
1-5 GHC	57 (46.7)
6-10 GHC	45 (36.9)
11-15 GHC	6 (4.9)
> 15 GHC	3 (2.4)
Don't know	10 (8.2)
No answer	1 (0.8)
Main Source of Income of Household [307]	
Farming	103 (84.4)
Trade and Commerce	38 (31.1)
Other	14 (11.5)
Don't know	4 (3.3)

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[307] several options permitted

TABLE 21: KAP of (previously) BU affected People: (1) Factors – Assets (continued)

Characteristic	BU Affected (%)
Frequent Means of Transport [308]	
Trotro	105 (86.1)
Taxi	59 (48.4)
Walking	60 (49.2)

Source: Author's own

TABLE 22: KAP of (previously) BU affected People: (1) - Social Interaction

Characteristic	BU Affected (%)
Treatment Recommendation	
Nodule [309] (N = 94)	38 (40.4)
Plaque [310] (N = 7)	7 (100.0)
Oedema [311] (N = 20)	14 (70.0)
Ulcer [312] (N = 100)	61 (61.0)
Decision about Treatment in Case of a Disease [313]	
Father	56 (45.9)
Mother	50 (41.0)
Own decision	48 (39.3)
Both parents	47 (38.5)
Experienced people	38 (31.1)
Other people (doctor, nurse, family members etc.)	11 (9.0)

Source: Author's own

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[308] several options permitted

[309] Recommendation by: friends, colleagues, family members, herbalists, CSBVs, Health workers/ doctors/ nurses, neighbours and a "white woman"

[310] Recommendation by: herbalists, CSBVs, family members, friends

[311] Recommendation by: CSBV, friends, herbalists, family members

[312] Recommendation by: CSBVs, colleagues, friends, health workers/ nurses/ doctors, neighbours, a "white lady", assembly men, herbalists, teachers, radio, family members

[313] several options permitted

2. Characteristics of BU and its Perception

TABLE 23: KAP of (previously) BU affected People: (2) - Characteristics of encountered BU Lesions

Characteristic	BU Affected (%)
State of Lesion N = 122	
New/ active lesion	32 (26.2)
Chronic lesion	13 (10.7)
Old healed lesion/ scar	77 (63.1)
Year of Healing, N = 77	
2010	13 (10.7)
2009	24 (19.7)
2008	21 (17.2)
2007	19 (15.6)
Multiple Lesions, N = 122	
Yes	28 (23.0)
No	94 (77.0)
Location of the Lesion [314], N = 122	
Lower limb right	49 (40.2)
Lower limb left	40 (32.8)
Upper limb right	15 (12.3)
Upper limb left	15 (12.3)
Back	8 (6.6)
Face	3 (2.5)
Abdomen	3 (2.5)
Neck	2 (1.6)
Chest	1 (0.8)
Type of Lesion [315], N = 122	
Nodule	8 (6.6)
Plaque	3 (2.5)
Oedema	7 (5.7)
Ulcer	26 (21.3)
Old healed lesion/ scar	81 (66.4)
Chronic lesion	13 (10.7)

Source: Author’s own

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[314] several options permitted
[315] several options permitted

TABLE 24: KAP of (previously) BU affected People: (2) - Aetiological Model

Characteristic	BU Affected (%)
Do you know how BU starts?	
Yes	107 (87.7)
No	12 (9.8)
Don’t know	2 (1.6)
No answer	1 (0.8)
Knowledge of specific Symptoms [316]	
Nodule/ painless *“boil”*	97 (79.5)
Oedema/ *“swelling”*	13 (10.7)
Ulcer	3 (2.5)
Plaque	8 (6.6)
Other	2 (1.6)
Don’t know	4 (3.3)
Perceived Cause of the Disease [317]	
Drinking water from lakes and rivers	53 (43.4)
Swimming/ wading in rivers/ stagnant water	23 (18.9)
Rainwater	15 (12.3)
Lack of personal hygiene	13 (10.7)
“Gutter water”	9 (7.4)
Other	7 (5.7)
Don’t know	52 (42.6)
No answer	1 (0.8)
Knowledge of Preventive Measures	
Yes	67 (54.9)
No	8 (6.6)
Don’t know	46 (37.7)
No answer	1 (0.8)
Perceived Preventive Measures	
Avoid wading in rivers/ mud/ dirty *“gutter”* water	30 (24.6)
Drink clean water (boil water/ water from borehole)	17 (13.9)
Keep the environment clean	7 (5.7)
Observe hygiene/ cover food	5 (4.1)
Other	8 (6.6)
No answer	55 (45.1)

Source: Author’s own

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[316] several options permitted
[317] several options permitted

TABLE 25: KAP of (previously) BU affected People: (2) - Stigma/ Social Exclusion

Characteristic	BU Affected (%)
How do Community Members treat BU Patients?	
With full sympathy	75 (61.5)
With partly sympathy	29 (23.8)
With unsure sympathy	8 (6.6)
With no sympathy	6 (4.9)
Don’t know	4 (3.3)
Are BU Patients welcome at social Functions?	
Yes	91 (74.6)
No	24 (19.7)
Don’t know	7 (5.7)
If Yes: Why are they welcome to attend? (N = 91)	
“Everybody is invited to attend social functions”	22 (24.2)
“It depends on the patient him-/ herself and on the severity	21 (23.1)
“People do not want to exclude them”	12 (13.2)
“If they are able to walk they may attend”	8 (8.8)
“Anyone may fall sick and contract BU”	6 (6.6)
Other	6 (6.6)
Don’t know	2 (2.2)
No answer	15 (16.5)
If No: Why may they not attend social functions? (N = 24)	
“BU smells”	5 (21.7)
“BU is a severe disease”	5 (21.7)
“BU patients can’t walk”	3 (13.0)
“BU patients suffer from pain”	3 (13.0)
Other	6 (25.0)
No answer	1 (4.3)
Do Children with BU continue Schooling?	
Yes	38 (31.1)
No	77 (63.1)
Don’t know	7 (5.7)
If Yes: When do they continue schooling? (N = 38)	
“If it is not so serious/ painful”	10 (26.3)
“If it is treated early”	7 (18.4)
“Education is important/ they need to study”	4 (10.5)
“Some children attend school”	4 (10.5)
“If they are not deformed/ disabled”	4 (10.5)
Don’t know	1 (2.6)
No answer	8 (21.1)

TABLE 25: KAP of (previously) BU affected People: (2) - Stigma/ Social Exclusion (continued)

Characteristic	BU Affected (%)
If No: Why don't they continue schooling? (N = 77)	
"They continue schooling only after the lesion is healed"	34 (44.2)
"BU affected children are deformed/ disabled/ may not be able to walk"	12 (15.6)
"BU affected children suffer from pain"	11 (14.3)
"BU is a severe/ dangerous disease"	7 (9.1)
"Other children will laugh at them/ tease them"	3 (3.7)
Other	8 (6.6)
Don't know	1 (1.3)
No answer	1 (1.3)
Would other Community Members accept a BU Patient as a Leader?	
Yes	14 (11.5)
No	54 (44.3)
Don't know	53 (43.4)
No answer	1 (0.8)
If Yes: Why are they accepted? (N = 14)	
"If the person is strong and able to do the work he/ she can be a leader"	5 (35.7)
Other	5 (35.7)
Don't know	1 (7.1)
No answer	3 (21.4)
If No: Why are they not accepted? (N = 54)	
"A sick person can't lead healthy people/ a leader may not be deformed/ disabled"	11 (20.8)
"A sick person can't become a leader"	13 (24.5)
"Tradition doesn't allow"	8 (15.1)
"Sick people can't work well"	5 (9.4)
"BU has to heal completely"	4 (7.5)
"BU patients won't be elected"	3 (5.7)
Other	3 (5.7)
Don't know	2 (3.8)
No answer	4 (7.5)
May BU Patients have to face Difficulties with Sexual Functioning? (N = 85)	
Yes	43 (50.6)
No	11 (12.9)
Don't know	29 (34.1)
No answer	2 (2.4)

Source: Author's own

3. Enabling Factors

TABLE 26: KAP of (previously) BU affected People: (3) - Accessibility

Characteristic	**BU Affected (%)**
Means of getting to the Health Facility [318]	
Walking	69 (56.6)
Public transport	78 (63.9)
Other	3 (2.5)
How long does it take to get there?	
0-5 min	16 (13.1)
6-10 min	12 (9.8)
11-15 min	8 (6.6)
16-20 min	22 (18.0)
21-25 min	1 (0.8)
26-30 min	33 (27.0)
31-35 min	4 (3.3)
> 35 min	23 (18.9)
Don’t know	3 (2.5)

Source: Author’s own

The average duration to the closest health facility for a BU patient was 28.8 minutes (min: 0 minutes; max: 120 minutes; SD = 23.3 min).

TABLE 27: KAP of (previously) BU affected People: (3) - Appeal of Treatment

Characteristic	**BU Affected (%)**
Reasons not to seek medical Treatment [319]	
Financial reasons	68 (55.7)
Fear of medical treatment	25 (20.5)
Don’t know the disease	21 (17.2)
“Herbalists know the right treatment”	10 (8.2)
Long distance to facility	8 (6.6)
Not serious enough	8 (6.6)
Other reasons	25 (20.5)
Don’t know	23 (18.9)
Perception about Antibiotic Treatment	
“The antibiotic treatment cures/ heals the disease/ ulcer”	22 (18.0)
“The antibiotic treatment includes (too) many injections”	20 (16.4)
“The antibiotic treatment is very good” [320]	17 (13.9)
Side effects [321]	11 (9.0)
Other	1 (0.8)
Don’t know	23 (18.9)
No answer	28 (23.0)

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[318] several options permitted

[319] several options permitted

[320] Mentioned benefits were: *„It dissolves/ softens the nodule“, „eases the pain“*

[321] Mentioned side effects were: eye problems, scars, pain, swollen body parts, tiredness, inability to walk

TABLE 28: KAP of (previously) BU affected people: (3) - Acceptability and Quality of available Health Services

Characteristic	BU Affected (%)
Are you satisfied with the local Health Facilities?	
Yes	87 (71.3)
No	15 (12.3)
Don't know	17 (13.9)
No answer	3 (2.5)
Reasons for Satisfaction (N = 87)	
"They take good care/ attend to the patients"	40 (46.0)
"They receive patients well/ do their best"	30 (34.1)
"I was healed"	6 (6.8)
"They are very patient"	4 (4.5)
"They provide treatment without money"	3 (3.4)
Other	3 (3.4)
No answer	2 (2.3)
Reasons for Dissatisfaction (N = 15)	
"Sometimes the nurses/ health workers are impatient/ do not take particular attention"	5 (29.4)
"The provided medicine does not serve the people"	3 (17.6)
"Health workers don't have time for patients"	2 (11.8)
Other	6 (40.0)
No answer	1 (5.9)

Source: Author's own

TABLE 29: KAP of (previously) BU affected People: (3) - Health Education and Communication

Characteristic	BU Affected (%)
Did you ever hear about BU?	
Yes	87 (71.3)
No	35 (28.7)
Knowledge of Treatment Options for BU [322]	
Drug treatment	82 (67.2)
Herbal treatment	69 (56.6)
Dressing	8 (6.6)
Surgery	5 (4.1)
Other	4 (3.2)
Don't know	17 (13.9)
No answer	1 (0.8)

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[322] several options permitted

TABLE 29: KAP of (previously) BU affected People: (3) – Health Education and Communication (continued)

Characteristic	BU Affected (%)
How did you get to know about BU? [323]	
Friends and neighbours	42 (34.4)
Personal infection	84 (68.9)
Family members	32 (26.2)
NGO	6 (4.9)
Other	10 (8.2)
Don’t know	1 (0.8)
No answer	2 (1.6)
Information about BU within the last 6 Months	
Yes	52 (43.0)
No	68 (56.2)
No answer	1 (0.8)
Type of Information [324]**, N = 52**	
NGO/ video show	21 (40.4)
Health worker/ nurses	20 (38.5)
Posters and pamphlets	9 (17.3)
Radio	4 (7.7)
Other	6 (11.5)
Do you think you have sufficient Information about BU?	
Yes	16 (13.1)
No	60 (49.2)
Partially	37 (30.3)
Don’t know	4 (3.3)
No answer	5 (4.1)
What would you like to know about BU?	
Preventive measures/ mode of transmission	33 (29.0)
No need for information	14 (11.5)
Treatment/ permanent cure	12 (9.8)
Early symptoms/ disease progression	7 (5.7)
More information (in the local language)	4 (3.3)
Don’t know	36 (29.5)
No answer	16 (13.1)

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[323] several options permitted

[324] several options permitted

TABLE 29: KAP of (previously) BU affected People: (3) – Health Education and Communication (continued)

Characteristic	BU Affected (%)
How is BU treated in a hospital/ in a clinic? [325]	
Antibiotics (*“Pills & Injections”)*	91 (74.6)
Wound care	76 (62.3)
Surgery	7 (5.7)
Other	7 (5.7)
Don’t know	18 (14.8)

