SOCIO-CULTURAL FEATURES OF BURULI ULCER AND IMPLICATIONS FOR CONTROL IN GHANA

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Prof. Dr. Martin Spiess
Dekan

O LORD, thou art my God; I will exalt thee, I will praise thy name; for thou
hast done wonderful things!

Dedicated to:
My dear husband, Jasper, and the children, Makafui and Janice

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AH	-	Amasaman Hospital
BU	-	Buruli Ulcer
BUD	-	Buruli Ulcer Disease
BUPaT	-	Buruli Ulcer Prevention and Treatment
CAM	-	Complementary and Alternative Medicine
CE	-	Cultural Epidemiology
CI	-	Confidence Interval
DALYS	-	Disability Adjusted Life Years
DOTS	-	Directly Observed Treatment Strategy
EKBB	-	Ethikkommission beider Basel
GBUI	-	Global Buruli Ulcer Initiative
GSM	-	Ga-South Municipality
GWM	-	Ga-West Municipality
CBSV	-	Community-based Surveillance Volunteers
CHPS	-	Community Health
EMIC	-	Explanatory Model Interview Catalogue
FGD	-	Focus Group Discussion
GBUI	-	Global Buruli ulcer Initiative
GPS	-	Global positioning system
HAT	-	Human African Trypanosomiasis
HH	-	Heads of Households
HS	-	Help-Seeking
IEC	-	Information Education Communication
KAC	-	Kojo Ashong Clinic

KAP	Knowledge, attitude and practices
KCCR	Kumasi Centre for Collaborative Research
KII	Key Informant Interview
MA	Municipal Assembly
MC	Medical Care
MCE	Municipal Chief Executive
MEHO	Municipal Education Health Officer
MHD	Municipal Health Directorate
MHMT	Municipal Health Management Team
MOH	Ministry of Health
MOU	Memorandum of Understanding
MS	Microsoft Corporation
NBUCP	National Buruli Ulcer Control Programme
NMIMR	Noguchi Memorial Institute for Medical Research
NHIS	National Health Insurance Scheme
NTD	Neglected Tropical Disease
NYEP	National Youth Employment Programme
OHC	Obom Health Centre
OR	Odds Ratio
PC	Perceived Causes
PCR	Polymerase Chain Reaction
PD	Patterns of Distress
PDA	Personal Digital Assistant
RPSB	Reconstructive Plastic Surgery and Burns
SD	Standard Deviation

SF - Stakeholder Forum

SHEP - School Health Education Programme

SMS - Short message service

SPSS - Statistical Package for the Social Sciences

Swiss TPH - Swiss Tropical and Public Health Institute

TB - Tuberculosis

TH - Traditional Healer

TM - Traditional Medicine

US - United States

USA - United States of America

USD - United States Dollar

WHO - World Health Organisation

WVG - World Vision Ghana

WVI - World Vision International

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Summary

Buruli ulcer (BU) infection, caused by *Mycobacterium ulcerans*, an environmental pathogen, is a disfiguring disease of the skin and occasionally the bones. Although mortality is rare, morbidity is high. All age groups are affected but children less than 17 years-of-age are at highest risk. BU has been reported in several tropical and sub-tropical regions of the world, particularly among poor, rural populations with limited access to basic water, sanitation and health facilities. However, most cases are from West-Africa and Ghana reports about 1,000 cases annually.

Since the mode of transmission for BU is unclear and considering the extent of BU-related morbidity, public health programmes to control BU are very important. This research examined the role of demographic, gender-related and socio-cultural features of BU and how these features affect the quality of timely treatment for BU clinical management and control in Ghana. The research was conducted in the Ga-West and Ga-South municipalities of Ghana. These areas are the fifth most endemic for BU in Ghana, yet they have the highest burden in terms of healed and active lesions.

The research had three components. A community study surveyed 504 heads of households, conducted 7 focus group discussions and assessed knowledge, attitudes and practices (KAP) of BU-affected persons in 2005. This study was motivated by the paucity of base-line socio-cultural data in the study areas and provided the rational for the inception of a Buruli ulcer prevention and treatment programme (BUPaT). A cultural epidemiological

(CE) study, focusing on illness experience, meaning and help-seeking was carried out from November 2008 to July 2009 among 181 affected persons from 67 endemic communities and in 3 major health treatment centres in the study area. During this same period, the health system performance in the first phase of the BUPaT phase 1 programme was assessed.

The KAP study found a low level of knowledge about the causes of BU: only 5.5% of respondents mentioned swimming and wading in ponds as a risk factor; 5.2% mentioned witchcraft, and 53% did not know the cause. There was considerable use of herbalists as the first recourse after infection, and medical treatment was often considered as a last alternative. Reasons for delayed medical treatment included a fear of prolonged hospitalisation, delays in treatment at the hospital, difficulty in obtaining transport for medical treatment, high transport costs and loss of income because of time spent in seeking medical treatment. There was a high level of compassion and acceptance of BU-affected persons, more among adults than children. Children's discrimination of BU-affected persons was based on fear of contagion. It was widely believed that BU-affected persons stayed away from public because they were embarrassed about their illness.

The KAP study suggested the need for community health education specifically on the risk factors for BU infection, and recognition of early stages of BU infection. It showed that improved access to health services and facilities was needed, and that access would benefit from community-based surveillance and a referral system to encourage timely medical treatment. The study also recommended the inclusion of information about BU in the school curriculum to allay fears of contagion among children. Because of the community preference for herbal treatment, it was suggested that herbalists should be trained to recognise all clinical features of BU and integrated in the health system so they could recognise and refer cases.

Results of the CE study showed the influence of illness experience, meaning and health system factors on help- seeking for BU. Findings revealed the extent of anxiety about anticipated illness outcomes and immense physical suffering of persons with pre-ulcers and ulcers. Study findings also drew attention to the socio-economic impact of BU illness both on affected persons and their family; many affected persons lost their livelihoods and had their education interrupted. The welfare of the family was further compromised when the main income-earner was infected with BU.

The demands for care for BU-affected sick relatives in the hospital and at home required mothers and adult female family members to make very difficult decisions. Work was often affected and young children were left unattended at home, when mothers were in the hospital, either seeking treatment for themselves or providing care for others. Younger female children were more likely than male children to suffer from school absenteeism to provide care for sick relatives. These findings suggest far-reaching implications for welfare, development and economic empowerment.

Additional findings from the CE study indicated that although the use of herbalists was extensive, awareness of features of BU had increased since the KAP study in 2005. Consequently, a high proportion of respondents

sought medical care for ulcers (66.9%) although the proportion who sought help for pre-ulcers was comparatively low (17.1%). Findings showed that affected persons used private health practitioners hoping that this would enable them continue with work and school.

Nevertheless, difficulties in diagnosing early lesions and progression of pre-ulcer lesions to large, slow-healing ulcers supported local concepts of witchcraft as a perceived cause of BU. Ideas of witchcraft did not prevent respondents from seeking medial care, but it prejudiced them against health messages that emphasised water contact as a risk factor for BU infection. Furthermore, respondents were sceptical of health education messages that failed to explain disease contagion in persons who appeared to have had no water contact. Some respondents also requested explanations for the absence of BU disease in persons who had frequent exposure to water, yet had no illness.

Help-seeking included substantial use of herbs at home for treatment of pre-ulcer lesions and the local excision of nodules to expose infected tissues, after which herbs were placed on sores. Analgesics, balms, blood tonics and antibiotics - particularly Terramycin and Phenxymethylpenicillin (commonly known as penicillin v) - were purchased from local chemists and itinerant drug peddlers. Herbalists were used extensively as the first-line treatment provider because of their consanguine relationship with respondents, easy access to their itinerant services and anticipation that their treatment would enable respondents to continue with work and school.

The main aim of the health system in the BuPaT phase 1 programme was to reduce BU-related suffering and disability through early detection and treatment of cases. Various community-based approaches and improved case management strategies were used to achieve this aim. Five main achievements of the health system were notable: (1) Extensive collaboration of all stakeholders across all levels, (national, municipal and community), which helped to strengthen the health system. (2) Enhanced capacity of health staff in antibiotic treatment and wound care. (3). A cadre of teachers, municipal environmental health officers, community health nurses and community-based surveillance volunteers were trained to give correct health education messages and to screen and refer infected persons for medical treatment. (4) The creation of a patient database using recommended WHO forms. (5) The introduction of antibiotics recommended by the WHO for improved treatment and cure, particularly for early lesions, thus preventing recurrences. Notwithstanding these achievements, problems remained with access, accommodation (lack of sufficient ward space), inappropriate use of traditional treatment, loss to follow-up and non-adherence to treatment.

In conclusion, this thesis has clarified the extent and nature of the substantial suffering and burden of BU-affected persons and their families. Although findings indicate an increase in awareness and the increased use of medical treatment, they also highlight pervasive ideas of witchcraft as a perceived cause which seemed to explain illness experience and burden of disease, and which reflected scepticism of health education messages that emphasise contact with rivers, ponds and lakes as risk factors for contagion.

The study showed that health system features such as collaboration among stakeholders and the use of community-based initiatives such as surveillance, community and school education, screening and referral of infected persons, and improving access to treatment were necessary for BU control.

To reduce the use of herbalists as first-line providers, access to medical treatment, particularly antibiotic treatment recommended by WHO is critical. Since community residents use private health practitioners, training and incorporating them in the health system should improve access to antibiotic treatment. The health system should also devise innovative ways to include traditional healers, particularly herbalists, in the health system to improve referral.

However, illness experience, meaning and help-seeking behaviors are influenced by the socio-cultural contexts of affected persons, which are likely to change with exposure to health information and improved socio-economic status. Regular socio-cultural assessments are needed to guide public health programmes to address current treatment needs and gaps. Since the mode of transmission remains unclear, further interdisciplinary research on the role of environmental, socio-cultural and genetic factors that explain in BU contagion is needed.

Zusammenfassung

Buruli-Ulkus (BU) ist eine durch das Umweltpathogen *Mycobacterium ulcerans* verursachte Infektionskrankheit, welche zu Haut verunstaltenden Geschwüren führt und gelegentlich auch die Knochen befällt. Obwohl die Morbidität hoch ist, führt BU selten zum Tod. Obwohl alle Altersgruppen davon betroffen sind, tragen Kinder unter 17 Jahren das höchste Erkrankungsrisiko. BU ist vor allem in tropischen und subtropischen Gegenden verbreitet, wobei vor allem arme, ländliche Bevölkerungsschichten mit beschränktem Zugang zu Wasser, sanitärer Infrastruktur und Gesundheitsdiensten betroffen sind. Die meisten Fälle treten jedoch in Westafrika auf, wo in Ghana alleine 1'000 Erkrankungen pro Jahr gemeldet werden.

Da die Übertragungsarten von BU noch nicht geklärt sind, und angesichts der hohen durch BU verursachten Morbidität, sind Gesundheitsprogramme zur BU-Bekämpfung von höchster Priorität. Die vorliegende Forschungsarbeit untersuchte den Einfluss demografischer, genderspezifischer und soziokultureller Merkmale von BU in Bezug auf die Qualität rechtzeitiger medizinischer Behandlung und die Bekämpfung von BU in Ghana. Diese Forschungsarbeit wurde in den Munizipalitäten Ga-West und Ga-South in Ghana durchgeführt. Beide Munizipalitäten gehören zum fünfthöchsten Endemiegebiet für BU in Ghana; sie sind aber von der höchsten Anzahl an geheilten und aktiven Läsionen betroffen.

Diese Forschungsarbeit beinhaltete drei Komponenten. Im Jahr 2005 wurden in einer Gemeindebasierte Studie 504 Haushaltsoberhäupter befragt, 7 Fokusgruppendiskussionen durchgeführt und der Wissenstand, die Einstellungen und Verhaltensweisen von durch BU betroffenen Personen mittels einer „KAP-Studie“ ermittelt. Diese Studie war durch den Mangel an soziokulturellen Grundlagedaten in den untersuchten Gemeinden motiviert und lieferte den Anlass für die Lancierung eines Buruli-Ulkus Präventions- und Behandlungsprogramms („BUPaT“). Zwischen November 2008 und Juli 2009 wurden Krankheitserfahrungen, Ursachenzuschreibungen und das Hilfesuchverhalten aus Sicht von 181 von BU betroffenen Personen mittels einer sogenannten kulturell-epidemiologischen Studie („CE-Studie“) erhoben. Die Teilnehmenden dieser Studie wurden aus 67 endemischen Gemeinden und den drei grossen Gesundheitszentren im Studiengebiet rekrutiert. Gleichzeitig wurde die Leistung des Gesundheitssystems in der erste Phase von „BUPaT“ evaluiert.

Die „KAP-Studie“ ermittelte einen tiefen Wissenstand bezüglich der Ursachen von BU: bloss 5.5% der Studienteilnehmenden erwähnten Schwimmen und Waten in Teichen als Risikofaktor; während 5.2% Hexerei als Ursache erwähnten, konnten 53% keine Ursache identifizieren. Herbalisten wurden von vielen als erste Hilfemassnahme nach einer Infektion aufgesucht, während die medizinische Behandlung als letzte Alternative angeschaut wurde. Gründe für die verspätete medizinische Behandlung bezogen sich auf Ängste bezüglich einer verlängerten Hospitalisation, Verzögerungen bei Behandlungen im Spital, Schwierigkeiten hinsichtlich Transportmöglichkeiten ins Spital, hohen Transportkosten und Einkommensausfällen wegen der langwierigen medizinischen Behandlung. Von BU betroffene Personen konnten auf viel Mitgefühl und Akzeptanz zählen, und zwar mehr unter Erwachsenen als unter Kindern. Diskriminierung von Personen mit BU durch Kinder basierte auf deren Angst vor Ansteckungen. Es wurde allgemein angenommen, dass von BU betroffene Personen die Öffentlichkeit meiden, weil ihnen ihre Erkrankung peinlich ist.

Die Resultate der „KAP-Studie“ deuteten auf einen Bedarf an Gesundheitsaufklärung in der Gemeinde hin, vor allem bezüglich Risikofaktoren und Erkennung von frühen Stadien von BU-Infektionen. Der Zugang zu Gesundheitsdiensten und –zentren wurde als weiteres Bedürfnis erkannt; dieser Zugang würde von einem in der Gemeinde verankerten Überwachungs- und Überweisungssystem profitieren, das eine rechtzeitige medizinische Behandlung ermöglichen würde. Zusätzlich empfiehlt diese Studie, Informationen über BU in die Lehrpläne an Schulen aufzunehmen, um Kinder hinsichtlich deren Befürchtungen zur Ansteckungsgefahr zu beschwichtigen. Wegen der Wichtigkeit der Kräuterheikunde in den untersuchten Gemeinden sollen Herbalisten bezüglich klinischer Merkmale von BU trainiert und auch vermehrt in das Gesundheitssystem integriert werden. Dadurch werden sie besser in der Lage sein, Personen mit BU zu diagnostizieren und diese an die Gesundheitszentren zu überweisen.

Die „CE-Studie“ präsentierte den Einfluss von Krankheitserfahrungen, Ursachenzuschreibungen und Aspekte des Gesundheitssystems auf das

Hilfesuchverhalten für BU. Resultate zeigten die Besorgnis über die Konsequenzen dieser Erkrankung auf und das damit verbundene immense physische Leiden von Personen mit Läsionen und Geschwüren. Zusätzlich zeigte diese Studie die negativen sozioökonomischen Auswirkungen von BU auf betroffene Personen und deren Familien auf; viele betroffene Personen hatten ihren Lebensunterhalt verloren und ihre Ausbildung wurde durch die Erkrankung unterbrochen. Familien, wo die für das Haushaltseinkommen hauptsächlich zuständige Person mit BU infiziert war, hatten besonders unter prekären finanziellen Verhältnissen zu leiden.

Mütter und andere weibliche Familienmitglieder mussten schwerwiegende Entscheidungen treffen, um die pflegerischen Bedürfnisse ihrer von BU betroffenen Verwandten im Spital zu befriedigen. Die tägliche Arbeit wurde vernachlässigt und junge Kinder wurden zu Hause nicht mehr beaufsichtigt, weil ihre Mütter zur Behandlung im Spital waren oder dort andere von BU betroffene Familienmitglieder pflegen mussten. Jüngere Mädchen hatten mehr Schulabsenzen zu erleiden als Knaben, da sie vermehrt Verwandte pflegen mussten. Die Resultate dieser Studie deuten auf weit reichende Konsequenzen bezüglich Wohlergehen, Entwicklung und ökonomischer Unterstützung hin.

Obwohl Herbalisten sehr begehrt waren, hat die „CE-Studie“ auch aufgezeigt, dass sich das Bewusstsein zu Merkmalen von BU seit der „KAP-Studie“ im Jahr 2005 erhöht hat. Entsprechend hatte ein hoher Anteil der Studienteilnehmenden, die an Geschwüren litten, medizinische Hilfe in

Anspruch genommen (66.9%); aber nur 17.1% der Teilnehmenden, die an Vorstadien zu Geschwüren litten, hatten solche Hilfe bezogen.

Nichtsdestotrotz deuteten Schwierigkeiten in der Diagnose von Läsionen im Frühstadium und das Fortschreiten von kleineren zu grossflächigen, langsam heilenden Geschwüren darauf hin, dass lokale Konzepte, die Hexerei als Ursache von BU annehmen, immer noch wirksam sind. Obwohl Teilnehmende, die an Hexerei glaubten, dennoch medizinische Pflege benutzten, waren sie gegenüber Gesundheitsbotschaften, welche Kontakt mit Wasser als Risikofaktor für BU betonten, voreingenommen. Dazu waren Teilnehmende auch skeptisch gegenüber Gesundheitsbotschaften, welche die Ansteckung von Personen ohne Wasserkontakt nicht erklären konnten. Einige Teilnehmende verlangten auch eine Erklärung, warum Personen mit häufigem Wasserkontakt nicht an BU erkrankt waren.

Hilfe zu Hause beinhaltete vor allem die kräutermedizinische Behandlung von Läsionen bevor sie zu Geschwüren wurden; auch wurde infiziertes Gewebe nach der lokalen Entfernung von Knötchen mit Kräutern behandelt. Analgetika, Balsam, Bluttonika und Antibiotika, vor allem Tetramycin und Phenoxymethylpenicillin (bekannt als Penicillin V), wurden in lokalen Drogerien und von fliegenden Medikamentenhändlern gekauft. Als erste Behandlungserbringer wurden hauptsächlich Herbalisten, die in Blutsverwandtschaft mit den Studienteilnehmenden stehen, aufgesucht. Herbalisten waren als Herumziehende auch einfach zu kontaktieren und nach deren Behandlung wurde erwartet, dass mit der Arbeit oder der Schule weiter gefahren werden kann.

Das Hauptziel der ersten Phase von „BuPaT“, das auf der Ebene des Gesundheitssystems ansetzte, bestand darin, durch frühe Wahrnehmung und Behandlung von Fällen zur Verminderung von durch BU verursachtem Leiden und Behinderung beizutragen. Zur Erreichung dieses Ziels wurden verschiedene Ansätze auf Gemeindeebene und verbesserte Strategien zum Fallmanagement eingesetzt. Die fünf Haupterrungenschaften im Gesundheitssystem waren folgende: (1) Umfangreiche Zusammenarbeit aller Akteure auf allen Ebenen (national, Munizipalität und Gemeinde) zur Stärkung des Gesundheitssystems. (2) Verbesserte Fähigkeiten des Gesundheitspersonals bezüglich Antibiotikaeinsatz und Wundpflege. (3) Lehrerkader, zuständige Beamte für Umwelt und Gesundheit auf Munizipalitätsstufe und Pflegepersonal und Freiwillige zur Überwachung in Gemeinden wurden trainiert, um korrekte Gesundheitsbotschaften zu vermitteln und um infizierte Personen zu erkennen und zur medizinischen Behandlung zu überweisen. (4) Es wurde eine Patientendatenbank geschaffen, die mit den offiziell empfohlenen WHO-Formularen arbeitete. (5) Es wurden neuerdings Antibiotika eingesetzt, die von der WHO zur besseren Behandlung und Heilung empfohlen sind. Diese werden vor allem bei Läsionen im Frühstadium eingesetzt, um deren Wiederauftreten zu verhindern. Ungeachtet dessen bestehen weiterhin Probleme hinsichtlich des Zugangs zur Behandlung und bezüglich fehlender Unterkünfte (nicht genügend Plätze auf Stationen), inadäquater Behandlungen mit traditioneller Medizin, Follow-Up-Verlusten und Nichtbefolgung der Behandlung.

Fazit: Diese Arbeit hat das substanzielle Ausmass und die Natur des Leidens und der Belastung von an BU erkrankten Personen und deren Familien aufgezeigt. Obwohl die Resultate auf ein verbessertes Bewusstsein und vermehrte Inanspruchnahme von medizinischer Behandlung hinweisen, wurde Hexerei weit verbreitet als Ursache wahrgenommen. Diese Ursachenzuschreibung könnte die Krankheitserfahrung und -belastung und den Skeptizismus gegenüber Gesundheitsbotschaften, welche Kontakt mit Flüssen, Weihern und Seen als Risikofaktoren für eine Ansteckung betonen, erklären.

Diese Studie zeigte, dass die Berücksichtigung folgender Faktoren im Gesundheitssystem wichtig war für die Bekämpfung von BU: die Zusammenarbeit zwischen Akteuren und die in Gemeinden verankerten Initiativen zur Überwachung, zur Gesundheitsbildung in Schulen, zur Erkennung und Überweisung von infizierten Personen und für einen verbesserten Zugang zur Behandlung. Um die Attraktivität von Herbalisten als Erstanbieter zu vermindern, sind der Zugang zu medizinischer Behandlung, insbesondere mit Antibiotika, wie von der WHO empfohlen, entscheidend. Da die Bevölkerung private Therapeuten konsultiert, sollten diese entsprechend ausgebildet und in das Gesundheitssystem integriert werden, damit der Zugang zu Antibiotika verbessert werden kann. Ausserdem sollten innovative Wege erdacht werden, um traditionelle Heiler, insbesondere Herbalisten, in das Gesundheitssystem zu integrieren und um die Überweisungsrate zu verbessern.

Allerdings werden Krankheitserfahrungen, Ursachenzuschreibungen und das Hilfesuchverhalten durch die soziokulturellen Kontexte der betroffenen Personen beeinflusst, welche sich wahrscheinlich nach der Vermittlung von Gesundheitsinformationen und mit verbessertem sozioökonomischem Status verändern. Somit sind regelmässige soziokulturelle Beurteilungen nötig, um den Programmen im öffentlichen Gesundheitswesen geeignete Informationen bereitzustellen; damit können aktuelle Behandlungsprobleme und -lücken angegangen werden. Da die Art der Übertragung von BU weiterhin unklar ist, sind weitere interdisziplinäre Forschungen auf diesem Gebiet nötig, um die Rolle von umweltrelevanten, soziokulturellen und genetischen Faktoren hinsichtlich einer Ansteckung mit BU zu erklären.

Chapter 1

Introduction

1.1 Description and clinical manifestation of *Mycobacterium ulcerans* infection (Buruli ulcer)

Mycobacterium ulcerans infection, caused by an environmental pathogen, is a disease of the skin, underlying tissues and sometimes the bones. It is commonly referred to as Buruli Ulcer (BU). BU is the third most common mycobacterium infection of immuno-competent hosts after tuberculosis and leprosy, and it is the most poorly understood of the three diseases (Amofah et al., 2002; Meyers et al., 1996; Sizaire et al., 2006). The BU disease has two stages – the pre-ulcer stage and the ulcer stage.

Figure 1.1: Clinical features of Buruli ulcer

a. Nodule b. Plaque c.Oedema

d. Papule e. Ulcer f. Deformed hand

Source: photos (a - c) – Courtesy Ga-West municipal health directorate and used with permission. d. (World Health Organisation, 2000). Photos e and f taken by Mercy Ackumey, 2007.

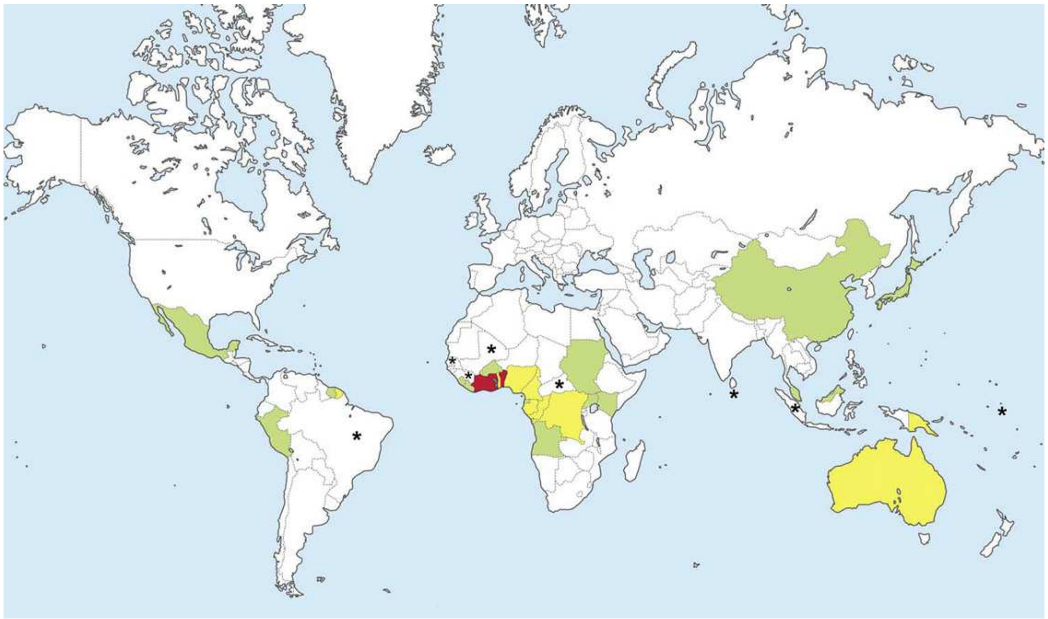
The pre-ulcer stage is presented as a nodule, plaque, oedema or papule. All these forms, except papules are common in Africa; papules are only common in Australia (Portaels et al., 2009) (figure 1.1). When pre-ulcer conditions are left untreated, they progress to ulcers which may enlarge, destroy wide areas of the skin, infect the bone (osteomyelitis) and cause contractures and disabilities. Although mortality is rare, morbidity is serious (Sizaire et al., 2006; World Health Organization, 2009). Ulcers are usually painless unless infected by secondary bacteria. Small ulcers are also known to heal spontaneously without treatment if not infected (Portaels et al., 2009; Walsh et al., 2008; World Health Organization & Global Buruli Ulcer Initiative, 1998).

1.2 History and global distribution of Buruli ulcer

Various names for the condition often indicate the locale where cases in a region were initially identified. *Mycobacterium ulcerans* infection was first described in 1897 by Sir Alfred Cook, a missionary doctor, in the Buruli County (now called Nakasongola District) in Uganda, and it was subsequently named after this county (World Health Organisation, 2000). However, there has been no reported incidence of the disease in Nakasongola District since the 1980s. In Australia, in 1948, the first case of the BU disease was published (MacCallum et al., 1948). *M. ulcerans* infection is generally referred to as Bairnsdale ulcer in Australia after the Bairnsdale town where a group of patients were found to have the disease in the late 1930s (Radford, 2009). However in the Daintree River catchment area in north Queensland, Australia, it is locally referred to as ‘Daintree Ulcer’, named after the river (Steffen et al., 2010).

It is difficult to establish the prevalence of BU by country and by different locations within a country due to variability in clinical presentations, seasonal variations, insufficient knowledge of the disease among health workers, geographical barriers to access and communication in remote endemic areas (Amofah et al., 2002; Portaels et al., 2009). However, it is estimated that more than 7000 people are infected with BU annually and the highest incidence rates are in West Africa (figure 1.2) (World Health Organization, 2008).

Figure 1.2: Global distribution of *M. ulcerans* infection



Source: (Walsh et al., 2011)

*Colours indicate relative endemicity: Red=high; moderate = yellow; green = low; asterisks = countries with suspected cases. Imported BU is occasionally diagnosed in the United States, Canada, and Europe.

BU has been reported from over 30 countries in the Americas, South east Asia, Western Pacific the Eastern Mediterranean and African regions (World Health Organization, 2008). BU was reported in several Sub-Saharan African countries prior to the 1980s including Democratic Republic of Congo (Smith, 1970), Uganda (The Uganda Buruli Group, 1971), Gabon (Burchard & Bierther, 1986), Nigeria (Oluwasanmi et al., 1976), Cameroon and Ghana (Bayley, 1971). Since 1980, there have been dramatic increases in the incidence of BU in West African countries like Benin (Debacker et al., 2004a), Republic of Côte d'Ivoire (Marston et al., 1995) and Ghana (Amofah et al., 2002). Ghana reports an average of 1000 cases annually (World Health Organization, 2008).

1.3 Context of Neglected Tropical Diseases

Buruli ulcer is intended among the so-called neglected tropical diseases (NTDs). According to a WHO report (World Health Organization, 2009), at least 1 billion people, representing one sixth of the world's population of over 6 billion people, suffer from one or more NTDs. They represent about 17% of the global burden of parasitic and infectious diseases and are endemic in rural communities of Sub-Saharan Africa and poor urban areas in low-income countries in Asia and Latin America. An estimated 534,000 people worldwide die from a NTD each year (World Health Organization, 2009).

In addition to BU, other diseases categorised as NTDs include, leprosy, cholera, Human African Trypanosomiasis (HAT), dracunculiasis (guinea-worm disease) lymphatic filariasis, onchocerciasis and schistosomiasis. For some

NTDs - such as leprosy, filariasis, onchocerciasis and schistosomiasis – effective interventions for treatment and control are available in the form of chemotherapy, personal hygiene and environmental sanitation. For others including BU, cholera and other diarrhoeal diseases, and HAT, the only option available is systematic case finding, early detection and management (World Health Organization, 2009). Surprisingly, estimates of disability adjusted life years (DALYs) for BU, like other NTDs such as guinea worm, echinococcosis, endemic syphilis, foodborne trematode infections (clonorchiasis, fascioliasis, opisthorchiasis) and rabies are not explicitly stated in WHO published data (World Health Organisation, 2010).

BU like other NTDs is a serious public health concern because it typically affects impoverished populations in the developing world. Unsafe water, lack of access to health services, malnutrition and poor sanitation all increase vulnerability to infection. NTDs are neglected because they affect the countries' most vulnerable segment of the population - women, children, uneducated and the poor. They are often underreported or unnoticed because the sufferers lack political voice to make their concerns known and insufficient government budgetary allocations to the health sector. Thus, only the highly prioritised diseases with high mortality rates receive attention and resources. Social, psychological and economic impacts of these diseases include long years of intense suffering, pain, loss of productivity, disrupted education, impaired mental and physical development, stigma and distress. All these factors widen the poverty gap and make the sufferers even more vulnerable (World Health Organization, 2009).

1.4 Epidemiology of Buruli ulcer

BU is endemic in rural aquatic environments of tropical African countries, rural areas of Papua New Guinea, Malaysia, French Guiana and Mexico (Johnson et al., 2005; Portaels et al., 2009). Recently, there have been increases of the incidence of BU in some previously endemic parts of Australia (Johnson et al., 1996; World Health Organisation, 2003).

1.4.1 The role of environmental factors in Buruli ulcer disease transmission

BU occurs in areas where there has been significant disturbance to the environment through mineral and sand mining, damming, irrigation, deforestation and rapid urbanisation (Asiedu & Portaels, 2000; Barker, 1971; Duker et al., 2004; Oluwasanmi et al., 1976; The Uganda Buruli Group, 1971; Veitch et al., 1997; Zeifer et al., 1981). Studies suggest that contact with water bodies such as ponds, lakes, rivers and dams through farming, fishing, bathing and wading are risk factors (Aiga et al., 2004; Asiedu & Portaels, 2000; Duker et al., 2006; Marston et al., 1995; Oluwasanmi et al., 1976; Raghunathan et al., 2005; The Uganda Buruli Group, 1971).

Based on epidemiological evidence, person-to-person transmission is rare or impossible (Johnson et al., 2005; Portaels et al., 2009; Sizaire et al., 2006; van der Werf et al., 2005). The main mode of infection from the environment to humans and the exact reservoirs remain unclear. However, it is hypothesised that the aetiological agent enters the body through skin trauma (Meyers et al., 1974) or insect bites (Portaels et al., 1999; Silva et al., 2007).

1.4.2 The role of animals and insects in Buruli ulcer transmission

Studies have suggested that other animal reservoirs could be involved in *M. ulcerans* infection. Bites from water bugs from the generae *Naucoris and Diplonychus,* which feed on water filtering insects, have been proposed as a possible mechanism of infection (Portaels et al., 1999). It is hypothesised that these insects could infect persons who have had no water contact(Portaels et al., 1999). Other studies have proposed aquatic insects and snails, koalas, ringtail possums and a captive alpaca as natural reservoirs. (Eddyani et al., 2004; Marsollier et al., 2004; Portaels et al., 2001). Furthermore, recent epidemiological reports from Australia suggest that mosquitoes and terrestrial mammals may play an important role in the transmission of BU (Fyfe et al., 2010; Wallace et al., 2010). A rare case of BU infection has been reported, following a human bite (Debacker et al., 2003).

1.4.3 Age and gender

All age groups are affected but a higher prevalence is found in children younger than 15 years-of-age.(Ackumey et al., 2011b; Amofah et al., 1993; Debacker et al., 2006; Marston et al., 1995; Noeske et al., 2004; The Uganda Buruli Group, 1971; van der Werf et al., 1989). Generally, there are no sex differences in BU disease prevalence. However, some studies have found differences in prevalence between males and females: One study in Benin found that men aged 59 years and older were more at risk of BU infection than women (Debacker et al., 2004b). In two separate studies in Ghana, male children younger than 15 years and females older than 59 years were more at risk of BU infection (Amofah et al., 1993; Hospers et al., 2005).

1.5 Socio-cultural features of Buruli ulcer

Current case management strategies emphasise the importance of early reporting and timely and appropriate medical treatment of nodules before they ulcerate and give rise to debilitating disease sequelae of osteomyelitis, contracture deformities and disabilities (World Health Organisation, 2001; World Health Organization, 2008). However, there are a wide range of social, demographic and gendered factors that influence experience, meaning and behaviour for BU.

1.5.1 Illness experience and meaning for Buruli ulcer

Illness experience refers to various aspects of BU as seen from the vantage point of affected persons. This includes the experiences of physical symptoms, psychological, emotional and social impacts of BU, enacted and anticipated stigma and concerns about anticipated outcomes. The social, psychological and emotional stressors of BU, local ideas of disease contagion and attribution of BU illness to supernatural forces, environmental and hereditary factors, vulnerability, poor sanitation and hygiene are commonly referred to as the experience and meaning of illness (Weiss, 1997). Collectively, illness experiences and meanings are associated with local names for BU; they influence help-seeking choices, timeliness of medical treatment and have implications for BU control strategies.

1.5.2 Socio-cultural features of help-seeking for Buruli ulcer

Local ideas of witchcraft as a cause of BU, perceived seriousness of BU infection, perceived effectiveness of medical treatment, fear of recurring infections, surgery and amputation constitute socio-cultural features of BU that affect preferences for herbal treatment and delayed medical treatment (Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Mulder et al., 2008; Renzaho et al., 2007; Stienstra et al., 2002).

Aside from cultural factors, socio-economic factors such as high transport costs to health centres, loss of livelihoods and income because of BU infection and hospital admission, absence from work or school to give care at home or in the hospital are some reasons that account for late medical treatment (Ackumey et al., 2011a; Ackumey et al., 2011b; Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Grietens et al., 2008).

In cultural and legal terms, the welfare of children is the responsibility of parents or care-givers. Therefore in the event of BU infection, the choice and timeliness of treatment for children is determined by parents or care-givers. Social consequences of treatment delay for children include prolonged absence from school and eventual drop-out. BU infection therefore poses a serious socio-economic problem to families. Some care-givers are unable to cope with these exigencies and therefore abandon their wards (Grietens et al., 2008).

1.5.3 Gendered features of help-seeking

The socio-cultural dimensions of BU include the ways in which gender related-roles of care affect work, school and family welfare. Effects on care-givers, particularly women, include long periods of absence from home and the combined pressures of providing care for hospitalised children and wards and securing livelihoods. Young female children too are often absent from school to provide care for family members at home and the hospital. This has serious implications for their future development. Family welfare is further compromised when the affected person is the main income earner. Economic constraints and the desire to continue working to support the family, compel income-earners to choose between other treatment types and medical treatment.