Source: Author’s own

TABLE 30: KAP of (previously) BU affected People: (3) - Costs

Characteristic	BU Affected (%)
How is the Cost of medical Treatment taken care of?	
“Medical treatment for BU is provided for free”	74 (60.7)
Payment for treatment	17 (13.9)
“Treatment is provided for free – except for transportation/ petrol”	3 (2.5)
“Treatment is provided for free – except for some additional medicine”	3 (2.5)
Other	4 (3.2)
Don’t know	18 (14.8)
No answer	3 (2.5)
Do you have a valid Health Insurance at the Moment?	
Yes	42 (34.3)
No	79 (64.8)
Don’t know	1 (0.8)
If no, why don’t you have a valid Health Insurance? (N = 79) [326]	
No money	86 (50.9)
Too expensive	74 (43.8)
Never used it	49 (29.0)
Expired/ forgot to renew	18 (10.7)
Other	24 (30.4)
Don’t know	4 (2.4)
No answer	2 (1.2)

---

[325] several options permitted

[326] several options permitted

TABLE 30: KAP of (previously) BU affected People: (3) – Costs (continued)

Characteristic	BU Affected (%)
How much does it cost to get to the Health Facility (one way)?	
0 (walking distance)	49 (40.2)
0,1 – 0,5 GHC	46 (37.7)
0,6 – 1,0 GHC	22 (18.0)
> 1 GHC	2 (1.6)
No answer	3 (2.5)

Source: Author's own

N = 119 (min: 0 GHC; max. 3.0 GHC – average 0.38 GHC; SD = 0.44)

4. Choice of Health Care Resources

TABLE 31: KAP of (previously) BU affected People: (4) - Therapeutic Itineraries

Characteristic	BU Affected (%)
Treatment for Nodule [327], N = 94	
No treatment	7 (7.4)
Self-treatment	21 (22.3)
Herbalist	40 (42.6)
Hospital/ clinic	41 (43.6)
Church/ prayer camp	1 (1.1)
Treatment for Plaque [328], N = 7	
No treatment	1 (14.3)
Herbalist	5 (71.4)
Hospital/ clinic	3 (42.9)
Treatment for Oedema [329], N = 20	
Herbalist	10 (50.0)
Hospital/ clinic	14 (70.0)
Church/ prayer camp	1 (5.0)
Treatment for Ulcer [330], N = 100	
Self-treatment	4 (4.0)
Herbalist	33 (33.0)
Hospital/ clinic	82 (80.0)
Spiritualist	1 (1.0)
Church/ prayer camp	1 (1.0)

Source: Author's own

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[327] several options permitted
[328] several options permitted
[329] several options permitted
[330] several options possible

TABLE 32: KAP of (previously) BU affected People: (4) - Herbal/ Spiritual Treatment

Specification of the Treatment (Nodule)

- Application of a herb/ mixture of herbs on the nodule until the *“cotton wool”* came out/ it burst
- Name of herbs applied: *'Megbezzli', ‘Aflaki’, ‘Gboti', ‘Afideme’, 'Akidi/Kpanukeke’, ‘Agalagbe',* pawpaw leaves, *‘Ahame’, ‘Tweenteen’ root, 'Atsiakyrnakpa', 'Danumegbe', ‘Duasudua’*
- Herbalist cut the nodule through
- Application of a mixture of tortoise and snail shell

Specification of the Treatment (Plaque)

- Some herbs were mixed and applied on the plaque and tied with a bandage
- Herbal medicine from the market was ground with water and then applied on the plaque

Specification of the Treatment (Oedema)

- A mixture of herbs was smeared on the swell
- The oedema was put in a mixture of boiled herbs
- Names of herbs (from the market): *‘Dufani’*
- Pounded *‘Nyamedua’* root was mixed with water and applied on the oedema

Specification of the Treatment (Ulcer)

- A mixture of herbs was applied on the ulcer until it healed
- Some herbs were cooked and used to clean the lesion
- Herbal mixture was smeared on the sides of the wound
- Some leaves were boiled and spread over the ulcer

Source: Author’s own

TABLE 33: KAP of (previously) BU affected People: (4) - Hospital/ Clinic

Specification of the Treatment (Nodule)

- Unspecific antibiotic treatment
- Antibiotic treatment *“with pills and injections”*
- Some patients were in need of an operation

Specification of the Treatment (Plaque)

- Antibiotic treatment with *“pills and injections”*
- Skin grafting

Specification of the Treatment (Oedema)

- Antibiotic Treatment with “pills and injections”
- Dressing

Specification of the Treatment (Ulcer)

- Wound dressing and antibiotic treatment (injections and drugs)
- Surgery/operation/ amputation

Source: Author’s own

TABLE 34: KAP of (previously) BU affected People: (4) - Self-Treatment

Specification of the Treatment (Nodule)

- A towel was soaked in hot water and placed on the nodule
- A "boil medicine" was applied on the nodule
- Some capsules (e.g. penicillin) were applied on the nodule
- The father cut the nodule through
- Shea butter mixed with ash was applied on the nodule

Specification of the Treatment (Plaque)

- Application of *'Ekrobewu'*

Specification of the Treatment (Ulcer)

- Cleaning with hot water

Source: Author's own

TABLE 35: KAP of (previously) BU affected People: (4) - Church / Prayer Camp

Characteristic	Total Distribution (%)
Specification of the Treatment (Oedema)	
• A pastor was consulted for prayers and treatment	
Specification of the Treatment (Ulcer)	
• Consultation of a pastor who also provided herbal treatment	

Source: Author's own

Differences among (previously) BU affected People by Gender (specific objective 3)

2. Characteristics of BU and its Perception

TABLE 36: KAP (Differences by Gender): (2) - Aetiological Model

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Do you know how BU starts?				
Yes	52 (88.1)	55 (87.3)	107 (87.7)	
No	5 (8.5)	7 (11.1)	12 (9.8)	
Don't know	1 (1.7)	1 (1.6)	2 (1.6)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.732
Knowledge of specific Symptoms [331]				
Nodule/ painless *"boil"*	48 (81.4)	49 (77.8)	97 (79.5)	0.660
Oedema/ *"swelling"*	7 (11.9)	6 (9.5)	13 (10.7)	0.773
Ulcer	4 (6.8)	4 (6.3)	8 (6.6)	1.000
Plaque	1 (1.7)	2 (3.2)	3 (2.5)	1.000
Other	0 (0.0)	2 (3.2)	2 (1.6)	0.496
Don't know	3 (5.1)	1 (1.6)	4 (3.3)	0.353
Perceived Cause of the Disease [332]				
Drinking water from lakes and rivers	26 (44.1)	27 (42.9)	53 (43.4)	1.000
Swimming/ wading in rivers/ stagnant water	12 (20.3)	11 (17.9)	23 (18.9)	0.815
Rainwater	8 (13.6)	7 (11.1)	15 (12.3)	0.785
Lack of personal hygiene	7 (11.9)	6 (9.5)	13 (10.7)	0.773
"Gutter water"	5 (8.5)	4 (6.3)	9 (7.4)	0.758
Other	5 (8.5)	2 (3.2)	7 (5.7)	0.353
Don't know	21 (35.6)	31 (49.2)	52 (42.6)	0.146
No answer	1 (1.7)	0 (0.0)	1 (0.8)	0.484
Knowledge of Preventive Measures				
Yes	33 (55.9)	34 (54.0)	67 (54.9)	
No	2 (3.4)	6 (9.5)	8 (6.6)	
Don't know	23 (39.0)	23 (36.5)	46 (37.7)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.409

Source: Author's own

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[331] several options permitted
[332] several options permitted

TABLE 37: KAP (Differences by Gender): (2) - Stigma/ Social Exclusion

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
How do Community Members treat BU Patients with Ulcers?				
With full sympathy	34 (57.6)	41 (65.1)	75 (61.5)	
With partly sympathy	19 (32.2)	10 (15.9)	29 (23.8)	
With unsure sympathy	2 (3.4)	6 (9.5)	8 (6.6)	
With no sympathy	2 (3.4)	4 (6.3)	6 (4.9)	
Don’t know	2 (3.4)	2 (3.2)	4 (3.3)	
				0.200
Are BU Patients welcome at social Functions?				
Yes	47 (79.7)	44 (69.8)	91 (74.6)	
No	10 (16.9)	14 (22.2)	24 (19.7)	
Don’t know	2 (3.4)	5 (7.9)	7 (5.7)	
				0.383
Do Children with BU continue Schooling?				
Yes	17 (28.8)	21 (33.3)	38 (31.1)	
No	42 (71.2)	35 (55.6)	77 (63.1)	
Don’t know	0 (0.0)	7 (11.1)	7 (5.7)	
No answer	0 (0.0)	0 (0.0)	0 (0.0)	
				0.019*
Would other Community Members accept a BU Patient as a Leader?				
Yes	7 (11.9)	7 (11.1)	14 (11.5)	
No	26 (44.1)	28 (44.4)	54 (44.3)	
Don’t know	26 (44.1)	27 (42.9)	53 (43.4)	
No answer	0 (0.0)	1 (1.6)	1 (0.8)	
				0.810
May BU Patients have to face Difficulties with Sexual Functioning? (N = 176)				
Yes	18 (46.2)	25 (54.3)	43 (50.6)	
No	2 (5.1)	9 (19.6)	11 (12.9)	
Don’t know	17 (46.6)	12 (26.1)	29 (34.1)	
No answer	2 (5.1)	0 (0.0)	2 (2.4)	
				0.047*

Source: Author’s own

3. Enabling Factors

TABLE 38: KAP (Differences by Gender): (3) - Appeal of Treatment

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Reasons not to seek medical Treatment [333]				
Financial reasons	31 (52.5)	37 (58.7)	68 (55.7)	0.585
Fear of medical treatment	12 (20.3)	13 (20.6)	25 (20.5)	1.000
Don't know the disease	10 (16.9)	11 (17.5)	21 (17.2)	1.000
Long distance to facility	4 (6.8)	4 (6.3)	8 (6.6)	1.000
Not serious enough	5 (8.5)	3 (4.8)	8 (6.6)	0.481
"Herbalists know the right treatment"	5 (8.5)	5 (7.9)	10 (8.2)	1.000
Not a *"hospital disease"*	3 (5.1)	1 (1.6)	4 (3.3)	0.353
Advice of family members	1 (1.7)	3 (4.8)	4 (3.3)	0.620
Other	11 (18.7)	7 (11.1)	18 (14.0)	0.413
Don't know	13 (22.0)	10 (15.9)	23 (18.9)	0.488
No answer	0 (0.0)	0 (0.0)	0 (0.0)	1.000
Perception about Antibiotic Treatment				
"The antibiotic treatment cures/ heals the disease/ ulcer"	13 (22.0)	9 (14.3)	22 (18.0)	
"The antibiotic treatment includes (too) many iniections"	10 (16.9)	10 (15.9)	20 (16.4)	
"The antibiotic treatment is very good" [334]	8 (13.6)	9 (14.3)	17 (13.9)	
Side effects [335]	8 (13.6)	3 (4.8)	11 (9.0)	
Other	0 (0.0)	1 (1.6)	1 (0.8)	
Don't know	11 (18.6)	12 (19.0)	23 (18.9)	
No answer	9 (15.3)	19 (30.2)	28 (23.0)	
				0.273

Source: Author's own

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[333] several options permitted

[334] Mentioned benefits were: *„It dissolves/ softens the nodule", „eases the pain"*

[335] Mentioned side effects were: eye problems, scars, pain, swollen body parts, tiredness, inability to walk

TABLE 39: KAP (Differences by Gender): (3) - Acceptability and Quality of available Health Services

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Are you satisfied with the local Health Facilities?				
Yes	37 (62.7)	50 (79.4)	87 (71.3)	
No	7 (11.9)	8 (12.7)	15 (12.3)	
Don't know	13 (22.0)	4 (6.3)	17 (13.9)	
No answer	2 (3.4)	1 (1.6)	3 (2.5)	
				0.072