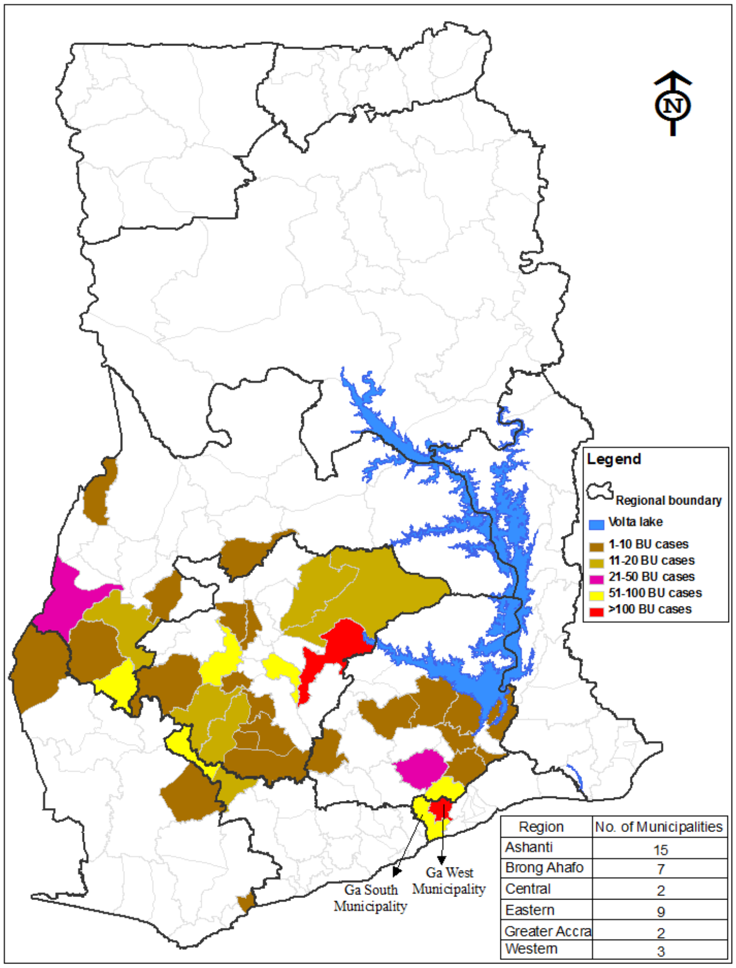
1.6 Epidemiology of Buruli ulcer in Ghana

The national prevalence rate for BU in Ghana is 20.7/100,000 (Amofah et al., 2002). The BU disease was first detected in a girl from a community in the Ga district, now Ga-West municipality (Bayley, 1971), in 1970. In 1989, 96 cases of BU were detected in the Asante-Akim North District of the Ashanti Region (van der Werf et al., 1989).

In 1993, a passive surveillance system for reporting BU was initiated in Ghana, and by the end of 1998, approximately 1,200 cases had been reported from four regions (Amofah et al., 2002). This surveillance system was fraught with problems of gross underreporting because most cases were known to be in relatively deprived and inaccessible areas. At the end of the case search, approximately, 6000 cases were identified in all ten regions of the country. The Amansie West, Ashanti region with a prevalence of 150 per

100,000 emerged as the most endemic district. The Ga- West[1] district with a prevalence of 87 per 100,000 is the fifth most endemic district, although it has the highest case-load of people with healed and active lesions (Amofah et al., 2002).

Figure 1.3: Buruli ulcer endemic regions and municipalities in Ghana, 2010



Region	No. of Municipalities
Ashanti	15
Brong Ahafo	7
Central	2
Eastern	9
Greater Accra	2
Western	3

Source: Data for map provided the national Buruli ulcer control programme.

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[1] By a Government legislative act, the Ga-West district was divided into two municipalities, the Ga-West and Ga-South municipalities, in February 2009 for easy administrative purposes.

1.7 Global control efforts for Buruli ulcer

Until the introduction of antimicrobial therapy in 2005 (WHO & GBUI, 2004), wide surgical excision, sometimes followed by skin grafting, was the main treatment strategy for all forms of the BU disease (Asiedu & Etuaful, 1998; Sizaire et al., 2006). Clinical trials in Ghana using an anti-tuberculosis drug combinations rifampicin and an aminoglycoside (streptomycin or amikacin), showed the efficacy of these drugs to shrink early lesions, such as nodules, and to reduce the diameter of ulcers, thereby avoiding the need for surgery (Chauty et al., 2007; Etuaful et al., 2005; Johnson et al., 2005; Nienhuis et al., 2010; WHO & GBUI, 2004) Furthermore, recurrence is minimal after antibiotic therapy (Ackumey et al., 2011b; Etuaful et al., 2005; Kibadi et al., 2010; Nienhuis et al., 2010).

Based on this evidence, the WHO recommends antimicrobial treatment for 8 weeks with rifampicin and streptomycin, with or without surgery, depending on the nature of the lesion. WHO also recommends follow-up of patients, for at least 10 months after treatment, to assess treatment outcomes, complications, and possible recurrence.

Aside from antibiotic treatment and surgery, WHO also recommends various community and clinical management, and control strategies. These include: (1) Early detection of cases at the community level, and information, education and communication. (2) Training of health workers and village health workers. (3) Case management (a combination of antibiotics, surgery and prevention of disability/rehabilitation). (4) Laboratory confirmation of cases. (5) Standardized recording and reporting system using specialised forms (BU 01 and BU 02). (6) Strengthening of health facilities. (7) Monitoring and evaluation of control activities (World Health Organisation, 2001).

1.7.1 The National Buruli Ulcer Control Programme (NBUCP)

Ghana signed the Yamoussoukro declaration in 1998, which enjoined governments of endemic countries to establish national Buruli ulcer control programmes (World Health Organisation & Global Buruli Ulcer Initiative, 2000). Subsequently, the Ghana NBUCP was established in 2002 and currently operates under the Ghana Health Service. The main aims of the NBUCP are:

- To create awareness of BU among medical practitioners and the general public.
- To collaborate with health centres to train health and community workers to increase awareness of BU, and recognise and screen early cases of BU for referral.
- To improve case-management and surgical skills of clinical staff
- To collaborate with research and medical institutions to conduct environmental, clinical, immunological and drug-related studies on BU.
- To provide community health services, and increase access to treatment using the directly observed treatment strategy (DOTS) approach.

The NBUCP collaborates closely with several research institutions in the following capacities in pursuance of its mandate:

1.7.1.1 Early case detection, treatment, research and capacity development

The St. Martin’s Catholic hospital, Agroyesum, in the Ashanti region of Ghana, serves as a specialist treatment and referral centre for BU in the middle-belt of Ghana (St.Martin's hospital, 2011). This hospital was the centre for a multi-institutional and international collaborative study which demonstrated the efficacy of rifampin and streptomycin in inhibiting growth of *M. ulcerans* in early lesions of BU (Etuaful et al., 2005). Based on the evidence from this study, these drugs were recommended by WHO for the treatment and management of BU.

The Reconstructive Plastic Surgery and Burns (RPSB) unit of the Korle-Bu Teaching Hospital in Accra, Ghana, offers reconstructive surgery for BU patients who need it. Currently, the RPSB collaborates with the municipal health directorate of the Ga-West and South municipalities for surgical treatment of patients.

The NBUCP works closely with a network of laboratories at various levels in hospitals and research institutions, such as the Noguchi Memorial Institute for Medical Research (NMIMR), Accra, the Komfo Anokye Teaching Hospital, Kumasi, and the Kumasi Centre for Collaborative research (KCCR). These laboratories collaborate with clinical staff in endemic areas of the country to provide accurate laboratory-confirmed incidence and prevalence data on *M. ulcerans* infection, conduct research in BU-endemic areas and provide training on appropriate laboratory procedures.

The NMIMR is one of the research institutions collaborating with the Stop Buruli Initiative, a global initiative committed to research and advocacy on BU. The KCCR collaborated with several research and health institutions in the country and abroad to conduct comparative studies on the sensitivity of different diagnostic methods for BU that are suitable for poorly resourced health facilities. Based on evidence from these studies, the WHO recommends dry Polymerase Chain Reaction (PCR) tests for confirmation of BU cases in endemic settings (Siegmund et al., 2005).

The Agogo Presbyterian Hospital, located in the Ashanti-Akim North municipality of Ghana is one of the designated training, research and treatment centres, by WHO and the Ministry of Health (MOH), Ghana. The Agogo hospital has collaborated with other research and medical centres in the country to conduct studies on the pharmacokinetics of Rifampin and Clarithromycin in persons treated for *M. ulcerans* infection (Alffenaar et al., 2010) and drug trials for the efficacy of combinations of streptomycin and rifampicin, clarithromycin and rifampicin and streptomycin and clarithromycin (Nienhuis et al., 2010).

1.7.1.2 Health system strengthening

Since 2002, the Agogo hospital has trained surgeons and medical staff from endemic countries in Africa, including Ghana, in recommended BU surgical and wound management procedures. Furthermore, regional, municipal and on-site skill enhancement workshops are conducted regularly to bring medical staff up-to-date with clinical management techniques for BU.

Community-based surveillance volunteers who are largely volunteers of guinea worm, tuberculosis and schistosomiasis programmes and community health personnel are trained to increase awareness on BU, identify all forms of *M. ulcerans* infection and refer for medical treatment. School teachers are also trained to educate pupils and students about risk factors for *M. ulcerans* infection and also identify cases for referral to medical facilities.

The Global Buruli Ulcer Control Initiative (GBUI) of the WHO has developed information, education and communication (IEC) materials, such as posters; information guides for CBSVs, health workers and teachers; and comics for pupils and students. These materials are used in Ghana and have been distributed in endemic areas. As a result of these IEC programmes, the number of self-referrals is substantial and an indication of successful programme impact (table 1.1).

Table 1.1: Referrals of Buruli ulcer-affected persons in Ghana, 2010

Endemic Regions	Persons referring BU-affected individuals						Total
	CBSV	Former Patient	Health Worker	Other	Self	School Teacher	
Ashanti	70	40	175	16	151	0	452
Brong Ahafo	3	0	0	0	36	0	39
Central	1	72	13	1	11	2	100
Eastern	35	11	52	1	44	6	149
Greater Accra	16	3	80	8	98	3	208
Western	1	0	5	0	2	0	8

Source: National Buruli ulcer control programme

1.8 Buruli ulcer treatment and control in the Ga-West and Ga-South municipalities

Surgery used to be the standard form of treatment for BU in the Ga-West and South municipalities, like other endemic areas of Ghana. In 2005, the first phase of a Buruli Ulcer prevention and treatment (BUPaT) programme was initiated for the period 2005-2008, to decrease the incidence of active BU in the district. It aimed to increase BU treatment and improve early case detection. To achieve this, the programme carried out the following WHO-recommended strategies: (1) Compiling a data base of all BU patients in the district. (2) Providing surgical and antibiotic therapy for all BU patients. (3) Building capacity of nurses and other para-medical staff for effective case management at designated health centres. (4) Recruitment and training of community-based surveillance volunteers (CBSVs), school teachers, health workers and traditional healers (THs) to enhance BU knowledge among community residents and school children, in particular, for early detection and improved management (figure 1.4). (5) Establishing a community-based disease surveillance system with the help of CBSVs.

Figure 1.4: Health education session in Asofaa Junior Secondary School, Ga-West Municipality *

*A community heath nurse gives a talk on BU using IEC materials provided by the WHO. (Photo by Mercy Ackumey, 2007).

These strategies were undertaken by a health system with participation of several partners. They include the NBUCP, programme staff of the BUPaT from World Vision Ghana, (WVG), the municipal health management team (MHMT), the municipal director of health services (MDHS), Municipal Assembly (MA), surgeons from the RPSB, Korle-Bu Teaching Hospital, Accra, some health staff in both municipalities, municipal school health education programme (SHEPs) coordinators, municipal environmental health officers (MEHOs), CBSVs, THs and community members.

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Chapter 2

Study aims, objectives and methods

2.1 Introduction

The Ga-West and Ga-South municipalities, are the fifth-most endemic municipalities, yet have the highest case-loads in terms of healed and active lesions (Amofah et al., 2002)**.** A motivation for this study was the paucity of socio-cultural research on Buruli ulcer (BU) needed to guide public health programmes, although bacteriological and immunological studies (Diaz et al., 2006; Yeboah-Manu et al., 2006) have been done in these municipalities. An additional motivation for the study and the choice of the study area was based on prior experience with field work on BU in 2001, 2005 and 2008. In 2001, a study entitled 'Local Perceptions of Buruli Ulcer in the Ga District, Greater Accra region' (Ackumey, 2002) was conducted towards the acquisition of a Masters degree in Public Health (MPH). This study informed the design of the knowledge, attitudes and practice (KAP) baseline study in 2005.

In 2005, a KAP BU baseline study was undertaken for World Vision Ghana, an international non-Governmental organisation. This study justified the inception of the Buruli ulcer prevention and treatment (BUPaT) programme which was initiated in the Ga-West and Ga-South municipalities in 2005, to improve early case-detection and treatment of *Mycobacterium ulcerans* infection. The programme employed WHO-recommended strategies for Buruli ulcer management and control, combining community-based health education and surveillance programmes with improved clinical wound care and management. Before the inception of this programme, surgery was the standard treatment for BU. However, under the programme, WHO-recommended antibiotics, streptomycin and rifampicin were introduced for the management of BU, for the first time.

Against this background, this thesis assesses socio-cultural features of BU illness for pre-ulcers and ulcers distinctively and the impact of these features on help-seeking behaviour in general, including timely medical treatment for BU. The health system performance of the BUPaT programme for early case-detection and treatment of *M. ulcerans* infection are also investigated in this thesis.

Sections 2.2 and 2.3 outline the aims and specific objectives of this thesis, respectively. The study area and population are described in section 2.4. Section 2.5 presents the conceptual framework of the study, the cultural epidemiological framework and section 2.6 explains the explanatory model interview catalogue (EMIC). An overview of the study design and chapters are stated in section 2.7.

2.2 The study aim

The main aim of this thesis is to clarify the role of demographic, gender-related, and socio-cultural features of BU and how these features impact on the quality of timely treatment for BU and control in Ghana.

2.3 The study objectives

1. **Clarify community knowledge, attitudes and practices on the mode of transmission, prevention and treatment of the Buruli ulcer in Ga-West District, Ghana**

Specifically the objective:

i. Examined communities' understanding of the causes of Buruli ulcer

ii. Examined communities' perceptions of, and attitudes towards BU affected-persons.
iii. Clarified treatment seeking behaviour of affected persons from the perspective of unaffected persons in the community.

2. **Clarify socio-cultural features of BU (illness experience, meaning and behaviour) from the perspective of affected persons in the community.**

Specifically this objective:

i. Explained perceived causes and patterns of distress for BU from the perspective of affected persons.
ii. Examined the socio-cultural and socio-economic impact of BU on the welfare of the family.
iii. Examined the gender dimensions of care and its impact on productivity, education and welfare.
iv. Explained help-seeking behaviour of affected people for *M. ulcerans* infection

3. **Clarify socio-cultural determinants of timely, appropriate treatment of BU**

Specifically this objective:

i. Examined the previous help-seeking behaviours of affected persons and its impact on timely, appropriate treatment
ii. Examined socio-cultural and health system features of timely, appropriate treatment of BU.

4. **Clarify health system priorities, strategies and operations for control of BU**

Specifically this objective:

i. Examined health system's strategies, achievements and challenges for BU treatment and control.
ii. Documented lessons learnt from the health system's response to BU management

2.4 The study area

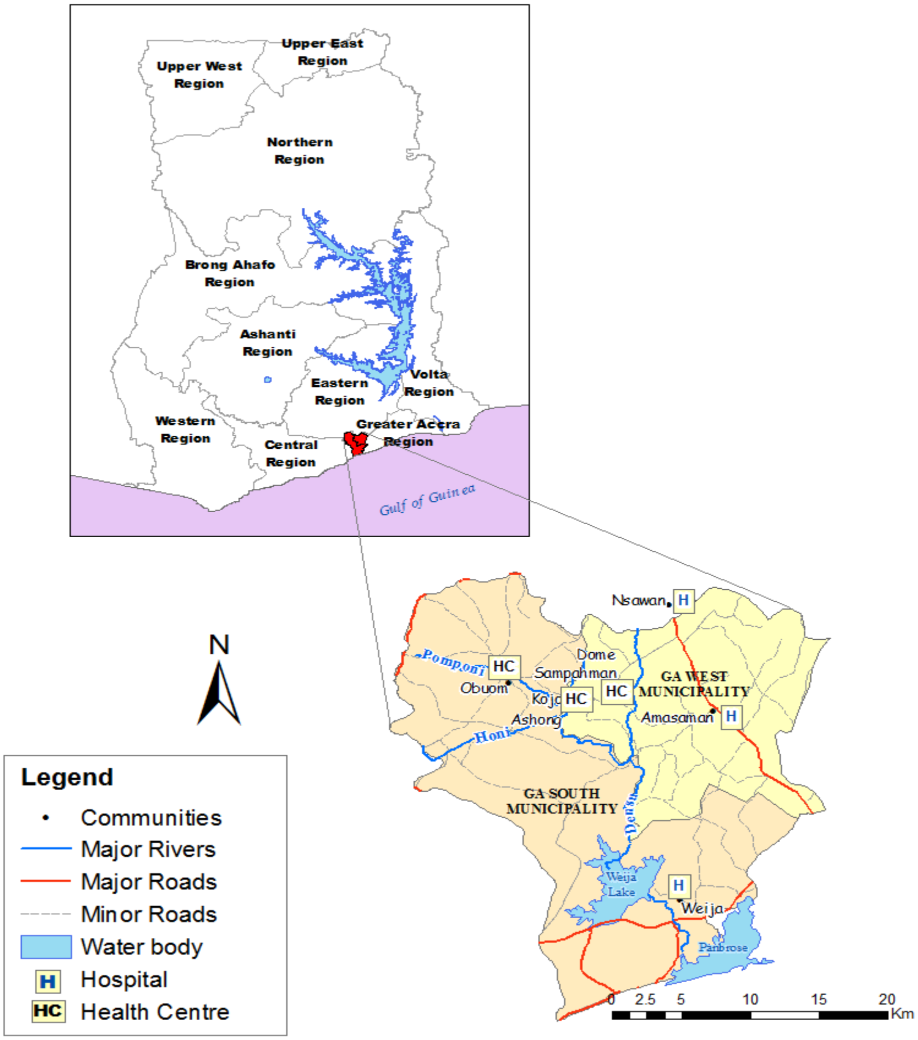
2.4.1 Study location and population

The study was undertaken in the Ga-West and Ga-South Municipalities of the Greater Accra region (figure 2.1). The population of the Ga-West Municipality (GWM) for 2009 was 215, 824, based on projected population estimates from the national housing and population census. (Annual report- Municipal Health Management Team, Ga-West Municipality). The GWM is predominantly rural. The projected population of the Ga-South Municipality (GSM) for 2009 is 284,712. About 76% of the GSM is predominantly urban and peri-urban while 24% is rural (Ga-South Municipal Directorate, 2011). Both municipalities have a similar population structure; 35% of the population is below the ages of 15 years and 65% are 15 years-of-age and above.The dominant ethnic group of the two municipalities is the Ga, who are the landlords. The Ewe, settler farmers, are the second largest ethnic group. Other minority ethnic groups are the Hausa, Dagarti, Grunshie and Akan.

2.4.2 Economic activities

In the GWM, about 95 percent of the farmers are small holders with 5 percent being large scale holders. Small-scale holders are mostly settler farmers cultivating mainly maize and cassava during the major rainy season, and assorted fruits and vegetables during the minor season. The main economic activities of the GSM are fishing along the coast and in the lakes and farming in the rural parts. There are also many small-scale subsistence farmers who cultivate maize, cassava and various vegetables in the GSM and there are large commercial farms that grow fruits and vegetables for export. These farms employ local farm hands. There are a few industries and manufacturing companies in the urban parts of both municipalities.

Figure 2.1: Map of the study area – the Ga-West and Ga-South Municipalities *



*Inset is the map of Ghana, showing the location of the study municipalities

2.4.3 Drainage, access to water and sanitation facilities

The river Densu, the largest water body in the study area, flows from north to south in the GWM and is dammed at Weija, the capital of the GSM. Weija is also the site of a major water treatment and supply company that supplies water to the eastern and western parts of the Accra Metropolis including the peri-urban parts of the GSM. Sadly, the GWM does not benefit from this company.

Other rivers, which are tributaries of the Densu are the Adeiso, Honi and Ponpon rivers. There are also small ponds and seasonal streams. In addition, numerous surface water bodies have sprung up as a result of extensive sand-mining activities to supply the building industry in the urban parts of both municipalities and the neighbouring Accra metropolis. These water bodies are significant for economic activities such as fishing (to a lesser extent), farming and are responsible for water-related diseases such as BU, schistosomiasis and malaria.

Less than 40 percent of the populace has access to pipe-borne water and toilets; a few communities in both municipalities have boreholes, yet usage is low because of the high salinity and iron content of the water. Thus most communities depend on ponds, dams, streams and the river Densu for their supply of water for domestic and agricultural activities. Currently, there are initiatives from government and non-governmental organisations in the water sector to provide safe water to many communities in both municipalities.

2.4.4 Access to health facilities and services

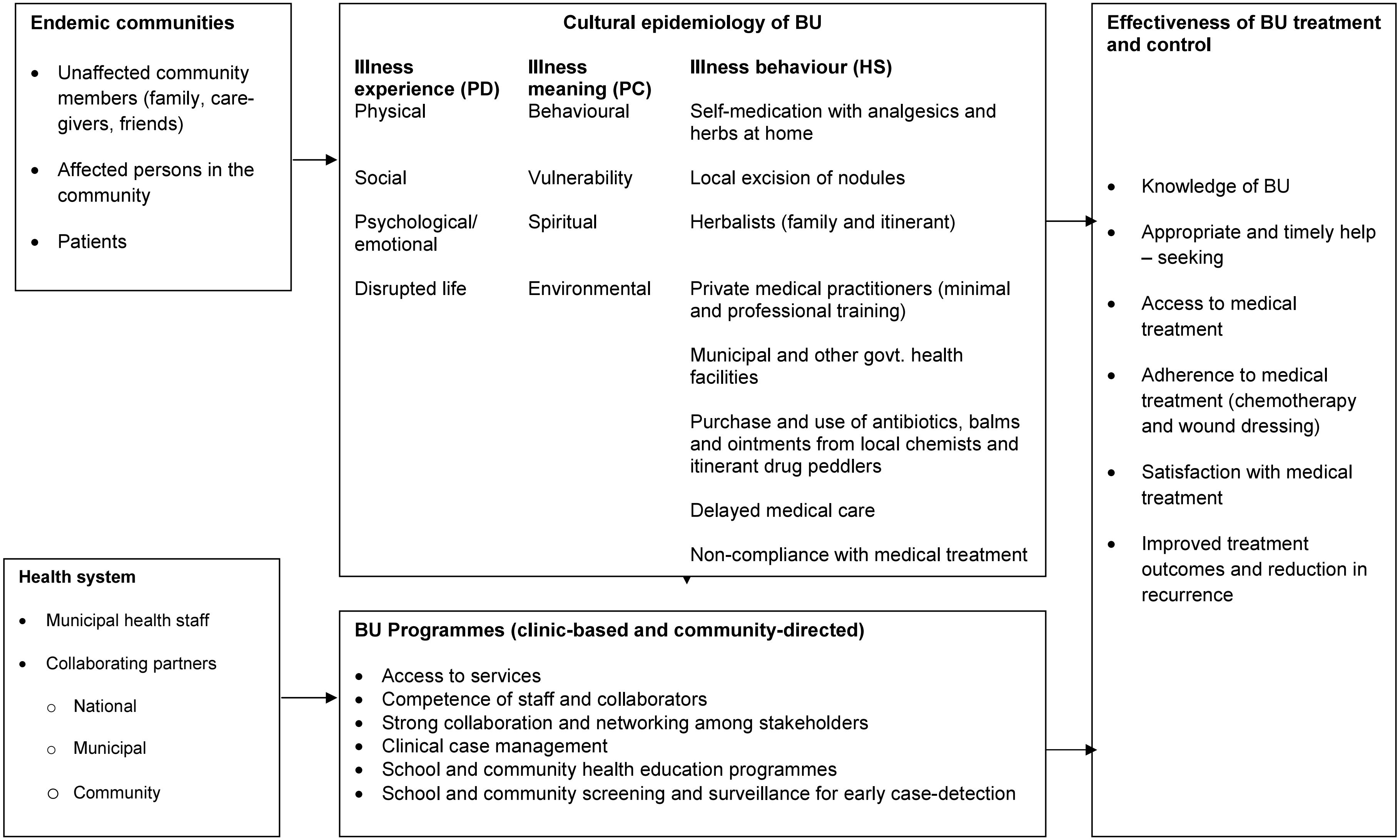
There is one major hospital at Amasaman in the GWM and it is one of the main surgical and referral centres for BU cases in the Greater Accra, Eastern and Central regions of Ghana. Aside from this hospital, medical treatment for BU, excluding surgery is provided in two other clinics located at, Kojo Ashong and Dome Sampahman. The major government hospital that serves the Ga-South Municipality in Weija, its capital, does not provide comprehensive medical care for BU. However, the Obom health centre located in the GSM provides wound care, antibiotic treatment and minor excisions for BU. There are other private clinics and maternity homes at Domeabra and Oduman in the GWM and Jei – Krodua in the GSM. However, these facilities do not provide BU treatment.

Road networking in the study area is very poor and about eighty-five (85) percent of access roads are untarred and deteriorate further during the rainy season. The poor condition of these roads makes access to health and other socio-economic services such as schools and markets a major problem in the municipalities. The majority therefore seek home-made (local) herbal treatment for most ailments as a first line of action.

2.5 The conceptual framework - the cultural epidemiological framework

This thesis is guided by the cultural epidemiology framework which integrates concepts and methods of epidemiology and anthropology. Epidemiology quantifies disease burden, risk factors and determinants of disease outcomes. Medical anthropology is more concerned with the relationship between illness, culture and social context. Cultural epidemiology is therefore the study of locally valid representations of illness and their distribution. These representations are specified by variables, descriptions and narratives accounting for the experience of illness, its meaning and associated behaviour. The cultural epidemiology framework arose from efforts to develop an interdisciplinary approach including instruments to clarify quantitative and qualitative features of illness meaning, experience and behaviour (Weiss, 2001). Explanatory model interviews collectively identified as the EMIC are typically used in these studies. The EMIC tool is discussed in detail in section 2.6.

Figure 2.2: The conceptual framework



Endemic communities

- Unaffected community members (family, care-givers, friends)
- Affected persons in the community
- Patients

Cultural epidemiology of BU

Illness experience (PD)	**Illness meaning (PC)**	**Illness behaviour (HS)**
Physical	Behavioural	Self-medication with analgesics and herbs at home
Social	Vulnerability	Local excision of nodules
Psychological/ emotional	Spiritual	Herbalists (family and itinerant)
Disrupted life	Environmental	Private medical practitioners (minimal and professional training)
		Municipal and other govt. health facilities
		Purchase and use of antibiotics, balms and ointments from local chemists and itinerant drug peddlers
		Delayed medical care
		Non-compliance with medical treatment

Effectiveness of BU treatment and control

- Knowledge of BU
- Appropriate and timely help – seeking
- Access to medical treatment
- Adherence to medical treatment (chemotherapy and wound dressing)
- Satisfaction with medical treatment
- Improved treatment outcomes and reduction in recurrence

Health system

- Municipal health staff
- Collaborating partners
  - National
  - Municipal
  - Community

BU Programmes (clinic-based and community-directed)

- Access to services
- Competence of staff and collaborators
- Strong collaboration and networking among stakeholders
- Clinical case management
- School and community health education programmes
- School and community screening and surveillance for early case-detection

Figure 2.2 provides a graphic presentation of the conceptual framework of the study. There are two main components in this study; community and health-system factors. For the community component, features of Illness experience (PD), meaning (PC) and behaviour (HS) were studied from the perspective of three population groups; unaffected community members, BU patients and affected persons in the community. Illness behaviour of the communities is guided by their local understanding of BU experience and meaning. Illness experience is the course of BU sickness and is explained by the degree of severity and its impact on the physical, spiritual, financial, psychological well-being of the affected persons. Illness meaning refers to lay perceptions of BU aetiology which influences choice of first–help and subsequent help-seeking behaviours. Help-seeking is defined as the variety of options that affected persons have and use as treatment for BU which include home-remedies, traditional and spiritual therapy and medical treatment. All these factors (Illness meaning, experience and behaviour) are influenced by the socio-cultural environment in which the communities live.

The role of unaffected community members as family and care-takers of affected persons has profound psychological and social impacts on their welfare. Unaffected community members face an imminent risk of BU-infection because they live in BU-endemic areas. Their knowledge of BU provides; a reasonable assessment of the impact of health education programmes, an indication of knowledge gaps and an insight into anticipated help-seeking behaviour.

The second component is the health system. The health system comprises the health staff and collaborating partners at the national, municipal and community levels. The collaborating partners at these levels are the National Buruli ulcer control programme (NBUCP), the World Vision Ghana (WVG) the community-based surveillance volunteers (CBSVs), school teachers, and the communities. The health system manages the BUPaT programme which has both a treatment and a control component. Activities comprising the treatment component are the combination antibiotic treatment, surgery and wound dressing. Control activities are community and school-based health education programmes focussing on identification of BU and the importance of timely and appropriate help-seeking and community surveillance for early case finding. The treatment component of the programme is targeted at patients while the control component is for the entire community. For the health system to be effective in BU treatment and control, its players must have a fair understanding of illness experiences and local perceptions of BU causation which is likely to influence behaviour. Health system strategies must consider the socio-cultural context of affected persons.

The underlying success of an effective BU control programme is to increase knowledge and detect early cases of BU, ensure that affected persons seek timely and appropriate treatment, and adhere to full medical treatment regimes to improve treatment outcomes and reduce recurrences. In order to achieve these aims, medical treatment must be accessible and barriers to appropriate help-seeking that are influenced by features of PD and PC must be fully understood, and addressed by the health system activities.

2.6 The explanatory model interview catalogue (EMIC) interview

The various methods used for each study component are reported in detail in the methods section of each chapter. However, the explanatory model interview catalogue (EMIC) is described in detail in this chapter because EMIC interviews were used extensively in this study to elicit information on illness meaning, experience and behaviour, and to assess socio-cultural and health system features of timely treatment.

The EMIC interviews are instruments used particularly in the cultural epidemiological framework of understanding the impact of a broad range of socio-cultural factors that include, gender, stigma and culture on illness experience, meaning and behaviour from the perspective of affected and unaffected persons. The use of EMIC interviews for cultural epidemiology research focuses on local concepts of illness rather then professional concepts of disorder. EMIC interviews have their own structure for eliciting responses which can be generated into quantitative and qualitative data.

EMIC interviews have been used successfully in several studies such as leprosy (Weiss et al., 1992), onchocercal skin diseases (Vlassoff et al., 2000), tuberculosis (Gosoniu et al., 2008; Weiss et al., 2008) schizophrenia (Raguram et al., 2004), 2004) and malaria (Ahorlu et al., 2006), cholera (Schaetti et al., 2010) and mental health (Paralikar et al., 2011; Parkar et al., 2008; Raguram et al., 2004).

Prior ethnographic research and earlier studies (Ackumey et al., 2011; Renzaho et al., 2007) informed the design and the formulation of questions for the EMIC. The instruments were developed in English, but interviews were conducted in the local Ghanaian languages (Ga, Ewe and Twi) spoken by respondents in the study areas.

The EMIC questions examined patterns of distress (PD), perceived causes (PC) and help-seeking (HS). Patterns of distress refer to illness-related problems and concerns, local experiences and meanings of BU illness. Perceived causes denote local ideas of causes for BU. The EMIC elicited responses for the most troubling (PD) and the most important (PC). Help-seeking practices are home-based care, places visited for help, and providers approached for care outside the home. The first source of outside-help, reasons for this choice and the most helpful outside-help were queried in the EMIC interview. To enable comparison, the same set of questions was asked for pre-ulcer and ulcer conditions. The structure of the EMIC allows the integration of quantitative and qualitative variables. This feature enables the use of phenomenological analysis of narratives to clarify the meaning context and dynamic features of the relationship of explanatory variables with quantitative variables of PD, PC, HS and other socio-cultural variables of interest.

2.7 Overview of study methods and chapters

A cross-sectional study on knowledge, attitudes and practice (KAP) of BU was carried out between July and August 2005 in the Ga-West and South municipalities of Ghana to examine communities' understanding of the aetiology of BU, perceptions and attitudes towards BU-affected persons, and to clarify help-seeking of affected persons and reasons for delayed treatment. A total of 504 heads of households were randomly selected and interviewed from 25 endemic communities. Seven (7) Focus Group Discussions (FGDS) were also conducted. This study which is presented in chapter 3 formed the basis for a Buruli Ulcer Prevention and Treatment (BUPaT) Programme described in chapter 7 of this thesis.

From November 2008 to June 2009, 181 respondents were purposively selected from 67 BU-endemic communities and 3 main health facilities in the study municipalities to examine socio-cultural features of illness meaning (PD), perceived causes (PC) and illness behaviour (HS) for BU, and examine socio-cultural determinants of timely and delayed treatment for BU. This study used EMIC interviews (explained in section 2.6). Study findings are presented in chapters 4 to 6 of this thesis.

Chapter seven describes achievements, challenges and implications for BU control of an assessment of the first phase of the BUPaT programme which was carried out from November 2008- June 2009.

Chapter eight presents the conclusions, discussions and recommendations of the entire thesis.

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Chapter 3

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

Andre M. N. Renzaho[1*], Paul V. Woods [2], Mercy M. Ackumey [3,4,5], Simon K. Harvey [6] and Jacob Kotin [7]

1. Honorary and Senior Research Fellow, School of Health and Social Development, Deakin University, Australia and Programme Quality Advisor, Programme Effectiveness, World Vision Australia, East Birwood, Vic., Australia.
2. Senior Country Programme Coordinator, World Vision Australia, East Birwood, Vic., Australia
3. School of Public Health, University of Ghana, Legon
4. Swiss Tropical and Public Health Institute, Basel, Switzerland
5. University of Basel, Switzerland
6. Business, School, University of Ghana, Legon, Ghana
7. World Vision Ghana, Accra, Ghana.

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3.0 Abstract

Introduction

The Buruli ulcer disease (BUD), a devastating tropical disease caused by *Mycobacterium ulcerans* and occurs in more than 80% of the administrative districts of Ghana. The aim of this study was to elucidate community perceptions and understanding of the aetiology of BUD, attitudes towards Buruli patients and treatment-seeking behaviours.

Methods

We conducted a survey with 504 heads of households and seven focus group discussions in Ga West District, Ghana.

Key findings

Although 67% of participants regarded BUD as a health problem, 53% did not know its cause. Sixteen per cent attributed the cause to drinking non-potable water, 8.1% mentioned poor personal hygiene or dirty surroundings, and 5.5% identified swimming or wading in ponds as a risk factor. About 5.2% thought that witchcraft and curses cause BUD, and 71.8% indicated that BU sufferers first seek treatment from herbalists and only refer to the hospital as a last resort. The main reasons were prospects of prolonged hospital stay, cost of transport, loss of earnings and opportunity associated with parents attending their children’s hospitalisation over extended period, delays in being attended by medical staff, and not knowing the cause of the disease or required treatment. The level of acceptance of BUD sufferers was high in adults but less so in children.

Conclusion

The challenge facing health workers is to break the vicious cycle of poor medical outcomes leading to poor attitudes to hospital treatment in the community. Because herbalists are often the first people consulted by those who contract the disease, they need to be trained in early recognition of the pre-ulcerative stage of Buruli lesions.

3.1 Introduction

Buruli ulcer disease (BUD) is a chronic debilitating skin disease caused by Mycobacterium ulcerans (Phillips et al., 2005). BUD has been reported in the subtropical regions of Asia, in Latin America, in the Western Pacific region and in Eastern and Central Africa (Burchard & Bierther, 1986; Duker et al., 2004; Meyers et al., 1974; The Uganda Buruli Group, 1971) But Western Africa is the region most affected by the disease (Addo, 1995; Amofah et al., 1998; Meyers et al., 1996; Monson et al., 1984; van der Werf et al., 2005). Up to 22% of the population in some villages in Ghana have BUD (Amofah et al., 1993; World Health Organisation, 2001). In 1999, Ga West District had a prevalence rate of 87.7/ 100 000 and was the district with the highest number of active cases (Amofah et al., 2002). The crude prevalence of 20.7/100 000 in Ghana suggests that BU is the second most prevalent mycobacterial disease after tuberculosis.

The Buruli ulcer disease evolves in three stages. The first pre-ulcerative phase is characterised by a firm, non-tender nodule and sometimes plaques or oedema. In the second phase skin ulcerates, causing osteomyelitis as a possible complication. In the third phase of the disease, a granulomatous healing response takes place followed by fibrosis, scarring, calcification and contractures, with the possibility of permanent disabilities (Stienstra et al., 2001; Stienstra et al., 2002; Stienstra et al., 2004). Possible modes of BUD transmission are:

- swimming in a river or pond (Aiga et al., 2004; Barker, 1973; Marston et al., 1995; Oluwasanmi et al., 1976; The Uganda Buruli Group, 1971)

- residence near swampy and riverine areas (Asiedu & Etuaful, 1998; Marston et al., 1995), especially those enriched with arsenic(Duker et al., 2004)
- bites from or contact with insects inhabiting plant roots in swamps (Marston et al., 1995; Muelder & Nourou, 1990; Portaels et al., 1999)
- skin pricks, small breaks or trauma in the skin (Johnson et al., 1999; Portaels et al., 2001), and
- person-to-person infection after a human bite (Debacker et al., 2002; Debacker et al., 2003; Muelder & Nourou, 1990).

Under normal circumstances, person-to-person transmission through physical contact, through changing and washing infected dressings or through caring for a patient is not considered a major risk (Aiga et al., 2004). Demographic and socioeconomic risk factors are (i) age under 15 years (Amofah et al., 1993; Ellen et al., 2003; Marston et al., 1995), (ii) female sex (World Health Organisation, 2000), and (iii) impoverished and remote living circumstances (Duker et al., 2004; Hayman & McQueen, 1985; Rook et al., 1979; Tacquet et al., 1973; World Health Organisation, 2000).

Wearing of long pants has been reported to protect against BUD (Amofah et al., 1993; Marston et al., 1995). Bacille Calmette–Guérin vaccination confers protection against BUD or delays the onset of symptoms (Smith et al., 1976). Because the disease affects the most impoverished, treatment costs are unaffordable for most patients without external financial support to both them and the health facilities (Asiedu & Etuaful, 1998; World Health Organisation, 2000). Delayed treatment or untreated BUD can cause extreme deformities and disabilities (Ellen et al., 2003), along with serious stigmatisation, leading to patients' alienation and social isolation (Stienstra et al., 2002).

Large surgical excision is the first treatment, then followed by skin grafting are the only effective treatment to date (Asiedu & Etuaful, 1998; van der Werf et al., 1999). Late diagnosis and drastic surgery required at an advanced stage means that contractures, big scars, amputation and blindness can occur. As a result of late reporting, the average hospital admission time for BUD patients in Ghana is 3 months (Stienstra et al., 2002). As many as 25% of those with healed lesions are left with disabilities that have a long-term social and economic impact on the patient (Asiedu & Etuaful, 1998). However, early diagnosis and treatment provides a good chance of complete cure with minimal scarring. Animal studies have found that combined therapy of rifampin–amikacin [used in the treatment of tuberculosis (World Health Organisation, 1997) and leprosy (Pattyn & Royackers, 1995) respectively] for 12 weeks, given 5 days a week, cured mice in the early stage of the disease, without subsequent post-treatment growth (Dega et al., 2002). As with tuberculosis, where clinical signs develop in only 10% of infected persons, it has been hypothesised that a large proportion of the population living in *M. ulcerans*-endemic areas are infected but do not develop the disease (Bellamy & Hill, 1998; Stienstra et al., 2004).

As many infected people seek help only at an advanced stage due to the indolent course of the disease, they sustain massive skin necrosis and disfiguration, requiring extensive surgery and longer hospital stay (Asiedu & Etuaful, 1998; Stienstra et al., 2002). Despite the array of epidemiological studies on BUD, there is a paucity of research into its local perceptions (Aujoulat et al., 2003) and the few studies conducted in Ghana have focused solely on Buruli patients and a small number of matched controls, rather than on general community (Stienstra et al., 2002) . Community perceptions and responses are particularly important in BUD because of their influence on treatment-seeking behaviour and because rapid diagnosis and treatment are essential for minimising the physical, economic and social impact of the disease. Therefore, the purpose of this paper was twofold: (i) to examine the social aspects of BUD in Ga West District of Ghana focusing on community's understanding of the aetiology of the disease and perceptions and attitudes towards Buruli patients, and (ii) to understand treatment-seeking behaviour of affected families and reasons for delayed treatment.

3.2 Methods

3.2.1 Study area and population

Ga West District was chosen as the target area for this study because this district has one of the highest prevalence rates in Ghana (prevalence of 87.7 active cases per 100 000 population compared with a national average of 20.7 per 100 000) (Amofah et al., 2002). The presence of many stagnant fresh water ponds left over from sand mining is thought to predispose the district to the disease. The river Densu, the largest water body, flows from the northern part of the district to the south. The coastal lands are mainly covered with mangrove swamps and blackish water lagoons. Because of the presence of large mosquito breeding areas, malaria is common in the district as well as schistosomiasis. Skin diseases such as scabies, acute respiratory infections and diarrhoea are also prevalent. The district has seven health centres with qualified health staff (3 to 45 professional staff per centre) which, if properly equipped and supported, can manage the surgical treatment of less advanced ulcers. However, advanced cases are referred to Korle-Bu Hospital in the capital city, Accra, and surgeons from there occasionally come to perform operations at the health centres.

3.2.2 Study design, sample and procedure

This was a cross-sectional design involving interviews with household heads in 25 communities and seven focus group discussions (FGDs) between 25 July 2005 and 6 August 2005. The sample size was simply taken as 10% of the number of households in the district, equating to 504 households. Households were selected using a systematic sampling technique. A list of endemic villages and the number of households in each village was constructed with the help of World Vision staff and some local people. All these households were given a unique identification number. The sampling interval (t) was determined by dividing the total number of households in all selected villages with the number of households to be interviewed (504 households). The first household to be surveyed was randomly selected by choosing a number between 1 and t using a table of random umbers. After the first household was identified, the rest of households were selected by adding the sampling interval to the first randomly selected number. Trained enumerators administered the questionnaire. Data were collected by two teams of four. Each team was managed by a supervisor. Each supervisor ensured the accuracy of the collected data. To triangulate data obtained from the household survey, FGDs were held with opinion leaders, adults, the youth and children in some of these communities to solicit community views on the disease.

This research was part of an on-going project being implemented in the community, and was thus being seen as beneficial by the community. Prior to data collection, there were consultations with the District Director of Health at the Ghana Health Service and the District Chief Executive. Consistent with the district's protocols for engaging communities, the District Chief Executive provided some staff to review the questionnaire and to oversee the process at the planning stage. The assigned district staff, some of whom later served as field interviewers, commented on and suggested ways of improving the questionnaire. Then they informed community elders and assembly men about the research and the importance of the research findings in informing the district health policy. In turn, community elders and assembly men informed, mobilised and secured the consent of the target communities some days ahead of the data collection day. Each team of enumerators consulted community elders on the day of the data collection.

All consulted community elders consented to the research and assisted with organising people for the FGDs. Heads of selected households or guardians were told that participation in the study was voluntary, and that they were free to withdraw at any stage and that data would be aggregated and treated with strict confidentiality. All contacted households and selected FGD participants consented and participated in the study. Parents or guardians consented ‘on behalf of children.’

3.2.3 The survey instruments

3.2.3.1 Structured questionnaire

A structured questionnaire was used to collect data at the household level. It had four sections: demographics of household members (age, gender, ethnic group, educational attainment and religion), community understanding of the disease, treatment-seeking behaviours and community perception and attitudes towards BUD sufferers. The questionnaire was field tested prior to data collection for cultural appropriateness and clarity and was administered in English.

3.2.3.2 Focus group discussions

A total of seven FGDs were carried out. Each FGD comprised 8–12 people depending on the availability of participants. The FGD guide was developed from the structured questionnaire. Questions that required in-depth information in order to understand the aetiology and treatment-seeking behaviour of *M. ulcerans* infection were included in the FGD guide.

3.2.4 Data analysis

Data were entered using epidata, version 3.1 (Lauritsen 2000–2006). Data cleaning, management and analysis were carried out by using Statistical Package for the Social Sciences software version 13.0 (SPSS Inc. Chicago, IL, USA). In the first instance, a descriptive univariate analysis on cases was undertaken. Then the relationship between two categorical variables (i.e. study outcome versus independent variable) was initially examined by chi-square test. Adjusted logistic regression analyses were performed to determine the best prediction of a dependent variable from several demographic and socioeconomic variables. For all the categorical variables, the lowest coded category was the reference. The level of statistical significance was set at a probability of $p < 0.05$ for all tests.

3.3 Results

3.3.1 Demographic characteristics

A total of 504 head of households were surveyed. There were more male-headed (66.1%) than female-headed households (33.9%). The study area is dominated by the Ga ethnic group (57%) followed by the Ewe (39.7%) and Akan (6.2%), with very few people of northern descent (3.4%). The major occupation among the interviewed participants was farming which constituted about 55%. In all, 72.2% were Christians, 12.1% were traditionalists, and 9.7% were Muslim. The surveyed population had a very low educational attainment (table 3.1)

3.3.2 Community understanding of the causes of BU and its risk factors in the district

Sixty-seven per cent regarded BUD as a health problem, 18.9% considered it infectious, and 37.3% believed that BUD can occur anytime. Approximately one in six (16.9%) believed the risk of BUD increased during the rainy season.

However, the understanding of the disease was a function of socio-demographic factors. Men were less likely to consider BUD as an infectious disease (χ^2 =10.42, $p < 0.01$) but more likely to believe that the risk of contracting the disease increased in the rainy season (χ^2 =6.11, $p < 0.05$). Those of lower educational attainment were more likely to consider BUD as a health problem than expected (χ^2 =6.54, $p < 0.05$). Although construction workers were more likely than expected to consider BUD as an infectious disease (χ^2 =16.77, $p < 0.05$), they were less likely to consider BUD as a health problem (χ^2 =14.12, $p < 0.001$), (table 3.1).

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Table 3.1: Characteristics of heads of households and their understanding of the Buruli ulcer (BU) disease

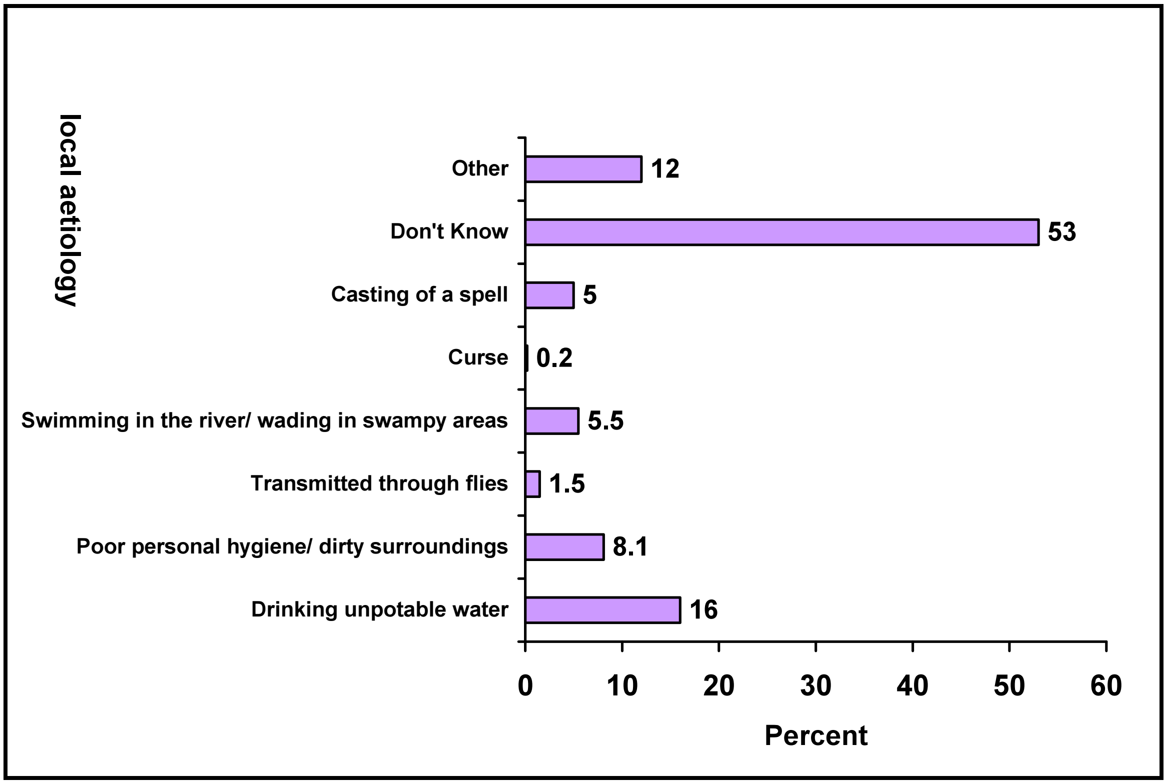
Demographic characteristics	**N (%)**	**BU is a health problem**	**BU can happen any time of the year (%)**	**The risk of BU may increase during the rainy season (%)**	**BU is an infectious disease (%)**
Sex		(χ^2 = 2.15, p=0.143)	(χ^2 = 0.03, p=0.879)	(χ^2 = 6.11, p=0.013)	(χ^2 = 10.42, p=0.005)
Male	333 (66.1)	64.9	37.5	19.8	18.1
Female	171 (33.9)	73.3	36.8	11.1	20.5
Age (years		(χ^2 = 5.24, p=0.162)	(χ^2 = 1.61, p=0.656)	(χ^2 = 0.02, p=0.999)	(χ^2 = 2.27, p=0.894)
<25	23 (4.6)	60.9	39.1	17.4	22.7
25-34	97 (19.2)	59.8	40.2	16.5	15.5
35-44	135 (26.8)	65.2	40.0	17.0	20.0
≥45	249 (49.4)	71.5	34.5	16.9	19.4
Highest level of education attained		(χ^2 = 6.54, p=0.038)	(χ^2 = 2.26, p=0.323)	(χ^2 = 0.21, p=0.898)	(χ^2 = 5.16, p=0.271)
Primary	286 (56.7)	69.9	39.9	17.5	17.5
Secondary	201 (39.9)	65.2	33.3	15.9	20.0
Technical / university	17 (3.4)	41.2	41.2	17.6	29.4
Religion		(χ^2 = 4.16, p=0..245	(χ^2 = 8.46, p=0.037)	(χ^2 = 4.42, p=0.219)	(χ^2 = 5.80, p=0.446)
Christian	364 (72.2)	66.8	40.9	15.7	16.6
Muslim	49 (9.7)	57.1	22.4	20.4	26.5
Traditional	61 (12.1)	72.1	29.5	14.8	23.0
Other	30 (6.0)	76.7	33.3	23.3	26.7
Occupation		(χ^2 = 14.12, p =0.007)	(χ^2 = 1.72, p=0.805)	(χ^2 = 3.59, p=0.465)	(χ^2 = 16.77, p=0.033)
Farming	276 (54.9)	72.1	39.5	19.6	19.6
Trading	89 (17.7)	70.8	33.7	12.4	18.0
Construction worker	35 (7.0)	54.3	34.3	17.1	22.9
Professional/ administration	26 (5.2)	50.0	38.5	15.4	19.2
Other	77 (15.3)	55.8	33.8	13.0	15.8
Total	504 (100)	67.1	37.3	16.9	18.9

Fifty-three per cent of participants did not know the cause of BUD; 16% attributed it to drinking non-potable water, 8.1% mentioned poor personal hygiene/dirty surroundings as a possible cause and 5.5% perceived BUD infection to be caused by swimming/wading in ponds/rivers (figure 3.1). Although only 5.2% attributed the disease to witchcraft and cursing, data from FGDs revealed otherwise. Expressed opinions included:

> *Some people in the communities curse others with the disease. If your mouth is strong [implying that if the words of the curse are powerful, or if one is really angry and means to curse] it will work! Some people have been bewitching others, so when you notice that your friend has the disease in its early stages, you are afraid to tell his/her parents because when you tell them, they will ask you how you got to know and accuse you of bewitching their children. When my cousin fell ill, his father consulted the oracle and the oracle informed him that some people were jealous of his son's brilliant performance at school and have therefore bewitched him. Why should the disease affect only the children, especially the young promising and intelligent ones – It has to be a curse!*

Results from the FGD with both children and adults showed that children had significantly different perceptions about the contagiousness of the disease. While children were emphatic that BUD is contagious, several adults insisted it was not. As one participant who reflected the views of many put it: 'No, it is not contagious. If it was I would have contracted it when I nursed two of my children who had the disease.' Interviewed communities identified what they perceived to be the most effective preventative measure against BU. Forty-one per cent indicated that the most prominent measure against BU is providing potable water while 13% mentioned 'avoiding swimming in the river.' However, about 72% of respondents indicated that the community had no programmes in place to curb the incidence of BUD.

Figure 3.1 Community's perception of the aetiology of Buruli Ulcer



3.3.3 Treatment-seeking behaviour

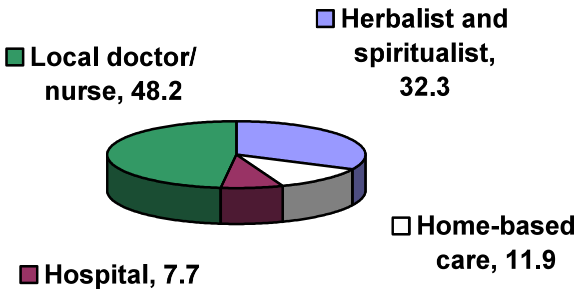
Of the interviewed heads of households, 41.6% believed that BUD victims seek treatment immediately after an infection is suspected, 39.8% believed that they sought treatment within a month after detecting an infection, 13.3% believed they sought treatment within 2–6 months, and 5.4% believed they sought treatment after 6 months of infection. Regarding the type of treatment sought, the majority of respondents (71.8%) indicated that traditional treatment, mainly herbal remedies, remains the first preferred treatment option. Only 22.8% of respondents thought BUD sufferers seek help at the hospital or local doctor/nurse as the first option. Of those who seek traditional medicine treatment first, only 7.7% go to hospital when the situation deteriorates while 48.2% go to the local doctor/nurse (figure 3.2). These findings confirm data from FGDs as demonstrated by the following excerpts:

> *A niece was bitten by a snake and taken to a herbalist for treatment. After treatment the affected body part became very hard. She therefore had to go for further treatment. During the course of the second phase of treatment, the place became very swollen. The herbalist suspected that the poison from the viper had caused the complications and therefore continued with his/her treatment. During the course of the treatment, the wound erupted and it was at this stage that the herbalist discovered that it was BUD infection. My niece was then asked to go to the Amasaman health centre.*
>
> *All I noticed was this swelling on my right arm, which later on developed into a boil. This boil grew bigger and bigger. My mother started treating it at home with all the local remedies she could think of, but my arm was still swelling. Later on, it developed into a very nasty wound… then one day someone told my mother to bring me to Amasaman health centre. It was here that I was told it is BUD.*
>
> *I accompanied my father to the farm and I sustained a small cut on my toe while weeding the farm with a hoe. I ignored it at first then it got swollen and started hurting and developed into a sore. I went to the clinic and was injected with tetanus, but the sore would not heal. After several months of herbal treatment it is healing. A few months after I sustained this wound, my right thigh started swelling. I did not know the cause. The area of the swelling became very hard. … after consultations with the herbalist. I was told that it was this evil disease, Buruli ulcer.*

Multiple reasons were given as to why hospital visits were not favoured as a first treatment option: the prospects of prolonged hospitalisation required (up to 6 months); the distance and cost of transport; lost earnings and opportunity cost associated with parents attending their children's hospitalisation over extended periods; delay and waiting lists at the hospital and not knowing the cause of the disease. In expressing their opinion, community members provided the following views:

> *The high cost of transportation is what deters people from reporting at the Health Centre when sick. It is more convenient yet more expensive for those of us in this community to get to Amasaman through Kasoa* [a commercial Centre in the Eastern Region, which is 15 km drive from the local town] *since no vehicles ply between our community and Amasaman. If one really has to go to Amasaman, then one will have to take 'dropping'* [hired taxi] *to Ashaladza, the nearest town which will cost ¢30 000* […]*. There are social costs involved. When I was hospitalized my mother had to leave whatever work she was doing and stayed with me in the hospital. There are costs of feeding*
>
> *The delays in the health system are a crucial factor why people feel reluctant to report at the Health Centre. Imagine going through all the trouble and cost to get to the hospital and one is told the doctor is not available or one will have to go and come the next day. It is too expensive and unaffordable [taxi] and many of us are poor people!*
>
> *The reason why people do not report at the health centre for treatment is that it begins as a harmless, painless boil which the victim is not sure of. When it happens this way the victim seeks herbal treatment because he/she is unsure of the cause. The herbalist then applies his herbal preparation for a long period until the entire skin surface ruptures. Herbal dressings are still applied for the wound to heal. Some patients are not lucky; their wounds take longer to heal, for others too, their wounds don't heal at all and they are compelled to go to the Amasaman Health Centre.*

Figure 3.2: Continuity of treatment after first contact with herbalist *



*Values are in percentages

3.3.3 Community perception and attitudes toward Buruli ulcer sufferers

Although more than a third (39.5%) stated explicitly that they would not accept a BUD sufferer as a community leader, 69.5% indicated that they would interact with BU victims, 57.5% would allow their children to play or interact with BU victims, 91.3% would accept a BU victim as a teacher in their community and 72.6% would welcome BU sufferers in their households. The overall acceptance of BU sufferers was echoed by FGD data. Participants stated:

> *We are very sympathetic towards them, because this disease is strange; no one knows where it is from. You could be the next victim. There is one thing about the disease if you ridicule someone who has it, you will get infected. We do not discriminate against them, we live normally with BU victims. We do not prevent them from attending social functions. The disease is so painful, we have to show them sympathy but they shy away from gatherings because of the stench and the pain. If you are infected, you cannot teach, you will not be able to sit here with us and interact so freely… you will also feel uncomfortable because of the stench from the wound!*

Nevertheless, other participants showed reservation by making comments such as:

> *The stench from the wound is so strong that it is very difficult for relatives and spouses to get close to the patients. The pus from the wound is very thick and very difficult to wash out of a fabric.*

Despite the positive attitudes displayed in FGDs, data from the household survey depict a negative attitude that has social implications. While less than 1% of interviewed heads of households believed that BU sufferers are not suitable for marriage, 6.9% believed that BU sufferers are plagued with evil and should be locked up in a room. Additionally, 3% believed that BU sufferers should be stripped of any social responsibilities and should not be welcomed to social and community functions, 4.4% believed that BU sufferers should not be allowed to attend school while 2.2% indicated that BU sufferers should not be allowed to perform household chores. However, discrimination against BU victims was more pronounced among children. Comments such as *I will not enter the classroom if a teacher with BU is teaching* or *I do not think if the teacher has BU and marks our exercise books we will handle them*, were common during FGDs with children. Children indicated that they often tease victims of BU. They stated:

> *…children have been insulting their peers who are victims of BU and the common teasing phrase include 'lame leg', 'one legged person', 'go and look for some banku* (a meal prepared from fermented maize and eaten with soup) *to patch up your wound*

Community perceptions and attitudes towards BU sufferers were influenced by socio-demographic factors (tables 3.2 and 3.3). Non-parametric tests indicated that men were less likely than women to believe that BU sufferers are plagued by evil forces and should be locked in a room ($\chi^2 = 5.4$, $p < 0.05$), (table 3.2) and men were more likely to indicate that they would interact with BU sufferers ($\chi^2 = 5.04$, $p < 0.05$), welcome them. In their homes ($\chi^2 = 16.4$, $p < 0.001$), allow their children to interact with them ($\chi^2 = 6.16$, $p < 0.05$) and accept a BU sufferer in a position of power such as a chief or a teacher ($\chi^2 = 7.6$, $p < 0.01$) (table 3.3). Younger people (<25 years) were less likely to accept BU in a position of power (e.g. teacher, village chief) than people aged 25 years and over ($\chi^2 = 18.5$, $p < 0.001$), (table 3.3). In addition, Muslims were more likely to consider BU as a sign of being plagued with evil forces than other religious groups ($\chi^2 = 10.11$, p <

0.05), (table 3.2). .Findings from the non-parametric tests were in agreement with multiple logistic regression, adjusting for the other variables in the table, (tables 3.4 and 3.5).

of respondents) of the community's attitude towards BU sufferers by socio-demographic variables

	N (%)	**BU victims are people plagued with evil forces and should be locked up in a room**	**BU affected persons should not be allowed to go to school**	**BU affected persons should be stripped off social responsibilities and should not be allowed to attend social and community functions**
		(χ^2 = 5.41, p=0.048)	(χ^2 = 0.06, p=0.801)	(χ^2 = 0.25, p=0.614)
	171 (33.9)	9.4	4.7	3.5
	333 (66.1)	5.4	4.2	2.7
		(χ^2 = 4.24, p=0.237)	(χ^2 = 0.60, p=0.898)	(χ^2 = 0.88, p=0.830)
	23 (4.6)	17.4	4.3	4.3
	97 (19.2)	7.2	3.1	4.1
	135 (26.8)	6.7	5.2	2.2
	249 (49.4)	6.0	4.4	2.8
of		(χ^2 = 6.31, p=0.171)	(χ^2 = 3.62, p=0.460)	(χ^2 = 5.57, p=0.234)
	286 (56.7)	5.2	4.2	1.7
	201 (39.9)	9.5	4.5	5.0
y	17 (3.4)	5.9	5.9	0.0
		(χ^2 = 10.11, p=0.02	(χ^2 = 0.12, p=0.942)	(χ^2 = 4.80, p=0.091)
	364 (72.2)	6.3	4.9	3.3
	49 (9.7)	16.3	6.1	2.0
	61 (12.1)	1.6	0.0	1.6
	30 (6.0)	10.0	3.3	3.3
		(χ^2 = 9.99, p =0.019)	(χ^2 = 3.52, p=0.319)	(χ^2 = 0.67, p=0.882)
	276 (54.9)	7.2	3.3	1.4
	89 (17.7)	11.2	7.9	5.6
	35 (7.0)	0.0	5.7	5.7
	26 (5.2)	7.7	3.8	3.8

Table 3.3: Level (% of respondents) of the community's acceptance of BU sufferers by socio-demographic **variables**

Demographic characteristics	**N (%)**	**Would interact with a BU victim**	**Would allow children to interact or play with a BU victim**	**Would accept a BU victim as a teacher in the community**	**Would welcome a BU victim into the house**
Gender		(χ^2 = 5.04, p=0.025)	(χ^2 = 6.16, p=0.013)	(χ^2 = 7.60, p=0.006)	(χ^2 = 16.37, p=0.000)
Female	171 (33.9)	64.9	50.0	89.5	61.4
Male	333 (66.1)	74.5	61.6	95.8	78.4
Age (years		(χ^2 = 1.86, p=0.602)	(χ^2 = 5.88, p=0.117)	(χ^2 = 18.48 p=0.000)	(χ^2 = 5.64, p=0.130)
<25	23 (4.6)	60.9	43.5	73.9	60.9
25-34	97 (19.2)	74.2	49.5	91.8	79.4
35-44	135 (26.8)	72.6	60.4	97.0	75.6
≥45	249 (49.4)	70.3	60.6	94.4	68.5
Highest level of education attained		(χ^2 = 9.33, p=0.041)	(χ^2 = 4.68, p=0.321)	(χ^2 = 1.29, p=0.863)	(χ^2 = 6.30, p=0.178)
Primary	286 (56.7)	72.4	57.2	93.7	73.1
Secondary	201 (39.9)	69.2	57.7	93.0	71.6
Technical / university	17 (3.4)	76.5	64.7	100.0	76.5
Religion		(χ^2 = 0.83, p=0.659	(χ^2 = 0.37, p=0.831)	(χ^2 = 1.28, p=0.527)	(χ^2 = 0.25, p=0.881)
Christian	364 (72.2)	70.1	56.9	94.0	72.3
Muslim	49 (9.7)	77.6	62.5	95.9	71.4
Traditional	61 (12.1)	73.8	60.7	90.2	78.7
Other	30 (6.0)	70.0	53.3	98.7	66.7
Occupation		(χ^2 = 1.42, p =0.702)	(χ^2 = 1.72, p=0.805)	(χ^2 = 1.73, p=0.630)	(χ^2 = 1.72, p=0.632)
Farming	276 (54.9)	73.2	59.6	94.2	75.0
Trading	89 (17.7)	67.4	55.1	92.1	64.0
Construction worker	35 (7.0)	88.6	65.7	97.1	82.9
Professional/ administration	26 (5.2)	69.2	61.5	92.3	69.2
Other	77 (15.3)	62.3	48.1	93.5	70.1

Table 3.4: Adjusted odds ratios and 95% confidence intervals of the communities' acceptance of BU affected persons by demographic variables

Demographic characteristics	**N (%)**	**Would interact with a BU victim**	**Would allow children to interact or play with a BU victim**	**Would accept a BU victim as a teacher in the community**	**Would welcome a BU victim into the house**
Sex					
Female	171 (33.9)	Ref	Ref	Ref	Ref
Male	333 (66.1)	**1.6 (1.1, 7.4)**	**1.7 (1.1, 2.8)**	**3.1 (1.2, 7.8)**	**2.5 (1.5, 4.2)**
Age (years					
<25	23 (4.6)	Ref	Ref	Ref	Ref
25-34	97 (19.2)	1.7 (0.6, 4.4)	1.1 (0.4, 2.8)	**4.2 (1.2, 14.9)**	**2.4 (1.0, 6.6)**
35-44	135 (26.8)	1.5 (0.6, 3.8)	1.7 (0.7, 4.3)	**12.4 (2.9, 52.3)**	1.8 (0.7, 4.8)
≥45	249 (49.4)	1.4 (0.6, 3.5)	1.9 (0.8, 4.5)	**7.4 (2.3, 23.6)**	1.4 (0.5, 3.4)
Highest level of education attained					
Primary	286 (56.7)	Ref	Ref	Ref	Ref
Secondary	201 (39.9)	0.9 (0.3, 3.2)	0.9 (0.3, 2.7)	0.7 (0.3, 1.5)	**0.6 (0.4, 0.9)**
Technical / university	17 (3.4)	0.7 (0.2, 2.3)	1.1 (0.4, 3.3)	-	0.7 (0.3, 3.0)
Religion					
Christian	364 (72.2)	Ref	Ref	Ref	Ref
Muslim	49 (9.7)	1.0 (0.4, 2.3)	1.2 (0.6, 2.3)	1.5 (0.3, 7.2)	0.9 (0.5, 1.9)
Traditional	61 (12.1)	1.1 (0.6, 2.2)	1.4 (0.5, 3.6)	**0.3 (0.1, 0.9)**	1.1 (0.5, 2.1)
Other	30 (6.0)	1.0 (0.4, 2.3)	0.9 (0.4, 2.7)	0.8 (0.2, 4.0)	0.7 (0.3, 1.7)
Occupation					
Farming	276 (54.9)	Ref	Ref	Ref	Ref
Trading	89 (17.7)	0.9 (0.5, 1.6)	1.6 (0.9, 2.7)	0.9 (0.3, 2.7)	0.9 (0.5, 1.6)
Construction worker	**35 (7.0)**	**2.7 (1.4, 8.1)**	1.7 (0.9, 3.4)	1.6 (0.2, 13.5)	1.3 (0.5, 3.3)
Professional/ administration	**26 (5.2)**	**4.2 (1.3, 13.4)**	**2.1 (1.0, 4.8)**	0.4 (0.1, 2.0)	0.7 (0.3, 1.8)
Other	77 (15.3)	1.2 (0.5, 3.3)	1.6 (0.6, 4.0)	1.0 (0.3, 3.1)	0.9 (0.5, 1.6)

* Model adjusted for factors in the table. Figures in bold indicate statistical significance ($p<0.05$)

Table 3.5: Adjusted odds ratios (OR) and 95% confidence intervals (CI) of the communities attitude towards BU sufferers by socio-demographic variables*

Demographic characteristics	**N (%)**	**BU suffers are people plagued with evil forces and should be locked up in a room**	**Should not be allowed to go to school**	**Stripped off social responsibilities and should not be allowed to attend social and community functions**
Sex				
Female	171(33.9)	Ref	Ref	Ref
Male	333 (66.1)	0.5 (0.2, 1.2)	1.5 (0.5, 4.8)	0.8 (0.2, 3.1)
Age (years				
<25	23 (4.6)	Ref	Ref	Ref
25-34	97 (19.2)	0.3 (0.1, 1.4)	0.6 (0.1, 6.2)	0.7 (0.1, 6.7)
35-44	135 (26.8)	0.3 (0.1, 1.2)	1.1 (0.1, 9.8)	0.3 (0.0, 3.9)
≥45	249 (49.4)	0.3 (0.1, 1.1)	1.0 (0.1, 8.6)	0.7 (0.1, 6.1)
Highest level of education attained				
Primary	286 (56.7)	Ref	Ref	Ref
Secondary	201 (39.9)	**2.8 (1.2, 6.3)**	1.0 (0.4, 2.7)	**3.9 (1.1, 14.0)**
Technical / university	17 (3.4)	1.5 (0.2, 14.3)	1.1 (0.1, 10.9)	0.0
Religion				
Christian	364 (72.2)	Ref	Ref	Ref
Muslim	49 (9.7)	**2.6 (1.0, 6.6)**	1.1 (0.3, 3.9)	0.6 (0.1, 4.8)
Traditional	61 (12.1)	0.3 (0.0, 2.1)	0.0	1.0 (0.1, 8.7)
Other	30 (6.0)	1.8 (0.5, 6.8)	0.6 (0.1, 5.0)	1.7 (0.2, 15.4)
Occupation				
Farming	276 (54.9)	Ref	Ref	Ref
Trading	89 (17.7)	1.1 (0.4, 2.8)	2.7 (0.8, 9.0)	**4.5 (1.0, 21.3)**
Construction worker	35 (7.0)	0.0	1.5 (0.3, 7.4)	**3.6 (1.2, 22.3)**
Professional/ administration	26 (5.2)	0.8 (0.2, 4.0)	0.8 (0.1, 7.5)	2.2 (0.2, 22.6)
Other	77 (15.3)	0.4 (0.1, 1.4)	1.0 (0.3, 3.8)	2.3 (0.4, 11.3)

* Model adjusted for factors in the table. Figures in bold indicate statistical significance ($p<0.05$)

3.4 Discussion

Our preliminary hypothesis was that a lack of information or awareness of BUD were not the only reasons for delayed treatment seeking, but was likely to be influenced by cultural beliefs such as the cause of the disease, the likely costs and consequences of treatment including the fear of disfigurement, attitudes of others towards BU sufferers and perceptions about the effectiveness of different forms of treatment. The results of the study confirmed that more than two-thirds of adults in Ga West have an awareness of BUD and consider it a major health problem. This tends to confirm the high prevalence of the disease reported in the district, more than four times the national average (Amofah et al., 2002). Although the disease itself was well known, there were a wide variety of perceptions about its causes and modes of transmission. Our findings indicate that communities in Ga District have a poor understanding of the aetiology of the disease. A case–control study in the Amansie West District of Ghana (Aiga et al., 2004) showed that the only significant risk factor for BUD was swimming in rivers on a habitual basis, a conclusion that is consistent with the results of other studies (Aiga et al., 2004; Barker, 1973; Marston et al., 1995; Oluwasanmi et al., 1976; The Uganda Buruli Group, 1971). In the Amansie West study the source of water used for drinking or cooking was not found to be a risk factor, neither were occupation, or presence of an infected person in the household (Aiga et al., 2004).

Communities in Ga West had a different understanding of BUD causative factors. Although 5.5% believed correctly that swimming in a river or wading in swampy areas was a risk factor, 16% believed that drinking of water from a river or pond was a likely cause with very few believing that BUD is caused by witchcraft and casting of a spell (5.2%). This contrasts to studies carried out several years earlier in Ghana, in which BUD was attributed to witchcraft (Stienstra et al., 2002) . This indicates that community education programmes conducted over recent years have been successful. Witchcraft has been invoked in many other studies on BUD in West Africa and the possibility of witchcraft was brought up frequently in the FGDs in our research, which suggests a lingering uncertainty within the community. In another study in Ghana, 59% ascribed witchcraft as a possible cause of BUD, but the authors suggested that witchcraft may be invoked when no other explanation for a phenomenon can be found (Stienstra et al., 2002). This was not supported by our study in which many respondents (53%) reported not knowing the cause of BUD but only 5.5% reported witchcraft or spells. The low rate of people reporting witchcraft in the survey in contrast to the frequent mention of witchcraft and spells during the FGDs could be due to the fact that the latter provided people with an opportunity to talk about their prior beliefs while the survey may reflect their current beliefs.