SOURCE: AUTHOR'S OWN

TABLE 40: KAP (Differences by Gender): (3) - Health Education and Communication

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Did you ever hear about BU?				
Yes	42 (71.2)	45 (71.4)	87 (71.3)	
No	17 (28.8)	18(28.6)	35 (28.7)	
				1.000
Knowledge of Treatment Options for BU [336]				
Drug treatment	43 (72.9)	39 (61.9)	82 (67.2)	0.248
Herbal treatment	35 (59.3)	34 (54.0)	69 (56.6)	0.587
Dressing	2 (3.4)	6 (9.5)	8 (6.6)	0.275
Surgery	2 (3.4)	3 (4.8)	5 (4.1)	1.000
Other	3 (5.1)	2 (3.2)	4 (3.2)	0.610
Don't know	6 (10.2)	11 (17.5)	17 (13.9)	0.301
No answer	1 (1.7)	0 (0.0)	1 (0.8)	0.484
How did you get to know about BU? [337]				
Friends and neighbours	21 (35.6)	21 (33.3)	42 (34.4)	0.850
Personal infection	40 (67.8)	44 (69.8)	84 (68.9)	0.847
Family members	15 (25.4)	17 (27.0)	32 (26.2)	1.000
NGO	3 (5.1)	3 (4.8)	6 (4.9)	1.000
Other	6 (10.2)	4 (6.4)	10 (8.3)	1.000
Don't know	0 (0.0)	1 (1.6)	1 (0.8)	1.000
No answer	1 (1.7)	1 (1.6)	2 (1.6)	1.000
Information about BU within the last 6 Months				
Yes	24 (41.4)	28 (44.4)	52 (43.0)	
No	33 (56.9)	35 (55.6)	68 (56.2)	
Don't know	0 (0.0)	0 (0.0)	0 (0.0)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.559

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[336] several options permitted

[337] several options permitted

TABLE 40: KAP (Differences by Gender): (3) - Health Education and Communication (continued)

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Type of Information [338] (N = 52)				
Posters and pamphlets	3 (5.1)	6 (9.5)	9 (17.3)	0.493
NGO/ video show	11 (18.6)	10 (15.9)	21 (40.4)	0.811
Radio	1 (1.7)	3 (4.8)	4 (7.7)	0.620
Health worker/ nurses	10 (16.9)	10 (15.9)	20 (38.5)	1.000
Other	1 (1.7)	5 (7.9)	6 (11.5)	0.209
Do you think you have sufficient Information about BU?				
Yes	9 (15.3)	7 (11.1)	16 (13.1)	
No	25 (42.4)	35 (55.6)	60 (49.2)	
Partially	19 (32.2)	18 (28.6)	37 (30.3)	
Don’t know	3 (5.1)	1 (1.6)	4 (3.3)	
No answer	3 (5.1)	2 (3.2)	5 (4.1)	
				0.555
What would you like to know about BU?				
Preventive measures/ mode of transmission	19 (32.2)	14 (22.2)	33 (29.0)	
No need for information	6 (10.2)	8 (12.7)	14 (11.5)	
Treatment/ permanent cure	3 (5.1)	9 (14.3)	12 (9.8)	
Early symptoms/ disease progression	4 (6.8)	3 (4.8)	7 (5.7)	
More information (in the local language)	2 (3.4)	2 (3.2)	4 (3.3)	
Don’t know	18 (30.5)	18 (28.6)	36 (29.5)	
No answer	7 (11.9)	9 (14.3)	16 (13.1)	
				0.635
How is BU treated in a hospital/ in a clinic? [339]				
Antibiotics (*“Pills & Injections”*)	49 (83.1)	42 (66.7)	91 (74.6)	0.060
Wound care	37 (62.7)	39 (61.9)	76 (62.3)	1.000
Surgery	4 (6.8)	3 (4.8)	7 (5.7)	0.711
Herbs	3 (5.1)	1 (1.6)	4 (3.3)	0.353
Other	0 (0.0)	3 (4.8)	3 (2.5)	0.245
Don’t know	7 (11.9)	11 (17.5)	18 (14.8)	0.450

Source: Author’s own

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[338] several options permitted

[339] several options permitted

Table 41: KAP (Differences by Gender): (3) - Costs

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
How is the Cost of medical Treatment taken care of?				
"Medical treatment for BU is provided for free"	35 (59.3)	39 (61.9)	74 (60.7)	
Payment for treatment	12 (20.3)	5 (7.9)	17 (13.9)	
"Treatment is provided for free – except for transportation/ petrol"	1 (1.7)	2 (3.2)	3 (2.5)	
"Treatment is provided for free – except for some additional medicine"	1 (1.7)	2 (3.2)	3 (2.5)	
Other	2 (3.4)	2 (3.2)	4 (3.2)	
Don't know	7 (11.9)	11 (17.5)	18 (14.8)	
No answer	1 (1.7)	2 (3.2)	3 (2.5)	
				0.354
Do you have a valid Health Insurance at the Moment?				
Yes	13 (22.0)	29 (46.0)	42 (34.3)	
No	46 (78.0)	33 (52.4)	79 (64.8)	
Don't know	0 (0.0)	1 (1.6)	1 (0.8)	
				0.010*

Source: Author's own

4. Choice of Health Care Resources

TABLE 42: KAP (Differences by Gender): (4) - Therapeutic Itineraries

Characteristic	Male BU (%)	Female BU (%)	Total distribution (%)	Significance p *
Treatment for Nodule [340]				
No treatment	2 (4.9)	5 (9.4)	7 (7.4)	1.000
Self-treatment	10 (24.4)	11 (20.8)	21 (22.3)	0.804
Herbalist	20 (48.4)	20 (37.7)	40 (42.6)	0.301
Hospital/ clinic	19 (43.6)	22 (41.5)	41 (43.6)	0.679
Church/ prayer camp	1 (2.4)	0 (0.0)	1 (1.1)	0.436
Treatment for Plaque [341]				
No treatment	0 (0.0)	1 (25.0)	1 (14.3)	1.000
Herbalist	2 (66.7)	3 (75.0)	5 (71.4)	1.000
Hospital/ clinic	1 (33.3)	2 (50.0)	3 (42.9)	1.000
Treatment for Oedema [342]				
Herbalist	7 (63.6)	3 (33.3)	10 (50.0)	0.370
Hospital/ clinic	7 (63.6)	7 (77.8)	14 (70.0)	0.642
Church/ prayer camp	1 (9.1)	0 (0.0)	1 (5.0)	1.000
Treatment for Ulcer				
Self-treatment	2 (4.0)	2 (3.8)	4 (4.0)	1.000
Herbalist	17 (35.4)	16 (30.8)	33 (33.0)	0.674
Hospital/ clinic	41 (85.4)	39 (75.0)	82 (80.0)	0.220
Spiritualist	0 (0.0)	1 (1.9)	1 (1.0)	1.000
Church/ prayer camp	1 (2.1)	0 (0.0)	1 (1.0)	0.480

Source: Author’s own

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[340] several options permitted
[341] several options permitted
[342] several options permitted
[343] several options possible

Differences among (previously) BU affected People by Generation (specific objective 4)

2. Characteristics of BU and its Perception

TABLE 43: KAP (Differences by Generation): (2) - Aetiological Model

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Do you know how BU starts?				
Yes	39 (83.0)	68 (90.7)	107 (87.7)	
No	5 (10.6)	7 (9.3)	12 (9.8)	
Don’t know	2 (4.3)	0 (0.0)	2 (1.6)	
No answer	1 (2.1)	0 (0.0)	1 (0.8)	
				0.169
Knowledge of specific Symptoms [344]				
Nodule/ painless *“boil”*	38 (80.9)	59 (78.7)	97 (79.5)	0.771
Oedema/ *“swelling”*	2 (4.3)	11 (14.7)	13 (10.7)	0.079
Ulcer	5 (10.6)	3 (4.0)	8 (6.6)	0.258
Plaque	0 (0.0)	3 (4.0)	3 (2.5)	0.284
Other	0 (0.0)	2 (2.7)	2 (1.6)	0.522
Don’t know	3 (6.4)	1 (1.3)	4 (3.3)	0.297
Perceived Cause of the Disease [345]				
Drinking water from lakes and rivers	26 (55.3)	27 (36.0)	53 (43.4)	0.036
Swimming/ wading in rivers/ stagnant water	15 (31.9)	8 (10.7)	23 (18.9)	0.003
Rainwater	10 (21.3)	5 (6.7)	15 (12.3)	0.023
Lack of personal hygiene	10 (21.3)	3 (4.0)	13 (10.7)	0.005
“Gutter water”	3 (6.4)	6 (8.0)	9 (7.4)	1.000
Other	2 (4.2)	5 (6.6)	7 (5.7)	1.000
Don’t know	12 (25.5)	40 (53.3)	52 (42.6)	0.003
No answer	1 (2.1)	0 (0.0)	1 (0.8)	0.385
Knowledge of Preventive Measures				
Yes	35 (75.4)	32 (42.7)	67 (54.9)	
No	1 (2.1)	7 (9.3)	8 (6.6)	
Don’t know	10 (21.3)	36 (48.0)	46 (37.7)	
No answer	1 (2.1)	0 (0.0)	1 (0.8)	
				0.002

Source: Author’s own

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[344] several options permitted

[345] several options permitted

TABLE 44: KAP (Differences by Generation): (2) - Stigma/ Social Exclusion

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
How do Community Members treat BU Patients?				
With full sympathy	30 (63.8)	45 (60.0)	75 (61.5)	
With partly sympathy	11 (23.4)	18 (24.0)	29 (23.8)	
With unsure sympathy	2 (4.3)	6 (8.0)	8 (6.6)	
With no sympathy	1 (2.1)	5 (6.7)	6 (4.9)	
Don't know	3 (6.4)	1 (1.3)	4 (3.3)	
				0.386
Are BU Patients welcome at social Functions?				
Yes	32 (68.1)	59 (78.7)	91 (74.6)	
No	11 (23.4)	13 (17.3)	24 (19.7)	
Don't know	4 (8.5)	3 (4.0)	7 (5.7)	
				0.368
Do Children with BU continue Schooling?				
Yes	9 (19.1)	29 (38.7)	38 (31.1)	
No	38 (80.9)	39 (52.0)	77 (63.1)	
Don't know	0 (0.0)	7 (9.3)	7 (5.7)	
				0.003
Would other Community Members accept a BU Patient as a Leader?				
Yes	6 (12.8)	8 (10.7)	14 (11.5)	
No	22 (46.8)	32 (42.7)	54 (44.3)	
Don't know	19 (40.4)	34 (45.3)	53 (43.4)	
No answer	0 (0.0)	1 (1.3)	1 (0.8)	
				0.799

Source: Author's own

TABLE 45: KAP (Differences by Generation): (2) - Appeal of Treatment

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Reasons not to seek medical Treatment [346]				
Financial reasons	24 (51.1)	44 (58.7)	68 (55.7)	0.411
Fear of medical treatment	11 (23.4)	14 (18.7)	25 (20.5)	0.528
Don't know the disease	13 (27.7)	8 (10.7)	21 (17.2)	0.016
Long distance to facility	4 (8.5)	4 (5.3)	8 (6.6)	0.483
Not serious enough	3 (6.4)	5 (6.7)	8 (6.6)	1.000
"Herbalists know the right treatment"	2 (4.3)	8 (10.7)	10 (8.2)	0.314
Not a *"hospital disease"*	1 (2.1)	3 (4.0)	4 (3.3)	1.000
Advice of family members	1 (2.1)	3 (4.0)	4 (3.3)	1.000
Other	4 (8.5)	14 (18.7)	17 (14.0)	0.402
Don't know	10 (21.3)	13 (17.3)	23 (18.9)	0.588
Perception about Antibiotic Treatment				
"The antibiotic treatment cures/ heals the disease/ ulcer"	10 (21.3)	12 (16.0)	22 (18.0)	
"The antibiotic treatment includes (too) many iniections"	9 (19.1)	11 (14.7)	20 (16.4)	
"The antibiotic treatment is very good" [347]	6 (12.8)	11 (14.7)	17 (13.9)	
Side effects [348]	3 (6.4)	8 (10.7)	11 (9.0)	
Other	1 (2.1)	0 (0.0)	1 (0.8)	
Don't know	7 (14.9)	16 (21.3)	23 (18.9)	
No answer	11 (23.4)	17 (22.7)	28 (23.0)	
				0.717

Source: Author's own

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[346] several options permitted

[347] Mentioned benefits were: *„It dissolves/ softens the nodule", „eases the pain"*

[348] Mentioned side effects were: eye problems, scars, pain, swollen body parts, tiredness, inability to walk

TABLE 46: KAP (Differences by Generation): (2) - Acceptability and Quality of the available Health Services

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Are you satisfied with the local Health				
Yes	31 (66.0)	56 (74.7)	87 (71.3)	
No	5 (10.6)	10 (13.3)	15 (12.3)	
Don't know	9 (19.1)	8 (10.7)	17 (13.9)	
No answer	2 (4.3)	1 (1.3)	3 (2.5)	
				0.396

Source: Author's own

TABLE 47: KAP (Differences by Generation): (2) - Health Education and Communication