In the FGDs it was apparent that children and adults differ markedly in their beliefs and perceptions about the cause of the disease with children more likely to discriminate against BU sufferers than adults. Such findings are supported by multiple logistic regression (table 3.4) suggesting that the younger one is the less the likelihood of accepting BU sufferer in a position of power (e.g. teacher, village chief). Large differences in perceptions towards BUD between children and adults have not previously been investigated even though prevalence rates of BUD amongst children are known to be higher than adults (Amofah et al., 2002; Asiedu & Etuaful, 1998). It was apparent in our study that the level of fear of the disease was heightened amongst children, which may suggest greater effort is required to incorporate BUD education within the school curriculum.

It has been postulated as part of research in Benin that treatment-seeking behaviour can be related to a patient's perception as to the cause of the illness (Aujoulat et al., 2003). Attending hospital is associated with illnesses that are perceived to be caused by natural factors while illnesses that are perceived to have been induced by sorcery need to be addressed by a traditional healer to counteract the sorcery. In our study, there was little evidence that the herbalists who were usually the first to be consulted were addressing supernatural forces, but were simply applying traditional herbal remedies. This is consistent with the response to the survey indicating that few believed BUD was caused by witchcraft. However, it was clear that BU sufferers seek medical treatment only as a last resort, when herbal remedies had failed to halt the infection. This supports other studies reporting that Buruli ulcers are not considered a 'hospital disease' in its early stages (Stienstra et al., 2002). The obstacles to hospital treatment in Ga West include poor accessibility, the uncertainty of seeing a doctor on any particular day, the high cost of transport because patients could not use public transport because of their unsightly and malodorous wounds, and the prospect of long and expensive hospital stay.

The results suggest that delayed treatment seeking may be more closely related to well-grounded fears of the disfigurement that can result from surgery when performed at a late stage and the costs of treatment rather than witchcraft or fear of supernatural forces. This implies a lack of understanding of the nature of the disease and the inevitability of the progression of the disease from a harmless looking nodule to a debilitating wound. The levels of trust in the formal hospital-based health system appeared to be low, based on experience of community members. This represents a dilemma – trust is low because there appear to be no good outcomes based on communities' experience and outcomes are generally poor because long delays occur before patients seek treatment. Under the circumstances, reluctance to seek medical attention appears to be well founded with the treatment currently being associated with long hospital stays, high costs, large surgical scars and even loss of limbs.

Our study revealed a general high level of acceptance and sympathy towards BU sufferers amongst adults in the community of Ga West, albeit more in men than women. Further research may help to explain this phenomenon. Nevertheless, these results differ markedly from other published reports about stigma and discrimination faced by BU sufferers. It has been suggested (Stienstra et al., 2002) that there could be a link between stigma and the prevalence of the disease in a given area – where prevalence rates are high, there may be a greater level of acceptance of sufferers because of familiarity. The only other study on beliefs and attitudes towards BUD in Ghana involved 12 Buruli cases attending hospital and 12 matched controls from three widely scattered districts with a range of prevalence levels (Stienstra et al., 2002). Ga West District, in the Greater Accra area, recorded its first Buruli case in 1971. It has a far higher number of active cases than any other district in Ghana (Amofah et al., 2002) . Hence it seems likely that the community has been exposed to the disease for a long period of time. The Ga West District's relative proximity to Accra probably facilitates information flow into the community and access to national health facilities such as Korle Bu Teaching Hospital, when compared with more remote regions of Ghana.

There were two major exceptions to the supportive attitudes reported in this study. The first was amongst children who reported during FGD that they believed the disease was contagious and that child BU sufferers were being taunted. The other major exception to tolerant attitudes concerned BU sufferers' suitability as community leaders or for undertaking chiefly roles. Chiefs in Ghana are seen in this society as role models who are expected to have no social or physical handicaps (Stienstra et al., 2002). Overall the data show that adult BU sufferers are not discriminated against and not stigmatised in Ga West, although certain public roles would not be open to them. This may support other studies which have shown that stigma may be less serious when the cause is thought to be natural rather than supernatural (witchcraft or spells) (Aujoulat et al., 2003). It has been found elsewhere in Ghana that perceptions of the cause of the disease influences the level of stigma experienced by sufferers (Stienstra et al., 2002). In that study high levels of stigma were associated with belief in witchcraft as the cause. This possible link is supported by the results of our study showing both low levels of stigma and low ranking on survey questions about witchcraft as the cause of the disease.

3.5 Conclusions

Lack of scientific understanding of the precise modes of transmission of the disease and the lack of an effective drug regime present a challenge for community education. Because herbalists are often the first people consulted by those who contract the disease, they should be trained in early recognition of the pre-ulcerative stage of the Buruli lesion based on appearance. The results of this study suggest that communities do not need general awareness raising, but specific information on the known risk factors such as allowing children to swim and play around stagnant ponds and rivers. The emphasis in public awareness campaigns needs to be on early recognition and referral to hospital. Inviting patients who were cured without disfigurement to act as role models within their communities may be one strategy for demonstrating the benefits of early treatment. This may include forming a voluntary association of cured BUD patients that could be called upon to meet community groups and discuss their experience with BUD treatment. With children found to have significant fear of the disease, schools can have a major role to play in educating school age children. Including BU awareness in school curriculum could provide better outcomes. Public campaigns to educate communities will need to be carried out in conjunction with investments in the public health system required to speed up referrals and access to high quality surgical treatment at low cost to the individual. Above all, we need to ensure integration between the community-based referral system, the herbalists and the formal health network of health clinics and hospitals.

3.6 Acknowledgement

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Chapter 4

Illness meanings and experiences for pre-ulcer and ulcer conditions of Buruli ulcer in Ghana

Mercy M. Ackumey, [1 2 3 §], Margaret Gyapong [1 4], Matilda Pappoe[1,] Cynthia Kwakye-Maclean[5] , Mitchell G. Weiss[2 3]

1. School of Public Health, College of Health Sciences, University of Ghana.
2. Swiss Tropical and Public Health Institute, Basel, Switzerland
3. University of Basel, Switzerland.
4. Dodowa Health Research Centre, Ghana Health Service, Ghana.
5. Ga-West Municipal Health Administration, Amasaman, Ghana.

[#] Corresponding author

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4.0 Abstract

Background

Ghana is a Buruli ulcer (BU) endemic country yet there is paucity of socio-cultural research on BU. Examining distinctive experiences and meanings for pre-ulcers and ulcers of BU may clarify the disease burden, illness experience and local perceptions of causes and spread, and environmental features of BU, which is useful to guide public health programmes and future research. This study aimed to explain local meanings and experiences of BU for persons with pre-ulcers and ulcers in the Ga-West and Ga-South municipalities in Accra.

Methods

Semi-structured interviews based on the Explanatory Model Interview Catalogue framework were administered to 181 respondents comprising 15 respondents with pre-ulcers and 166 respondents with ulcers. The Wilcoxon rank-sum test was used to compare categories of illness experiences (PD) and perceived causes (PC) among respondents with pre-ulcer and ulcer conditions. The Fisher's exact test was used to compare the most troubling PD and most important PC variables. Qualitative phenomenological analysis of respondents' narratives clarified illness experiences and meanings with reference to PC and PD variables.

Results

Families of respondents with pre-ulcers and the respondents themselves were often anxious about disease progression, while families of respondents with

ulcers, who had to give care, worried about income loss and disruption of school attendance. Respondents with pre-ulcers frequently reported swimming in ponds and rivers as a perceived cause and considered it as the most important PC (53.3%). Respondents with ulcers frequently attributed their BU illness to witchcraft (64.5%) and respondents who claimed they had no water contact, questioned the credibility of health messages

Conclusions

Affected persons with pre-ulcers are likely to delay treatment because of social and financial constraints and the absence of pain. Scepticism on the role of water in disease contagion and prolonged healing is perceived to make ideas of witchcraft as a PC more credible, among respondents with ulcers. Health messages should address issues of locally perceived risk and vulnerability. Guided by study findings, further research on the role of environmental, socio-cultural and genetic factors in BU contagion, is also needed to clarify and formulate health messages and strengthen public health initiatives.

4.1 Background

Buruli ulcer (BU) caused by the environmental pathogen *Mycobacterium ulcerans,* is a debilitating skin disease (Johnson et al., 2005a; Marston et al., 1995; WHO, 2008). However, the mode of BU transmission remains unclear (Portaels et al., 2009). Socio-cultural studies of malaria (Ahorlu et al., 2005), tuberculosis (Weiss et al., 2008) and lymphatic filariasis (Gyapong et al., 1996) show how socio-cultural factors influence illness perceptions, experiences and outcomes. An assessment of illness experiences of BU is needed to clarify illness-related problems and concerns, and the distinctive, psychological, social and socio-economic impact of pre-ulcer and ulcer conditions. These assessments are useful to reveal the social and economic burden of BU, local needs and information gaps, and to guide pragmatic public health interventions for treatment, that take into consideration the social, cultural and environmental contexts of affected persons.

Since the discovery of BU in the 1900s (MacCallum et al., 1948), there have been several epidemiological studies (Amofah et al., 2002; Marston et al., 1995; Noeske et al., 2004; Suykerbuyk et al., 2009; van der Werf et al., 1989; van der Werf et al., 1999). Some studies have also highlighted water contact as a risk factor for BU illness which form the basis for health education messages that emphasise water contagion from unpotable sources as a risk factor for BU infection (Aiga et al., 2004; Debacker et al., 2004; Debacker et al., 2006; Marston et al., 1995; Pouillot et al., 2007; Raghunathan et al., 2005).

Yet, there is a paucity of socio-cultural research on BU, particularly in Ghana where the disease was first reported in 1971 (Bayley, 1971). The extent of the BU-related disease burden for pre-ulcer and ulcer conditions cannot be explained adequately by epidemiological studies alone. Few studies have indicated the impact of the socio-economic burden of the BU illness on productivity, family welfare, education and treatment (Ackumey et al., 2011b; Asiedu & Etuaful, 1998; Grietens et al., 2008; Renzaho et al., 2007) and have indicated the influence of perceived spiritual causes on help-seeking behaviour (Aujoulat et al., 2003; Renzaho et al., 2007; Stienstra et al., 2002). Moreover, there is little research on the implications of the BU disease burden on gender roles, gender dimensions of care and implications for productivity, and family welfare.

Health programmes often assume that BU public health initiatives based on scientific research are well understood by the affected community but this is not necessarily so. Socio-cultural studies of pre-ulcer and ulcer conditions of BU are therefore indispensable to clarify issues of susceptibility to infection, knowledge gaps and the impact of BU on the individual as well as the family. These assessments are critical for designing effective BU control programmes that are sensitive to the cultural and environmental context of endemic communities. The purpose of this study was to explain local meanings and experiences of BU infection for respondents with pre-ulcer and ulcer conditions in the Ga-West and Ga-South municipalities in Accra.

4.2 Methods

4.2.1 The study area

This study was conducted from November 2008 to July 2009 in the Ga-West and Ga-South Municipalities of the Greater Accra region. The 2009 population estimates for the Ga-West municipality (GWM) is 215,824 (Ga-West Municipal Health Directorate, annual report, unpublished). About 60% of the population reside in 200 rural scattered communities; the rest of the land area is peri-urban and densely populated. The GWM shares boundaries with the Ga-South municipality (GSM) to the west, and has an estimated population of 210,727 located in about 362 communities, mainly peri-urban (Ga-South Municipal Directorate, 2011). Both municipalities have a similar population structure; 35% of the population are below the ages of 15 years and 65% are 15 years-of-age and above. The major BU medical treatment centres are the Amasaman hospital (AH) and the Kojo Ashong Clinic (KAC) in the GWM, and the Obom Health Centre (OHC) in the GSM. The AH is the main referral centre for BU treatment. These municipalities are the fifth most endemic with respect to BU, yet have the highest case-loads in terms of healed and active lesions (Amofah et al., 2002). BU continues to be a major cause of morbidity in these two municipalities with increasing numbers of related disabilities.

4.2.2 The study sample and sampling strategy

To identify as many BU affected persons as possible, a sample of 181 respondents was obtained from 67 communities and 3 BU treatment centres. Respondents who had pre-ulcer conditions rather than ulcers, at the time of the study were classified as ‘pre-ulcers’. AH admits approximately 90 persons with BU infection each year. Based on these estimates, we enlisted all BU patients receiving treatment at the AH, KAC and OHC and all affected persons from 67 endemic communities. The intention to interview respondents from health facilities and communities enabled us to obtain an adequate sample of BU-affected people to compare pre-ulcer and ulcer conditions.

A list of endemic communities was obtained from the municipal health directorates of the GWM and GSM. These communities were visited and community participants were located with the assistance of community-based surveillance volunteers (CBSVs) who kept registers of all affected persons. Neighbouring communities (which were not listed as endemic), were entered and affected persons were located and interviewed with the help of CBSVs. The research team compiled a register of persons that had been interviewed to avoid duplicate interviews of the same respondent. Community participants who indicated that they were out-patients were checked on our register to ascertain if they had already been interviewed in the health centres. Schools in sampled communities were also visited, and with the permission of the head teacher and class teacher, a WHO BU picture guide (WHO & Global Buruli Ulcer Initiative, 1998) was shown to the children. Children who admitted to having suspicious lesions were screened by health personnel from the KAC for confirmation. In endemic areas with a long history of BU infection, trained health workers are capable of identifying cases using the WHO classification (WHO & Global Buruli Ulcer Initiative, 1998). With the exception of children less than 5 years-of-age whose parents acted as proxy respondents, older children were interviewed first and subsequently care-takers, who were invariably parents of children. Coded responses reflected consensus opinion.

4.2.3 The Explanatory Model Interview Catalogue Interview

A semi-structured interview schedule was developed to study and clarify socio-cultural concepts of illness from the perspective of persons who are directly affected (Weiss, 1997). This explanatory model interview schedule was based on the framework of the Explanatory Model Interview Catalogue (EMIC) for cultural epidemiology. Like other EMIC interviews, this one had a common core structure to examine illness experiences and meanings of BU.

The design of the EMIC instrument was informed by preliminary ethnographic field experience, focus group discussions and earlier studies (Ackumey et al., 2011b; Renzaho et al., 2007). The instrument was developed in English and translated for interviews in the local Ghanaian languages, spoken by respondents in the study areas, (Ga, Ewe and Twi). The EMIC interviews elicited responses for illness meanings and experiences for BU. Questions on illness meanings (PC) explored various ideas about causes for BU such as ingestion, injury, environmental, behavioural and spiritual. Information on illness experiences (PD) was obtained by asking questions about physical conditions, social, psychological or emotional problems and the impact on caretakers work or school, to provide support. Children were not asked PD questions that were irrelevant, such as questions related to marriage, income and employment. To enable a comparative analysis of PD and PC variables for pre-ulcers and ulcers, the same EMIC interview was administered to all respondents. Respondents' narratives to open-ended questions elaborated and explained responses to coded categories.

4.2.4 Data Management and Analysis

Categorical and numeric data from the EMIC interviews were double entered using EPI Info (Centers for Disease Control and Prevention, Atlanta, GA, USA, version 3.4.1) and subsequently cleaned and analysed using STATA 10.1 data analysis and statistical software (StataCorp, Lakeway Drive, College Station, Texas). The analysis compared illness experiences and meanings for respondents with pre-ulcers and ulcers to elucidate similarities or differences in the ways that respondents experienced and explained their conditions.

Total frequencies and prominence of variables for PD and PC were compared for pre-ulcers and ulcers. Responses were classified on a prominence scale as follows: a spontaneous response was assigned a value of 2, a response after a probe (in the absence of a spontaneous answer) a value of 1, and no response, a value of 0. Respondents were asked to indicate the most troubling PD and the most important PC. These responses contributed an additional value of 3. A cumulative prominence (ranging from 0-5) was then computed for PD and PC variables which facilitated a comparative analysis for pre-ulcers and ulcers. The Wilcoxon rank-sum test for non-parametric data was used to compare the ranked prominence of PD and PC variables for pre-ulcers and ulcers. The Fisher's exact test was also used to compare the frequency of each reported category of most troubling PD and most important PC. Individual cultural epidemiological variables for PD and PC were also grouped thematically for analysis and comparison of overarching concepts (physical conditions, social problems and psychological for PD; ingestion, illness/injury, environmental, behaviour and spiritual for PC). Furthermore, we examined the perceived seriousness of BU, the social effect of respondents' illness conditions on the family and the gender dimensions of care for pre-ulcer and ulcer conditions.

Narrative data were transcribed into English during the interview by the data collector and entered into Microsoft Word 2002. These narrative data were analysed with MAXQDA 10 (Verbi Software Consult Sozialforschung, GmbH, Marburg, Germany) software for textual analysis. Phenomenological analyses of PD and PC were compared for selected respondents' narratives based on thematic deductive coding. Narratives were selected for qualitative analysis according to coded responses imported into the qualitative data programme (MAXQDA) from the qualitative data set in Epi Info. This approach clarified essential features of explanatory variables associated with illness meanings and experiences for pre-ulcers and ulcers.

4.2.5 Ethical considerations

Verbal informed consent was obtained from all adult respondents and parental caretakers or guardians of children. The study was approved by the ethical review committee of the Ministry of Health, Ghana, and the ethics commission of Basel (Ethikkommission beider Basel, EKBB), in Switzerland.

4.3 Results

4.3.1 Sample characteristics

A total of 181 respondents were interviewed. The majority of respondents had ulcers (91.7%) and only 8.3% had pre-ulcers. Respondents with pre-ulcers and ulcers had similar background characteristics. Most respondents had at least completed primary school. Very few respondents were skilled or professional workers and very few had regular income (Table 4.1).

Table 4.1: Demographic Characteristics of respondents

Demographic Characteristics	**Pre-ulcer N=15**	**Ulcer N=166**	**Total N=181**
	N (%)	**N (%)**	**N (%)**
Sex			
Males	7 (46.7)	80 (48.2)	87 (48.1)
Females	8 (53.3)	86 (51.2)	94 (51.9)
Age of respondents			
Minimum age	6	3	3
Maximum age	64	87	87
Mean age	19	22.8	22.46
Standard deviation	14.9	18.3	18.07
Education			
No education	3 (20.0)	39 (23.5)	42 (23.2)
Primary	8 (53.3)	90 (54.2)	98 (54.1)
Secondary and above	4 (26.7)	37 (22.3)	41 (22.7)
Occupation			
Pupil/student	11 (73.3)	89 (53.6)	100 (55.2)
Unskilled labour	3 (20.0)	44 (26.5)	47 (26.0)
Skilled labourer/Professional	1 (6.7)	12 (7.2)	13 (7.2)
Unemployed	0	14 (8.4)	14 (7.7)
Other (too young to be either employed or in school)	0	7 (4.2)	7 (3.9)
Income			
Regular and dependable	5 (33.3)	29 (17.3)	34 (18.8)
Uncertain/ Cannot tell	4 (26.7	65 (39.2)	78 (43.1)
Irregular	6 (40.0)	72 (43.4)	69 (38.1)
Marital status			
Never married	11 (73.3)	114 (68.7)	125 (69.0)
Married	4 (26.7)	38 (22.9)	42 (23.2)
Separated / divorced	0	5 (3.0)	5 (2.8)
Widowed	0	9 (5.4)	9 (5.0)

4.3.2 Burden of BU and impact on family well-being

Features of the impact of BU were disrupted livelihoods, loss of income, absence from work or school for care, and anxiety about disease progression. While respondents with pre-ulcers emphasised the point that their families were more concerned about the progression and course of their illness (66.7%), respondents with ulcers emphasised loss of income as the main concern of family members (80.1%) (Table 4.2).Respondents with nodules indicated in their narratives that their condition did not pose any threat to their well-being and family welfare since they were in no pain, could use affected limbs, and therefore were able to perform their daily routines of school and work, without any limitation. Family members of respondents with pre-ulcer conditions worried about the progression of the illness of their relatives. They were concerned about the outcome of *swollen* (oedematous) limbs or plaques and nodules that were likely to progress into ulcers with debilitating consequences of pain, disability and high costs of care. Narratives of respondents with ulcers referred to various effects of their condition on their family. These included disruption of work to provide care in the hospital and at home, and depletion of family income and resources for treatment costs. Family members of respondents with ulcers too were often concerned about disease progression and prolonged treatment, and the likelihood of disability.

4.3.3 Gender dimensions of BU-burden and care

Socially constructed gender roles of care and work affected livelihoods, income and education of those providing care for sick relatives. The socio-economic status of families also worsened if the affected person was the main income-earner. Generally, for respondents with ulcers, mothers (52%) were more likely to miss work for caretaking than fathers (6%); daughters (7.2%) were more likely to stay away from school than sons (0.6%), and more sisters (8.4%) than brothers (1.2%) stayed at home to care for sick relatives. Similarly, pre-ulcer respondents with plaques and oedematous lesions also identified mothers as care-givers. The following illness narrative explains how the loss of livelihoods, anxiety, and the need for care affects the social and economic well-being of the family.

> *It started as a hard boil (nodule). I showed it to a health worker at Hobor* (a community in the GSM). *He told me it was Buruli ulcer and said I should go to the hospital. I did not have enough money then, so I stayed at home for 3 weeks before going to the hospital. I am the bread winner of the family and now I am in hospital. My daughter comes here occasionally with food and money for me, and to wash my bandages. Since I am not working, my parents send me money and some provisions occasionally. When my parents do not have money, they do not send anything.*
>
> (28-year-old female respondent)

Table 4.2: Impact of respondent's illness condition on family

Illness impact	Pre-ulcers, N= 15			Ulcers, N=166			
	Total %	Spon. %	Mean Prominence	Total %	Spon. %	Mean Prominence	P-values
Loss of income	33.3	13.3	0.47	80.1	60.8	1.41	***
Sadness, anxiety and worry	60.0	6.7	0.67	71.7	28.9	1.01	
Concern about course of illness	66.7	26.7	0.93	81.9	35.5	1.17	
Miss work for care-taking	26.7	0.0	0.27	85.5	54.2	1.40	***
None	26.7	20.0	0.47	1.2	1.2	0.02	***
Left the family without support	6.7	6.7	0.13	1.8	1.8	0.04	

Categories reported by less than 5% of respondents were not included in the table. Columns indicate total reported responses in percentages, spontaneously reported responses in percentages and the mean prominence. The mean prominence was based on assigned values to each reported category (2 = spontaneous response, 1 = probed response, 0 = not reported). The Wilcoxon ranksum test was used to compare means for pre-ulcers and ulcers (*p≤0.05, **p≤0.01, ***p≤0.001).

4.3.4 Patterns of distress

Respondents with pre-ulcers and ulcers expressed their distress differently (Table 4. 3). Those with pre-ulcers frequently reported psychological or emotional problems (86.7%), particularly anxiety (66.7%) and physical problems, mostly pain (66.7%). Psychological or emotional problems were mentioned as the most troubling category of distress and were more prominent for pre-ulcers. Pain was often associated with oedematous lesions. For ulcers, physical problems (98.2%) were frequently and more prominently reported. Pain and problems with mobility or use of affected limbs were physical problems that respondents with ulcers emphasised as distressing (Table 4.3). Disrupted education was the most frequently reported social problem.

Narratives showed that respondents with pre-ulcers were often anxious about the progression of their illness to ulcers. This concern was influenced by prior knowledge of the debilitating nature of illness progression from pre-ulcers to ulcers, uncertainty of disease outcomes and concern about transportation costs for treatment. One respondent worried that *it* (nodule) *will become a sore just like those of other people who already have it, and my leg will be cut.* Respondents who were not familiar with pre-ulcer conditions too were often anxious about the outcome of their illnesses. Desperation and desire for clarification of their conditions and relief led them to seek advice and help from friends and family, and to shop for care from various providers, such as herbalists, church, and private health practitioners. Many respondents with pre-ulcers did not want normal work and school attendance to be disrupted. Therefore, they used itinerant providers who could provide services in the respondents' homes.

Table 4.3: Reported categories of distress for respondents with pre-ulcers and ulcers

Categories of distress	**Pre-ulcers, N = 15**				**Ulcers, N= 166**				
	Total %	**Spon. %**	**Most important %**	**Mean Prominence**	**Total %**	**Spon. %**	**Most important %**	**Mean Prominence**	**P-values**
Physical problems	**80.0**	**60.0**	**13.3**	**1.80**	**98.2**	**94.6**	**46.4**	**3.32**	***
Fever	26.7	13.3	0.0	0.40	28.9	9.6	0.6	0.40	
Pain	66.7	46.7	6.7	1.33	86.8	72.3	14.5	2.02	*
Smell	6.7	0.0	0.0	0.07	66.3	14.5	1.2	0.84	***
Weight loss	13.3	0.0	0.0	0.13	56.6	18.7	0.6	0.77	***
Loss of appetite	20.0	0.0	0.0	0.20	43.4	9.0	0.0	0.52	
Weakness	26.7	6.7	0.0	0.33	37.4	8.4	0.0	0.46	
Problems with mobility and use of affected limbs	40.0	13.3	6.7	0.73	83.1	68.7	29.5	2.40	***
Condition is ugly	13.3	6.7	0.0	0.20	41.6	3.6	0.0	0.45	*
Social problems	**40.0**	**26.7**	**40.0**	**1.87**	**89.2**	**67.5**	**36.1**	**2.65**	*
Rejection from family	0.0	0.0	0.0	0.00	19.3	2.4	0.0	0.22	
Rejection by friends / peers	6.7	0.0	0.0	0.07	22.9	3.6	0.0	0.27	
Disrupted education	33.3	20.0	33.3	1.53	56.6	45.2	26.5	1.81	
Loss of income	6.7	6.7	6.7	0.33	38.0	22.3	9.6	0.89	*
Psychological /emotional	**86.7**	**20.0**	**46.7**	**2.47**	**78.9**	**28.9**	**16.3**	**1.57**	
Anxiety	66.7	13.3	33.3	1.80	61.5	15.1	9.6	1.05	
Fear of surgery	20.0	0.0	0.0	0.20	18.7	3.6	1.8	0.28	
Embarrassed about condition	20.0	6.7	13.3	0.67	49.4	12.7	4.2	0.75	
Miscellaneous	**0.0**	**0.0**	**0.0**	**0.00**	**12.7**	**12.7**	**1.2**	**0.29**	
Disrupted life and sleeplessness	0.0	0.0	0.0	0.00	12.7	12.7	1.2	0.29	

Categories reported by less than 5% of respondents were not included in the table. Columns indicate total reported responses in percentages, spontaneously reported responses in percentages and the mean prominence. Total reported values include combined spontaneous and probed responses. The mean prominence was calculated based on assigned values to each reported category (3=Most troubling distress, 2 = spontaneous response, 1 = probed response, 0 = not reported). The Wilcoxon ranksum test was used to compare mean prominence for pre-ulcers and ulcers (*p≤0.05, **p≤0.01 ***, p≤0.001).

Like respondents with pre-ulcers, respondents with ulcers who were in school often worried about their education being disrupted (56.6%) and expressed anxiety (61.5%) about the outcome of their ulcers. Narrative accounts of respondents with ulcers revealed that their distress was influenced by a combination of physical, social and psychological problems. For example, anxiety was often triggered by the intensity of pain and the inability to use affected limbs or move around easily, which hampered work and school. As recourse for cure, and to continue with work and school, respondents with ulcers too, preferred help from itinerant providers such as herbalists, private health practitioners and other government employed health workers, who provided care in their homes after work. As their illness conditions worsened and pain intensified, respondents were compelled to seek help from the municipal health facilities. A female respondent explained how pain and immobility had affected her livelihood and income. Desperate to recover quickly and to continue working and taking care of her children, she used various providers and eventually used medical care.

> *I have been suffering for some time now. My leg hurts and I cannot walk properly with this leg. I used to be an okra farmer, but I cannot farm anymore. I do not make money anymore to take good care of my children. I bought all kinds of drugs from the people who sell medicine* (drug peddlers), *but they did not work. I visited so many places for help. I bought any medicine I heard of, but none of them helped me. My pastor told me to go to the health centre as it was getting worse but I rather went to see a herbalist, but his treatment did not work, the sore was getting bigger and bigger. I wanted to get well quickly to go back to farming. I finally came to the hospital.*
>
> (28-year-old female respondents)

Likewise, a mother's anxiety about her son's condition focused on the fear that he might drop out of school. Aside from her child's distress, she also bemoaned her absence from the home because of care, loss of work and the gradual dwindling of her trading capital, and eventual poverty.

> *Now that he has Buruli ulcer when will he recover in order to go back to school? Sometimes I am afraid that this is it; he may never go back to school. Since I am his mother, I have to be with him at the hospital. I had to spend Christmas here in the hospital, away from the family. I have stopped trading and my capital which was a loan from the bank has been spent on looking after my son. Meanwhile, it is still building-up interest. How am I going to pay back the money when I have stopped work?*
>
> (Mother of 9-year-old male child)

4.3.5 Perceived causes

Respondents mentioned a variety of causes to explain their illness. For both pre-ulcers and ulcers, perceptions of causes were based on observation, behaviour, the influence of health messages on contagion, and the logic of explanations they had for their illness.

Respondents with pre-ulcers frequently and prominently reported behaviour-related causes, particularly swimming in ponds and rivers which was also considered as the most important perceived cause (53.3%) (Table 4.4). Respondents, who reported swimming in ponds and rivers, linked their condition to their own risky behaviour. Some respondents, who said they had no contact with water bodies, questioned the credibility of health messages that linked contagion to contact with unclean water. They referred to the absence of the disease in other community members with whom they shared the same water sources (rivers and ponds). Furthermore, about half of respondents with pre-ulcers attributed their illness to drinking unclean water (53.3%), and about a third (33.3 %) of respondents could not tell the cause of their illness.

Table 4.4: Reported categories of perceived causes for respondents with pre-ulcers and ulcers

Perceived causes	**Pre-ulcers, N = 15**				**Ulcers, N= 166**				
	Total %	**Spon. %**	**Most important %**	**Mean Prominence**	**Total %**	**Spon.%**	**Most important %**	**Mean Prominence**	**P-values**
Ingestion	**53.3**	**26.7**	**6.7**	**1.00**	**33.7**	**11.5**	**4.2**	**0.58**	
Drinking unclean water	53.3	26.7	6.7	1.00	33.7	11.5	4.2	0.58	
Illness/ Injury	**20.0**	**0.0**	**0.0**	**0.20**	**44.0**	**27.1**	**9.0**	**0.98**	*
Prone to illness	13.3	0.0	0.0	0.13	13.9	4.8	0.6	0.20	
Insect bites	13.3	0.0	0.0	0.13	7.2	2.4	0.6	0.11	
Scratches on skin	13.3	0.0	0.0	0.13	14.5	7.2	1.8	0.27	
Weakness of blood	20.0	0.0	0.0	0.20	38.6	24.1	6.0	0.81	
Environmental	**40.0**	**6.7**	**0.0**	**0.47**	**34.3**	**15.7**	**4.2**	**0.63**	
Poor sanitation	40.0	0.0	0.0	0.40	27.7	10.2	1.2	0.42	
Poor personal hygiene	26.7	0.0	0.0	0.27	21.1	5.4	2.4	0.34	
Exposure to sand	20.0	6.7	0.0	0.27	23.5	7.8	0.6	0.33	
Behaviour	**60.0**	**40.0**	**53.3**	**2.60**	**48.2**	**28.9**	**18.1**	**1.31**	
Swimming in ponds and rivers	60.0	40.0	53.3	2.60	43.4	25.9	18.1	1.23	*
Contact with animals	6.7	6.7	0.0	0.13	9.0	3.0	0.0	0.12	
Spiritual	**20.0**	**6.7**	**0.0**	**0.27**	**64.5**	**51.2**	**39.7**	**2.35**	**
Witchcraft	20.0	6.7	0.0	0.27	64.5	51.2	39.7	2.35	**
Miscellaneous	**46.7**	**46.7**	**40.0**	**2.13**	**31.9**	**31.9**	**24.7**	**1.38**	
Cuts, abrasions, unexplained swelling of limbs	13.3	13.3	13.3	0.67	8.4	8.4	6.6	0.37	
Cannot say/ uncertain	33.3	33.3	26.7	1.47	24.1	24.1	18.1	1.02	

Categories reported by less than 5% of respondents were not included in the table. Columns indicate total reported responses in percentages, spontaneously reported responses in percentages and the mean prominence. Total reported values include combined spontaneous and probed responses. The mean prominence was calculated based on assigned values to each reported category (3=Most important perceived cause, 2 = spontaneous response, 1 = probed response, 0 = not reported). The Wilcoxon ranksum test was used to compare mean prominence for pre-ulcers and ulcers (*p≤0.05, **p≤0.01, ***p≤0.001

Some respondents with pre-ulcers, who remembered how their illness started, were certain that they had no water contact. They attributed their illness to various factors like scratches, stings, abrasions and unexplained swellings of the limbs. Those respondents, who related their condition to bad drinking water, based this idea on health information from health workers, community-based surveillance volunteers and teachers. They admitted however, to drinking unclean water from rivers, ponds and dug-out wells and explained that they had no other option.

Respondents with ulcers emphasised witchcraft as a likely perceived cause and the most important perceived cause for their illness. Aside from such spiritual causes, swimming in ponds and rivers (43.4%), weakness of blood (38.6%)and drinking unclean water (33.7%) were also mentioned (Table 4.4). Like respondents with pre-ulcers, some respondents with ulcers could not tell the cause of their condition (24.1%).

Respondents' narratives related ideas of witchcraft to a variety of other factors. These included: The absence of a logical explanation for infection within the context of health messages that emphasised contact with aquatic sources as a risk factor for contagion (especially when other persons exposed to risk factors like swimming, fishing and bathing in rivers were never infected); inability to explain the cause of the disease; progression of abrasions, small cuts and swellings into debilitating ulcers that took a long time to heal. Some parents could not understand how children, who were too young to swim and therefore had no contact with aquatic sources, were infected. An adult respondent explained her choice for medical care after a recurring BU infection. She mentioned witchcraft as a perceived cause of her illness and dismissed water contact as a plausible explanation:

> *When it happened the first time, I tried herbal treatment and I really suffered before I got cured. So when it happened this time, I decided to go to the hospital. We have a pond in this village and no one swims or wades in this pond. I am a neat person and my house and compound are always clean. I do not swim or wash in bad water. So I don't believe that this disease is from the water as the nurses here are saying. I believe that this condition is due to witchcraft because that is what witches do; they destroy people's lives. This disease is terrible, it cripples you and ties you down for months and even years. We will be happy if a stronger and faster treatment can be found for this illness.*
> (45-year-old female respondent)

Narratives indicated that scepticism of health messages, and reference to witchcraft as a PC, did not prevent respondents from using medical care. Illness experiences (PD), persistence of the lesion and failure to recover, and awareness of medical care for BU, influenced their choice of medical care. However, witchcraft-related explanations prejudiced notions of transmission and prevention. Many respondents with pre-ulcers (40.0%) and ulcers (50.0%) stated that their conditions could not be prevented because *witchcraft cannot be stopped.* Nevertheless, respondents with pre-ulcers (56.7 %) and ulcers (46.4%) mentioned *avoiding swimming and bathing in rivers and ponds* as an effective preventive measure. Narratives revealed that this information was obtained from health messages in the communities, school and health centres.

Like respondents with pre-ulcers, respondents with ulcers who mentioned water contact through swimming as a likely cause of their condition, blamed their associated behaviour for their illness and not a matter of lack of awareness. They explained that unclean water sources could not be avoided since there was no better alternative. These sources of water were used for bathing, washing, cooking and irrigation. Sometimes, during the rainy season, respondents had to wade through ponds as a thoroughfare.

Additionally, vulnerability to BU infection due to low immunity, referred to locally as *weakness of blood,* was mentioned as a possible cause of infection. Infected children, particularly those who had recurring lesions, were often described as having *weak blood.* A child explained why *weakness of blood* was more likely cause than water contact:

> *I believe my condition is due to the weakness of my blood because all of us at home go to the river to fetch water and we use the same water. Why am I the only one to get infected? I had it some time ago and it has reoccurred.*
>
> (16-year-old male respondent)

4.4 Discussions

To the best of our knowledge, this is the first study to compare illness meanings and experiences of BU for pre-ulcers and ulcers. Our study findings draw attention to the gendered burden of care for BU-affected persons and its impact on family welfare, work and school, the extent and nature of anxiety for pre-ulcers (on anticipated disease outcomes) and ulcers and disability from ulcers. Perceived causes for pre-ulcers and ulcers indicated the mismatch between professional and local ideas on disease contagion and revealed information gaps that need guidance from further research. Such scepticism about health messages, however, did not deter respondents from seeking medical care, which was influenced largely by illness experiences and the desire for recovery from persisting lesions. Study findings indicate a myriad of social, cultural, physical and behavioural issues associated with illness meanings and experiences. These findings highlight the need for health professionals to clarify messages on contagion and dispel fears of BU being perceived as a mysterious disease to encourage early medical treatment. Improving BU surveillance, case-detection and access to treatment is important and could reduce the social and economic impact of BU.