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Did you ever hear about BU?				
Yes	33 (70.2)	54 (72.0)	87 (71.3)	
No	14 (29.8)	21 (28.0)	35 (28.7)	
				0.832
Knowledge of Treatment Options for BU [349]				
Drug treatment	34 (72.3)	48 (64.0)	82 (67.2)	0.340
Herbal treatment	26 (55.3)	43 (57.3)	69 (56.6)	0.827
Dressing	3 (6.4)	5 (6.7)	8 (6.6)	1.000
Surgery	3 (6.4)	2 (2.7)	5 (4.1)	0.372
Other	1 (2.1)	4 (5.4)	4 (3.2)	0.522
Don't know	7 (14.7)	10 (13.3)	17 (13.9)	0.809
No answer	1 (2.1)	0 (0.0)	1 (0.8)	0.385
How did you get to know about BU? [350]				
Friends and neighbours	21 (44.7)	21 (28.0)	42 (34.4)	0.059
Personal infection	25 (53.2)	59 (78.7)	84 (68.9)	0.003
Family members	20 (42.6)	12 (16.0)	32 (26.2)	0.001
NGO	4 (8.5)	2 (2.7)	6 (4.9)	0.203
Other	4 (8.5)	6 (8.0)	10 (8.3)	1.000
Don't know	1 (2.1)	0 (0.0)	1 (0.8)	0.385
No answer	2 (4.3)	0 (0.0)	2 (1.6)	0.146
Information about BU within the last 6 Months				
Yes	26 (55.3)	26 (35.1)	52 (43.0)	
No	20 (42.6)	48 (64.9)	68 (56.2)	
No answer	1 (2.1)	0 (0.0)	1 (0.8)	
				0.033

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[349] several options permitted
[350] several options permitted

TABLE 47: KAP (Differences by Generation): (2) - Health Education and Communication (continued)

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Type of Information [351] (N = 52)				
Posters and pamphlets	5 (19.2)	4 (15.4)	9 (17.3)	1.000
NGO/ video show	13 (50.0)	8 (30.8)	21 (40.4)	0.158
Radio	2 (7.7)	2 (7.7)	4 (7.7)	1.000
Health worker/ nurses	10 (38.5)	10 (38.5)	20 (38.5)	1.000
Other	2 (3.8)	4 (7.7)	6 (11.5)	1.000
Do you think you have sufficient Information about BU?				
Yes	5 (10.6)	11 (14.7)	16 (13.1)	
No	18 (38.3)	42 (56.0)	60 (49.2)	
Partially	19 (40.4)	18 (24.0)	37 (30.3)	
Don’t know	4 (8.5)	0 (0.0)	4 (3.3)	
No answer	1 (2.1)	4 (5.3)	5 (4.1)	
				0.018
What would you like to know about BU?				
Preventive measures/ mode of transmission	9 (19.1)	24 (32.0)	33 (29.0)	
No need for information	6 (12.8)	8 (10.7)	14 (11.5)	
Treatment/ permanent cure	4 (8.5)	8 (10.7)	12 (9.8)	
Early symptoms/ disease progression	3 (6.4)	4 (5.39	7 (5.7)	
More information (in the local language)	1 (2.1)	3 (4.0)	4 (3.3)	
Don’t know	17 (32.2)	19 (25.3)	36 (29.5)	
No answer	7 (14.9)	9 (12.0)	16 (13.1)	
				0.716
How is BU treated in a hospital/ in a clinic? [352]				
Antibiotics (*“Pills & Injections”*)	36 (76.6)	55 (73.3)	91 (74.6)	0.687
Wound care	31 (66.0)	45 (60.0)	76 (62.3)	0.509
Surgery	1 (2.1)	6 (8.0)	7 (5.7)	0.247
Herbs	1 (2.1)	3 (4.0)	4 (3.3)	1.000
Other	0 (0.0)	3 (4.0)	3 (2.5)	0.284
Don’t know	8 (17.0)	10 (13.3)	18 (14.8)	0.576

Source: Author’s own

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[351] several options permitted

[352] several options permitted

TABLE 48: KAP (Differences by Generation): (2) - Costs

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
How is the Cost of medical Treatment taken care of?				
“Medical treatment for BU is provided for free”	30 (63.8)	44 (58.7)	74 (60.7)	
Payment for treatment	5 (10.6)	12 (16.0)	17 (13.9)	
“Treatment is provided for free – except for transportation/ petrol”	0 (0.0)	3 (4.0)	3 (2.5)	
“Treatment is provided for free – except for some additional medicine”	2 (4.3)	1 (1.3)	3 (2.5)	
Other”	1 (2.1)	3 (4.0)	4 (3.2)	
Don’t know	8 (17.0)	10 (13.3)	18 (14.8)	
No answer	1 (2.1)	2 (2.7)	3 (2.5)	
				0.496
Do you have a valid Health Insurance at the Moment?				
Yes	17 (36.2)	25 (33.3)	42 (34.3)	
No	29 (61.7)	50 (66.7)	79 (64.8)	
Don’t know	1 (2.1)	0 (0.0)	1 (0.8)	
				0.412

Source: Author’s own

4. Choice of Health Care Resources

TABLE 49: KAP (Differences by Generation): (4) - Therapeutic Itineraries

Characteristic	Up to 15 years (%)	Above 15 years (%)	Total distribution (%)	Significance p *
Treatment for Nodule [353]				
No treatment	3 (6.4)	4 (5.3)	7 (7.4)	1.000
Self-treatment	6 (12.8)	15 (20.0)	21 (22.3)	0.303
Herbalist	20 (42.6)	20 (26.7)	40 (42.6)	0.069
Hospital/ clinic	18 (38.3)	23 (30.3)	41 (43.6)	0.385
Church/ prayer camp	1 (2.1)	0 (0.0)	1 (1.1)	0.385
Treatment for Plaque [354]				
No treatment	0 (0.0)	1 (1.3)	1 (14.3)	1.000
Herbalist	2 (4.3)	4 (5.3)	5 (71.4)	1.000
Hospital/ clinic	3 (6.4)	3 (4.0)	3 (42.9)	0.675
Treatment for Oedema [355]				
Herbalist	2 (4.3)	10 (13.3)	10 (50.0)	0.127
Hospital/ clinic	6 (12.8)	12 (16.0)	14 (70.0)	0.624
Church/ prayer camp	0 (0.0)	1 (1.3)	1 (5.0)	1.000
Treatment for Ulcer				
Self-treatment	1 (2.1)	3 (4.0)	4 (4.0)	1.000
Herbalist	11 (23.4)	22 (29.3)	33 (33.0)	0.473
Hospital/ clinic	30 (63.8)	52 (69.3)	82 (80.0)	0.529
Spiritualist	0 (0.0)	1 (1.3)	1 (1.0)	1.000
Church/ prayer camp	0 (0.0)	1 (1.3)	1 (1.0)	1.000

Source: Author’s own

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[353] several options permitted
[354] several options permitted
[355] several options permitted
[356] several options possible

Early Care-Seekers vs. Late Care-Seekers (specific objective 5)

1. Predisposing Factors

TABLE 50: KAP (Early vs. Late Care-Seekers): (1) - Age and Sex Distribution

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Age by time of infection (in years)				
0-10	18 (30.5)	16 (25.4)	34 (27.9)	
11-20	18 (30.5)	14 (22.2)	32 (26.2)	
21-30	2 (3.4)	10 (15.9)	12 (9.8)	
31-40	6 (10.2)	3 (4.8)	9 (7.4)	
41-50	7 (11.9)	6 (9.5)	13 (10.7)	
51-60	2 (3.4)	7 (11.1)	9 (7.4)	
61-70	4 (6.8)	4 (6.3)	8 (6.6)	
71-80	0 (0.0)	2 (3.2)	2 (1.6)	
81 and above	2 (3.4)	1 (1.6)	3 (2.5)	
				0.303
> 15	25 (42.4)	22 (34.9)	47 (38.5)	0.458
Sex				
Male	27 (45.8)	32 (50.8)	59 (48.4)	
Female	32 (54.2)	31 (49.2)	63 (51.6)	
				0.578

Source: Author’s own

TABLE 51: KAP (Early vs. Late Care-Seekers): (1) - Household Characteristics

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Number of People in Household				
1-5	17 (28.8)	21 (33.3)	38 (31.1)	
6-10	30 (50.8)	31 (49.2)	61 (50.0)	
11-15	5 (8.5)	7 (11.1)	12 (9.8)	
16-20	4 (6.8)	0 (0.0)	4 (3.3)	
21-25	1 (1.7)	0 (0.0)	1 (0.8)	
“Many”	2 (3.4)	4 (6.3)	6 (4.9)	
Average	8.3	6.9		
				0.277
Marital Status of Study Participant * (≥ 18 years)				
Single	12 (42.9)	15 (38.5)	27 (40.3)	0.803
Married	16 (57.1)	24 (61.5)	40 (59.7)	0.803
Divorced	2 (7.1)	1 (2.6)	3 (4.5)	0.567
Widowed	3 (10.7)	6 (15.4)	9 (13.4)	0.724

***** several options permitted

TABLE 51: KAP (Early vs. Late Care-Seekers): (1) - Household Characteristics (continued)

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Number of Children in Household				
No children	0 (0.0)	9 (14.3)	9 (7.4)	
1-2	14 (23.7)	15 (23.8)	29 (23.8)	
3-4	23 (39.0)	17 (27.0)	40 (32.8)	
5-6	14 (23.7)	14 (22.7)	28 (23.0)	
7-8	5 (8.5)	7 (11.1)	12 (9.8)	
> 8	3 (5.1)	1 (1.6)	4 (3.3)	
				0.072

Source: Author's own

TABLE 52: KAP (Early vs. Late Care-Seeker): (1) - Ethnic Group, Religion

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Mother Tongue				
Twi (Akan)	26 (44.1)	28 (44.4)	54 (44.3)	
Ewe	40 (40.7)	28 (44.4)	52 (42.6)	
Krobo	5 (8.5)	2 (3.2)	7 (5.7)	
Ga	2 (3.4)	1 (1.6)	3 (2.5)	
Other	2 (3.4)	4 (6.3)	6 (4.9)	
				0.638
Religion				
Christian	51 (86.4)	55 (87.3)	106 (86.9)	
Muslim	2 (3.4)	2 (3.2)	4 (3.3)	
None	6 (10.2)	5 (7.9)	11 (9.0)	
Other	0 (0.0)	1 (1.6)	1 (0.8)	
				0.774

Source: Author's own

TABLE 53: KAP (Early vs. Late Care-Seekers): (1) - Formal Education

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Highest education level (participants ≥ 6 years), **N = 116**				
No formal education	17 (30.9)	22 (36.1)	39 (33.6)	
Primary school	21 (38.2)	16 (26.2)	37 (31.9)	
Junior Secondary School (JSS)	13 (23.6)	19 (31.1)	32 (27.6)	
Senior Secondary School (SSS)	3 (5.5)	4 (6.6)	7 (6.0)	
Post-Secondary	1 (1.8)	0 (0.0)	1 (0.9)	
				0.595

Source: Author's own

TABLE 54: KAP (Early vs. Late Care-Seekers): (1) - Occupation

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Occupation (participants > 15 years), **N = 150**				
Student/ pupil	7 (21.2)	3 (7.7)	13 (17.3)	
Farming	17 (51.5)	23 (59.0)	40 (53.3)	
Unemployed	3 (9.1)	5 (12.8)	8 (10.7)	
Trade and	2 (6.1)	4 (10.3)	6 (8.0)	
Other	4 (12.1)	4 (10.3)	8 (10.7)	
				0.527

Source: Author's own

TABLE 55: KAP (Early vs. Late Care-Seekers): (1) - Assets

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Money for Food, Water and Transportation				
1-5 GHC	29 (49.2)	28 (44.4)	57 (46.7)	
6-10 GHC	17 (28.2)	28 (44.4)	45 (36.9)	
11-15 GHC	4 (6.8)	2 (3.2)	6 (4.9)	
> 15 GHC	3 (5.1)	0 (0.0))	3 (2.4)	
Don't know	5 (8.5)	5 (7.9)	10 (8.2)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
Average	7.6	6.8		
				0.403
Main Source of Income of Household *				
Farming	49 (83.1)	54 (85.7)	103 (84.4)	0.804
Trade and	18 (30.5)	20 (31.7)	38 (31.1)	1.000
Other	6 (10.2)	8 (12.7)	14 (11.5)	0.779
Frequent Means of Transport *				
Trotro	50 (84.7)	55 (87.3)	105 (86.1)	0.796
Taxi	26 (44.1)	33 (52.4)	59 (48.4)	0.372
Walking	22 (37.3)	38 (60.3)	60 (49.2)	**0.012**

* several options permitted

Source: Author's own

TABLE 56: KAP (Early vs. Late Care-Seekers): (1) - Social Interaction

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Treatment Recommendation				
Nodule [357], N = 94	24 (50.0)	14 (30.4)	38 (40.4)	
Plaque [358], N = 7	3 (75.0)	2 (66.7)	7 (100.0)	1.000
Oedema [359], N = 20	8 (53.3)	2 (40.0)	14 (70.0)	1.000
Ulcer [360], N = 100	16 (42.1)	44 (71.0)	61 (61.0)	**0.006**
Decision about Treatment in Case of a Disease *				
Father	26 (44.1)	30 (47.6)	56 (45.9)	0.719
Mother	21 (35.6)	29 (46.0)	50 (41.0)	0.272
Own decision	17 (28.8)	31 (49.2)	48 (39.3)	**0.026**
Both parents	21 (35.6)	26 (41.3)	47 (38.5)	0.579
Experienced people	16 (27.1)	22 (34.9)	38 (31.1)	0.435
Medical doctor	2 (3.4)	2 (3.2)	4 (3.3)	0.435
Other People	3 (5.1)	1 (1.6)	4 (3.3)	1.000
Nurse	2 (3.4)	0 (0.0)	2 (1.6)	0.353
Whole family	1 (1.7)	0 (0.0)	1 (0.8)	0.484

Source: Author's own

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[357] Recommendation by: friends, colleagues, family members, herbalists, CSBVs, Health workers/ doctors/ nurses, neighbours and a "white woman"

[358] Recommendation by: herbalists, CSBVs, family members, friends

[359] Recommendation by: CSBV, friends, herbalists, family members

[360] Recommendation by: CSBVs, colleagues, friends, health workers/ nurses/ doctors, neighbours, a "white lady", assembly men, herbalists, teachers, radio, family members

2. Characteristics of BU and its Perception

TABLE 57: KAP (*'Early' vs. 'Late Care-Seeker'*): (2) - Characteristics of encountered BU Lesions

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
State of Lesion N = 122				
New/ active lesion	19 (32.2)	13 (20.6)	32 (26.2)	
Chronic lesion	7 (11.9)	6 (9.5)	13 (10.7)	
Old healed lesion/	33 (55.9)	44 (69.8)	77 (63.1)	
				0.266
Year of Healing, N = 77				
2010	7 (21.2)	6 (13.6)	13 (10.7)	
2009	10 (30.3)	14 (31.8)	24 (19.7)	
2008	9 (27.3)	12 (27.3)	21 (17.2)	
2007	7 (21.2)	12 (27.3)	19 (15.6)	
				0.817
Multiple Lesions, N = 122				
Yes	12 (20.3)	26 (25.4)	28 (23.0)	
No	47 (79.7)	47 (74.6)	94 (77.0)	
				0.527
Location of the Lesion *, N = 122				
Visible lesion site	57 (96.6)	55 (87.8)	112 (91.8)	0.097

Source: Author's own

* several options permitted

TABLE 58: KAP (*'Early' vs. 'Late Care-Seeker'*): (2) - Aetiological Model

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Do you know how BU starts?				
Yes	52 (88.1)	55 (87.3)	107 (87.7)	
No	6 (10.2)	6 (9.5)	12 (9.8)	
Don't know	0 (0.0)	2 (3.2)	2 (1.6)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.398
Knowledge of specific Symptoms*				
Nodule/ painless	47 (79.7)	50 (79.4)	97 (79.5)	1.000
Oedema/ *"swelling"*	9 (15.3)	4 (6.3)	13 (10.7)	0.145
Ulcer	4 (6.8)	4 (6.3)	3 (2.5)	1.000
Plaque	1 (1.7)	2 (3.2)	8 (6.6)	1.000
Other	0 (0.0)	2 (3.2)	2 (1.6)	0.496
Don't know	0 (0.0)	4 (6.3)	4 (3.3)	0.120
Perceived Cause of the Disease *				
Drinking water from lakes and rivers	28 (47.5)	25 (39.7)	53 (43.4)	0.465
Swimming/ wading in rivers/ stagnant water	15 (25.4)	8 (12.7)	23 (18.9)	0.104
Rainwater	8 (13.6)	7 (11.1)	15 (12.3)	0.785
Lack of personal	6 (10.2)	7 (11.1)	13 (10.7)	1.000
"Gutter water"	6 (10.2)	3 (4.8)	9 (7.4)	0.312
Other	4 (6.8)	3 (4.8)	7 (5.7)	0.484
Don't know	22 (37.3)	30 (47.6)	52 (42.6)	0.276
No answer	1 (1.7)	0 (0.0)	1 (0.8)	0.484
Knowledge of Preventive Measures				
Yes	40 (67.8)	27 (42.9)	67 (54.9)	
No	2 (3.4)	6 (9.5)	8 (6.6)	
Don't know	16 (27.1)	30 (47.6)	46 (37.7)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.022

Source: Author's own

***** several options permitted

TABLE 59: KAP (*‘Early’ vs. ‘Late Care-Seeker’*): (2) - Stigma/ Social Exclusion

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
How do Community Members treat BU Patients?				
With full sympathy	38 (64.4)	37 (58.7)	75 (61.5)	
With partly sympathy	10 (16.9)	19 (30.2)	29 (23.8)	
With unsure sympathy	3 (5.1)	5 (7.9)	8 (6.6)	
With no sympathy	6 (10.2)	0 (0.0)	6 (4.9)	
Don’t know	2 (3.4)	2 (3.2)	4 (3.3)	
				0.057
Are BU Patients welcome at social Functions?				
Yes	37 (62.7)	54 (85.7)	91 (74.6)	
No	16 (27.1)	8 (12.7)	24 (19.7)	
Don’t know	6 (10.2)	1 (1.6)	7 (5.7)	
				0.010
Do Children with BU continue Schooling?				
Yes	24 (40.7)	14 (22.2)	38 (31.1)	
No	33 (55.9)	44 (69.8)	77 (63.1)	
Don’t know	2 (3.4)	5 (7.9)	7 (5.7)	
				0.068
Would other Community Members accept a BU Patient as a Leader?				
Yes	9 (15.3)	5 (7.9)	14 (11.5)	
No	25 (42.4)	29 (46.0)	54 (44.3)	
Don’t know	25 (42.4)	28 (44.4)	53 (43.4)	
No answer	0 (0.0)	1 (1.6)	1 (0.8)	
				0.479
May BU Patients have to face Difficulties with Sexual Functioning? (Participants ≥ 18 years), **N = 60**				
Yes	13 (48.1)	21 (63.6)	43 (50.6)	
No	5 (18.5)	2 (6.1)	11 (12.9)	
Don’t know	8 (29.6)	9 (27.3)	29 (34.1)	
No answer	1 (3.7)	1 (3.0)	2 (2.4)	
				0.448

Source: Author’s own

3. Enabling Factors

TABLE 60: KAP (*'Early' vs. 'Late Care-Seeker'*): (3) - Accessibility

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Means of getting to the Health Facility *				
Public transport	28 (47.5)	41 (65.1)	69 (56.6)	0.067
Walking	36 (61.0)	42 (66.7)	78 (63.9)	0.574
Other	2 (3.4)	1 (1.6)	3 (2.5)	0.610
How long does it take to get there?				
0-5 min	11 (18.6)	5 (7.9)	16 (13.1)	
6-10 min	6 (10.2)	6 (9.5)	12 (9.8)	
11-15 min	4 (6.8)	4 (6.3)	8 (6.6)	
16-20 min	12 (20.3)	10 (15.9)	22 (18.0)	
21-25 min	1 (1.7)	0 (0.0)	1 (0.8)	
26-30 min	12 (20.3)	21 (33.3)	33 (27.0)	
> 30 min	13 (22.0)	14 (22.2)	27 (22.1)	
Don't know	0 (0.0)	3 (4.8)	3 (2.5)	
				0.440

Source: Author's own

* several options permitted

TABLE 61: KAP (*'Early' vs. 'Late Care-Seeker'*): (3) - Appeal of Treatment

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Perception about Antibiotic Treatment				
"The antibiotic treatment cures/ heals the disease/ ulcer"	13 (22.0)	9 (14.3)	22 (18.0)	
"The antibiotic treatment includes (too) many injections"	8 (13.6)	12 (19.0)	20 (16.4)	
"The antibiotic treatment is very good" [361]	11 (18.6)	6 (9.5)	17 (13.9)	
Side effects [362]	5 (8.5)	6 (9.5)	11 (9.0)	
Treatment stopped due to lack of drug supply	0 (0.0)	1 (1.6)	1 (0.8)	
Don't know	9 (15.3)	14 (22.2)	23 (18.9)	
No answer	13 (22.0)	15 (23.8)	28 (23.0)	
				0.519

Source: Author's own

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[361] Mentioned benefits were: *„It dissolves/ softens the nodule", „eases the pain"*

[362] Mentioned side effects were: eye problems, scars, pain, swollen body parts, tiredness, inability to walk

TABLE 62: KAP (*'Early' vs. 'Late Care-Seeker'*): (3) - Acceptability and Quality of the available Health Services

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Are you satisfied with the local Health Facilities?				
Yes	51 (86.4)	36 (57.1)	87 (71.3)	
No	2 (3.4)	13 (20.6)	15 (12.3)	
Don't know	4 (6.8)	13 (20.6)	17 (13.9)	
No answer	2 (3.4)	1 (1.6)	3 (2.5)	
				0.001

Source: Author's own

TABLE 63: KAP (*'Early' vs. 'Late Care-Seeker'*): (3) - Health Education and Communication

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Did you ever hear about BU?				
Yes	44 (74.6)	43 (68.3)	87 (71.3)	
No	15 (25.4)	20 (31.7)	35 (28.7)	
				0.549
How did you get to know about BU? *				
Friends and neighbours	24 (40.7)	18 (28.6)	42 (34.4)	0.185
Personal infection	34 (57.6)	50 (79.4)	84 (68.9)	**0.011**
Family members	14 (23.7)	18 (28.6)	32 (26.2)	0.681
NGO	6 (10.2)	0 (0.0)	6 (4.9)	**0.011**
Other	10 (11.9)	3 (5.0)	10 (8.2)	0.610
Don't know	0 (0.0)	1 (1.6)	1 (0.8)	1.000
No answer	2 (3.4)	0 (0.0)	2 (1.6)	0.232
Information about BU within the last 6 Months?				
Yes	28 (47.5)	24 (38.7)	52 (43.0)	
No	30 (50.8)	38 (61.3)	68 (56.2)	
No answer	1 (1.7)	0 (0.0)	1 (0.8)	
				0.337
Do you think you have enough information about BU?				
Yes	9 (15.3)	7 (11.1)	16 (13.1)	
No	29 (49.2)	31 (49.2)	60 (49.2)	
Partially	16 (27.1)	21 (33.3)	37 (30.3)	
Don't know	2 (3.4)	2 (3.2)	4 (3.3)	
No answer	3 (5.1)	2 (3.2)	5 (4.1)	
				0.900

Source: Author's own

***** several options permitted

TABLE 64: KAP (*'Early' vs. 'Late Care-Seeker'*): (3) - Costs

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Do you have a valid Health Insurance at the Moment?				
Yes	21 (35.6)	21 (33.3)	42 (34.3)	
No	37 (62.7)	42 (66.7)	79 (64.8)	
Don't know	1 (1.7)	0 (0.0)	1 (0.8)	
				0.553
How is the Cost of medical Treatment taken care of?				
"Medical treatment for BU is provided for free"	40 (67.8)	34 (54.0)	74 (60.7)	
Payment for treatment	4 (6.8)	13 (20.6)	17 (13.9)	
"Some people pay for the treatment – others not"				
"Treatment is provided for free – except for transportation/ petrol"	2 (3.4)	0 (0.0)	2 (1.6)	
"Treatment is provided for free – except for some additional medicine"	1 (1.7)	2 (3.2)	3 (2.5)	
"Treatment is for free if people have a health insurance"	3 (5.1)	0 (0.0)	3 (2.5)	
"Treatment is provided for free – except for dressing material"	0 (0.0)	1 (1.6)	1 (0.8)	
Don't know	7 (11.9)	11 (17.5)	18 (14.8)	
No answer	2 (3.4)	1 (1.6)	3 (2.5)	
				0.090

Source: Author's own

4. Choice of Health Care Resources

TABLE 65: KAP (*'Early' vs. 'Late Care-Seeker'*): (4) - Therapeutic Itineraries

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Total distribution (%)	Significance p
Treatment for Nodule *, N = 94				
No treatment	1 (2.1)	6 (13.0)	7 (7.4)	0.056
Self-treatment	3 (6.3)	18 (39.1)	21 (22.3)	**< 0.001**
Herbalist	16 (33.3)	24 (52.2)	40 (42.6)	0.095
Hospital/ clinic	41 (85.4)	0 (0.0)	41 (43.6)	**< 0.001**
Church/ prayer camp	0 (0.0)	1 (2.2)	1 (1.1)	0.489
Treatment for Ulcer *, N = 100				
Self-treatment	0 (0.0)	4 (6.5)	4 (4.0)	0.294
Herbalist	9 (23.7)	24 (38.7)	33 (33.0)	0.132
Hospital/ clinic	32 (84.2)	48 (77.4)	82 (80.0)	0.453
Spiritualist	0 (0.0)	1 (1.6)	1 (1.0)	1.000
Church/ prayer camp	1 (2.6)	0 (0.0)	1 (1.0)	0.380

Source: Author's own

* several options permitted

Risk Factors for delayed Medical Treatment for BU (specific objective 5)