4.4.1 Study limitations and implications

Respondents were queried about illness experiences and meanings of their current conditions, and there were few respondents with pre-ulcers (15) compared with ulcers (166). Efforts to identify more respondents with pre-ulcers suggested that the low numbers of respondents with pre-ulcers may result from hastened progression to ulcers from cutting nodules and piercing oedematous tissue. This practice rapidly transforms pre-ulcer conditions into ulcers (Table 4.5). A recent study in a BU-endemic area in Ghana also showed fewer pre-ulcer cases (23.3%) than ulcer cases (76.7%) during an initial health-screening exercise. However, the situation reversed after one year of intensive health education (Agbenorku et al., 2011). Nevertheless, our findings are clearly relevant for our study communities and for other BU-endemic areas in Ghana.

Table 4.5: Local practices that transform pre-ulcers into ulcers

Background characteristics of respondent	**Narrative**	**Procedure adopted**
Father of 12-year-old female child	A herbalist cut the boil open and placed a herbal dressing on it.	Nodule was cut
Father of 4-year-old male child	We took him (son) to see his grandfather who cut the boil and it became a sore. His grandfather has been cutting other people's boils that is why we took him to see him.	Nodule was cut
Father of 4- year-old male child	The boil became big and we cut it open and placed some herbal preparations on it.	Nodule was cut
A 13-year-old male respondent	My uncle used a sharp object to cut the boil so that the blood could come out. Then he applied some black powder and put some in alcohol for me to drink.	Nodule was cut
A 26-year-old female respondent	I burst the boil because I did not know what it was and then I cleaned the sore everyday with hot water.	Nodule was cut
A 48-year-old adult male respondent	My father put some herbs on the boil to open it up.	Herbs applied to the boil to open it up
An 18-year-old female respondent	My grandmother ground herbs mixed with salt and placed it on the boil so that it could burst.	Herbs applied to the boil to open it up
A 43-year-old female respondent	I had a swelling on my ankle for one week. My husband slit it and then it gradually became a big sore.	Oedema cut open

*Narrative data of other respondents with ulcers (not presented in this table) suggests that herbal preparations were placed on nodules, oedemas and plaques to open up the skin to expose the necrotic tissues. Subsequently herbal dressings were applied to the exposed tissues.

4.4.1.1 Gender roles, gender dimensions of care and impact on family welfare

Because pre-ulcer conditions are normally painless and less debilitating than ulcers, medical care is often delayed. However, owing to the incapacitating nature of ulcers and prolonged healing required care for affected persons is considerable (Adamba & Owusu, 2011; Muela et al., 2009). The gendered nature of care in our study has far reaching social and economic implications for the care-givers. First, when mothers and spouses are pre-occupied with caring for sick relatives, they have less capacity for other productive work which may jeopardise the welfare of the family, particularly young children.(Adamba & Owusu, 2011; Asiedu & Etuaful, 1998). The absence of children from school because of their own illness or a need to care for others has serious implications for their future development and economic empowerment (Stienstra et al., 2004). Economic constraints require affected persons who were the main income-earners to choose between medical and herbal treatment, and alternatives, considering the economic well-being of the family.

Health care providers should ensure that community members understand the benefits of early treatment to minimise suffering and the need for extended care. As much as possible, over-reliance on family health care providers in the health centres should be discouraged. Perhaps, young people from the national youth employment programme (Government of Ghana & Ministry of Youth and Sports, 2011), employed as health extension workers, could assist with the care of young patients and other patients with disability, providing community-based social support that relieves the burden on the family.

4.4.1.2 Substantial psychological and social impact of BU among respondents

The frequency with which anxiety about disease progression was reported by respondents with pre-ulcers and ulcers suggests high levels of awareness about BU, the debilitating consequences if pre-ulcers are not treated early, and the implications of the cost of treatment. Medical care is free in our study communities (Ackumey et al., 2011b; Adamba & Owusu, 2011). It is therefore expected that illness experiences associated with pre-ulcers and ulcers would prompt early medical care. However, some respondents delayed treatment for pre-ulcers as long as there was no pain or disability. Respondents with ulcers also delayed medical treatment irrespective of their pain, anxiety and disability until they could acquire enough money for transport and food while hospitalised.

BU is known to affect impoverished rural communities with poor access to health facilities, thus exacerbating poverty and suffering (Marston et al., 1995; Walsh et al., 2009; WHO, 2008) and limiting opportunities for education and productivity (Asiedu & Etuaful, 1998; Grietens et al., 2008). The social and economic impact of the BU illness is critical because the majority of the people in our study communities depend on subsistence agriculture (Adamba & Owusu, 2011). Research shows that in the Ga-West municipality a patient with a nodule may be hospitalised for 74 days, and a patient with an ulcer may spend nearly a year (301 days), on average, in treatment. This same study (Adamba & Owusu, 2011) also revealed that families and BU-affected persons sold assets and properties like farm equipment and livestock, used up savings and borrowed money to pay for transport and food while in treatment at the hospital, and for the upkeep of the family. Relatives of respondents and respondents, who had to miss work or school understandably bemoaned the socio-economic impact of BU affecting their own well-being and the welfare of the family.

4.4.1.3 Support groups and counselling services

Peer support groups for affected persons, mothers and care-givers may represent a cost-effective and culturally appropriate intervention for the psychological, social and medical management of BU, particularly in geographically dispersed communities such as our study area. The benefits of support groups or networks are far reaching and include information sharing on appropriate help-seeking behaviour, encouragement to initiate timely treatment and adherence to treatment (Gordillo et al., 1999; Johansson & Winkvist, 2002; Macq et al., 2007; Morisky et al., 2001; Yirga et al., 2010). Peer support groups of former or current affected persons may serve as points of psychological encouragement and counselling and are vital for sharing illness experiences and learning coping strategies, thus limiting the effects of stigma or social exclusion (Ackumey et al., 2011a; Johansson & Winkvist, 2002; Macq et al., 2007; Morisky et al., 2001; Worley et al., 2009; Yirga et al., 2010).

4.4.1.4 Perceived causes, implications for BU prevention and the role of health education

The high proportion of respondents in our study that reported witchcraft as a perceived cause (20% of respondents with pre-ulcers and 64.5% of respondents with ulcers) is much higher than indicated by findings from an earlier study of BU knowledge in the Ga-West and South municipalities in which 5.2% of respondents mentioned witchcraft- related causes (Renzaho et al., 2007). Explanations for witchcraft-related causes in our study were based on the sudden and inexplicable swelling of limbs, and the progression of pre-ulcers into painful ulcers which healed slowly and led to deformities. Perception of spiritual factors are likely when BU disease is prolonged (Mulder et al., 2008; Stienstra et al., 2002; Vandelannoote et al., 2010). Linking BU infection with a spiritual cause is likely to influence help-seeking from traditional healers to counteract the spell of the disease, especially spiritualists (Aujoulat et al., 2003; Mulder et al., 2008; Noeske et al., 2004). However, the majority of respondents in our study used herbalists and not spiritualists for treatment of their conditions, and not to liberate themselves from the spell of BU.

Furthermore, ideas of witchcraft as a perceived cause did not prevent our study respondents from seeking medical care. Local ideas about pervasiveness of witchcraft prejudiced them against some health messages. Scepticism about standard prevention strategies based on avoiding contact with rivers and ponds prevents a challenge to health professionals. Since slow healing of ulcers suggests ideas of witchcraft, health messages should emphasise that BU is an ordinary disease that will heal more quickly if treatment is initiated early during the pre-ulcer phase of infection.

4.4.1.5 Early case-detection and disease surveillance for prompt medical care

For impoverished BU endemic areas, a comprehensive approach for prevention and treatment that addresses the health, social and economic impact of the BU illness would be ideal. Periodic screening in schools and communities by health professionals, CBSVs and teachers should endeavour to detect early cases for screening and treatment regularly (Ackumey et al., 2011b; Agbenorku et al., 2011). Periodic screening might be useful in diagnosing all forms of skin trauma, lesions, stings and bites which may be unrecognised onset of BU and refer promptly for medical care. Teachers and community-based surveillance volunteers in our study communities have already been trained to screen school children and community members (Ackumey et al., 2011b). However, there is the need to strengthen this skill by re-training former CBSVs and teachers, and training new teachers that have been posted to these communities.

4.4.1.6 Improving access to medical care

Health education, early screening and case detection alone may not achieve its goal of encouraging and sustaining early medical care and lessen the social and economic hardships, unless treatment centres are provided within reach of communities, ensuring easy access to treatment at minimum cost.

WHO-recommended antibiotics has been proven to shrink nodules and ulcers and prevent recurrences (Ackumey et al., 2011b; Chauty et al., 2007; Etuaful et al., 2005; Nienhuis et al., 2010). Surgery may also be required for oedematous lesions and plaques after antibiotic treatment. Decentralising health care by partnering with private health care providers to provide antibiotic treatment in close proximity to residences could minimise length of hospitalisation and socio-economic impacts. These strategies have been discussed in detail in previous papers (Ackumey et al., 2011a; Ackumey et al., 2011b). Mobile health services may contribute to improving access to antibiotic treatment and should be integrated into the community-based health planning and services (CHPS) initiative. The CHPS concept is a national health policy initiative that aims to improve access to care and disease surveillance in poor, rural and dispersed communities. Health workers reside within a community and provide mobile health services and follow-up on patients within catchment areas (Nyonator et al., 2005). Studies have documented the usefulness of such initiatives that combine screening, education and surveillance in disease control to minimise disease morbidity (Brieger, 1996; Cairncross et al., 1996).

4.4.1.7 Providing transport and feeding to encourage early treatment

Anxiety, experienced by respondents with pre-ulcers was linked to imminent progression of pre-ulcer conditions to ulcers, and the inherent costs of transports and feeding associated with treatment. BU public health programmes need to consider transport and feeding as a cost effective strategy to encourage early treatment seeking during the pre-ulcer phase of infection to minimise delayed treatment for ulcers that may require surgery and possibly prolonged healing and hospitalisation (Sagbakken et al., 2008). Since the host immune response is critical for BU disease progression and healing (Johnson et al., 2005a; Portaels et al., 2009; van der Werf et al., 2005), feeding programmes may boost the immune system and improve treatment outcomes (Sagbakken et al., 2008). These feeding initiatives already exist in the Amasaman Hospital and need to be extended to other health facilities in the study area.

4.4.1.8 Improving access to clean water

The absence of clean water for basic domestic and hygiene activities, such as washing, cleaning, cooking and bathing in our study communities explains why reliance on unclean infected sources persists. Most BU-endemic communities are rural and lack basic amenities, including clean water (World Health Organization, 2009). The continuous use of unclean water defeats the purpose of health messages that emphasise contact with unclean water as a risk factor for BU infection. Although some respondents are farmers, they practice rain-fed agriculture and small-scale fishing. (Ga-West Municipality, 2011). Providing clean water is likely to reduce BU infections considerably. Municipal authorities should solicit help from Non-Governmental Organisations (NGOs) to provide boreholes.

4.4.1.9 Needed research to explain the role of environmental factors for BU contagion

Recent environmental studies on BU transmission confirm the presence of *M. ulcerans* in aquatic environments (Johnson et al., 1999; Williamson et al., 2008). Environmental factors have been mentioned as a cause of BU infection in previous socio-cultural studies (Renzaho et al., 2007; Stienstra et al., 2002), although it has been argued in one study that respondents' views on the role of environmental factors in BU contagion were influenced by health messages rather than indigenous cultural ideas.(Stienstra et al., 2002). Although the mechanism of BU transmission remains unclear (Johnson et al., 2005b; Portaels et al., 2009; WHO, 2008), health messages link disease contagion to water-related activities and encourage endemic communities to minimise water contact (Aiga et al., 2004; Asiedu & Etuaful, 1998; Marston et al., 1995). The empirical basis of these health messages is widely accepted and some respondents acknowledged their own risky behaviour as contributing to infection. Other respondents, however, were sceptical of these health messages. For them, messages failed to explain why persons with risky behaviour were not infected, and why others without such water contact nevertheless got BU. This shows a mismatch and an information gap between professional knowledge that requires credible bridging.

It has been argued that alternate explanations for BU transmission should be more widely acknowledged, especially direct skin contact with contaminated water (Aiga et al., 2004; Asiedu & Portaels, 2000; Duker et al., 2006; The Uganda Buruli Group, 1971) and the possible role of animal and anthropoid vectors (Fyfe et al., 2010; Merritt et al., 2010). Immunological research indicates that persons exposed to *M. ulcerans* might never develop the BU disease due to host immunity (Portaels et al., 2009). A deeper understanding of the social and environmental contexts of BU is needed, considering, for example, whether persons living in non-aquatic environments can be infected by insects (Portaels et al., 1999). Future environmental studies need to investigate transmission of *M. ulcerans* in non aquatic environments in endemic areas, to clarify health messages and appropriate community guidance. Clearer, credible explanations of transmission patterns will instil confidence in the health system, health professionals and health messages for effective public health action.

4.5 Conclusions

The social burden of BU is enormous. Our study suggests that besides physical pain, disability and anxiety about the progression of the disease, BU affects livelihoods, interrupts education and jeopardises the welfare of affected families. Persons with pre-ulcer conditions are likely to delay treatment because of social and financial constraints and the absence of pain. Communities remain sceptical about the role of water in disease contagion, and these questions make ideas about witchcraft as a perceived cause more credible among people with ulcers. Study results suggest that health education messages should acknowledge locally perceived risk and vulnerability. Health education is not enough, however, and peer support groups are also needed to provide emotional and social support, to boost self esteem and to encourage early treatment. Since the mode of transmission remains unclear, further research on the role of environmental, socio-cultural and genetic factors in BU contagion is needed for practical and useful guidance for communities and to strengthen public health initiatives. Our study findings are relevant for other BU-endemic regions and communities in the country.

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Chapter 5

Help-seeking for pre-ulcer and ulcer conditions of *Mycobacterium ulcerans* disease (Buruli ulcer) in Ghana

Mercy M. Ackumey [1 2 3*], Margaret Gyapong [4], Matilda Pappoe [1] and Mitchell G. Weiss [2 3]

1. School of Public Health University of Ghana, Legon, Accra, Ghana
2. Swiss Tropical and Public Health Institute, Basel
3. University of Basel, Switzerland
4. Dodowa Health Research Centre, Ghana Health Service, Ghana

* Corresponding author

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5.0 Abstract

Introduction

This study examined socio-cultural features of help-seeking (HS) for BU-affected persons with pre-ulcers and ulcers in an endemic area of Ghana. A sample of 181 respondents, were purposively selected.

Methods

The Fisher's exact test was used to compare HS variables for pre-ulcers and ulcers. Qualitative phenomenological analysis of narratives clarified the meaning and content of selected quantitative HS variables.

Results

For pre-ulcers, herbal dressings were used to expose necrotic tissues and subsequently applied as dressings for ulcers. Analgesics and left-over antibiotics were used to ease pain and reduce inflammation. Choices for outside-help were influenced by the perceived effectiveness of the treatment, the closeness of the provider to residences, and family and friends.

Conclusion

Health education is required to emphasise the risk of self-medication with antibiotics, the importance of medical treatment for pre-ulcers, and to caution against the use of herbs to expose necrotic tissues which could lead to co-infections.

5.1 Introduction

Buruli ulcer (BU) is a debilitating disease of the skin and bone tissue. It affects people of all ages, though children less than 15 years-of-age are more vulnerable to infection (Amofah et al., 1993; Asiedu & Etuaful, 1998; Johnson et al., 2005; Marston et al., 1995; World Health Organization, 2008). Since the mode of BU transmission is unknown (Johnson et al., 2005), public health programmes in affected countries encourage early medical treatment to alleviate suffering and avoid disabilities (World Health Organization, 2008). Studies on help-seeking of affected persons are important since they highlight the influence of social, cultural, economic and behavioural influences on help-seeking choices. These influences and help-seeking preferences also account for delays in seeking effective medical treatment for pre-ulcer conditions before progressing into painful ulcers. Socio-cultural studies of help-seeking practices for BU feature strongly on the research agenda of the World Health Organisation (WHO) and are necessary to guide public health strategies for treatment and control(World Health Organization, 2008).

The BU disease usually starts as a painless nodule, swelling (oedema) or plaque (firmness of the skin), which is commonly referred to as the pre-ulcer stage of infection. If treatment is not sought at this stage, the disease is likely to progress into painful ulcers (Johnson et al., 2005; Marston et al., 1995; World Health Organization, 2008) .There have been reported cases of BU from at least 30 countries in tropical and sub-tropical regions of the world especially in West African countries such as Benin, Côte d'Ivoire and Ghana, where the majority of cases reside (World Health Organization, 2008). Ghana reports approximately 1000 cases of BU a year (World Health Organization, 2008), and has a national prevalence of 20.7/100,000;BU prevalence is 87.7/100,000 in the Ga-West and South municipalities (Amofah et al., 2002).

Past studies have shown that the majority of persons with BU infection do not seek early treatment. Cultural beliefs, financial capacity, access to treatment facilities, prolonged hospitalisation and the fear of surgical outcomes are possible explanations (Mulder et al., 2008; Phanzu et al., 2006; Renzaho et al., 2007; Sizaire et al., 2006; Webb et al., 2009). However, there is limited information to distinguish help-seeking for pre-ulcer and ulcer infections. Explaining the distinguishing features of socio-cultural features of help-seeking for pre-ulcer and ulcer conditions is important. This will clarify the status of actual help-seeking practices at early and late stages of BU, the range of providers consulted, the influence of initial help-seeking on delay in reaching effective services, and reasons for choice of provider types. All these factors affect management of BU and they are useful to inform health service providers and managers, and help to reduce the treatment gap for BU. This study examined socio-cultural features of help-seeking for BU-affected persons with pre-ulcerative and ulcer conditions in the Ga-West and Ga-South municipalities in Accra.

5.2 Methods

5.2.1 Research setting

The study was undertaken in the Ga-West and Ga-South Municipalities of the Greater Accra region from November 2008 to July 2009. The population of the Ga-West Municipality (GWM) for 2009 is 215, 824, based on projected population estimates from the national housing and population census. The GWM is rural (Annual Report- Municipal Health Management Team, Ga-West Municipality). The projected population of the Ga-South Municipality (GSM) for 2009 is 284, 712. About 76% of the municipality is predominantly urban and peri-urban while 24% is rural (Ga-South Municipal Directorate, 2011). Both municipalities have a similar population structure; 35% of the population are below the ages of 15 years and 65% are 15 years-of-age and above. The major BU medical treatment centres are the Amasaman hospital (AH) and the Kojo Ashong clinic (KAC) in the GWM, and the Obom health centre (OHC) in the GSM. The AH is the main referral centre for BU treatment.

5.2.2 The study sample

A sample of 181 respondents was obtained from 3 BU treatment centres and 67 communities in both municipalities. With the exception of children less than 5 years-of-age whose parents acted as proxy respondents, older children were interviewed first and subsequently care-takers who were invariably parents of children. The AH clinical records indicated that about 90 persons are treated medically for BU annually. We therefore interviewed all patients in treatment at the AH, KAC and OHC, and purposively selected all affected persons from 67 endemic communities. The intention to interview respondents from health facilities and communities, therefore, was not to compare help-seeking behaviours among these two groups but rather to obtain a fairly adequate sample to make inferences for help-seeking behaviours for pre-ulcers and ulcers.

A list of endemic communities was obtained from the municipal health directorates of the GWM and GSM. These communities were visited and community participants were located with the assistance of community-based surveillance volunteers

(CBSVs) who kept registers of all affected persons. Neighbouring communities (which were not listed as endemic), were entered and affected persons were located and interviewed with the help of CBSVs. Schools in sampled communities were also visited, and with the permission of the head teacher and class teacher, a WHO BU picture guide (World Health Organization & Global Buruli Ulcer Initiative, 1998) was shown to the children. Children who admitted to having suspicious lesions were screened by health personnel from the municipalities for confirmation. In endemic areas with a long history of BU infection, trained health workers are capable of identifying cases using the WHO classification (World Health Organization & Global Buruli Ulcer Initiative, 1998). A register of all respondents was compiled to avoid double interviews of out-patients resident in the communities who had already been interviewed at health facilities.

5.2.3 The explanatory model interview catalogue (EMIC)

An explanatory model interview was used based on the EMIC framework for cultural epidemiology (Weiss, 1997). The core structure of the EMIC was developed to examine patterns of help-seeking for BU. The design of the semi-structured interview was informed by preliminary ethnographic field experience, focus group discussions and earlier studies (Ackumey et al., 2011; Renzaho et al., 2007). Help-seeking practices were elicited by questions on self-help, home-based care, places visited for help, and providers approached for care outside the home. The first source of outside-help, reasons for this choice and the most helpful outside-help were queried in the interview. To enable comparison, the same set of questions was asked for pre-ulcer and ulcer conditions. Narratives in response to open-ended questions elaborated and explained coded categories and their responses. The instruments were developed in English, but interviews were conducted in the local Ghanaian languages (Ga, Ewe and Twi) spoken by respondents in the study areas.

5.2.4 Data management and analysis

Categorical and numeric data from the EMIC interviews were double entered using EPI Info (Centers for Disease Control and Prevention, Atlanta, GA, USA, version 3.4.1), and later cleaned and analysed using STATA Statistics/Data analysis software (Stata Corporation, Lakeway Drive College Station, Texas).We examined and compared frequencies of self-help, home-based care, and use and first use of provider types for respondents with pre-ulcers and ulcers. Individual categories of treatment and provider-type were grouped thematically for analysis and comparison based on overarching concepts (e.g. home-based remedies/self medication, traditional and faith healers, private doctors and facilities and government health facilities for help-seeking). Total reported responses were tabulated by summing spontaneous and probed responses. The Fisher's exact test was used to compare associations between categorical help-seeking (HS) variables for pre-ulcers and ulcers. A two-sample test for proportions was used to test associations between effectiveness of treatment from providers for ulcers. Proportions were computed by dividing the number of respondents who considered the treatment by the number of respondents who used the provider.

Narrative data were transcribed into English during the interview by the data collector, entered into Microsoft Office Word 2007 (Microsoft Corporation) and imported into MAXqda. The MAXqda software, 2010 (verbi Software Consult Sozialforschung, GmbH, Marburg, Germany) for textual analysis, was used for a phenomenological analysis of HS quantitative variables of interest for selected respondents' records based on thematic coding. This approach allowed the clarification of the content and dynamic features of explanatory variables associated with help-seeking preferences.

5.2.5 Ethical considerations

The study was approved by the ethical review committee of the Ministry of Health, Ghana, and the ethics commission of Basel (Ethikkommission beider Basel, EKBB) in Switzerland. Verbal consent was preferred to written ones since it did not pose any psychological threat and reassured all interviewees of anonymity. Both ethical review boards approved of verbal consent as long as participation in the study was voluntary, participants had been informed of the study aims and had the opportunity to ask questions. Prior to the start of all interviews, interviewees were informed of the study aims, type of questions to be asked and the intended use of findings to guide BU related health programmes, and for publications in academic journals and reports. They were informed of their rights to decline participation.

5.3 Results

5.3.1 Sample characteristics

A total of 181 respondents were interviewed comprising 48.1% males and 51.9% females. The mean age was 22.5 years. Most respondents had been enrolled in school; 54.1 % had at least completed primary school and 23.8 % had no education. About 26.0% of respondents were unskilled labourers, 7.7% were unemployed and 55.3% were still in school (table 5.1)

Table 5.1: Demographic characteristics of respondents

Demographic Characteristics	**No (%)**
Sex	
Males	87 (48.1)
Females	94 (51.9)
Age of respondents	
Minimum age	3
Maximum age	87
Mean age	22.5
Standard deviation	18.1
Education	
No education	43 (23.8)
Primary	98 (54.1)
Secondary/ Vocational	40 (22.1)
Occupation	
Pupil/student	100 (55.3)
Unskilled labor	47 (26.0)
Skilled labourer/Professional	13 (7.2)
Unemployed	14 (7.7)
Other (too young for school and employment)	7 (3.8)
Income	
Regular and dependable	34 (18.8)
Uncertain/ Cannot tell	78 (43.1)
Irregular	69 (38.1)
Marital status	
Never married	125 (69.0)
Married	42 (23.2)
Separated / divorced	5 (2.8)
Widowed	9 (5.0)

5.3.2 Home treatment

Help-seeking refers to various home remedies used, self-help actions and subsequently outside providers who were visited for treatment of BU illness. Generally, respondents mainly used herbal dressings, left over drugs and pills; some did not seek help. Respondents were more likely to treat pre-ulcers (63%) than ulcers (51.9%) by placing herbal dressings on affected body parts, ($p < 0.001$). They also used pills, mainly analgesics for pain management, and left-over antibiotics and blood tonics, for pre-ulcers (34.3%) and ulcers (49.7%, $p < 0.001$), (table 5.2).

Table 5.2: Self-help at home among respondents with pre-ulcers and ulcers*

Categories of self-help	Pre-ulcers N=181	Ulcers N= 181	P-values
Drank herbal concoctions at home	23.8	29.8	<0.001
Placed herbal dressing on pre-ulcer/ulcers	63.0	51.9	<0.001
Used pills and other drugs at home	34.3	49.7	<0.001
Offered prayers at home	7.7	16.6	<0.001
Nothing	26.0	32.6	0.003
Other home remedies (hot compress, massage, slitting nodules)	5.0	4.4	0.341

*Categories reported by less than 5% of respondents not presented in the table. Total reported values in percentages include combined spontaneous and probed responses. Fisher's exact test used for pre-ulcer and ulcer comparisons

Narratives suggested that herbs were often obtained from the backyard. Herbal dressings were placed on pre-ulcers so that the skin would open up and expose the *odonti* (local term for necrotic tissues, meaning cotton wool). Herbal dressings were then directly applied to the exposed wound to speed up healing. When nodules did not burst, herbalists slit them open. Leftover analgesics at home or purchased across the counter from local chemists were often taken to ease the pain, and ointments and balms were used to reduce swellings. Blood tonics were taken to *strengthen the blood* as respondents often mentioned that they looked *pale,* felt *weak,* or were anaemic as a result of their illness. Some respondents attributed oedemas to evil spells because of the swelling of affected body parts and applied ointments to reduce swelling. An adult explained:

> *It started as a sharp burning sensation with pain, and the skin looked red. I believe that someone placed some juju (black magic) at my work place. I applied some ointments at home to the affected part to reduce swelling.*
> (38 year-old male respondent)

Adult respondents with ulcers commonly explained the need for quick recovery to continue working and fulfil family support obligations, as reasons for using home-based remedies.

About 26% of respondents with pre-ulcers and 32.6% with ulcers ($p = 0.003$) did nothing for their conditions at home, and reasons for this varied. Some said that they thought that nodules were ordinary boils that would burst in time, and since nodules were painless, they thought they posed no immediate health concern. Respondents were cautious with interventions for oedemas, which they called *swellings,* because of fear that the condition could be made worse. They expressed a need to confer with family members and friends about types of treatment to use. Some respondents also mentioned difficulty identifying oedemas and plaques as pre-ulcer infections. They described the cause of their illness as small scratches, bruises or swellings sustained through work-related activities or play; these lesions were initially dismissed as trivial. Respondents who said they did 'nothing' for ulcer conditions either said they had not yet sought help because they wanted to confer with neighbours, relatives or friends on what to do, or they just did not know what to do.

5.3.3 Outside help-seeking

Respondents sought outside-help for pre-ulcers and ulcers from traditional and faith healers, private doctors and facilities, and government health facilities. Analgesics, antibiotics, balms, ointments and blood tonics were also purchased from itinerant drug peddlers and chemist shops. Aside from the health worker (minimal training), and respondents who did not seek help, significant differences were observed for all the other providers (table 5.3). Generally, most respondents reported that they sought treatment from the herbalist first, both for pre-ulcers (42.5%) and ulcers (47.5%).

Table 5.3: Outside-help among respondents with pre-ulcers and ulcers*

Categories of Outside Help-Seeking	**Total Reported**			**Most Helpful**		
	Pre-ulcers N=181	**Ulcers N=181**	**P-values**	**Pre-ulcers N=181**	**Ulcers N=181**	**P-values**
Traditional and faith healers	**54.7**	**58.5**	**<0.001**	**46.4**	**24.9**	**<0.001**
Herbalist	49.2	53.0	<0.001	32.6	18.2	0.004
Fetish spiritualist	13.3	16.0	<0.001	7.2	5.5	<0.001
Prayer camp	14.9	19.3	<0.001	6.6	1.1	0.004
Private health practitioners	**12.2**	**26.5**	**<0.001**	**4.2**	**3.9**	**0.007**
Health worker (minimal training)	9.9	17.7	<0.018	3.3	0.6	1
Private practitioner (trained)	5.5	16.6	<0.016	1.1	3.3	1
Govt. health facilities	**17.1**	**66.9**	**0.003**	**12.2**	**51.9**	**0.042**
Health centre (Obom/ Amasaman)	14.4	58.0	0.002	9.9	41.4	0.083
Government hospital outside the district	2.8	18.8	0.237	2.2	10.5	0.055
Nothing	33.2	13.8	0.110	31.5	14.9	0.122
Others	**8.3**	**8.3**	**<0.001**	**5.5**	**4.4**	**<0.001**
Others (analgesics, antibiotics and balms obtained from drug peddlers or chemist shops)	8.3	8.3	<0.001	4.4	4.4	<0.000

*Grouped categories (in bold) computed from responses. Categories reported by less than 5% of respondents, not presented in the table, but included in group totals. Total reported values in percentages include combined spontaneous and probed responses. Fisher's exact test used for pre-ulcer and ulcer comparisons.

Though herbalists were frequently consulted for both pre-ulcers and ulcers, respondents were more inclined to seek medical help from government health facilities for ulcers (66.9%) than pre-ulcers (17.1%, p = 0.003), (table 5.3).

Furthermore, respondents with ulcers considered medical treatment from government health facilities as the most helpful provider-type (51.9%, p = 0.042), (table 5.3). They were also more likely to use medical facilities first for ulcers (20%) than pre-ulcers (10.5%). Diagnostic difficulty and the fear of possible deformities prompted some respondents to seek medical care for pre-ulcers. Health facilities utilised most were the municipal health hospital and clinics, where WHO-recommended antibiotics and surgery are administered.

Private health practitioners were also consulted by 26.5% of respondents with ulcers and 12.2% of respondents with pre-ulcers. (p < 0.001), (table 5.3). Narratives suggest that respondents used the services of private health practitioners for pain relief and because they lived nearby. Private health practitioners treated most respondents in their homes and often administered injections to prevent tetanus infection or to halt the spread of infection to other parts of the affected limb. Two narratives of respondents with ulcers indicate the rationale, referring to desire for a more effective alternative, perceived need for a specific intervention or motivation to respond to functional disability:

> *Herbal treatment was not helping so I had to seek help from the private clinic, but this hasn't worked either. It was very close to my house and people in the community were urging me to seek medical care.*
>
> (61 year-old female respondent)

> *When I could not move my leg, a private practitioner from Adeiso* (a neighbouring community) *came to inject me until I could move my leg.*
>
> (20 year-old male respondent)

A respondent with a pre-ulcer used a private practitioner based on the perceived need to prevent tetanus infection:

> *A private practitioner was injecting me at home. I needed to take some tetanus injections.*
>
> (15 year-old female respondent)

Narratives revealed that adults who had previously been infected relied on their prior personal experience to make choices for outside-help. Some respondents, however, had no prior knowledge of BU and realized the nature of their conditions after conferring with friends, neighbours, community-based surveillance volunteers and sometimes municipal health staff during community health programmes. Some respondents also mentioned that they were referred to the municipal health centres by health workers, CBSVs, family and friends. They expressed their desire for medical treatment but mentioned the need to save money to pay for transportation and hospitalization. Adult respondents also worried about their absence from the home and the need to find someone to take care of the family during their absence. Some respondents did not have to travel for herbal treatment. There were itinerant herbalists, and some herbalists were relatives who offered their assistance at no cost. Some of these herbalists were known to have treated BU-affected persons. In their accounts, respondents frequently mentioned that these herbalists assured them that they could *treat the sickness,* and they were displeased when respondents decided to abandon herbal treatment and seek medical treatment.

Children made use of self-help or outside-help selected by their parents'. Infected school children who did not want their education disrupted and parents who wanted to protect their livelihoods used a combination of various providers to lessen the pain and suffering to achieve recovery. Narratives suggested that some infected children living close to health facilities where BU treatment was available received daily antibiotic treatment and had their wounds dressed before proceeding to school.

Generally, it was common practice for respondents to use a combination of self-help and outside-help approaches to seek relief. A mother explained that her treatment approach had been influenced by insufficient money to take her child to the hospital, the need for a quick recovery to go back to school, and the absence of a care-giver to take care of the home or stay in hospital with a sick child:

> *I ground some herbs and mixed it with palm kernel oil and applied it to my son's sore. I also used the bark of the orange tree mixed with palm kernel oil as a dressing. I bought some caster oil from the chemist shop and placed it on the sore, which has helped to remove the odonti. When I went to the drug store to buy the oil, the store keeper asked me what I was going to do with it. When I told him, he advised me to take my child to the hospital but I did not have money. I did not want my son's condition to get worse. That is why I went to the drug store to purchase castor oil. I also bought penicillin v powder and ampicillin, mixed them together and used it on the sore. There is no one else to take care of the other children at home, and I am pregnant now. I will be giving birth soon, that is why I did not go to the hospital.*
>
> (Mother of 10 year-old child)

Factors influencing choice of first outside-help for pre-ulcers and ulcers are presented in table 5.4.

Table 5.4: Reasons for first-help seeking among respondents with pre-ulcers and ulcers*

Reasons	**Total in Percentages**		
	Pre-ulcers (N=124)	**Ulcers (N=154)**	**P-values**
Treatment is very effective	54.8	61.7	0.206
Closeness to home	54.0	42.9	<0.001
Affordable	23.4	20.8	<0.001
Self-referral	62.9	62.3	<0.001
Referral by family/ friends	71.0	70.1	<0.001
Referral by health worker (professional	8.0	13.0	0.002
Referral by CBSV	7.2	4.0	1
Education through IEC activities	10.5	9.7	0.031
Medical treatment is effective	21.0	21.4	<0.001
Herbal treatment not effective	17.7	21.4	0.119

*The table presents responses of persons who sought outside-help; responses of those who did not seek outside-help are not included. Categories reported by less than 5% of respondents are not presented in the table. Total reported values in percentages include combined spontaneous and probed responses. Fisher's exact test was used for pre-ulcer and ulcer comparisons.

Choices of treatment for first outside-help for pre-ulcers and ulcers were influenced by the perceived effectiveness of treatment, the closeness of the provider to the place of residence, and the influence of family and friends. Preferences differed significantly. There appeared to be little influence from professional health workers and CBSVs. Independent of the influence of family and friends, respondents also made decisions on their own about which provider to consult first for pre-ulcers (62.9%) and ulcers (62.3% , p<0.001), (table 5. 4). Narratives suggested that most adult respondents used the services of herbalists first for outside-help so they could stay close to the home to work and earn income.

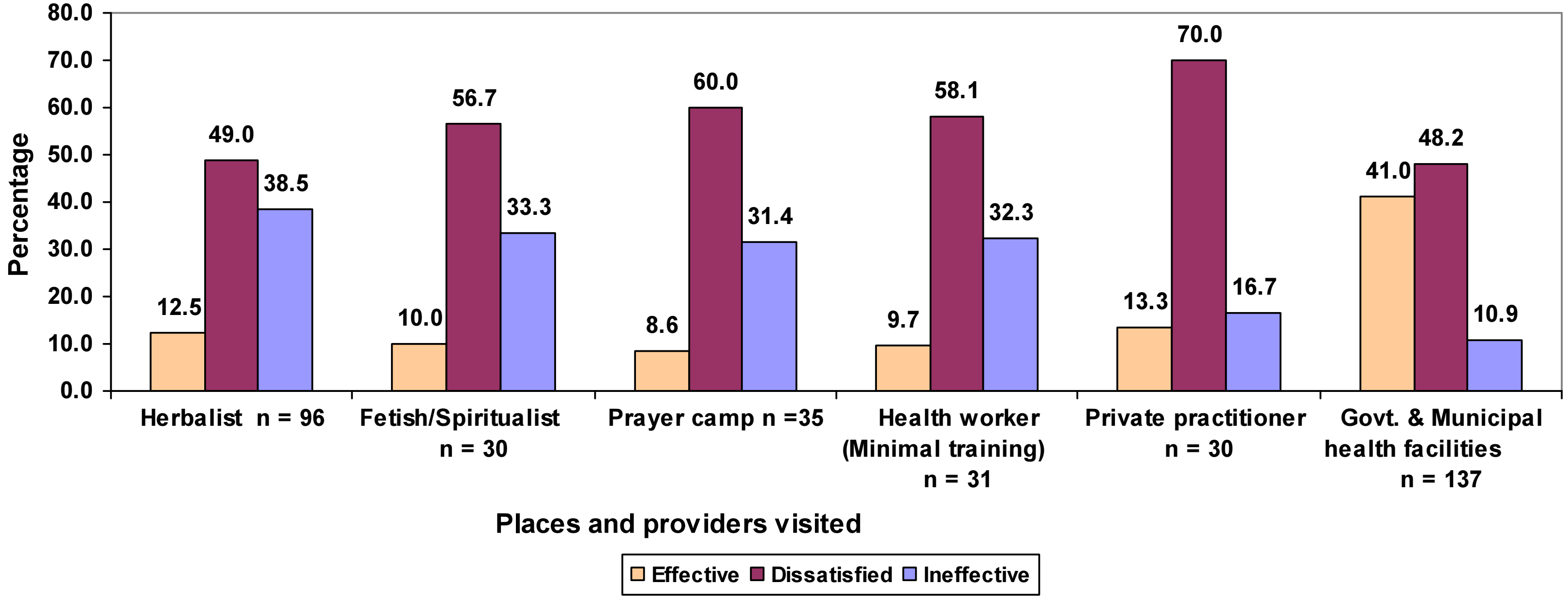
5.3.4 Perceived effectiveness of treatment from providers

Respondents ranked their perceptions of the effectiveness of treatment from providers on a three-point scale – effective, uncertain and ineffective. Treatment was considered effective when it fulfilled respondents' expectations of slowing disease progression and recovery. Respondents were uncertain about treatment when it was perceived as having some value, but was so too slow-acting and failed to meet expectations. Treatment regarded as ineffective did not have any impact on respondent's disease status. Respondents who consulted herbalists for ulcers expressed their misgivings on the effectiveness of herbal treatment; 12.5% said it was effective, 49.0% were dissatisfied and 38.5% said it was ineffective. Medical treatment at the government hospitals and municipal health centres was valued more than herbal treatment; 41% of respondents considered medical treatment effective, 48.2% were dissatisfied and 11.0 % said it was ineffective (fig 5.1). Treatment at health facilities was regarded as significantly more effective than treatment from all the other providers.

Respondents' explanations of the dissatisfaction with herbal treatment reflected disappointment in the slow process of recovery, despite assurances from the herbalists of effective treatment and cure. Those who mentioned that herbal treatment was ineffective did not see any change in their disease status; some said their condition worsened. Narratives showed that medical care was valued because respondents said it *cleans the sore*, implying that it clears the *odonti*. Respondents who were dissatisfied with medical care appeared dissuaded by hospitalisation and slow healing of ulcers, which disrupted their normal work routines and family life. Nevertheless, as ulcer conditions worsened and pain became unbearable, hospital care became the second option for outside help after traditional care. One adult explained how failure of home-based treatment to treat his condition and the desire to recover in order to continue with work, necessitated medical treatment:

> *I was applying balms and ointments at home, but there was no improvement. I decided to come here (Amasaman hospital). I have been away from work for a long time because of this condition. I am the one who supports the family. I do not know what to do now.*
>
> (35-year-old male respondent)

Figure 5.1: Respondets perceptions on the effectiveness of treament for ulcers*



*Columns show proportions. A two sample test of proportions comparing effectiveness of treatment from government and municipal health facilities with the other providers gave a p-value of <0.005

5.4 Discussion

Study findings highlight the preference for herbal treatment for pre-ulcers and ulcers and indicate that respondents are more likely to seek medical care for ulcers than pre-ulcers. This reflects a need to respond to the higher level of distress for ulcers. Findings present a challenge for BU prevention and management, as a considerable proportion of respondents did not seek help for pre-ulcers and ulcers in as much which delayed medical treatment, and increased risk of serious ulcerative disease sequelae.

Our study complements findings of earlier socio-cultural studies of BU (Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Renzaho et al., 2007; Stienstra et al., 2002) and clarifies help-seeking for pre-ulcers and ulcers of affected BU persons. This information is critical for health programming in the Ga-West and South municipalities, where socio-cultural research has been lacking. The first socio-cultural study of BU in the Ga-West municipality in 2005 explored community perceptions of BU in a study in which 71.8% of sampled heads of households indicated herbal treatment as the preferred treatment and stated that, 7.7% of affected persons would go to the hospital if their illness got worse, and 48.2% would use a local doctor or nurse. Additionally, 72% of respondents said there was no programme in place to address BU (Renzaho et al., 2007). Since then, there has been a public health initiative to create awareness about BU and availability of medical care, improve case-management and access to care. Our study not only supports previous findings of this study (Renzaho et al., 2007) about herbal medicine as the first treatment choice, but shows evidence of increasing awareness and use of medical treatment, and clarifies current treatment needs and gaps for BU. The study also draws attention to some socio-cultural features of help-seeking especially the difficulties in diagnosing pre-ulcers, the reliance on help-seeking advice from a network of friends and family (which include herbalists) and the itinerant nature of herbal treatment.

5.4.1 Features of help seeking and treatment

Study findings suggest that respondents had a fair knowledge of local herbs that were easily obtained from the backyard and used as first-aid. A significant proportion of respondents placed these herbal dressings on pre-ulcer lesions to open the skin. Nodules were also excised. Both practices heightened the transformation of pre-ulcers into ulcers. Though the health impact of these local practices has not been documented adequately, secondary infection could be a likely result. Another home remedy was the indiscriminate use of analgesics and left-over antibiotics to reduce pain and inflammation. The use of self-medication for BU has been reported in a study in Benin (Mulder et al., 2008). The indiscriminate use of antibiotics is a concern because of potentially undesirable health effects (Reeves et al., 1999) , implications for treatment, recovery and pharmacodynamic interactions with WHO-recommended antibiotics (rifampin and streptomycin) when given later to respondents at health centres.

A considerable proportion of respondents did not seek treatment for their pre-ulcers and ulcer conditions and various reasons were given for this behaviour. For pre-ulcers, these included a genuine difficulty in diagnosing illness conditions, perceived imminence of disease progression and severity, and absence of pain and disability which allowed them to carry on with normal routines of work and school.

Respondents with pre-ulcers needed to confer with family or friends for advice on provider type, or simply did not know what to do. Findings, particularly narratives, indicate a genuine difficulty in diagnosing some pre-ulcer conditions, which is consistent with prior research findings (Ackumey et al., 2011). Perceptions of the imminent severity or progression of BU have been identified as a contributing factor for delay in seeking medical treatment (Mulder et al., 2008; Stienstra et al., 2002).

BU is known to affect poor, rural communities (Huygen et al., 2009; Kibadi, 2007; Portaels et al., 2009; Renzaho et al., 2007; Webb et al., 2009; Yemoa et al., 2011). Only 19 percent of our respondents received regular income, 26.0 percent were unskilled workers, mainly subsistence farmers or petty traders, and majority were in school (55.3%). It is not unusual therefore, for our study respondents to be concerned about securing their livelihoods and worry about the disruption of education. These concerns have also been documented in other BU studies (Asiedu & Etuaful, 1998; Grietens et al., 2008). Furthermore, studies have linked delayed medical treatment for BU to other social issues of access and transport costs (Asiedu & Etuaful, 1998; Grietens et al., 2008; Mulder et al., 2008; Renzaho et al., 2007). Some respondents, therefore, used the services of nearby private health practitioners. Though it can be argued that private health practitioners provided medical treatment, the capacity of private practice to provide the recommended treatment for BU is doubtful and should be explored further.

Respondents with ulcers often sought advice for treatment options from family and friends, though a considerable proportion sought treatment on their own volition. Evidence from other studies on help-seeking for BU (Mulder et al., 2008), malaria (Samuelsen, 2004) and tuberculosis (Nyika, 2009) suggest that it is common for persons to rely on help-seeking advice from a network of friends and family. It is not clear from our study whether the advice from family and friends influenced the use of herbal treatment more than medical treatment. However, there is evidence from our study to suggest that some family and friends referred respondents to the appropriate health facilities for care. Considering the debilitating and distressing nature of the BU illness, a network of family and friends is beneficial for emotional and social support.

The influence of professional health staff and CBSVs on help-seeking for pre-ulcers and ulcers was minimal. An earlier research in our study municipalities showed the importance of community-based surveillance activities from CSBVs and health professionals to detect early cases, increase awareness on BU, and the availability and effectiveness of WHO-recommended antibiotic treatment (Ackumey et al., 2011). Community-based surveillance has been used successfully for early case detection and in the management of BU in the study municipalities (Ackumey et al., 2011) and for Guinea worm eradication programmes (Cairncross et al., 1996).

The presence of herbalists in the family (fathers, grandfathers and uncles) and other itinerant herbalists, made herbal treatment readily available and influenced respondent's choice of herbal treatment. The insistence of these herbalists to treat BU illness conditions resulted in delay of respondents starting medical treatment. Evidence from our study and other studies (Asiedu & Etuaful, 1998; Renzaho et al., 2007; Webb et al., 2009) shows how prior use of herbalists delays medical care. The role of herbalists, therefore, as first outside-help for the majority of respondents, who had pre-ulcers and ulcers, provides a big challenge with respect to early medical care for BU public health programmes.

Respondents had mixed feelings about the effectiveness of herbal treatment, because of the prolonged period of treatment. There is evidence from our study that respondents who had benefited from medical care from government health facilities considered it a better option than herbal treatment, and treatment from other providers. This is because they had "clean" wounds and experienced an improvement in their illness condition, particularly after antibiotic treatment with rifampin and streptomycin for 8 weeks. Despite the benefits of medical care, herbal treatment was the first choice for the majority, because it was easily accessible and provided the opportunity to continue with the normal routines of work and school. With increasing number of persons experiencing improvement in disease outcomes, affected persons might limit their dependence on herbal treatment.

Though there is paucity of research on the use of herbs for BU treatment and management, a study in Ghana has proven the effectiveness of herbal preparations, commonly used in the treatment of BU, to inhibit *M. ulcerans* activity in-vitro (Addo et al., 2008). According to the study, these herbs possess extended antimicrobial activity which may simultaneously treat secondary infections associated with BU (Addo et al., 2008).

WHO encourages countries to integrate traditional medicine in the health system to improve access to health care for poor, rural populations (WHO, 2002). Ghana has a WHO collaborating research centre for herbal medicine. There is also a national policy on traditional medicine (TM), and complementary and alternative medicine (CAM). Ghana's Ministry of Health is to ensure the inclusion of TM/CAM in the national health care system, however, it has failed to do this effectively (WHO, 2002). Nevertheless, to enhance research and practice of TM, the Kwame Nkrumah University of Science and Technology in Ghana, introduced a programme in 2001, the first in the whole of Africa (Adusi-Poku et al., 2010), to train medical or science students in TM. Hopefully, with the increasing numbers of graduates from this programme, known as medical herbalists, the use of TM would be streamlined into the main health care system, making it accessible to poor rural communities, for the treatment of Neglected Tropical Diseases (NTDs) like BU.

5.4.2 Study limitations and implications

This study was undertaken to examine help-seeking for pre-ulcers and ulcers. There is the likelihood of recall bias since study data was based on reported and not directly observed help-seeking behaviour for affected BU persons. Considering the ad-hoc use of home-based remedies and self medication, under-reporting is possible for these help-seeking practices. Because respondents with ulcers had to provide information on prior help-seeking for pre-ulcers, we presume a greater recall bias with respect to help-seeking for pre-ulcers for respondents with ulcers than those with pre-ulcers. Probes were used to minimise recall bias and under-reporting. Nevertheless, study findings are clearly relevant for the study communities, might have a broader relevance for other BU-endemic communities in the country, and clarify the socio-cultural dimensions of help-seeking.

Our study findings have implications for community awareness of BU, particularly the pre-ulcer stages of infection, early and appropriate medical care and access to appropriate health care. Other issues are the limited role of herbalists in the health system, the involvement of the community as disseminators of appropriate health messages and treated patients as advocates for appropriate help-seeking. The following recommendations, based on study findings, should be considered.

5.4.2.1 The role of health education

Health education is required first, to emphasise the risk of self-medication particularly with antibiotics, and the imminent danger of co-infection by exposing the necrotic tissue through local incision and the application of herbs on pre-ulcers, which may prolong healing. Health education should also highlight the effectiveness of treatment with WHO-recommended antibiotics for 8 weeks for early lesions (Chauty et al., 2007; Nienhuis et al., 2010; World Health Organization, 2008). This may minimie the deformities, the need for surgery and consequently prolonged hospitalization, thus reducing the social burden of suffering, and disruption of livelihoods and education. Health education must point out that BU is an ordinary disease and can be treated medically. Reliance on family and friends provides a basis for establishing community-based health education initiatives.

5.4.2.2 Implications for community action: Expanding health education initiatives, the role of CBSVs and private health practitioners

Health education initiatives can be sustained and expanded by creating a network of educators to include everyone in the community - former patients, community representatives, school teachers, parents, community members. Support groups could be formed with successfully treated former patients, to promote awareness and advocate for early medical treatment, by sharing stories about treatment and its impact on social life. To ensure the effectiveness of health education programmes, encourage early medical treatment and improve access to antibiotic treatment, more treatment centres must be provided. Private health practitioners are a useful resource to improve access to antibiotic treatment for pre-ulcers and consequently encourage early medical treatment. Their inclusion in the health system as service providers should be considered.

To ensure effective management of BU, public health programmes must increase awareness of all stages of BU infection for easy recognition, encourage medical treatment for all suspicious, stings, bites and lesions, and encourage affected persons to confer with CBSVs and health professionals when in doubt of BU infection. Furthermore, community-based surveillance activities and periodic community health screening programmes are also critical to identify pre-ulcer cases and refer them for medical treatment.

5.4.2.3 The potential role of herbalists as advocates for early medical care

The challenge facing BU public health programmes in the Ga-West and Ga-South municipalities is to dissuade affected persons from seeking herbal treatment first, and to minimise the influence of herbalists on provider choice. A complementary strategy should consider the potential role of herbalists as advocates for early medical care. This approach has not been considered or researched adequately. However, based on findings that some herbalists are family members provides opportunities to train them as health educators and advocates for change. First, health workers would have to win the confidence of herbalists by acknowledging their role as traditional health providers and consider them as partners. Collaborating with herbalists would enable them to refer patients for timely treatment and make a major contribution to BU control.

5.4.2.4 Further research on the effectiveness of herbs for the treatment of Buruli ulcer

Further research on the effectiveness of herbs in the treatment of BU is necessary. This research will improve herbalists' knowledge of the curative abilities of the herbs they use and enhance the scientific uses and benefits. These findings are also beneficial to a wider community of pharmacists, medical personnel, scientists, researchers and academics. Herbal medicine features strongly in health-care for the majority of Ghanaians, not only for BU (Renzaho et al., 2007; Stienstra et al., 2002) but for other illnesses like malaria (Asase & Oppong-Mensah, 2009). Consideration should be given, therefore, to the inclusion of TM in the health system.

5.5 Conclusions

Our study findings show how socio-cultural factors, the social context of poverty, the need to secure livelihoods and prevent the disruption of education, influenced help-seeking behaviour. It also reveals how appreciation of socio-cultural features of help-seeking can guide public health programmes. Socio-cultural studies of help-seeking reveal treatment gaps and are important assessments of the achievements and performance of the health system in BU control. However, help-seeking behaviours are influenced by the socio-cultural context of affected persons, which could change with exposure to health information and improvement in socio-economic status. This indicates the need for regular socio-cultural studies to guide public health programmes in order to address current treatment needs and gaps.

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Chapter 6

Socio-cultural determinants of timely and delayed treatment of Buruli ulcer: Implications for disease control

Mercy M. Ackumey [1, 2, 3], Margaret Gyapong [1,4], Matilda Pappoe [1], Cynthia Kwakye- Maclean [5], Mitchell G. Weiss [2, 3]

1. School of Public Health, College of Health Sciences, University of Ghana.
2. Swiss Tropical and Public Health Institute, Basel.
3. University of Basel, Switzerland.
4. Dodowa Health Research Centre, Ghana Health Service, Ghana.
5. Amasaman Hospital, Ghana Health Service

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6.0 Abstract

Introduction

Public health programmes recommend timely medical treatment for Buruli ulcer (BU) infection to prevent pre-ulcer conditions from progressing to ulcers, to minimise surgery, disabilities and the socio-economic impact of BU. Clarifying the role of socio-cultural determinants of timely medical treatment may assist in guiding public health programmes to improve treatment outcomes. This study clarified the role of socio-cultural determinants and health system factors affecting timely medical treatment for BU in an endemic area in Ghana.

Methods

A semi-structured explanatory model interview based on the explanatory model interview catalogue (EMIC) was administered to 178 BU-affected persons. Based on research evidence, respondents were classified as timely treatment (use of medical treatment 3 months from awareness of disease) and delayed treatment (medical treatment 3 months after onset of disease and failure to use medical treatment). The outcome variable, timely treatment was analysed with cultural epidemiological variables for categories of distress, perceived causes of BU, outside-help and reasons for medical treatment in logistic regression models. The median time for the onset of symptoms to treatment was computed in days. Qualitative phenomenological analysis of respondents' narratives clarified the meaning context and dynamic features of the relationship of explanatory variables with timely medical treatment.

Results

The median time for initiating treatment was 25 days for pre-ulcers, and 204 days for ulcers. Income loss and use of herbalists showed significantly negative associations with timely treatment. Respondents' use of herbalists was often motivated by the desire for *quick recovery* in order to continue with work and because herbalists were relatives and easily accessible. However, drinking unclean water was significantly associated with timely treatment and access to health services encouraged timely treatment (OR 8.5, p=0.012). Findings show that health system factors of access are responsible for non-compliance to treatment regimes.

Conclusions

Findings highlight the importance of a comprehensive approach to BU control and management considering the social and economic features that influence delayed treatment and factors that encourage timely medical treatment. This approach should consider periodic screening for early case-detection, collaboration with private practitioners and traditional healers, use of mobile services to improve access, adherence and treatment outcomes.

6.1 Introduction

Public health programmes recommend early medical treatment for Buruli ulcer (BU) infection to prevent pre-ulcer conditions from progressing to ulcers, minimise osteomyelytis (infectious inflammation of the bone or marrow), need for surgical intervention, disability and improve treatment outcomes (Webb, Hauck, Houp & Portaels, 2009; World Health Organization, 2008). However, affected persons may delay medical treatment due to various social, economic, cultural and health system factors (Mulder, Boerma, Barogui, Zinsou, Johnson, Gbovi et al. 2008; Phanzu, Bafende, Dunda, Imposo, Kibadi, Nsiangana et al. 2006; Renzaho, Woods, Ackumey, Harvey & Kotin, 2007; Sizaire, Nackers, Comte & Portaels, 2006). Clarifying the role of socio-cultural determinants of timely and delayed medical treatment for BU may assist in the design of public health programmes that are socio-culturally sensitive to improve disease outcomes, lessen the disease burden, and treatment costs to health facilities. This study examined socio-cultural and health system features of timely medical treatment for BU in Ghana.

Buruli ulcer, caused by the environmental pathogen, *M. ulcerans,* is a debilitating disease of the skin and sometimes the bone tissues (Debacker, Aguiar, Steunou, Zinsou, Meyers, Guedenon et al. 2004; Phanzu et al., 2006; Sizaire et al., 2006; World Health Organisation, 2001). The pre-ulcer stage of infection is characterised by nodules, plaques and oedemas (Portaels, Silva & Meyers, 2009; World Health Organisation, 2001). The time from progression of a pre-ulcer to an ulcer varies, ranging from a few weeks to several months (Debacker et al., 2004).

Until recently, wide surgical excisions that require lengthy hospital stays for recovery were the only treatment (Asiedu & Etuaful, 1998; Etuaful, Carbonnelle, Grosset, Lucas, Horsfield, Phillips et al. 2005; Sizaire et al., 2006; Stienstra, van der Graaf, Asamoa & van der Werf, 2002; van der Werf, van der Graaf, Groothuis & Knell, 1989). However, studies show that surgery alone cannot completely remove all necrotic tissues, and the possibility of recurrence is high (Amofah, Asamoah & Afram-Gyening, 1998; Rondini, Horsfield, Mensah-Quainoo, Junghanss, Lucas & Pluschke, 2006; Teelken, Stienstra, Ellen, Quarshie, Klutse, van der Graaf et al. 2003). Using antibiotics recommended by WHO – rifampin and streptomycin -for nodules and early lesions is effective in reducing lesions thus minimising the extent of surgical excision and disease sequalae (Ackumey, Kwakye-Maclean, Ampadu, de Savigny & Weiss, 2011; Chauty, Ardant, Adeye, Euverte, Guedenon, Johnson et al. 2007; Etuaful et al., 2005; Nienhuis, Stienstra, Thompson, Awuah, Abass, Tuah et al. 2010; World Health Organization, 2008).

Even though there is no standard definition for acceptable treatment delay, public health programmes encourage BU-affected persons to seek treatment as early as possible, during the pre-ulcer stage of infection, which is often characterised by a nodule, plaque, or oedema. When treatment is delayed and lesions progress into ulcers, they typically require a long time to heal, and scarring, contractures and disabilities result (Asiedu & Etuaful, 1998; Portaels et al., 2009; Sizaire et al., 2006; van der Werf et al., 1989; Walsh, Portaels & Meyers, 2008).

Studies in Benin and Ghana have investigated the obstacles to medical treatment which include, fear of recurring infections after surgical treatment, anxiety about the outcome of surgery, fear and concern about scarring and disabilities after treatment, late detection of BU-related skin trauma or lesions, perceived seriousness of infection and local beliefs of spiritual causes that require the use of traditional healers, particularly herbalists (Ackumey et al., 2011; Aujoulat, Johnson, Zinsou, Guedenon & Portaels, 2003; Mulder et al., 2008; Stienstra et al., 2002; Webb et al., 2009). Additional obstacles to seeking medical treatment are high transport costs of seeking treatment, costs of food during hospitalisation and the social and economic implications of providing care to affected relatives during hospital admissions. (Ackumey et al., 2011; Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Debacker et al., 2004; Mulder et al., 2008; Renzaho et al., 2007; Stienstra et al., 2002).

It is expected that awareness and knowledge of anticipated debilitating disease outcomes of BU may prompt timely and appropriate medical treatment. However, this is not the case in many BU-endemic countries (Ackumey et al., 2011; Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Mulder et al., 2008; Noeske, Kuaban, Rondini, Sorlin, Ciaffi, Mbuagbaw et al. 2004). Therefore, clarifying the role of socio-cultural barriers to timely treatment for BU is likely to strengthen case-detection, improve access to treatment and outcomes, and consequently lessen disease morbidity and financial costs of surgery to health facilities. Furthermore, socio-cultural studies for BU are a priority of the WHO research agenda (World Health Organization, 2008). Nevertheless, there are too few of such studies and many were conducted before the introduction of the WHO-recommended antibiotic therapy. This paper examined socio-cultural determinants of timely medical treatment for pre-ulcers and delayed medical treatment for ulcers in an endemic area in Ghana.

6.2 Methods

6.2.1 Study area

The study was undertaken in the Ga-West and Ga-South Municipalities of the Greater Accra region from November 2008 to July 2009. The Ga-West Municipality (GWM) is predominantly rural, with a population of 215,824, based on projected population estimates from the national housing and population census (Ga-West Municipal Health Directorate, annual report, unpublished). Both municipalities cover a land area of 692 square kilometres. Seventy-six percent of the land area of the GSM is predominantly urban and peri-urban while 24 % is rural (Ga-South Municipal Directorate, 2011). Health services are inaccessible to the majority of the population due to distance, terrain, poor road infrastructure and inadequate transport (figure 6.1). The GWM has 1 government hospital, 5 community clinics, 9 private hospitals and clinics, and 7 private maternity homes. The major BU medical treatment centres are the Amasaman hospital, which is the main referral centre for BU treatment in the Greater Accra region and the Kojo Ashong clinic. The Obom health centre provides medical treatment for BU patients in the GSM and the AH is one of the main referral centres for BU treatment in the Greater Accra region. BU ranks third on the list of top ten diseases reported at the out-patient departments in the government health facilities in both municipalities.

Figure 6.1: Map of study municipalities and communities

*Inset is a map of Ghana showing the location of the study municipalities. To avoid overcrowding on the map, only some communities are shown

6.2.2 The study sample sampling strategy

To identify as many BU affected persons as possible, a sample of 181 respondents was obtained from 67 communities and 3 BU treatment centres – The Amasaman hospital (AH), the Kojo Ashong clinic (KAC) and the Obom health centre (OHC). These health facilities provide antibiotic treatment (rifampicin and streptomycin) and surgery. The AH admits approximately 90 persons with BU infection each year. Based on these estimates, we enlisted all BU patients receiving treatment at the AH, KAC and OHC and all affected persons from 67 endemic communities. Parents acted as proxy respondents for children below 5 years of age. However, since help-seeking choices are largely determined by parents and guardians, children older than 5 years were interviewed first and subsequently parents and guardians; responses reflected consensus opinion.

6.2.3 The explanatory model interview catalogue (EMIC)

A semi-structured explanatory model interview based on the EMIC framework for cultural epidemiology (Weiss, 1997) was developed for this study. Prior ethnographic research and earlier studies (Renzaho et al., 2007) informed the design and the formulation of questions for the EMIC. The instruments were developed in English, but interviews were conducted in the local Ghanaian languages (Ga, Ewe and Twi) spoken by respondents in the study areas.

The EMIC examined use of timely medical treatment, patterns of distress (PD) and perceived causes (PC). Patterns of distress refer to illness-related problems and concerns and local experiences of BU illness. Perceived causes denote local ideas of causes for BU. Children were not asked PD questions that were irrelevant to their socio-cultural context. Such questions referred to marriage, income and employment. Respondents were asked to indicate the provider-type for pre-ulcers and ulcers. Those respondents who stated that they used medical treatment from recognised municipal and private health facilities were asked to indicate reasons for medical treatment and also asked to state the time lapse between onset of symptoms and medical treatment. Narratives in response to open-ended questions elaborated and explained coded categories and their responses.

6.2.4 Data management and analysis

Categorical and numeric data from the EMIC interviews were double entered using EPI Info (Centers for Disease Control and Prevention, Atlanta, GA, USA, version 3.4.1), and subsequently cleaned and analysed using STATA 10.1 data analysis and statistical software (StataCorp, Lakeway Drive, College Station, Texas). Median time lag from onset of symptoms and medical treatment were recorded in the manner in which they were reported, in days, weeks, months or years and were later converted to days for analysis.

Unlike malaria and tuberculosis, there is no standard definition distinguishing delay from timely treatment for BU. The pre-ulcer phase of BU infection could vary from a few weeks to several months (Merritt, Walker, Small, Wallace, Johnson, Benbow et al. 2010); one study has indicated an average time of 1-3 months (Portaels et al., 2009). Host immune inflammatory response plays an important role in the progression of pre-ulcers to ulcers and therefore this was taken into consideration in the operational definition for timely treatment (Duker, Portaels & Hale, 2006). Timely treatment was therefore defined as seeking medical treatment for pre-ulcers and ulcers within 3 months after the onset of infection. Those respondents who initiated medical treatment 3 months after infection and those with pre-ulcers and ulcers who did not seek medical treatment were classified as delayed treatment seeking. Initially 181 respondents were interviewed but three (3) respondents who had pre-ulcers (with illness duration from 10 days to 3 weeks), were not included in the analysis because their treatment status was inconclusive. It was presumed they might seek timely or delayed treatment later.

A binary outcome variable (timely treatment) was created. To determine how features of illness explanatory models affected timely treatment, unadjusted (univariate) analysis first considered demographic, PD, PC, HS and reasons for treatment variables at $p<0.25$ (Hosmer & Lemeshow, 2000) for the outcome variable. The only exception was ‘disrupted education’ ($p = 0.628$) because respondents’ narratives commonly suggested the influence of this variable on treatment. Adjusted (multiple regression) models considered variables from the unadjusted analysis with p-values <0.25. Odds ratios with their respective 95% confidence intervals were calculated for variables in the model.

Narrative data were translated and transcribed in English during the interview by the data collector, entered into MS Office Word 2007 (Microsoft Corporation) and imported into MAXQDA, software for textual analysis (verbi

Software Consult Sozialforschung, GmbH, Marburg, Germany). Illness narratives and quantitative variables of interest for PD, PC, HS and reasons for medical treatment were imported into MAXQDA to select respondents with a desired profile of responses for phenomenological qualitative analysis. This approach allowed clarification of the relationship of explanatory variables to timely and delayed medical treatment. The regression analysis explained which variables were related to timely or delayed medical treatment and the narratives were analysed to explain the nature of such effects.

6.2.5 Ethical considerations

Verbal informed consent was obtained from all adult respondents and parental caretakers or guardians of children. The study was approved by the ethical review committee of the Ministry of Health, Ghana, and the ethics commission of Basel (Ethikkommission beider Basel, EKBB) in Switzerland.

6.3 Results

6.3.1 Demographic characteristics of the study respondents

Based on our operational definition of timely treatment (see methods section), 48 (27.0%) respondents initiated timely treatment and 130 (73 %) respondents delayed treatment for their illness conditions. Among the 130 respondents who delayed treatment, 39 did not seek treatment for their illness conditions.

A total of 166 respondents had ulcers during the study: 37 (22.3%) initiated timely medical treatment, 91 (54.8%) delayed treatment and 38 (22.9 %) did not seek treatment. Fifteen (15) respondents had pre-ulcers during the study: 11 (73.3%) used timely treatment, 1 (6.7%) delayed treatment, and 3 (20%) respondents were not included in the analysis because their treatment status was undetermined (see methods).

Table 6.1: Demographic characteristics of respondents *

Demographic characteristics	**Timely Treatment N= 48**	**Delayed Treatment N=130**	**P-values N=178**
	(%)	(%)	
Treatment status			
Sex			0.398
Males	41.7	50.0	
Females	58.3	50.0	
Age			0.571
Less than 15-years-of age	56.3	44.6	
15-30 years	25.0	31.5	
30-45 years	6.3	10.8	
≥ 45 years	12.5	13.1	
Education			0.216
No education	14.6	26.9	
Primary	58.3	51.5	
Secondary and above	27.1	21.5	
Occupation			0.279
Pupil/student	64.6	52.3	
Unskilled labour	20.8	26.9	
Skilled labourer	2.1	9.2	
Unemployed	12.5	11.5	
Income			0.367
Regular and dependable	18.5	16.2	
Uncertain/ Cannot tell	42.7	43.1	
Irregular	38.8	40.8	
Marital status			0.962
Never married	70.8	67.7	
Married	22.9	23.8	
Separated, divorced and widowed	6.3	8.5	

*Results are stated in percentages. Fisher's exact test was used for comparison between 'timely treatment' and 'delayed treatment'.

Most of the respondents had completed primary school (58.3 % timely treatment and 51.5% delayed treatment). Respondents who were employed were mainly unskilled workers. Only 22.2 % of respondents who sought timely treatment and 17.9% of respondents who delayed treatment mentioned that their income was regular (table 6.1)

Table 6.2: Unadjusted (univariate) analysis of background variables associated with timely and delayed treatment

Socio-demographic variables	**Timely treatment N=178**	**P-values**
	OR (95% CI)	
Sex		
Males	Ref	
Females	1.4 (0.72, 2.73)	0.324
Age		
Less than 15-years-of age	Ref	
15-30 years	0.6 (0.29, 1.38)	0.249
30-45 years	0.5 (0.12, 1.74)	0.252
≥ 45 years	0.8 (0.27, 2.14)	0.601
Education		
Primary	Ref	
Secondary and above	1.1 (0.50, 2.45)	0.795
No education	0.5 (0.19, 1.21)	0.118
Occupation		
Pupil/student	Ref	
Unskilled labour	0.6 (0.28, 1.42)	0.265
Skilled labourer/Professional	0.2 (0.02, 1.47)	0.110
Unemployed	0.4 (0.08, 1.73)	0.205
Other (too young to be either employed or in school)	2.9 (0.62, 13.86)	0.176
Income		
Irregular	Ref	
Uncertain/ Cannot tell	1.2 (0.55, 2.52)	0.663
Irregular	1.9 (0.78, 4.67)	0.166
Marital status		
Never married	Ref	
Married	0.9 (0.42, 2.03)	0.833
Separated / divorced and widowed	0.7 (0.19, 2.69)	0.610

*Odds ratios, confidence intervals and p-values for all variables included in the adjusted model are shown in the table. OR = odds ratios, CI = confidence intervals

6.3.2 Illness experiences and treatment delay

The median time for initiating timely treatment was 30 days and 204 days for delayed medical treatment. Table 6.2 shows the univariate analysis of variables for demographic characteristics and table 6.3 shows univariate analysis for categories of illness experience (PD), illness meaning (PC), outside-help and reasons for medical treatment variables. Table 6.4 presents results for the adjusted (multivariate) logistic model for variables selected from the univariate analysis at $p<0.25$.

None of the demographic variables showed any significant association with timely treatment (table 6.2). However, functional disability and income loss as illness experiences were negatively associated with timely treatment only in the univariate analysis (table 6.3).

In their narratives, respondents linked income loss with the inability to continue working while seeking treatment. Respondents who delayed medical treatment also explained how their desire to continue with work overshadowed the need to use medical treatment. Many used herbalists and purchased analgesics, blood tonics and antibiotics from local chemists. They mentioned that the key reason for considering medical treatment, after herbal treatment had failed, was to get better to continue working. Most parents and guardians were unskilled workers and earned meagre wages. They expressed a genuine difficulty in stopping work to take their children and wards for medical treatment. However, respondents with pre-ulcers who initiated timely treatment continued working since they did not experience pain or much discomfort.

Table 6.3: Unadjusted (univariate) analysis of socio-cultural variables associated with timely and delayed treatment *

Explanatory variables	**Timely treatment N=178**	**P-values**
	OR (95% CI)	
Patterns of distress		
Pain	0.5 (0.21, 1.20)	0.118
Functional disability	**0.4 (0.20, 0.91)**	**0.029**
Disrupted education	0.8 (0.44, 1.65)	0.628
Loss of income	**0.4 (0.20, 0.92)**	**0.030**
Anxiety	0.6 (0.33, 1.27)	0.204
Embarrassed about condition	0.6 (0.29, 1.11)	0.098
Recurring infection	3.0 (0.90, 9.65)	0.073
Perceived causes		
Drinking unclean water	1.6 (0.83, 3.21)	0.158
Prone to illness	0.5 (0.16, 1.54)	0.229
Weakness of blood	0.6 (0.30, 1.26)	0.186
Outside-help		
Herbalist	**0.3 (0.15, 0.60)**	**0.001**
Fetish/spiritualist	**0.2 (0.07, 0.84)**	**0.025**
Prayer camp	0.4 (0.16, 1.08)	0.071
Municipal health centres	**2.7 (1.24, 5.88)**	**0.012**
Government hospital outside the district	0.6 (0.22, 1.49)	0.252
Nothing	0.3 (0.06, 1.13)	0.073
Reasons for medical treatment		
Easy access to health centre	**8.3 (2.46, 27.94)**	**0.001**
Self-referral	**2.3 (1.13, 4.57)**	**0.022**
Referral by family and friends	**2.9 (1.39, 6.09)**	**0.005**
Get well quickly	**3.7 (1.52, 8.79)**	**0.004**
Effectiveness of antibiotic treatment	**3.1 (1.38, 6.88)**	**0.006**

*Only variables with p-value <0.25 are shown in the table except disrupted education as a pattern of distress, because it was often mentioned in respondents' narratives with reference to medical treatment. Odds ratios, confidence intervals and p-values for all variables included in the adjusted model are shown in the table. Values in bold indicate statistical significance (p≤0.05).