TABLE 66: KAP: Univariate Analysis of selected Risk Factors among *'Early'* and *'Late Care-Seekers'*

Characteristic	Early care (%) N = 59	Late care (%) N = 63	Univariable OR [x] (95% CI)	P [y]
1. Predisposing Factors				
Age by time of infection				
< 15 years	25 (42.4)	22 (34.9)	0.7289 (0.3512-1.5164)	0.3985
Number of Children in Household				
> 4 children	22 (37.3)	22 (34.9)	**0.3912 (0.1885-0.8119)**	**0.0118**
Frequent Means of Transport				
Walking	22 (37.3)	38 (60.3)	**2.5564 (1.2317-5.3058)**	**0.0118**
Treatment Recommendation Nodule				
	N = 48	**N = 46**		
Yes	24 (50.0)	14 (30.4)	0.4375 (0.1879-1.0188)	0.0553
Treatment Recommendation Ulcer				
	N = 51	**N = 49**		
Yes	17 (28.8)	44 (69.8)	**18.6353 (6.2649-55.4320)**	**<0.001**
Decision about Treatment in Case of a Disease				
Own decision	17 (28.8)	31 (49.2)	**2.3934 (1.1314-5.0631)**	**0.0224**
2. BU Characteristics and its				
Location of the Lesion				
Visible lesion site[363]	57 (96.6)	55 (87.8)	0.2412 (0.0490-1.1867)	0.0802
Knowledge of specific Symptoms				
Oedema/ *"swelling"*	9 (15.3)	4 (6.3)	0.3766 (0.1094-1.2971)	0.1217
Perceived Cause of the Disease				
Swimming/ wading in rivers/ stagnant water	15 (25.4)	8 (12.7)	0.4267 (0.1658-1.0980)	0.0774
Knowledge of Preventive Measures				
	N = 42	**N = 33**		
Yes	40 (95.2)	27 (81.8)	0.2250 (0.0422-1.1990)	0.0806

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[363] Upper/ lower limb, face and neck were considered as being 'visible lesion sites'

TABLE 66: KAP: Univariate Analysis of selected Risk Factors among *'Early'* and *'Late Care-Seekers'* (continued)

Characteristic	Early care (%)	Late care (%)	Univariable OR ^{x} (95% CI)	P ^{y}
How do Community Members treat BU Patients?				
BU patients are treated with full sympathy (N = 118)	**N = 57**	**N = 61**		
	38 (66.7)	37 (60.7)	0.7708 (0.3630-1.6369)	0.4982
Are BU Patients welcome at social Functions?				
BU patients are welcome at social functions (N = 115)	**N = 53**	**N = 62**		
	37 (69.8)	54 (87.1)	**2.9189 (1.1332-7.5187)**	**0.0265**
Do Children with BU continue Schooling?				
BU affected children do not continue schooling (N = 115)	**N = 57**	**N = 58**		
	33 (57.9)	44 (75.9)	**2.2857 (1.0282-5.0812)**	**0.0425**
3. Enabling Factors				
Means of getting to the Health Facility				
Public transport	28 (47.5)	41 (65.1)	**2.0633 (0.9967-4.2714)**	**0.0510**
How did you get to know about BU?				
Personal infection	34 (57.6)	50 (79.4)	**2.8281 (1.2715-6.2900)**	**0.0108**
NGO	6 (10.2)	0 (0.0)	0.0648 (0.0036-1.1771)	0.0643
Are you satisfied with the local Health Facilities?				
Satisfied with local health facilities	**N = 53**	**N = 49**		
	51 (96.2)	36 (73.5)	**0.1086 (0.0231-0.5110)**	**0.0050**
How is the Cost of medical Treatment taken care of?				
"Medical treatment for BU is provided for free"	**N = 50**	**N = 61**		
	40 (80.0)	34 (66.7)	**0.3148 (0.1335-0.7422)**	**0.0083**
4. Choice of Health Care Resources				
Treatment for Nodule	**N = 48**	**N = 46**		
No treatment	1 (2.1)	6 (13.0)	7.0500 (0.8142-61.0473)	0.0762
Self-treatment	3 (6.3)	18 (39.1)	**9.6429 (2.6014-35.7439)**	**0.0007**
Herbalist	16 (33.3)	24 (52.2)	2.1818 (0.9480-5.0215)	0.0666
Treatment for Ulcer	**N = 38**	**N = 62**		
Herbalist	9 (23.7)	24 (38.7)	2.0351 (0.8226-5.0346)	0.1242

[x] ORs were calculated when p < 0.25.
[y] Boldface type indicates differences that were significant at P ≤0.05

Source: Author's own

Differences between (previously) BU affected People and the non-affected Population (specific objective 6)

1 .Predisposing Factors

TABLE 67: KAP (BU affected vs. non-affected): (1) - Age and Sex Distribution

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)
Age Category			
0-10	18 (30.5)	13 (20.6)	31 (25.4)
11-20	22 (37.3)	12 (19.0)	34 (27.9)
21-30	3 (5.1)	10 (15.9)	13 (10.7)
31-40	4 (6.8)	5 (7.9)	9 (7.4)
41-50	4 (6.8)	9 (14.3)	13 (10.7)
51-60	2 (3.4)	7 (11.1)	9 (7.4)
61-70	3 (5.1)	5 (7.9)	8 (6.6)
71-80	2 (3.4)	0 (0.0)	2 (1.6)
81 and above	1 (1.7)	2 (3.2)	3 (2.5)
Sex			
Male	59 (48.4)	59 (48.4)	118 (48.4)
Female	63 (51.6)	63 (51.6)	126 (51.6)

Source: Author's own

TABLE 68: KAP (BU affected vs. non-affected): (1) - Household Characteristics

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Number of People in Household				
1-5	38 (31.1)	38 (31.1)	76 (31.1)	
6-10	61 (50.0)	64 (52.5)	125 (51.2)	
11-15	12 (9.8)	9 (7.4)	21 (8.6)	
16-20	4 (3.3)	5 (4.1)	9 (3.7)	
21-25	1 (0.8)	2 (1.6)	3 (1.2)	
26-30	0 (0)	1 (0.8)	1 (0.4)	
"Many"	6 (4.9)	3 (2.5)	9 (3.7)	
				0.816
Marital Status of Study Participant[364]				
Single	40 (32.8)	45 (36.9)	159 (62.2)	0.502
Married	40 (32.8)	44 (36.1)	84 (34.4)	0.590
Divorced	3 (2.5)	5 (4.1)	8 (3.3)	0.472
Widowed	9 (7.4)	9 (7.4)	18 (7.4)	1.000

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[364] several options permitted

TABLE 68: KAP (Differences BU affected and non-affected): (1) Household Characteristics (continued)

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Number of Children in Household				
No children	9 (7.4)	9 (7.4)	18 (7.4)	
1-2	29 (23.8)	24 (23.8)	53 (23.8)	
3-4	40 (32.8)	45 (36.8)	85 (34.8)	
5-6	28 (23.0)	33 (27.0)	61 (25.0)	
7-8	12 (9.8)	5 (4.1)	17 (7.0)	
> 8	4 (3.3)	6 (4.9)	10 (4.1)	
				0.259

Source: Author's own

TABLE 69: KAP (BU affected vs. non-affected): (1) - Ethnic Group, Religion

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Mother Tongue				
Twi (Akan)	54 (44.3)	62 (50.8)	116 (47.5)	
Ewe	52 (42.6)	52 (42.6)	104 (42.6)	
Krobo	7 (5.7)	3 (2.5)	10 (4.1)	
Ga	3 (2.5)	1 (0.8)	4 (1.6)	
Other	6 (4.9)	4 (3.3)	10 (4.1)	
				0.470
Ethnic Background Mother				
Akan	54 (44.3)	59 (48.4)	113 (46.3)	
Ewe	52 (42.6)	53 (43.4)	105 (43.0)	
Ga	6 (4.9)	3 (2.5)	9 (3.7)	
Krobo	2 (1.6)	3 (2.5)	5 (2.0)	
Hausa	3 (2.5)	1 (0.8)	4 (1.6)	
Other	5 (4.1)	3 (2.5)	8 (3.3)	
				0.711
Ethnic Background Father				
Akan	54 (44.3)	58 (47.5)	112 (45.9)	
Ewe	52 (42.6)	55 (45.1)	107 (43.9)	
Ga	3 (2.5)	3 (2.5)	6 (2.2)	
Krobo	4 (3.3)	1 (0.8)	5 (2.5)	
Hausa	3 (2.5)	1 (0.8)	4 (1.6)	
Other	5 (4.1)	4 (3.3)	9 (3.7)	
Don't know	1 (0.8)	0 (0.0)	1 (0.4)	
				0.658
Religion				
Christian	106 (86.9)	99 (81.1)	205 (84.0)	
Muslim	4 (3.3)	6 (4.9)	10 (4.1)	
None	11 (9.0)	15 (12.3)	26 (10.7)	

TABLE 69: KAP (Differences BU affected and non-affected): (1) - Ethnic Group, Religion (continued)

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Other	1 (0.8)	0 (0.0)	1 (0.4)	
Traditional	0 (0.0)	1 (1.6)	2 (0.8)	
				0.373

Source: Author's own

TABLE 70: KAP (BU affected vs. non-affected): (1) - Formal Education

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Highest attained Education Level (participants ≥ 6 years), **N = 234**				
No formal education	39 (33.6)	39 (33.1)	78 (33.3)	
Primary school	37 (31.8)	38 (32.2)	75 (32.1)	
Junior High School (JSS)	32 (27.7)	33 (28.0)	65 (27.8)	
Senior Secondary School (SSS)	7 (6.0)	8 (6.8)	15 (6.4)	
Post-Secondary	1 (0.9)	0 (0.0)	1 (0.4)	
				0.797

Source: Author's own

TABLE 71: KAP (BU affected vs. non-affected): (1) - Occupation

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Occupation (participants > 15 years), **N = 150**				
Farming	40 (53.3)	41 (54.7)	81 (54.0)	
Student/ pupil	13 (17.3)	13 (17.3)	26 (17.3)	
Trade and commerce	6 (8.0)	13 (17.3)	19 (12.7)	
Unemployed	8 (10.7)	6 (8.0)	12 (8.0)	
Other	8 (10.7)	2 (2.7)	10 (6.7)	
				0.166

Source: Author's own

TABLE 72: KAP (BU affected vs. non-affected): (1) - Assets

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Money for Food, Water and Transportation				
1-5 GHC	57 (46.7)	50 (41.0)	107 (43.9)	
6-10 GHC	45 (36.9)	48 (39.3)	93 (38.1)	
11-15 GHC	6 (4.9)	6 (4.9)	12 (4.9)	
> 15 GHC	3 (2.4)	2 (1.6)	5 (2.0)	
Don’t know	10 (8.2)	16 (13.1)	26 (10.7)	
No answer	1 (0.8)	0 (0.0)	1 (0.4)	
				0.627
Main Source of Income of Household [365]				
Farming	103 (84.4)	95 (77.9)	198 (81.1)	0.190
Trade and Commerce	38 (31.1)	38 (31.1)	76 (31.1)	1.000
Other	14 (11.5)	11 (9.0)	25 (10.2)	0.527
Don’t know	4 (3.3)	8 (6.6)	12 (4.9)	0.375
Frequent Means of Transport [366]				
Trotro	105 (86.1)	109 (89.3)	214 (87.7)	0.436
Taxi	59 (48.4)	52 (42.6)	111 (45.5)	0.368
Walking	60 (49.2)	59 (48.4)	119 (48.8)	0.898
Don’t know	0 (0.0)	1 (0.8)	1 (0.4)	1.000

Source: Author’s own

2. Characteristics of BU and its Perception

TABLE 73: KAP (BU affected vs. non-affected): (2) - Aetiological Model

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Do you know how BU starts?				
Yes	107 (87.7)	73 (59.8)	180 (73.8)	
No	12 (9.8)	42 (34.4)	54 (22.1)	
Don’t know	2 (1.6)	7 (5.7)	9 (3.7)	
No answer	1 (0.8)	0 (0.0)	1 (0.4)	
				< 0.001*
Knowledge of specific Symptoms [367]				
Nodule/ painless *“boil”*	97 (79.5)	70 (57.4)	167 (68.4)	< 0.001*
Oedema/ *“swelling”*	13 (10.7)	4 (3.3)	17 (7.0)	0.041*
Ulcer	3 (2.5)	3 (2.5)	16 (6.6)	1.000
Plaque	8 (6.6)	8 (6.6)	6 (2.5)	1.000
Other	2 (1.6)	0 (0.0)	2 (0.8)	0.498
Don’t know	4 (3.3)	13 (10.7)	17 (7.0)	0.041*

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[365] several options permitted
[366] several options permitted
[367] several options permitted

Table 73: KAP (BU affected vs. non-affected): (2) - Aetiological Model (continued)