6.3.3 Perceived causes and treatment delay

From the univariate analysis, PC variables did not show any significant relationship with timely treatment. However after adjusting for confounding factors (such as education, PD variables, help providers aside from herbalists, reasons for medical treatment besides easy access to treatment), drinking unclean water as a PC, was significantly associated with timely treatment (OR 3.8, p=0.011) in the multivariate analysis (table 6.4). Respondents who linked their illness to drinking unclean water attributed this knowledge to messages from health staff. They bemoaned the absence of potable water in their communities and explained that they often fetched water from rivers, ponds and unprotected dams, (which animals also drank from), for domestic use. Sometimes rivers were used as thoroughfare to work and school. The following narrative explains the use of unclean water from a stream for drinking and as an access route to school:

> *I believe it is due to wading, fishing and drinking water from the Doblo stream which I drink often. I also go fishing in the stream. Sometimes I have to wade through the same stream on my way to school and the farm.*
>
> (15-year-old male respondent)

6.3.4 Help-seeking behaviour

Prior use of a traditional healer (herbalist and spiritualist) showed a negative association with timely treatment in the unadjusted model (table 6.3). Furthermore, the use of herbalists showed significantly negative associations with timely treatment after adjusting for confounding (OR, 0.2, p=0.002), (table 6.4). Respondents' use of herbalists was often motivated by the desire for *quick recovery* in order to continue with work. Narratives suggested that herbalists were relatives (Fathers, Uncles or Grandfathers), itinerant, and they lived nearby, thus making them easily accessible (figure 6.2). During interviews, there were occasional encounters with herbalists. They either came to review the BU-illness status of relatives or clients, or they were carrying out their itinerant business.

Figure 6.2: Herbal treatment for ulcers *

*Respondent has had BU for more than 3 years and is being treated at home by his grandfather, a herbalist. Respondent's current condition is from recurring BU infections. The green patches (arrowed) are herbal dressings. Note the multiple scarring. Picture taken by Mercy Ackumey, Otuapleam community, 2008

Respondents had initial confidence in the claims of herbalists about their ability to treat BU. They often explained that herbalists were good at exposing the *cotton wool,* (translation from local name for infected tissues) but were not very effective in treating the sores. Respondents, who delayed treatment for ulcers, indicated that herbal treatment was often used in combination with analgesics, antibiotics and balms obtained from drug peddlers or used alone.

Respondents resorted to medical treatment, when herbal treatment seemed *ineffective* and wounds were not healing fast enough. The following narrative explains how the dynamics of easy access to herbal treatment and assurances from the herbalist, coupled with the desire to resume work, influenced the respondent's choice for herbal treatment which subsequently delayed medical treatment. This respondent lives 8 kilometres away from the nearest health centre.

> *I applied herbs to the boil at home and later invited a herbalist to treat me at home, because my treatment was not working. The herbalist assured me that his treatment was effective. His treatment only removed the 'cotton wool',* (translation from the local name for infected tissues) *but left a very big sore. After herbal treatment a private practitioner was injecting me and giving me pills daily at home. I always felt dizzy after the injections. I wanted to be treated at home to recover quickly to go back to work. I have spent so much money treating this disease and I have not been able to work for 9 months since I had this condition. I am a hairdresser and I have lost all my customers.*
>
> (35-year-old female respondent)

Table 6.4: Adjusted (Multivariate) analysis of background variables and socio-cultural variables associated with timely and delayed treatment

Treatment status	**Timely treatment N=178**	**P-values**
	OR (95% CI)	
Education		
Primary	Ref	
Secondary and above	0.5 (0.16, 1.62)	0.254
No education	0.4 (0.09, 1.58)	0.180
Patterns of distress		
Problems with mobility and use of affected limbs	0.8 (0.29, 2.50)	0.762
Disrupted education	0.4 (0.12, 1.63)	0.220
Loss of income	0.5 (0.13, 1.75)	0.267
Anxiety	0.6 (0.25, 1.57)	0.316
Embarrassed about condition	0.6 (0.22, 1.41)	0.216
Recurring infection	3.5 (0.71, 17.63)	0.125
Perceived causes		
Drinking unclean water	**3.8 (1.34, 10.63)**	**0.011**
Prone to illness	0.2 (0.05, 1.09)	0.064
Weakness of blood	0.6 (0.24, 1.79)	0.406
Outside-help		
Herbalist	**0.2 (0.08, 0.56)**	**0.002**
Fetish/spiritualist	0.2 (0.05, 1.09)	0.064
Prayer camp	0.4 (0.13, 1.32)	0.136
Municipal health facilities	1.2 (0.31, 4.68)	0.792
Government hospital outside the district	0.3 (0.05, 1.56)	0.150
Nothing	0.4 (0.04, 2.96)	0.343
Reasons for medical treatment		
Easy access to health centre	**8.5 (1.61, 44.47)**	**0.012**
Self-referral	2.3 (0.74, 6.98)	0.151
Referral by family and friends	1.6 (0.57, 4.43)	0.374
Get well quickly	1.5 (0.30, 7.32)	0.620
Effectiveness of antibiotic treatment	2.8 (0.55, 14.51)	0.215

*Odds ratios, confidence intervals and p-values for all variables included in the adjusted model are shown in the table. Values in bold indicate statistical significance ($p \leq 0.05$). The fitness of the model was assessed with the p-value ($p < 0.001$). OR = odds ratios, CI = confidence intervals.

Respondents had initial confidence in the claims of herbalists about their ability to treat BU. They often explained that herbalists were good at exposing the *cotton wool,* (translation from local name for infected tissues) but were not very effective in treating the sores. Respondents, who delayed treatment for ulcers, indicated that herbal treatment was often used in combination with analgesics, antibiotics and balms obtained from drug peddlers or used alone.

Respondents resorted to medical treatment, when herbal treatment seemed *ineffective* and wounds were not healing fast enough. The following narrative explains how the dynamics of easy access to herbal treatment and assurances from the herbalist, coupled with the desire to resume work, influenced the respondent's choice for herbal treatment which subsequently delayed medical treatment. This respondent lives 8 kilometres away from the nearest health centre.

> *I applied herbs to the boil at home and later invited a herbalist to treat me at home, because my treatment was not working. The herbalist assured me that his treatment was effective. His treatment only removed the 'cotton wool',* (translation from the local name for infected tissues) *but left a very big sore. After herbal treatment a private practitioner was injecting me and giving me pills daily at home. I always felt dizzy after the injections. I wanted to be treated at home to recover quickly to go back to work. I have spent so much money treating this disease and I have not been able to work for 9 months since I had this condition. I am a hairdresser and I have lost all my customers.*
>
> (35-year-old female respondent)

6.3.5 Access to health facilities, knowledge of antibiotic treatment influence of family and friends and medical treatment

Self-referral, referral by family and friends, the desire for quick recovery and knowledge of the effectiveness of antibiotic treatment showed significant associations with timely medical treatment in the univariate analysis (table 6. 2). However, after adjusting for confounding only easy access to health facilities showed a significant association with timely medical treatment (OR 8.5, p = 0.012), (table 6.4). Respondents who accessed health centres with very little difficulty lived nearby and commuted easily for treatment. Respondents attributed their knowledge of the availability and effectiveness of antibiotic treatment at medical facilities to community health education programmes. They also conferred with family and friends for advice on treatment choices. In some cases, family and friends advised the use of medical treatment; others advised otherwise. The following narrative shows how advice from family could influence behaviour and possibly lead to delayed treatment, with implications for emotional, physical and financial distress.

> *This condition has caused me a lot of inconvenience. It* (sore) *smells so bad and I have lost the desire for food. I cannot sit on my bottom* (locus of the sore) *for months. I cannot explain my situation; I am in a total mess. I don't work anymore so I don't have any income. I have left the family behind at home and I am in the hospital. Men cannot take care of children properly so I worry about the situation in the house. I was advised by so many people – family and friends. Any time someone advises me to try something I do it. I tried all kinds of herbs, pills and balms. I also went for prayers. My Pastor said I should go to the hospital so that my condition does not become worse.*
>
> (32-year-old female respondent)

6.3.5 Challenges associated with treatment adherence

Aside from the desire to continue with work, narrative accounts of respondents identified the influence of other socio-economic factors responsible for treatment delay. These included the cost of food if admitted to the hospital and transport expenses to medical facilities. Many of these respondents, who delayed medical treatment, described these costs as enormous, which their meagre incomes from small-scale farming, other farm work, odd-jobs and petty trading could not support. They stated that they had to leave behind some money for the family upkeep when admitted for surgery at the hospital.

Of the 91 respondents who delayed medical treatment for ulcers, nine (9.9%) could not adhere to treatment. Reasons given were distance to the health centre, high costs of transport, difficulty in obtaining transport, dissatisfaction with slow-healing of antibiotics, lack of money for food while on admission, advice of family to discontinue treatment and the perceived ineffectiveness of medical treatment influenced by the idea that BU is caused by witchcraft.

Nine (9) of the 48 respondents (18.5%) who initiated timely medical treatment for their pre-ulcer conditions failed to adhere to treatment regimes. Some of them discontinued treatment and resorted to self medication with antibiotic capsules, particularly Terramycin and Phenoxymethylpenicillin (commonly known as penicillin v), which were purchased from chemist shops or itinerant drug peddlers. Explanations were based on difficulty obtaining transport to health centres, long distance to health centres from place of residence, travel time interfering with work schedules and lack of money for transport. The following account of a respondent, an itinerant petty trader, who lives 18 kilometres from the nearest health centre, is characteristic:

> *I wanted to get well quickly as the health people have been telling us. One day when I was selling, I met some people from the hospital giving a talk about Buruli ulcer. When I showed them my boil they said it was Buruli ulcer and they asked me to go to the*

> *Kojo Ashong clinic for treatment. Everyday, I had to walk for a long time to get to the Kojo Ashong clinic. I was given injections and pills. I did not have enough time to take care of the family before leaving home. The clinic is far away from my house and so it was very difficult to go each time. I come back from the clinic very tired, and then I have to go and sell.*
>
> (28 year-old female respondent)

6.4 Discussion

The aim of this study was to clarify the influence of socio-cultural factors on timely treatment for BU infection. Because of the absence of a standard definition for measuring timely treatment for BU, we formulated a working definition of timely treatment as medical treatment within 3 months of awareness of infection. This definition was based on studies that estimated an average time of 1-3 months for the pre-ulcer phase of BU (Merritt et al., 2010; Webb et al., 2009).

Our findings suggest that timely treatment for BU is greatly influenced by health system factors, poverty and the socio-cultural environment of affected persons. Access to health services, referral by family and friends and awareness of the effectiveness of medical care encouraged timely treatment. Furthermore, our findings confirm earlier studies that explained delayed medical treatment for BU as a result of social and economic factors, such as the absence of reliable transport to health facilities, high costs of transport to medical facilities, prolonged stay in the hospital and loss of income, and disrupted education (Adamba & Owusu, 2011; Asiedu & Etuaful, 1998; Aujoulat et al., 2003; Mulder et al., 2008; Noeske et al., 2004; Phanzu et al., 2006; Renzaho et al., 2007; Stienstra et al., 2002).

Previous studies have established an association between witchcraft as a PC and delayed medical treatment after prior use of traditional healers, particularly diviners. (Aujoulat et al., 2003; Mulder et al., 2008; Noeske et al., 2004). Our findings did not show any indication of such an association between local ideas of witchcraft delaying timely treatment. Nonetheless, the use of spiritualists and herbalists for treatment had a negative association with timely treatment. Spiritualists and herbalists were frequently used however because they were easily accessible and provided home-based care which minimised absenteeism from home for medical treatment.

6.4.1 Study limitations, strengths and implications for control

Recall bias may have been an issue since study data were mainly based on respondents' accounts. Because many respondents had to report both on providers visited and time when they initiated treatment retrospectively, recall bias is a potential problem. Probes were used however, to minimise recall bias and under-reporting. We interviewed fewer respondents with pre-ulcers (15) compared with those who had ulcers (166). The skewed nature of our data can be explained by local practices of incising nodules and applying herbs to pre-ulcer lesions which accelerates the progression of pre-ulcer lesions to ulcers (Ackumey, Gyapong, Pappoe & Weiss, 2011). A recent study in a BU-endemic area in Ghana also showed fewer pre-ulcer cases (23.3%) than ulcer cases (76.7) during an initial health-screening exercise. However, the situation reversed after one year of intensive health education(Agbenorku, Agbenorku, Amankwa, Tuuli & Saunderson, 2011).

Narratives explaining the influence of cultural epidemiological explanatory variables clarified the socio-cultural context of timely treatment and enhanced the social contextual analysis of logistic regression models. Findings provide insight into features of both timely and delayed treatment for BU and indicate programme-relevant issues for control. These include improving access to medical treatment and fostering provider-patient interactions through mobile services, involving private health care practitioners to improve access and strengthening support networks to raise awareness and provide emotional support. These points are discussed in greater detail in the discussion that follows.

6.4.1.1 Improved access to services for timely treatment and adherence

A study in Benin reported a shorter median time delay of 120 days for ulcers compared with 204 days in our study (Debacker et al., 2004). The median time for delayed treatment and the long duration of infection for ulcers is a matter of concern because this might lead to prolonged treatment with higher costs and disability that deepens poverty (Adamba & Owusu, 2011; Debacker et al., 2004; Phanzu et al., 2006; Renzaho et al., 2007). Based on the median time for initiating timely treatment in our study, which was 30 days and the average time for incubation for *M. ulcerans* (between 1-3 months) (Portaels et al., 2009), we suggest that persons infected with *M. ulcerans* infection, should seek medical treatment within a month after awareness of symptoms. It must be noted however that improved access to treatment is required to encourage affected persons to seek treatment within a month of infection, In Benin, median time delay for BU decreased from 120 days to 30 days after the implementation of a programme to improve access to care (Debacker et al., 2004). Study findings indicated that although proximity of health facilities to residences encouraged timely care, distance, travel time to health facilities that disrupted work schedules, lack of money for transport, unavailability of transport and loss of wages when seeking care accounted for non-adherence to a full course of antibiotic treatment. A study in Ghana revealed that low income also accounted for non-adherence to tuberculosis treatment. People defaulted when they felt a bit better in order to work and continue taking care of the family (Dodor & Afenyadu, 2005). Transport costs and distance from health facilities have been responsible for treatment delays and adherence for tuberculosis (van der Werf, Dade & van der Mark, 1990). Our study finding which confirms this link between access, poverty and disrupted livelihoods, on the one hand, and non-adherence to antimicrobials is a matter of concern; it is likely to increase antibiotic resistance and compromise effective treatment (Jackson, Lawton, Raynor, Knapp, Conner, Lowe et al. 2006).

It is important that public health practitioners consider the socio-economic conditions of BU-affected persons. These conditions have implications for designing programmes and providing services to improve disease outcomes, lessen disease burden, limit dependency on herbalists and encourage timely treatment, and mitigate the effects of poverty. Mobile services are likely to increase interactions between BU patients and health workers, which are crucial in motivating commitment to treatment, providing emotional support and encouraging adherence to antibiotic treatment regimes for positive treatment outcomes, namely cure and reduced recurrences.

The use of motorcycles to improve access to health services is not a new phenomenon in Africa. Motorcycle ambulances have been used in Malawi to improve access to health facilities, improve referrals and consequently reduce maternal mortality (Hofman, Dzimadzi, Lungu, Ratsma & Hussein, 2008). In South Africa, off-road motorcycles have been used for timely collection of blood-specimens that give remote clinics access to diagnostic laboratory services (Glencross, Mendelow & Stevens, 2003). Collaborating with private health practitioners might also be considered as a pragmatic and cost-effective approach to improve access (Ackumey, Gyapong, Pappoe, Kwakye-Maclean & Weiss, 2012; Ackumey et al., 2011). However, this intervention requires supervision and monitoring by the municipal health management team to ensure that drug protocols are followed strictly and wounds are managed properly.

6.4.1.2 The socio-cultural context of poverty and timely treatment

The failure to initiate timely medical treatment was associated with concern for securing livelihoods. Most BU-affected persons are poor, unskilled labourers, petty traders, farmers or fishermen, with irregular work schedules and incomes (Adamba & Owusu, 2011; Agbenorku et al., 2011; Asiedu & Etuaful, 1998; Grietens, Boock, Peeters, Hausmann-Muela, Toomer & Ribera, 2008; Renzaho et al., 2007). Their concern about loss of livelihoods and income is reasonable and well-founded. Studies have shown the immense socio-economic burden of BU on already impoverished families and households (Ackumey et al., 2011; Asiedu & Etuaful, 1998; Grietens et al., 2008). Some families, borrow money, sell assets and reduce farm sizes to pay for transportation and feeding costs related to BU treatment, thus entrenching them deeper into poverty (Adamba & Owusu, 2011; Agbenorku et al., 2011). Ironically, however, treatment delays account for longer periods of treatment, higher cost, longer hospitalisation, loss of livelihoods and increased poverty (Agbenorku et al., 2011).

6.4.1.3 Influence of use of herbalists on timely treatment

Many respondents who delayed treatment for ulcers had first used herbalists (43.1%). Herbal treatments and herbalists are used widely for various ailments in Ghana (Asase & Oppong-Mensah, 2009). The use of herbalists however, is known to delay medical treatment for BU (Renzaho et al., 2007; Webb et al., 2009) and tuberculosis (Barker, Millard, Malatsi, Mkoana, Ngoatwana, Agarawal et al. 2006). The pre-ulcer stages of BU infection are usually without pain and unless secondary infection is introduced, ulcers are generally painless (Walsh et al., 2008), which makes it easier to delay treatment to continue working.

6.4.1.1

6.4.1.1 The consanguine relationship of herbalists with our study respondents and the itinerant nature of their services made them easily accessible. Herbalists play a crucial role in providing services when biomedical treatment is inaccessible, particularly in a culture where herbal medicine is widely used (Asase & Oppong-Mensah, 2009). Previous studies recommend their integration in the health system to facilitate referrals (Ackumey et al., 2011; Renzaho et al., 2007). Currently, herbalists are being motivated to refer patients to health facilities, in the study areas (personal communication). This strategy, although laudable needs to be explored further to consider innovative ways to enlist their trust and cooperation.

6.4.1.4 Perceived causes and timely treatment

Respondents who initiated timely medical treatment were more likely to attribute the cause of their illness to drinking bad water. Even though the mode of BU transmission to humans is unclear (Johnson, Stinear, Small, Pluschke, Merritt, Portaels et al. 2005), support is weak for the assertion that ingestion of unclean water is a possible transmission route (Duker, Carranza & Hale, 2004).Local perceptions that link BU disease to drinking unclean water may result from misinterpretation of health messages that emphasise water contagion as a risk factor for BU disease. Furthermore, the study location was a previously guinea worm endemic area and health education messages then emphasised drinking unclean water as a risk factor.

Therefore, there is a tendency of generalising health messages across these two diseases. Public health programmes must consider the disease history of communities when designing health education programmes and present messages distinctly to avoid ambiguity. Nonetheless, study findings support the concern raised by earlier studies about the need for further research on the role of environmental factors, animals and insects in BU contagion (Marsollier, Aubry, Saint-Andre, Robert, Legras, Manceau et al. 2003; Merritt et al., 2010; Williamson, Benbow, Nguyen, Beachboard, Kimbirauskas, McIntosh et al. 2008). Such evidence would maybe help to guide and motivate the local population to clarify the validity of problems that affect timely medical treatment.

6.4.1.5 Support networks and health education for timely treatment

Self-referral, referral by family and friends and knowledge of WHO-antibiotic treatment was significantly associated with timely treatment only in the univariate analysis (table 6.3). Support networks such as family and friends provide social support and offer valuable help-seeking advice. (Ackumey et al., 2011; Mulder et al., 2008; Nyika, 2009; Samuelsen, 2004). The importance of community and school health education programmes to increase awareness of BU, and the availability and effectiveness of treatment at medical facilities cannot be overemphasised.

Health education should also explain how initial use of herbal treatment and self-medication delays medical treatment and healing. Furthermore, health messages should emphasise the effectiveness of WHO-recommended antibiotics for treating timely lesions.

6.5 Conclusions

Our findings highlight how health system factors such as access to treatment and knowledge about the effectiveness of medical services encouraged timely treatment, and how poor access to treatment and socioeconomic obstacles affected treatment adherence. The socio-cultural context of poverty discouraged timely treatment and influenced use of herbalists. The link between drinking water as a perceived cause and timely treatment is a clear indication of a positive response to health messages and shows the impact of the control programmes even through the scientific validity of this perceived cause is questionable. Nevertheless, findings highlight the importance of optimising public health control efforts. This calls for an integrated approach to BU management and care accounting for social and economic barriers to timely medical treatment. Recommended measures include, periodic screening for timely case-detection, collaboration with private practitioners to improve access to treatment and the introduction of mobile services to improve treatment outcomes and adherence, and case-detection.

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Chapter 7

Health services for Buruli ulcer control: Lessons from a field study in Ghana

Mercy M. Ackumey [1, 2, 3] *, Cynthia Kwakye - Maclean[4], Edwin O. Ampadu[5], Don de Savigny[2, 3], Mitchell G. Weiss [2, 3]

1. School of Public Health, College of Health Sciences, University of Ghana.
2. Swiss Tropical and Public Health Institute, Basel.
3. University of Basel, Switzerland.
4. Ga-West Municipal Health Administration, Amasaman, Ghana.
5. National Buruli Ulcer Control Programme, Accra, Ghana.

* Corresponding author

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7.0 Abstract

Background

Buruli ulcer (BU), caused by *Mycobacterium ulcerans* infection, is a debilitating disease of the skin and underlying tissue. The first phase of a BU prevention and treatment programme (BUPaT) was initiated from 2005-2008, in the Ga-West and Ga-South municipalities in Ghana to increase access to BU treatment and to improve early case detection and case management. This paper assesses achievements of the BUPaT programme and lessons learnt. It also considers the impact of the programme on broader interests of the health system.

Methods

A mixed methods approach included patients' records review, review of programme reports, a stakeholder forum, key informant interviews, focus group discussions, clinic visits and observations.

Principal Findings

Extensive collaboration existed across all levels, (national, municipality, and community), thus strengthening the health system. The programme enhanced capacities of all stakeholders in various aspects of health services delivery and demonstrated the importance of health education and community-based surveillance to create awareness and encourage early treatment. A patient database was also created using recommended World Health Organisation (WHO) forms which showed that 297 patients were treated from 2005-2008. The proportion of patients requiring only antibiotic treatment, introduced in the

course of the programme, was highest in the last year (35.4% in the first, 23.5% in the second and 42.5% in the third year). Early antibiotic treatment prevented recurrences which was consistent with programme aims.

Conclusions

To improve early case management of BU, strengthening existing clinics to increase access to antibiotic therapy is critical. Intensifying health education and surveillance would ultimately increase early reporting and treatment for all cases. Further research is needed to explain the role of environmental factors for BU contagion. Programme strategies reported in our study: collaboration among stakeholders, health education, community surveillance and regular antibiotic treatment can be adopted for any BU-endemic area in Ghana.

7.1 Introduction

In the absence of a proven strategy for preventing infection, control of Buruli Ulcer (BU) relies on efficient health services to prevent progression of pre-ulcerative conditions and treat ulcers. According to the World Health Organisation (WHO), service delivery is the primary function of any health system and entails the provision of “effective, safe, good quality care to those that need it with minimal waste”,(World Health Organisation, 2007) and to address health care needs through promotion, prevention, treatment and rehabilitation. WHO defines a health system as “all organisations, people and actions whose primary intent is to promote or to restore health” (World Health Organisation, 2007).

Buruli ulcer, caused by *Mycobacterium ulcerans* infection is a debilitating disease of the skin and underlying tissue which starts as a painless nodule, oedema or plaque and could develop into painful and massive ulcers if left untreated (Johnson et al., 2005). It is the third most common mycobacterial pathogen of humans, after *M. tuberculosis* (tuberculosis) *and M. leprae* (leprosy), but the most poorly understood (Johnson et al., 2005; Sizaire et al., 2006). Even though case fatality is low, morbidity is high for all age groups (Aujoulat et al., 2003; Sizaire et al., 2006; van der Werf et al., 1989) and the socio-economic implications to the individual and cost of management to the health system are enormous (Asiedu & Etuaful, 1998; Grietens et al., 2008).

Surprisingly, estimates of Disability Adjusted Life Years (DALYs) for Buruli ulcer, like other neglected tropical diseases (NTDs) such as guinea worm, endemic syphilis and food-borne trematode infections are not explicitly stated (World Health Organisation, 2010). BU has been reported in more than 33 tropical and sub-tropical climates particularly West African countries (Johnson et al., 2005; World Health Organisation, 2008), and Ghana reports an average of 1000 cases each year (World Health Organisation, 2008). The first case of BU was reported in Ghana in 1972 in the Ga-district (Bayley, 1971). A national case search in 1998 indicated a national prevalence of 20.7/100,000 and a prevalence of 87.7/100,000 for the former Ga-district (now the Ga-West and Ga-South municipalities), the fifth most endemic in the country, yet with the highest burden in terms of healed and active lesions (Amofah et al., 2002).

The first phase of a BU prevention and treatment programme (BUPaT) was initiated from 2005-2008, in the Ga-West and Ga-South municipalities in the Greater-Accra region, Ghana, to increase access to BU treatment and improve early case detection. Before the inception of the BUPaT programme, surgery was the main treatment for all BU patients. There was limited accessibility to treatment since all surgeries had to be done at the Amasaman hospital (AH), the main treatment and referral hospital for all BU cases in the Ga-West municipality. Antibiotic treatment had not been introduced and health staff had limited expertise in surgical procedures and BU case management.

The BUPaT programme employed WHO-recommended strategies which are: Building capacity of nurses and other para-medical staff for effective case detection, and management at designated health centres; training of community-based surveillance volunteers (CBSVs), school teachers, other health workers and traditional healers (THs), to enhance BU knowledge for early detection; establishing a community-based surveillance system with the help of CBSVs; compiling a database; providing surgical and antibiotic therapy for all BU patients (World Health Organisation, 2001b).

These strategies were undertaken by a health team that consisted of staff of the national Buruli ulcer control programme (NBUCP), the BUPaT programme from World Vision Ghana, the health directorates of the Ga-West and Ga-South municipalities, surgeons from the Korle-Bu teaching hospital in Accra, the municipal school health education programme (SHEP) coordinator, municipal environmental health officers (MEHOs), CBSVs, THs and community members. This paper assesses achievements of the BUPaT programme and lessons learnt for early case detection, case management and access to treatment in a BU-endemic rural area of Accra. It also considers the impact of the programme on broader interests of the health system.

7.2 Methods

7.2.1 Study setting

This study was conducted from November 2008 to July 2009 in the Ga-West and Ga-South municipalities. The Ga-West municipality shares boundaries with the Ga-South municipality to the west. It has a population of 215,824 inhabitants of which 48.2% are males and 51.8% are females. About 60% of the municipality's landscape is rural with about 200 scattered communities; 40% is urban and peri-urban and is densely populated. The population of the Ga-South municipality is estimated at 210,727 distributed in 362 communities.

Like the Ga-West municipality, 48.2 % inhabitants are males and 51.8% are females. The population is mainly concentrated along the peri-urban areas of the municipality.

At the time of conducting the survey, the Ga-West and Ga-South municipalities were known as the Ga-West District. The Ga-West district covered the same geographical area as these two municipalities (Ga-West and Ga-South). Through a government legislative instrument, the Ga-West district was divided into two separate municipalities in 2009 for easy governance and accessibility of health services.

Since 1999, BU continues to be a major cause of morbidity in both municipalities with increasing numbers of related disabilities. Health services are provided by 3 main government health centres, Weija hospital, Amasaman hospital (AH) and the Obom Health Centre (OHC), a few private clinics, and family planning and maternity homes.

7.2.2 Study design and research methods

The study employed a mixed methods approach using quantitative and qualitative methods to assess the effectiveness of the BUPaT programme in improving early detection and management of BU in the Ga-West and Ga-South municipalities. This approach provided the needed framework for obtaining, understanding, comparing and cross-validating contextual information from providers and beneficiaries of BU-related health service delivery strategies. The various methods were complementary; emerging and divergent issues arising during the course of one approach were clarified with another. Aside document reviews which was ongoing over the course of the study, all the other approaches followed sequentially.

7.2.2.1 Stakeholder forum (SF)

A day's forum was held with thirty five (35) persons that included the programme manager of the NBUCP, the municipal chief executive (MCE) of the Ga-West municipality, some municipal health staff, officials and BUPaT staff of World Vision Ghana, doctors and nurses from the AH and the OHC, officials from the Ghana education service, CBSVs and MEHOs. This forum reviewed the BUPaT programme activities, explored issues regarding health services delivery, capacity of health staff to deliver BU-related services and the integration of programme activities in communities and schools. Health service delivery interventions such as the role of CBSVs in case detection, early reporting and strengthening existing clinics in the community to increase access to health services were discussed. Consideration was given to community participation, sustainability of the programme as well as the next steps for future strategies at BU control.

7.2.2.2 Documents review

Quarterly and annual BUPaT programme reports were studied to provide background information and insights into programme objectives, strategies and challenges.

7.2.2.3 Key informant interviews (KIIs)

KIIs were held with the municipal health director (MHD) of the Ga-West municipality, the programme managers of the NBUCP and the World Vision Ghana, Ga-West municipality development programme. These persons were selected because of their pivotal role in the BUPaT programme. KIIs highlighted issues on access to care, successes and challenges of the programme and emphasised strategies requiring further strengthening.

7.2.2.4 Patients' records review

Already analysed records of 297 patients from the AH were reviewed to indicate the statistical trend, demographic characteristics of patients, assess indicators of treatment procedures, effectiveness of treatment and outcomes.

7.2.2.5 On-site clinic visits

Visits were made to the OHC and the Kojo Ashong clinic to assess the effectiveness of decentralising treatment and management of Buruli ulcer.

7.2.2.6 Focus group discussions (FGDs)

One FGD each was held in three randomly selected endemic communities (Kojo Ashong, Avornyokope, and Balagono). Each focus group was made up of 10 purposively selected persons, comprising treated and discharged adults, and care-takers of child patients. FGDs examined community perceptions about the programme, school-based strategies, and the effectiveness of medical treatment, particularly antibiotic treatment. FGDs also considered challenges and concerns that were raised at the SF and KIIs regarding low hospital/clinic attendance and late reporting.

7.2.3 Data management and analysis

Information from BUPaT programme reports were subjected to a thematic content analysis. Themes were derived from activities that formed health service delivery strategies. Thematic related activities, (community-based surveillance, community education, school-based education and antibiotic therapy) were examined for their contribution to awareness creation, access to timely treatment, care and management of BU, and how best they addressed the overall aim of the BUPaT programme. Consideration was also given to the extent of collaboration and coordination of activities among stakeholders. Documented successes and challenges of the programme as well as those mentioned at the SF and during KIIs and FGDs were noted.

Discussions and interviews from the SF and the KIIs were subjected to a thematic content analysis. Interviews were conducted in English and tape-recorded. During the interviews, elaborate notes were taken and themes that emerged during these discussions were noted. Subsequently, interviews were transcribed using Microsoft Word. Transcriptions were translated and edited, preserving the original style and context. The authors developed a coding framework based on themes pertinent to the main features and strategies of the BUPaT programme (Berg, 2009). These themes included ‘collaboration’, ‘health services ’, ‘ health education’, ‘access and utilisation’, ‘coverage’, ‘adequacy of facilities’ , ‘antibiotics’, ‘surgery’, ‘complications’, ‘recurrence’, ‘patients’, ‘feeding’, ‘transportation’, ‘community’, ‘traditional healers’ and ‘community-based surveillance volunteers’.

FGDs were conducted and recorded electronically in the local languages. Notes on content and context referred to recurring themes. FGDs were translated into English and transcribed using Microsoft Office Word. Similar to the procedure for analysing the SF and the KIIs, transcriptions were subjected to a thematic content analysis. A coding scheme was devised using themes that clarified perceptions of health service delivery strategies and medical treatment. These themes included ‘volunteers’, ‘treatment’, ‘late treatment’, ‘traditional healers’, ‘herbal treatment’, ‘medicines’ and ‘costs’.

Observations during clinical visits were recorded in a notebook. We paid attention to the type of treatment given to patients, number of patients who received antibiotic care and documentation of patient data. Subsequently, clinical registers were examined to ascertain the extent to which patients adhered to treatment.

Patient data captured on the WHO BU01 forms had already been extracted and analysed by health staff and therefore there was no need for any further analysis

7.2.4 Ethics statement

The study was approved by the ethical review committee of the Ministry of Health, Ghana, and the ethics commission of Basel (Ethikkommission beider

Basel EKBB) in Switzerland. Verbal consent was preferred to written ones since it did not pose any psychological threat and reassured all interviewees of anonymity. Both ethical review boards approved of verbal consent as long as participation in the study was voluntary, participants had been informed of the study aims and had the opportunity to ask questions. Prior to the start of all interviews, interviewees were informed about: the study aims, their rights to withdraw participation from the study, the intended use of findings to improve BU related health services and, for publications in academic journals and reports. Informed verbal consent was witnessed by two members of the BUPaT team who were not members of the research team.

7.3 Results

7.3.1 Collaboration and networking of all partners and stakeholders

Programme documents indicated that the BUPaT programme was initiated by WVG and the MHD of the Ga-West Municipality. The municipal chief executive (MCE) of the Ga-West Municipality and the NBUCP were engaged at the design stage. At the onset, a memorandum of understanding (MOU) was formalised with the MCE to ensure partnership with the local government authorities, and subsequently the municipal health staff and beneficiary communities. Table 7.1 shows a timeline of BU activities in the country and study municipalities.

Table 7.1 : Timeline of Buruli ulcer activities in Ghana

Dates and References	
1971 (Bayley, 1971)	First case of BU identified in a patient from the Ga district
1989 (van der Werf et al., 1989)	96 cases of Buruli ulcer infection were discovered in the Asante Akim North District in the Ashanti Region of Ghana.
1993 (Amofah et. al. 2002)	A passive surveillance system for reporting Buruli ulcer was initiated in Ghana by the Ministry of Health.
July 1998 (World Health Organisation & Global Buruli Ulcer Initiative, 2000)	Signing of the Yamoussoukro declaration on Buruli ulcer in Yamoussoukro, La Côte d'Ivoire, by the Director-General of the WHO and Heads of State of Ghana, Benin and Côte d'Ivoire. These governments agreed to mobilise resources to establish national Buruli ulcer control programmes, conduct epidemiological surveys on BU and establish surveillance systems with technical support from the WHO.
June-July 1999 (Amofah et al., 2002)	The Ghana Ministry of Health conducted a national case search on BU in the entire country. A total of 5,619 persons were identified with BU lesions at various stages in all 10 regions of the country. The national prevalence rate was computed as 20.7/100,000 and the Ga-district prevalence rate was 87.7/100,000 for active lesions.
2002(National Buruli Ulcer Control Programme, 2008)	The establishment of the Ghana National Buruli ulcer Control Programme in accordance with the Yamoussoukro declaration.
July – August 2005 (Renzaho et al., 2007)	Community-based study on knowledge, attitude and practice of Buruli ulcer conducted in the Ga-West district of Ghana.
2005	Buruli ulcer Prevention and Treatment Programme commenced in the Ga-West and Ga-South municipalities of the Greater Accra region of Ghana.
March 2009(World Health Organisation, 2009)	Cotonou declaration adopted in Cotonou, Benin, by the WHO Director-General, Minister of health, Ghana, other West African presidents and participants, to take all the necessary measures to alleviate the suffering caused by Buruli ulcer, and to contribute to further enhancement of knowledge about the disease..

Programme documents, the SF and KIIs indicated a strong partnership with the NBUCP which provided technical expertise and training of health staff. To create awareness and ensure the participation of civil society, programme documents revealed that the BUPaT programme was duly launched at a durbar in the capital of the municipality, Amasaman. THs, WVG staff, officials from the NBUCP, municipal executives, health staff, teachers, CBSVs, school children and community members were in attendance.

Programme documents indicated that the core management team of the programme was the WVG Ga-West municipality manager, the MHD and the municipal SHEP coordinator. Selection of members for this team was guided by the main activities of the programme which were community and school health education, screening, medical treatment, surgery and wound care, community surveillance, documentation and compilation of a patients' database.

Some individuals from the municipal health management team (MHMT) served as focal persons for various aspects of the programme. WVG too had a focal person for the programme, officially known as the BUPaT programme coordinator. This person was responsible for financial issues, logistics, monitoring, collation and analysis of patients' records, and served as a liaison between WVG and the MHMT. The MHD and the MHMT coordinated health activities related to BU.

A coalition of stakeholders including health, environmental, educational professionals, CBSVs and traditional rulers was formed to ensure diversity of expertise as well as community participation. As a practice, stakeholder meetings were organised quarterly to report on the progress of the programme. Additionally, a monitoring team comprising selected individuals from the stakeholder group was constituted to evaluate programme goals and objectives and follow-up on treated and discharged patients.