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Perceived Cause of the Disease [368]				
Drinking water from lakes and rivers	53 (43.4)	55 (45.1)	108 (44.3)	0.797
Swimming/ wading in rivers/ stagnant water	23 (18.9)	27 (22.1)	50 (20.5)	0.526
Rainwater	15 (12.3)	18 (14.8)	33 (13.5)	0.574
Lack of personal hygiene	13 (10.7)	14 (11.5)	27 (11.1)	0.838
"Gutter water"	9 (7.4)	9 (7.4)	18 (7.4)	1.000
Other	7 (5.7)	8 (6.6)	15 (6.1)	1.000
Don't know	52 (42.6)	48 (39.3)	100 (41.0)	0.603
No answer	1 (0.8)	0 (0.0)	1 (0.4)	1.000
Knowledge of Preventive Measures				
Yes	67 (54.9)	67 (54.9)	134 (54.9)	
No	8 (6.6)	11 (9.0)	19 (7.8)	
Don't know	46 (37.7)	42 (34.4)	88 (36.1)	
No answer	1 (0.8)	2 (1.6)	3 (1.2)	
				0.804
Perceived Preventive Measures				
Avoid wading in rivers/ mud/ dirty *"gutter"* water	30 (45.5)	36 (54.5)	66 (27.0)	
Drink clean water (boil water/ water from borehole)	17 (53.1)	15 (46.9)	32 (13.1)	
Keep the environment clean	7 (63.6)	4 (36.4)	11 (4.5)	
Observe hygiene/ cover food	5 (4.0)	6 (4.8)	11 (4.5)	
Other	8 (6.6)	6 (4.9)	14 (5.7)	
No answer	55 (44.0)	55 (44.0)	110 (45.1)	
				0.879

Source: Author's own

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[368] several options permitted

TABLE 74: KAP (BU affected vs. non-affected): (2) - Stigma/ Social Exclusion

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
How do Community Members treat BU Patients?				
With full sympathy	75 (61.5)	67 (54.9)	142 (58.2)	
With partly sympathy	29 (23.8)	24 (19.7)	53 (21.1)	
With unsure sympathy	8 (6.6)	9 (7.4)	17 (7.0)	
With no sympathy	6 (4.9)	6 (4.9)	12 (4.9)	
Don’t know	4 (3.3)	15 (12.3)	19 (7.8)	
No answer	0 (0.0)	1 (0.8)	1 (0.4)	
				0.138
Are BU Patients welcome at social Functions?				
Yes	91 (74.6)	71 (58.2)	162 (66.4)	
No	24 (19.7)	32 (26.2)	56 (23.0)	
Don’t know	7 (5.7)	18 (14.8)	25 (10.2)	
No answer	0 (0.0)	1 (0.8)	1 (0.4)	
				0.024*
Do Children with BU continue Schooling?				
Yes	38 (31.1)	29 (23.8)	67 (27.5)	
No	77 (63.1)	82 (67.2)	159 (56.2)	
Don’t know	7 (5.7)	10 (8.2)	17 (7.0)	
No answer	0 (0.0)	1 (0.8)	1 (0.4)	
				0.408
Would other Community Members accept BU Patients as a Leader?				
Yes	14 (11.5)	11 (9.0)	25 (10.2)	
No	54 (44.3)	66 (54.1)	120 (49.2)	
Don’t know	53 (43.4)	44 (36.1)	97 (39.8)	
No answer	1 (0.8)	1 (0.8)	2 (0.8)	
				0.495
May BU Patients have to face Difficulties with Sexual Functioning? (N = 176)				
Yes	43 (50.6)	36 (39.6)	79 (44.9)	
No	11 (12.9)	12 (13.2)	23 (13.1)	
Don’t know	29 (34.1)	41 (45.1)	70 (39.8)	
No answer	2 (2.4)	2 (2.4)	4 (2.3)	0.472

Source: Author’s own

3. Enabling Factors

Table 75: KAP (BU affected vs. non-affected): (3) - Appeal of Treatment

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Reasons not to seek medical Treatment [369]				
Financial reasons	68 (55.7)	73 (59.8)	141 (57.8)	0.517
Fear of medical treatment	25 (20.5)	33 (27.0)	58 (23.8)	0.229
Don't know the disease	21 (17.2)	17 (13.9)	38 (15.6)	0.480
Long distance to facility	8 (6.6)	7 (5.7)	15 (6.1)	0.790
Not serious enough	8 (6.6)	7 (5.7)	15 (6.1)	0.790
"Herbalists know the right treatment"	10 (8.2)	2 (1.6)	12 (4.9)	0.034
Lack of transport	3 (2.5)	7 (5.7)	10 (4.1)	0.333
Not a *"hospital disease"*	4 (3.3)	2 (1.6)	6 (2.5)	0.684
Other	18 (14.8)	13 (10.7)	31 (12.7)	0.688
Don't know	23 (18.9)	27 (22.1)	50 (20.5)	0.526
No answer	0 (0.0)	1 (0.8)	1 (0.4)	1.000
Perception about Antibiotic Treatment				
"The antibiotic treatment cures/ heals the disease/ ulcer"	22 (18.0)	13 (10.7)	35 (14.3)	
"The antibiotic treatment includes (too) many injections"	20 (16.4)	0 (0.0)	20 (8.2)	
"The antibiotic treatment is very good" [370]	17 (13.9)	6 (4.9)	23 (9.4)	
Side effects [371]	11 (9.0)	1 (0.8)	12 (4.9)	
Other	1 (0.8)	0 (0.0)	1 (0.4)	
Don't know	23 (18.9)	40 (32.8)	63 (25.8)	
No answer	28 (23.0)	62 (50.8)	90 (36.9)	
				< 0.001*

Source: Author's own

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[369] several options permitted

[370] Mentioned benefits were: *„It dissolves/ softens the nodule", „eases the pain"*

[371] Mentioned side effects were: eye problems, scars, pain, swollen body parts, tiredness, inability to walk

TABLE 76: KAP (BU affected vs. non-affected): (3) Acceptability and Quality of the available Health Services

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Are you satisfied with the local Health Facilities?				
Yes	87 (71.3)	91 (74.6)	178 (72.9)	
No	15 (12.3)	9 (7.4)	24 (9.8)	
Don’t know	17 (13.9)	22 (18.0)	39 (15.9)	
No answer	3 (2.5)	0 (0.0)	3 (1.2)	
				0.156

Source: Author’s own

TABLE 77: KAP (BU affected vs. non-affected): (3) - Health Education and Communication

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
Did you ever hear about BU?				
Yes	87 (71.3)	91 (74.6)	178 (73.0)	
No	35 (28.7)	29 (23.8)	64 (26.2)	
Don’t know	0 (0.0)	2 (1.6)	2 (0.8)	
				0.265
Information about BU within the last 6 Months				
Yes	52 (43.0)	56 (46.7)	108 (44.8)	
No	68 (56.2)	59 (49.2)	127 (52.7)	
Don’t know	0 (0.0)	4 (3.3)	4 (1.7)	
No answer	1 (0.8)	1 (0.8)	2 (0.8)	
				0.188
Type of Information[372]	**N = 52**	**N = 56**		
NGO/ video show	21 (40.4)	31 (55.4)	52 (48.1)	0.129
Health worker/ nurses	20 (38.5)	18 (32.1)	38 (35.2)	0.548
Posters and pamphlets	9 (17.3)	8 (14.3)	17 (15.7)	0.793
Radio	4 (7.7)	5 (8.9)	9 (8.3)	1.000
Other	6 (11.5)	11 (19.6)	17 (15.7)	0.324
Don’t know	0 (0.0)	3 (5.3)	3 (2.8)	
No answer	0 (0.0)	2 (3.6)	2 (1.9)	1.000
Do you think you have sufficient Information about BU?				
Yes	16 (13.1)	26 (21.3)	42 (17.2)	
No	60 (49.2)	48 (39.3)	108 (44.3)	
Partially	37 (30.3)	35 (28.7)	72 (29.5)	
Don’t know	4 (3.3)	6 (4.9)	10 (4.1)	
No answer	5 (4.1)	7 (5.7)	12 (4.9)	
				0.342

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[372] several options permitted

TABLE 77: KAP (BU affected vs. non-affected): (3) - Health Education and Communication (continued)

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
How is BU treated in a hospital/ in a clinic? [373]				
Antibiotics (*“Pills & Injections”)*	91 (74.6)	36 (29.5)	127 (52.0)	< 0.001
Wound care	76 (62.3)	37 (30.3)	113 (46.3)	< 0.001
Surgery	7 (5.7)	3 (2.5)	10 (4.1)	0.333
Other	7 (5.7)	1 (0.8)	8 (3.3)	0.247
Don’t know	18 (14.8)	77 (63.1)	95 (38.9)	< 0.001

Source: Author’s own

TABLE 78: KAP (Differences BU affected and non-affected): (3) - Costs

Characteristic	BU Affected (%)	Non-BU (%)	Total Distribution (%)	Significance p *
How is the Cost of medical Treatment taken care of?				
“Medical treatment for BU is provided for free”	74 (60.7)	42 (34.4)	116 (47.5)	
Payment for treatment	17 (13.9)	8 (6.6)	25 (10.2)	
“Some people pay for the treatment – others not”	2 (1.6)	4 (3.3)	6 (2.5)	
“Treatment is provided for free – except for transportation/ petrol”	3 (2.5)	2 (1.6)	5 (2.0)	
Other	5 (4.1)	2 (1.6)	7 (2.9)	
Don’t know	18 (14.8)	59 (48.4)	77 (31.6)	
No answer	3 (2.5)	5 (4.1)	8 (3.3)	
				< 0.001*
Do you have a valid Health Insurance at the Moment?				
Yes	42 (34.3)	32 (26.2)	74 (30.3)	
No	79 (64.8)	90 (73.8)	169 (69.3)	
Don’t know	1 (0.8)	0 (0.0)	1 (0.4)	
				0.216

Source: Author’s own

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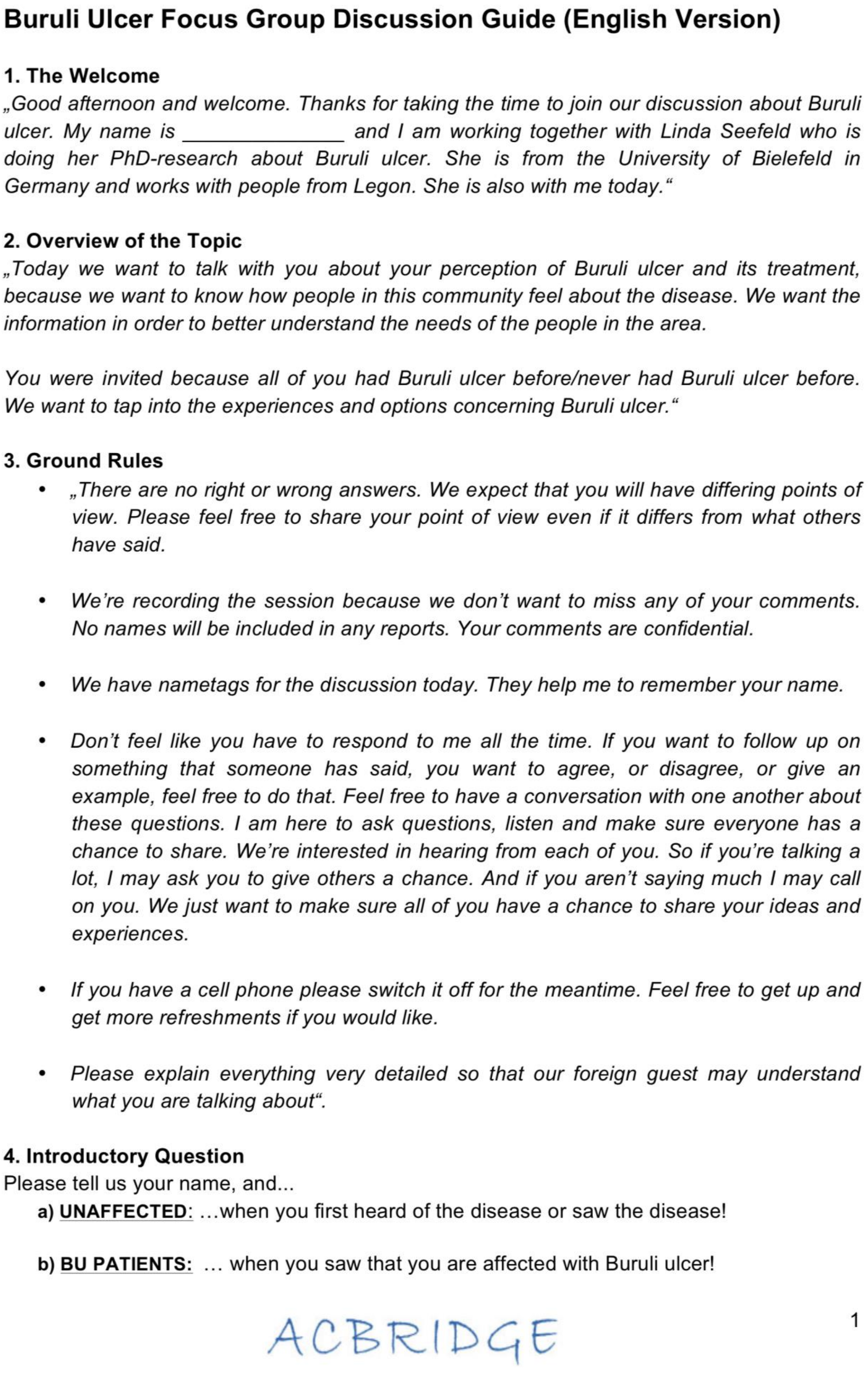
[373] several options permitted

Annex D: Focus Group Discussion Guide



Buruli Ulcer Focus Group Discussion Guide (English Version)

1. The Welcome

„Good afternoon and welcome. Thanks for taking the time to join our discussion about Buruli ulcer. My name is ______________ and I am working together with Linda Seefeld who is doing her PhD-research about Buruli ulcer. She is from the University of Bielefeld in Germany and works with people from Legon. She is also with me today.“

2. Overview of the Topic

„Today we want to talk with you about your perception of Buruli ulcer and its treatment, because we want to know how people in this community feel about the disease. We want the information in order to better understand the needs of the people in the area.

You were invited because all of you had Buruli ulcer before/never had Buruli ulcer before. We want to tap into the experiences and options concerning Buruli ulcer.“

3. Ground Rules

- *„There are no right or wrong answers. We expect that you will have differing points of view. Please feel free to share your point of view even if it differs from what others have said.*

- *We're recording the session because we don't want to miss any of your comments. No names will be included in any reports. Your comments are confidential.*

- *We have nametags for the discussion today. They help me to remember your name.*

- *Don't feel like you have to respond to me all the time. If you want to follow up on something that someone has said, you want to agree, or disagree, or give an example, feel free to do that. Feel free to have a conversation with one another about these questions. I am here to ask questions, listen and make sure everyone has a chance to share. We're interested in hearing from each of you. So if you're talking a lot, I may ask you to give others a chance. And if you aren't saying much I may call on you. We just want to make sure all of you have a chance to share your ideas and experiences.*

- *If you have a cell phone please switch it off for the meantime. Feel free to get up and get more refreshments if you would like.*

- *Please explain everything very detailed so that our foreign guest may understand what you are talking about“.*

4. Introductory Question

Please tell us your name, and...

a) UNAFFECTED: …when you first heard of the disease or saw the disease!

b) BU PATIENTS: … when you saw that you are affected with Buruli ulcer!

ACBRIDGE

1

5. Structured Guideline

(i) Sources of Information on BU	
FIRST CONTACT	**How did you hear about the disease?**
ADDITIONAL INFORMATION	Is there anything else you want to know about the disease?
INFORMATION PROVIDER	From whom do you want to get this information?
VARIOUS INSTITUTIONS	Do you think that there is a particular sector/ institution, which should be in charge of giving information about the disease but has not done it?
PREVENTIVE REASONS	In your opinion what do you think is preventing them from not educating people about the disease?
(ii) General Perception and Beliefs about BU	
MAIN IDEA	**What do you think about Buruli ulcer?**
EFFECT OF BU	What is the effect of the disease on the community?
SEVERITY OF BU	Do you see this disease to be a severe/ dangerous one?
REASONS FOR SEVERITY	What makes you think that it is a severe/ dangerous disease?
PROBLEMS OF BU	What are some of the effects/ problems of this disease?
SPIRITUAL ASPECT	If you look into the disease do people see the disease to be a spiritual disease?
(iii) Knowledge and Perception of the Mode of Transmission	
MODES OF CONTRACTION	**In which way do you believe that somebody can contract this disease?**
PREVENTIVE MEASURES	Do you think one can prevent him- or herself against the disease?
PREVENTIVE MEASURES: HOW	In which way?
PEOPLE'S PERCEPTION ABOUT PREVENTION	Do you know some people who believe they can prevent this disease?
REASONS FOR PERCEPTION	Do you know the reason why they think that way?
AFFECTED GROUPS	Which group of people is most affected with this disease?
SYMPTOMS OF REALISATION	If someone is affected with the disease what will make him/her realise that he/she has been affected with the disease?
(iv) Preferences, Knowledge & Beliefs about Treatment Options & Therapeutic Itineraries	
TREATMENT OPTIONS	**If people are affected with this disease which kind of treatment options do they use?**
DIFFERENT HEALTH PROVIDERS	What will make them visit the traditional herbalist or the hospital or any other place?
HOSPITAL VS. HERBAL MEDICINE	What is the difference between the treatment at the hospital and

	the traditional herbal medicine?
OTHER PREFERABLE TREATMENT OPTIONS	Do you know other treatment options with which the people would like to treat their diseases but they are not able to?
(v) Stigma or Social Exclusion	
INVOLVEMENT OF AFFECTED PEOPLE	**Do affected people involve themselves in community activities?**
PRECEPTION OF NON-AFFECTED ON AFFECTED	What do people who are not affected with Buruli ulcer think about those affected by the disease?
PREDJUDICES	Do you think that people have a prejudice mind about those who have the disease?
DISCRIMINATION & OTHER DISEASES	Are there any different diseases that bring about discrimination?
HIDDEN DISEASES	Are there any diseases that people know about but do not talk about them?
SEGREGATING DISEASES	Are there any different diseases that bring about division among those affected and those who are not affected?
EFFECTS ON THE LIFESTYLE	Are there any differences in the lifestyle of those affected with Buruli ulcer and those who are not affected?
INCLUSION OF BU PATIENTS	What do you think we can do to unite BU patients with the people in the community?
(vi) Perception about Health Services and Facilities	
PERCEPTION ABOUT HEALTH FACILITIES	**What is your perception about the health facilities around you?**
SATISFACTION	Do you like them?
REASONS FOR PRECEPTION	What makes happy or unhappy?
ATTITUDE OF THE WORKERS	What do you think about the attitude of the people working there?
ADVICE TO WORKERS	What would be your advice when you are given the chance to advice them?
FEEDBACK/AMENDMENT	We want you to help us to evaluate the services that are available. We want to know how to improve the service and to understand the advantages of herbal treatment. Is there anything that you came wanting to say that you didn't get the chance to say?

Annex E: Overview of available BU specific Frameworks/ Models for Health-Seeking Behaviour

TABLE 79: Overview of available BU specific Frameworks/ Models for Health-Seeking Behaviour
Unique Aspects of each Model are bolded

Research Approach or Detail of the Framework/ Model	Seefeld	Mulder et al., 2008	Grietens et al., 2012	Alferink et al., 2013
Title of the Model	Modified BU specific Framework for Health-Seeking Behaviour	Simplified model for healthcare seeking behaviour of patients with Buruli ulcer	Determinant factors for treatment choice in BUD patients' health itineraries	Model with level 1 and 2 factors potentially related to pre-hospital delay
Research Setting	Ghana	Benin	Cameroon	Benin
Study Participants	• All (formerly) BU affected people (or their caregivers) of the sub district • Non-affected community members • People working/ dealing professionally with BU affected people (*'professional experts'*)	• Participants affected with BU • Healthy community members	• Patients at the Ayos and Akonolinga hospitals and in four endemic communities belonging to the hospitals' catchment area • Community members • Health staff	• Healthy individuals aged > 18 years, living in BU-endemic areas
Inductive/ Deductive Approach	**1. Step:** deductive application/ matching of aspects with the framework by Kroeger on results of the published evidence (→ *'Adapted BU specific Framework for Health-Seeking Behaviour'*) **2. Step:** inductive inclusion of local characteristics and phenomena into the framework (→ *'Modified BU specific*	Inductive development of a model to explain health-seeking behaviour	Inductive development of a model to explain health-seeking behaviour	Deductive application/ matching of *'Leventhal's commonsense model of illness representations'* on results of the published evidence

Research Approach or Detail of the Framework/ Model	**Seefeld**	**Mulder et al., 2008**	**Grietens et al., 2012**	**Alferink et al., 2013**
	Framework for Health-Seeking Behaviour’)			
Methods	Triangulation of results from: - Systematic literature search - Expert interviews - KAP survey - FGDs	In-depth interviews with: - Patients treated in hospital and patients treated traditionally - Healthy community control subjects	Triangulation of results from: - Ethnographic research (participant observation, interviews, group discussions) - Quantitative data obtained through a survey	Cross-sectional survey among healthy individuals
Assessed Aspects				
Predisposing Factors (Social and Cultural Background)	- Age, sex - **Household Characteristics** - Ethnic Group and Religion - **Degree of formal Adaption** - Formal Education - Occupation - Assets - Social Interactions - **Disease Experience** - Other Factors	- Age, sex - Formal Education - Occupation - Assets - Social Interactions (*‘Advice of others’*) - Other Factors (*‘Other external reasons’*)	Not described/ included in the results	- Age, sex - Ethnic Group and Religion - Formal Education - Occupation - Assets
Characteristics of BU and Disease Perception	- **Chronic or acute** - Severity of the Symptoms	- Severity of the Symptoms (*‘Perceived severity of disease’*)	- Severity of the Symptoms (*‘Difficulties of symptom recognition’*)	- Severity of the Symptoms (*‘Illness perception’*)

Research Approach or Detail of the Framework/ Model	**Seefeld**	**Mulder et al., 2008**	**Grietens et al., 2012**	**Alferink et al., 2013**
	- Aetiological Model	- Aetiological Model (*‘Ideas on cause of the disease’*)	- Aetiological Model (*‘Perceived Aetiology’*)	- Aetiological Model (*‘Cause’, ‘Consequences’*)
	- Expected Benefits of the Treatment		- Expected Benefits of the Treatment (*‘Effectiveness of treatment’*)	- Expected Benefits of the Treatment (*‘Effectiveness of treatment’*)
	- Stigma/ Social Exclusion	- Stigma/ Social Exclusion (*‘Stigma’*)		- Stigma/ Social Exclusion (*‘Stigma’*)
				- **Emotional representations**
Enabling Factors - Health Service Characteristics	- Accessibility	- Accessibility (*‘Distance’*)	- Accessibility (*‘Place of treatment’*)	- Accessibility (*‘Transportation barriers’*)
	- Appeal of Treatment	- Appeal of Treatment *(‘Fear of treatment’*)	- Appeal of Treatment (*‘Length of treatment’*)	- Appeal of Treatment (*‘Cure/ control’*)
	- Acceptability and Quality of the available Health Services	- Acceptability and Quality of the available Health Services (*‘Duration of admission’*, *‘Confidence in the hospital’*)	- Acceptability and Quality of the available Health Services (*‘Doctor-Patient relationship’*)	- Acceptability and Quality of the available Health Services (*‘Timeline’*)
	- Health Communication		- Health Communication (*‘Knowledge’*)	- Health Communication (*‘Knowledge about symptoms, clinical manifestation’*)
	- Cost of Treatment	- Cost of Treatment	- Cost of Treatment (*‘Cost prevention strategy’*)	- Cost of Treatment (*‘Financial barriers’*)

Research Approach or Detail of the Framework/ Model	**Seefeld**	**Mulder et al., 2008**	**Grietens et al., 2012**	**Alferink et al., 2013**
Choice of Health-Care Resources	- Patient Itineraries - Delay (*'Early- & Late Care-Seekers'* – proxy for patient delay) - **No Treatment** - Self-treatment - Traditional healer - Governmental health facility - **Drug seller** - **Church and Prayer Camp**	- Patient Itineraries - Delay (*'Patient delay in days'*) - Self-treatment - Traditional healer ('*Traditional methods'*) - Governmental health facility (*'Hospital treatment'*)	- Patient Itineraries (*'Number of health encounters', 'alternation of treatment'*) - Delay (*'Time before seeking treatment'*) - Self-treatment (*'home treatment'*) - Traditional healer (*'traditional healing'*) - Governmental health facility (*'Biomedical treatment'*)	- Delay (*'Pre-hospital delay'* estimated by skin pictures presented to healthy individuals) - Governmental health facility (*'available standard treatment'*)
Levels related to health-seeking behaviour				- **Level 1: Individuals** - **Level 2: Villages**

Source: Author's own

Erklärung

Ich versichere, dass ich die Arbeit selbständig verfasst und keine anderen Quellen und Hilfsmittel als die angegebenen benutzt, sowie die Stellen der Arbeit, die anderen Werken entnommen sind, unter Angabe der Quelle als Entlehnung kenntlich gemacht habe. Das gilt auch für die verwendeten Tabellen und Abbildungen.

Ich versichere, dass die vorliegende Arbeit nicht anderweitig in dieser Form als Dissertation eingereicht wurde und ich bisher keine weiteren Versuche zur Promotion unternommen habe.

Bonn, Dezember 2014_________________________
Linda Seefeld