7.3.2 Training of health staff and other stakeholders for increased awareness, case detection, community-based surveillance and case management

According to programme documents, 120 CBSVs, 40 THs, 4 MEHOs and 113 teachers from 60 schools were trained to detect early cases of BU in communities and refer promptly to health facilities for treatment. BU information was included in the school curriculum. Documents and narratives from the SF revealed that officials from the NBUCP also trained 40 nurses in BU case-detection, surveillance, wound care and prevention of disabilities associated with BU. After training, these nurses were distributed among the municipal health facilities: AH, OHC and two newly opened health centres (one each at Dome Sampahman and Kojo Ashong communities). Programme documents, the SF and KIIs also revealed that refresher courses were held quarterly for nurses, CBSVs and MEHOs. The NBUCP arranged for two surgeons from the Korle-Bu teaching hospital to perform weekly surgical operations on patients.

7.3.3 Health education, screening and community-surveillance to improve early detection and treatment of cases

Programme documents indicated that the BUPaT programme aimed to reduce BU-related suffering and disability through early detection and treatment of pre-ulcer cases. The programme therefore employed health education to create awareness, screening and surveillance to detect all forms of BU, particularly early cases to increase early reporting for medical care, antibiotic care, wound dressing and surgery.

According to programme documents, AH staff and the SHEP coordinator conducted BU education and screening in 80 schools. Health staff, BUPaT programme staff and CBSVs combined efforts to conduct health education in over 600 communities. Sometimes these education campaigns culminated in BU screening. MEHOs also organised night-time film shows on BU and followed up the next day for screening. CBSVs mounted intense surveillance in their localities and paid random home visits to screen and verify suspected cases of *M. ulcerans* infection.

7.3.4 Improved clinical treatment and case management of Buruli ulcer

Programme documents, the SF and KIIs revealed that the WHO-recommended antimicrobial (rifampicin and streptomycin) therapy was introduced at the beginning of the BUPaT programme in 2005, and administered to all patients. Health staff were trained in the appropriate protocols to be observed when administering these antibiotics. By policy, BU treatment is covered under the National Health Insurance Scheme (NHIS).

Narratives from the SF and the KIIs indicated that these antibiotics which are anti-tuberculosis drugs were provided by the NBUCP. Medicines and dressings were provided by the Ministry of Health through the NBUCP and sometimes by World Vision Ghana when stocks were exhausted. The SF forum also mentioned that surgery was carried out at least once a week at the AH by a surgical team from the Korle-Bu teaching hospital. Documents highlighted the infrastructural limitations of the OHC and the Kojo Ashong clinic that made it impossible for surgical operations to be carried out there.

At the Kojo Ashong clinic, located 20 kilometres from the AH, in an endemic community, BU care was limited to antibiotic therapy. At the time of the research team's visit, 4 patients had been registered: 2 female adults and 2 male children. During the visit, the team observed treatment of the children and 1 adult. The children proceeded to school after treatment. In addition to antibiotic care, the OHC performs minor excisions; patients requiring major surgery are referred to the AH. At the time of the team's visit, 9 persons (6 children and 3 adults) had already received treatment, though clinic records indicated that 24 patients (15 children and 9 adults) had been registered. Patient records also showed that only those 9 registered patients had regular treatment and they lived close to the OHC. Although rehabilitation of patients with disabilities is an integral component of BU care, all key informants admitted that this did not feature on the programme's agenda for lack of capacity and infrastructure. One key informant explained:

> *We are exploring the possibility of referring patients who need to be rehabilitated but who will pay for this service?*

7.3.5 Compilation of a patient database

The NBUCP trained all health staff on the appropriate use of the stipulated WHO BU01 forms to record patient information, disease outcomes, and clinical and surgical procedures. Analysed data from these forms indicate that 297 patients were treated from June 2005 to June 2008. Children below 15 years constituted nearly half (146; 49%) of all admissions over the 3-year period. Patients presenting with ulcers formed the majority of all clinical forms: 52 (52.5%) in the first, 62 (73%) in the second and 67 (59.3 %) in the third yearly periods. There were 14 (14%) patients with recurring lesions (June 2005-May 2006) and none during the latter yearly periods (table 7.2).

Except for the last yearly period (June 2007-May 2008) where only 34.5 % of patients healed without deformities, more than 60 percent of patients healed without deformities for the first and second years, (table 7.3). The proportion of patients that reported early and therefore were given only antibiotic treatment over the programme period was encouraging, 35.4% in the first yearly period, 23.5% in the second yearly period and 42.5%, in the third. The programme recorded 4 BU-related deaths, (table 7.3). Utilisation of services for BU increased over the three-year period. Of the 297 BU patients treated during this period, 113 were treated in year 3 (38.0%) compared with 85 (28.6%) in year 2 and 99 (33.3%) in year 1, (table 7.3). Irrespective of these achievements a significant proportion of patients either absconded treatment or were lost to follow-up (14.1% in the first yearly period 9.4% in the second yearly period and 14.2%, in the third), (table 7.3).

Table 7.2: Patient characteristics and clinical forms of Buruli ulcer (2005-2008)

Patient characteristics	**Yearly periods ***		
	2005-2006 (%)	**2006-2007(%)**	**2007-2008 (%)**
	N=99	**N=85**	**N=113**
Less than 15years	56 (56.6)	40 (47.1)	50 (44.2)
15-49	38 (38.4)	38 (44.7)	52 (46.0)
Above 49 years	5 (5.1)	7 (8.2)	11 (9.7)
Sex			
Male	41 (41.4)	41 (48.2)	62 (54.9)
Female	58 (58.6)	44 (51.8)	51 (45.1)
Clinical form			
Nodule	22 (22.2)	3 (3.5)	18 (16.0)
Plaque	22 (22.2)	11 (13.0)	10 (8.8)
Oedema	2 (2.0)	7 (8.1)	7 (6.2)
Ulcer	52 (52.5)	62 (73.0)	67 (59.3)
Mixed	1 (1.0)	2 (2.4)	10 (8.8)
Osteomyelitis	0 (0.0)	0 (0.0)	1 (0.9)
Patient classification			
New	85 (86.0)	85 (100.0)	113 (100.0)
Recurrent	14 (14)	0 (0.0)	0 (0.0)
Specimen taken for lab confirmation			
Yes	15 (15.2)	19 (22.4)	28 (24.8)
No	84 (84.8)	66 (77.6)	85 (75.2)

Source: Patient data 2005-2008, Amasaman hospital

* Since the BUPaT programme was initiated in June 2005, a yearly period was calculated from June to May the next year.

7.3.6 Improving access to treatment by providing incentives to surgeons; feeding and transport to patients

WVG provided cash incentives to plastic surgeons to ensure continuity of surgical operations. It was apparent from programme documents that the BUPaT programme supported in-patients and in some cases relations or caregivers with two meals (breakfast and lunch). Other organisations and individuals within and outside the municipalities also contributed towards feeding of patients either through cash donations or food items. All transport costs of patients and accompanying CBSVs to the AH, OHC, and patients who were referred to Korle-Bu hospital for specialised care were reimbursed. Key informants remarked that although feeding and refund of transport costs was not considered in the original programme design, it had to be incorporated later taking into consideration the poverty of programme beneficiaries, and remarked that good nutrition enhanced the healing of wounds.

All 3 key informants and stakeholders highlighted the high costs of treatment which placed a huge strain on the limited health budgets of the municipalities. They perceived a major difficulty in sustaining the programme if World Vision Ghana withdrew its financial support especially in the absence of government budgetary funding.

Table 7.3: Treatment types, outcomes and surgical procedures for Buruli ulcer patients (2005-2008)

Patient information	**Yearly periods ***		
	2005-2006 (%)	**2006-2007 (%)**	**2007-2008 N (%)**
	N=99	**N=85**	**N=113**
Disability present on admission			
Limitation present	14 (14.0)	19 (22.4)	32 (28.3)
No limitation present	85 (86.0)	66 (77.6)	81 (71.7)
Treatment types			
Surgery only	37 (37.4)	4 (4.7)	0 (0.0)
Antibiotics only	35 (35.4)	20 (23.5)	48 (42.5)
Antibiotics and surgery	27 (27.3)	61 (71.8)	65 (57.5)
****Surgical procedures**			
Excision only	24 (37.5)	16 (24.6)	33 (50.8)
Skin grafting	36 (56.3)	41 (63.1)	28 (43.1)
Amputation	1 (1.6)	2 (3.1)	2 (3.1)
Wound debridement	3 (4.7)	6 (9.2)	2 (3.1)
Treatment outcomes			
Healed without deformity	67 (67.7)	53 (62.4)	39 (34.5)
Referral	13 (13.1)	14 (16.5)	6 (5.3)
Healed with deformity	4 (4.0)	9 (10.6)	14 (12.4)
Absconded / lost to follow-up	14 (14.1)	8 (9.4)	16 (14.2)
Died, Buruli ulcer related	1 (1.0)	1 (1.2)	2 (1.8)
Still on admission	0 (0.0)	0 (0.0)	36 (31.9)

Source: Patient data 2005-2008, Amasaman hospital

* Since the BUPaT programme was initiated in June 2005, a yearly period was calculated from June to May the next year.

** Surgical procedures explains treatment types for patients that had ‘surgery only’ and ‘antibiotics and surgery’

7.3.7 Achievements of the BUPaT programme

Among the contributions of the BUPaT programme to BU control, the following achievements are notable: improved collaboration among stakeholders, early case detection and treatment, increased community awareness of the priority of BU and improved access to treatment. Promoting awareness and access to improved services has made it possible to minimise surgical interventions, which the earlier programme had relied on almost exclusively.

The priority of early detection and treatment highlighted in programme documents (quarterly and annual reports), was consistent with accounts in the SF, KIIs and FGDs. FGD participants commended the community and school health education programmes, use of media especially documentary films and the efforts of the CBSVs. Participants regarded these strategies as helpful for increasing their awareness, promoting disease surveillance and encouraging early presentation of affected persons for treatment. A participant at the SF summarised the achievements of the programme as follows:

> *The success of this programme is due to the extensive collaboration and networking of all those involved across all levels; national, municipality and community. Community-based surveillance volunteers are our foot soldiers in the community and they have done extremely well in surveillance, case detection and referral. They are the link between the communities and the municipal hospital.*

Our three key informants asserted the primary success of the BUPaT programme in managing BU was best indicated by the increasing number of patients receiving treatment at the AH over the course of the programme period. Statistics from the Ga-West municipality showed that prior to establishing the programme there were 70 cases in 2001, 82 in 2002, 83 in 2003 and 71 in 2004 (Ga-West District Health Management Team, 2006). In 2005, when the BUPaT programme commenced, AH recorded 99 cases and the number increased to 113 in 2008 over the 3-year period of the programme

Before the BUPaT programme, surgery and wound care had been the only available treatment interventions. Improved outcomes of antibiotic therapy have been highly valued by key informants and stakeholders, who regarded it as a breakthrough. Antibiotic treatment has been appreciated because it has minimised recurrence of lesions, which was not possible under the old treatment regime. FGD participants also valued the effect of antibiotic therapy in shrinking lesions and removing necrotic tissue (figure 7.1). They made no mention of any negative side-effects of this treatment.

Figure 7.1: Resolution of Buruli ulcer, in a Ghanaian boy, using antibiotic treatment without surgery *

Before antibiotic treatment

After antibiotic treatment for 8 weeks

*Photos courtesy of Ga-West municipal health directorate and used with permission

7.3.8 Challenges of the BUPaT programme

Despite the achievements of the programme, stakeholders and key informants mentioned some major challenges: the inadequacy of ward space to accommodate affected persons who required surgery, the lack of requisite infrastructure in other municipal health centres to perform surgery and the limited health budgets of municipalities. Another challenge was the delay of some affected persons in seeking medical treatment. One stakeholder commented on the challenge of the AH as the main referral and treatment facility for BU as follows:

> *We wish we could admit all the patients because some of them report with bad ulcers. However, when there is no space, we can only tell them to go back home and come daily for antibiotic treatment, which does not make economic sense when you live so far away and are poor.*

FGD participants mentioned fears of amputation, loss of livelihoods and the inevitable long absence of the primary care-giver from the home (mostly the mother), when a child is on admission at the hospital, as reasons for delayed treatment. They also expressed concern about feeding (the programme provided two meals a day), transport costs (transport costs of care-givers paying repeated visits to children on admission were not refunded) and difficulties with the continuation of medical treatment if support for feeding and transport was withdrawn. A mother of a treated child explained:

> *When you realise that either you or your child has Buruli ulcer and you choose to go to the hospital, you need to prepare financially because of so many reasons: You will have to leave a family behind and you must leave money to take care of them. When you are together as a family it is very easy to cook and share, but when the family is not together it becomes expensive. Now we are given food at the hospital, but what happens to my work when I am away taking care of a sick child; I will lose money. It is easier to seek traditional care and pray it works.*

However, other explanations for delayed medical treatment were linked to misinformation from THs on the likelihood of amputation with medical treatment. Some THs also tried to convince affected persons that herbal treatment was more effective than medical care. Stakeholders indicated that at the beginning of the programme, THs were trained to identify and refer promptly, all cases of BU that were brought to their attention, for appropriate treatment but they acted contrariwise.

FGD participants also expressed difficulties in early diagnosis of their conditions as BU, because of the various presentations of BU infection. For many, it was difficult to know whether cuts, stings, scratches and abrasions were uncomplicated injuries or the beginning of the BU disease. In most cases, these were either unnoticed or dismissed as trivial. As the condition progressed, an assortment of remedies including herbs, balms and hot compresses were applied until BU infection was established; in some cases, after the affected part opened up (revealing the necrotic tissue).

7.3.9 Stakeholders' suggestions for future services

Stakeholders regarded collaboration, networking and the community-based surveillance system as vital components of the BUPaT programme that had to be sustained. Stakeholders and key informants also mentioned the need to equip existing clinics to serve as treatment centres for wound care and antibiotic treatment. This was considered important to improve access to treatment and reduce severity of reported cases and disabilities, thus reducing the cost burden to the health system.

FGD participants agreed that health education and community-based surveillance activities should continue to increase awareness, improve case detection and encourage early reporting. They also implored the programme to continue to defray transport costs to lessen the economic burden of the disease.

7.4 Discussion

The primary goal of the BUPaT programme was to reduce BU-related suffering and disability through early detection and treatment of cases. Using a mixed method approach, study findings showed the contribution of the health system to BU control in an endemic area in Ghana. Extensive collaboration existed across all levels, (national, municipality and community), which contributed to strengthening the health system. The programme strengthened capacities of health staff in antibiotic treatment and wound care, and trained teachers, MEHOs and CBSVs in health education, screening, early detection and prompt referral for medical treatment. A patient database was also created using recommended WHO forms. WHO-recommended antibiotics improved treatment and cure, particularly for early lesions, thus preventing recurrences. Providing feeding and refund of transport costs proved a useful strategy in encouraging medical care. Irrespective of these achievements, there were still problems of access, accommodation (lack of sufficient ward space), use of traditional treatment, loss to follow-up and non-adherence to treatment.

The broader impact of the BUPaT programme on the health system could be seen in its effects on some of the six building blocks, or subsystems, of the health system, but not on others. With reference to the WHO framework

(World Health Organisation, 2007), the programme mainly affected governance, human resources, medicines and technology, and health delivery; it had less impact on the financing and information systems. Collaboration and networking among stakeholders strengthened the governance sub-system and improved health delivery of the programme. Training different groups of stakeholders - namely, health staff, CBSVs, MEHOs, teachers and THs - enhanced the human resource sub-system.

The administration of WHO-recommended antibiotics improved treatment outcomes and revolutionised the medicines and technologies sub-system. Each of these subsystems contributed to improved health delivery. Minimising expensive surgery by promoting alternative interventions reduced the strain on the limited resources of the finance sub-system. Although the BUPaT programme now routinely compiles patient data using WHO-recommended forms in an electronic database, community epidemiological data are needed for an integrated data system based on community surveillance.

Patient data showed that a significant proportion of admissions comprise children under 15 years-of-age (49 %), consistent with other study findings on the susceptibility of children to BU infection (Debacker et al., 2004; Marston et al., 1995). Even though most cases of BU were not confirmed by laboratory tests, all cases were diagnosed by qualified health staff and surgeons on the basis of WHO clinical case definitions. (World Health Organisation, 2001a) The BUPaT project aimed to improve early case detection, particularly for nodules, plaques and oedemas, though patient data showed the proportion of patients with pre-ulcer conditions remained less than for ulcer patients. Stakeholders argued that this was not a failure of the programme, however, because people with ulcers who would not previously have used the health system were now seeking medical care instead of remaining with THs.

Consequently, improved awareness has led to treatment of more patients with both pre-ulcerative conditions and ulcers. The reluctance of some people with BU to seek medical care is consistent with findings of other studies (Debacker et al., 2005; Renzaho et al., 2007; Stienstra et al., 2002). Studies suggest that the socio-economic impact of BU is a determining factor in the choice of treatment and adherence to medical treatment (Asiedu & Etuaful, 1998; Grietens et al., 2008). Traditional therapy has been the first choice for treatment for some affected persons because of easy local access, compared with the burden of high transport costs, and loss of income due to absence from work while in medical treatment at a distant site (Aujoulat et al., 2003; Renzaho et al., 2007; Stienstra et al., 2002).

Although increasing community awareness has been bringing more patients to medical treatment, FGDs also showed that various presentations (cuts, bites, stings and abrasions) were not identified as a possible indication of *M. Ulcerans* infection that would benefit from treatment. The effectiveness of antibiotics in preventing recurrences was documented in the patient data. Narratives from stakeholders and key informants referred to this, and they also indicated satisfaction with the minimal cost of antibiotic treatment compared with the high cost of surgery. These findings are consistent with other studies on drug effectiveness (Etuaful et al., 2005; Johnson et al., 2005; Nienhuis et al., 2010).

Even though there were no recurrent infections as observed previously when surgery was the only treatment procedure, a significant proportion of patients healed with deformities, most of these patients had ulcers. To minimise deformities, post-operative health care and physiotherapy is required and prosthesis would be needed for amputees. The cost of these services is indeed enormous for an already burdened and poorly resourced rural health service (Asiedu & Etuaful, 1998; Johnson et al., 2005). WHO recommends the need for rehabilitation of patients (World Health Organisation, 2006), yet there is paucity of research on its success and integration in the health system.

Based on our study findings, we offer recommendations for effective BU control, particularly for poorly resourced rural health systems. These include health education and community surveillance, collaboration with research laboratories for confirmation of cases, improving access to antibiotic treatment and wound care, integrating BU care with the management of similar diseases and disease mapping:

Our findings show the tremendous impact of health education and community surveillance strategies in BU control. Though this is a laudable community-directed initiative, there is the need for more concerted efforts of the programme to intensify these strategies to reduce BU-related morbidity and increase timely access to medical treatment. All teachers should be trained to identify all forms of *M. ulcerans* infection and refer for medical treatment. School children and others in the community should be encouraged to identify and report suspected cases to teachers, school authorities and community-based surveillance volunteers for verification. Local political commitment is needed by involving chiefs, traditional and religious leaders to support these efforts.

Health education messages should not only focus on creating awareness. They should also emphasise the importance of early reporting and appropriate care to avoid disease sequalae. Messages should encourage affected persons to seek early medical treatment for cuts, abrasions, stings or suspicious swellings. They should correct local ideas about the cause of BU that may discourage appropriate help-seeking. In this regard, it is important that all suspicious pre-ulcerative lesions should be evaluated with laboratory tests. WHO recommends a polymerase chain reaction (PCR) test to confirm cases and diagnosis. Results of this test can be obtained in two days (World Health Organisation, 2008). Given the absence of infrastructure and expertise to perform such analyses, the health system could benefit from collaboration with research laboratories and institutions.

The Ga-West municipality has opened health centres in a few localities to make chemotherapy accessible but these have proven woefully inadequate. There are quite a number of private clinics and maternity homes in both municipalities managed by qualified health personnel who have a large clientele. Integrating them in the health system could boost coverage and access to chemotherapy. The municipal health directorates should assume a supervisory and monitoring role to ensure compliance to case management and chemotherapy protocols.

The cost of managing BU like any other neglected tropical disease is enormous and places a huge strain on a limited rural health budget. Cost-effective interventions should aim at integrating diseases of similar characteristics. Since tuberculosis (TB) case management relies on the Directly Observed Treatment Strategy, all TB centres in the study municipalities could serve as referral treatment centres for identified cases of *M. ulcerans* infection.

Understanding the demographics, epidemiology and geographical distribution of areas that require interventions is critical for cost-effective BU control. The disease is known to be endemic in riverine communities and is attributed to a myriad of factors that include direct exposure to water and swampy areas (Debacker et al., 2006; Meyers et al., 1996). These features and documented cases could serve as indices for classifying communities into three categories: priority-endemic areas, requiring the most interventions, endemic and non-endemic, requiring further research to enhance understanding of the disease. First, basic demographic knowledge of all communities must be documented, updated periodically and entered into a central database that will enable mapping and tracking of cases. This is a task for which spatial analytic research is needed.

7.5 Conclusions

Findings demonstrate the role of extensive health education, community-based surveillance, capacity building and collaboration among stakeholders for BU disease control. Treatment with the administration of WHO-recommended antimicrobials has proven effective at least for early lesions. Threats to livelihoods and feeding and transport expenses influence delay to seeking medical care. Findings also indicate the need for an integrated health service delivery approach by incorporating diseases requiring similar antibiotic treatment regimes. A further step towards integration will be to include private health-care providers in the health system to increase access to antibiotic therapy in close proximity to the population. Health education is required in this regard to emphasise the effectiveness of treatment with antibiotics to reduce disease sequalae and the importance of seeking medical treatment for all skin lesions, whether big or small. Evidence from this study suggests that intensifying health education and surveillance would ultimately improve access to treatment for all cases. Further research is needed to explain the role of environmental factors for BU contagion. Health service delivery strategies reported in our study can be adopted for any BU-endemic area in Ghana.

7.6 Acknowledgments

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Chapter 8

Discussions and implications

8.1 Introduction

The mode of transmission for *M. ulcerans* infection commonly known as Buruli ulcer (BU) still remains a mystery. Although mortality is rare, morbidity is high, therefore pubic health programmes in endemic countries encourage early medical treatment to reduce suffering and disease burden. However, control efforts are often fraught with problems. The aim of this thesis therefore was to clarify the role of demographic, gender-related, and socio-cultural features of BU and how these features impact on the quality of timely treatment for BU treatment and control in Ghana. Each chapter examined a complementary aspect of this aim and provided useful findings for public health and questions for research.

8.2 Methodological issues

Field research activities reported in this thesis included a study of community knowledge, attitudes, and practices (KAP) (chapter 3), a cultural epidemiological framework (chapters 4-6) and a mixed-method health system study of BU control (chapter 7).

8.2.1 The knowledge, attitudes and practices (KAP) survey

Apart from a small-scale survey conducted in 2002, (Ackumey, 2002) a comprehensive study on knowledge, attitudes, and practices (KAP) of a representative sample of the population in the Ga-West municipality had not been done previously. The KAP study was required to provide an assessment of the level of BU awareness, local perceptions and practices. Findings from an earlier survey informed the structure of the semi-structured interview guide for the KAP study (Ackumey, 2002). The KAP study, explored local ideas about communication channels and pragmatic solutions for BU control. Findings of this study formed the basis for the BUPaT programme, presented in chapter 7. KAP studies have been used extensively to gather base-line information for major public health interventions, including advocacy and social marketing for various communicable and non-communicable diseases (Dodor et al., 2008; Iriemenam et al., 2011; Kheir et al., 2011; Kibadi, 2004).

8.2.2 The cultural epidemiological framework

The cultural epidemiological (CE) field and hospital study was based on the interdisciplinary framework of classical epidemiology and anthropology. It examined illness meanings, experiences and behaviour of BU, (chapters 4-6). The CE study proceeded with integrated quantitative and qualitative methods to explain local illness meanings, experiences and behaviour (Weiss, 2001), using semi-structured explanatory model interview catalogue (EMIC) interviews.

The EMIC interviews adapted for the studies reported in chapters 4-6, were based on prior ethnographic research (Ackumey, 2002) and KAP study findings (Renzaho et al., 2007) (chapter 1). The EMIC highlighted the extent of physical and emotional suffering, and the dimensions of social impacts of BU on the individual and the family, and among respondents with pre-ulcers and ulcers. An advantage of the CE framework was to explain and consider local ideas of BU illness meanings as distinct from professional concepts, thus revealing information gaps and needs.

Analysis of EMIC interviews showed how meaning and experiences of BU prompted the use of a combination of home-based herbal treatment, self-medication and risk-related practices. Clarifying BU experiences and meanings enabled a comprehensive understanding of the relationship of social, cultural and health system features of delayed treatment.

A phenomenological qualitative analysis of EMIC narratives clarified the relationship of quantitative explanatory variables and narratives for salient features of illness experience, meaning and behaviour and how these are related to timely and delayed medical treatment. Furthermore, for logistic regression analysis of explanatory variables for timely treatment, narratives from EMIC interviews enhanced analysis. (Chapter 6 tables 3 and 4).

A strength of the mixed-methods approach (chapter 7) was the triangulation of methods to assess important outcomes and strategies of the health system in the first phase of the Buruli ulcer prevention and treatment (BUPaT) programme. This interest suggested a framework for obtaining, analysing, comparing and cross-validating contextual information from providers and beneficiaries of health services (Leeuw & Vaessen, 2009). Achievements, strengths and challenges were noted. Activities and strategies of the BUPaT phase 2 were derived from experiences and lessons of phase 1.

8.2.2.1 Study limitations

A limitation of findings of the CE study (chapters 4-6) is the low numbers of respondents with pre-ulcers (15) compared to those with ulcers (166).

National statistics (NBUCP unpublished data) hint to this anomaly. Local practices of excising nodules to expose infected tissues have the undesirable effect of transforming pre-ulcers into ulcers (chapter 5). The mismatch in the number of pre-ulcers and ulcers indicates previous cultural practices that the control programme must address. Our study findings are based on all available pre-ulcer and ulcer patients and therefore relevant indications of the situation in the region. Consequently, they are also likely to be relevant for other areas of the country.

8.3 The study area

The Ga-West and Ga-South municipalities were chosen as study areas because they are the fifth most endemic municipalities for BU in the country, yet with the highest burden in terms of healed and active lesions (Amofah et al., 2002). Furthermore, to the best of our knowledge and at the time of conducting this study, only one socio-cultural study had been conducted (Ackumey, 2002), thus providing a rational to embark on this study.

The uniqueness of this thesis is the prime information it provides on socio-cultural features of BU for the Ga-West and Ga-South municipalities and an assessment of health system performance for BU control. Studies reported in this thesis provide baseline data for future socio-cultural assessments as the activities for BU control continues.

Collecting data in the study areas was both challenging and interesting. Unlike the community KAP study, which used a sampling frame of endemic communities (chapter 1), the CE study used purposive sampling and recruited all patients at the major municipal health facilities – the Amasaman hospital (AH), Kojo Ashong clinic (KAC) and the Obom health centre (OHC) - and affected persons in the community (chapters 4-6). The main intention was to interview as many infected persons as possible regardless of recruitment setting, rather than comparing community and clinic patients.

Recruiting community participants required extensive travel across difficult terrains with poor access. Nevertheless, these experiences and field observations enabled us to clarify the reality of access to services and challenges for the health system providing community outreach services. The recruiting process of community participants and data collection facilitated extensive interaction with the municipal health directors, programme staff of World Vision Ghana at the Ga-West municipality, municipal health staff, community health workers and community-based surveillance volunteers (CBSVs). Expertise of health workers was often required to verify suspected cases of BU to recruit for interviews and health workers benefited from this opportunity to document their data-base, and they also provided one-on-one education to respondents, after the interviews.

Apart from providing a unified platform for all stakeholders to review BUPaT programme activities, the stakeholder forum (chapter 7) also helped to disseminate and discuss preliminary findings from field studies and observations. This process is critical for health systems strengthening, scaling-up of pragmatic interventions and implementing new strategies suitable for the socio-cultural context.

8.4 Overview of study findings

8.4.1 Illness meanings, experiences and behaviour

Chapter 3 is based on community knowledge of BU, attitudes towards affected persons and anticipated help-seeking for affected persons. BU was attributed to many factors, such as drinking unclean water (16.0%), poor personal hygiene and dirty surroundings (8.1%), swimming and wading in ponds and rivers (5.5%) and witchcraft (5.2%). Many people (53%) did not know the cause of BU. Concerning help-seeking, herbal treatment was the preferred treatment option (32.3%), and medical treatment was only considered when herbal treatment failed or the illness worsened. Nurses with minimal training were also used in lieu of appropriate medical treatment. Narratives suggested that reasons for the substantial use of herbal treatment and the delay in medical treatment were based on anticipation of prolonged hospitalisation because providing care in the hospital would affect livelihoods. It was also difficult to get transport to health centres which were costly. Difficulty diagnosing BU during the pre-ulcer stage has been discussed as a problem for control.

Generally, BU-affected persons were not stigmatised although it was suggested that they shied away from public view because they were embarrassed about their sickness. Adults were more likely than children to empathise with BU-affected persons. These findings clarify an essential distinction between social stigma and personal shame that is highly relevant for public health. Findings confirmed earlier studies on the influence of socio-economic factors on delayed treatment and local ideas of causation based on witchcraft. Findings of this chapter provided prior ethnographic and socio-cultural information as a baseline for further studies reported in subsequent chapters, and clarified features of the community setting for the BUPaT control programme study (chapter 7).

Unlike the KAP study in chapter 3, which focused on unaffected community members, chapter 4 examined actual illness meanings, experiences and behaviour for pre-ulcers and ulcers from the perspectives of BU-affected persons. Anxiety was frequently associated with pre-ulcers (66.7%) and respondents with ulcers commonly mentioned physical problems (98.2%) such as pain and functional mobility and disrupted education (56.6%) as a social problem. Itinerant drug peddlers and herbalists who were mostly relatives of affected persons were used frequently because of easy access that made it possible to continue with school and work. Family and friends were frequently consulted for diagnosis of pre-ulcer conditions when respondents were in doubt, and for advice on treatment options. Some respondents attributed their illness to risky behaviour of swimming in rivers, ponds and streams. However, others questioned the credibility of health messages that emphasised water contagion as a risk factor for BU disease, since respondents asked about the absence of BU disease in other persons who practiced risky behaviour of exposure to water.

Distinguishing socio-cultural features of help-seeking for pre-ulcer and ulcer conditions was the focus of chapter 5. At home, people with pre-ulcers were generally treated with herbs obtained from the backyard (63.0%). Balms and ointments were used for nodules and oedematous lesions; nodules were locally excised if they failed to burst after the application of herbs. Ulcers were managed with herbal dressings (51.9%) and left-over analgesics and antibiotics. Additionally, antibiotics and blood tonics at home (49.7%) were used or purchased from chemists or itinerant drug peddlers. The chapter shows the desperation of persons with ulcers for relief to continue with work, resulting in use of various forms of available treatment that was offered by unqualified providers.

This substantial use of herbalists accounted for delays in medical treatment, (also mentioned in chapters 3, 4, 6 and 7), and the difficulty in identifying early lesions delayed medical treatment (chapters 3 and 7). Nevertheless, findings showed the impact of health education messages in creating awareness about medical treatment and the effectiveness of appropriate antibiotics. For those who used medical treatment after using other providers, medical treatment was considered more effective than the other provider types. Similar factors influencing late medical treatment, reported in the KAP study (chapter 1), which included difficulty with obtaining transport to health facilities, prolonged hospitalization, loss of work and wages, and disrupted education, resulting from seeking medial treatment, were confirmed in this chapter. Chapter 6 clarified the role of socio-cultural and health system features of timely treatment for BU. We first formulated a working definition of timely treatment. It was based on studies that estimated 3 months as the average time for the incubation of *M. ulcerans* (Merritt et al., 2010; Webb et al., 2009). This operational definition of timely treatment for BU within 3 months after first awareness of the onset of infection was the focus for our analysis. Delayed treatment was operationally defined as appropriate medical treatment 3 months or more after infection or failure to seek medical treatment.

Delayed treatment for BU was greatly influenced by socio-cultural factors such as the desire to continue working to secure fragile livelihoods. Access to health facilities, knowledge of the effectiveness of the recommended antibiotic treatment, which encouraged respondents to seek timely medical treatment on their own, indicated the positive impact of public health education programmes. Drinking unclean water was a perceived cause that encouraged timely treatment. It appears to be influenced by public health messages that mentioned water contact as a risk factor for BU infection.

8.4.2 Gendered-features of Buruli ulcer

Chapter 4 also highlighted the importance of BU illness on the gendered nature of care, especially for ulcers. Mothers, female spouses, sisters and daughters were more likely than their male counterparts to stay away from work and school to give care. Care-giving of mothers at the hospital also jeopardised the development and welfare of younger children. The welfare of families was compromised further when the main income earner was affected with BU. This situation influenced timely treatment, as the main income earner resorted to use of herbal treatment or other alternatives to continue work.

8.4.3 Health services for Buruli ulcer control

The health system has responsibilities for epidemiological information, delivering appropriate health education messages, improving access to treatment and improving disease outcomes for BU. Chapter 6 investigated the health system's response to BU control by assessing the achievements and challenges of the first phase of the BUPaT programme (2005-2008). The chapter also considered the impact of the programme on broader interests of the health system.

Collaboration and networking among all stakeholders at the national, municipal and community levels strengthened the health system. Capacities of health staff for providing antibiotic treatment and wound care were being strengthened. Teachers, municipal environmental health officers (MEHOs) and CBSVs were being trained to give the right health messages, to screen for early cases of BU and refer promptly for medical treatment. A patient data base had been introduced by the programme. WHO-recommended antibiotics had been introduced by the programme for the first time, and they improved treatment and cure, particularly for early lesions, and prevented recurrences. Nevertheless, there were problems of access to treatment, accommodation (lack of sufficient ward space), substantial use of herbal treatment, loss to follow-up and non-adherence to treatment. These challenges have been reported in earlier chapters. With reference to the building blocks of the health system (de Savigny et al., 2009), the BUPaT programme was mainly associated with governance, human resources, medicines and technology and health delivery. It has less impact on financing and information systems.

8.5 Study implications for Buruli ulcer management and control

Study findings presented in this thesis suggest that knowledge about BU has increased considerably in the study communities and among affected and non-affected persons since the inception of the BUPaT programme (chapter 7). Community-based surveillance has helped to improve detection and referral of cases, and WHO-recommended antibiotic treatment administered alone or in combination with surgery has improved treatment outcomes (chapters 4-7).

Nevertheless, findings of the thesis research highlighted issues related to the genuine difficulty in diagnosing early lesions. This finding also suggested an information gap about disease transmission indicated by the mismatch between professional health messages on risk factors and local ideas about BU transmission (chapter 5 and 6). Conferring with family and friends for advice indicated the role of support groups and other community members in information dissemination (chapter 4). A big challenge for health professionals is to consider innovative ways of incorporating traditional healers (THs) in the system for referral of all affected persons, to improve early treatment.

Strategies for the BUPaT phase 2 programme were based on lessons learnt from the BUPaT phase 1 documented in chapter 7. Additional implications not presented elsewhere in this thesis are relevant for other BU endemic areas in the country, and are summarised in the following paragraphs:

8.5.1 Health education as a powerful tool

Since the mode of transmission for BU is unknown, public health programmes need to promote research to clarify relevant features of transmission.

Problems with misdiagnosis and perceptions of low severity of early lesions have featured consistently in this thesis (Ackumey et al., 2011; Renzaho et al., 2007) and have been documented in other BU studies (Aujoulat et al., 2003; Mulder et al., 2008; Stienstra et al., 2002). WHO has produced various pictorial IEC materials, which describe the clinical presentation of BU, provide information on risk factors and advice on appropriate help-seeking. These materials are used extensively by health workers, teachers and CBSVs in health programmes and are posted prominently in clinics, classrooms and other community buildings (World Health Organisation, 2001; World Health Organization & Global Buruli Ulcer Initiative, 1998). Furthermore, a WHO educational comic book has been distributed to school children (World Health Organization & GBUI, 2001).

Findings (chapters 5, 6 and 7) suggested that awareness has increased considerably since 2005 (chapter 3). However, it was not clear if the informative poster entitled “Recognising Buruli ulcer in your community” has been disseminated to all households (World Health Organization & Global Buruli Ulcer Initiative, 1998). In endemic areas, it is important for every household to have a copy of this poster (figure 8.1) to clarify clinical presentations and prevent pervasive notions of witchcraft linked with slow healing of ulcers (chapter 4).

Figure 8.1: IEC poster – Recognising Buruli ulcer in your community

Source: http://www.who.int/buruli/information/iec/POSTER-EN.pdf

The electronic media, for disseminating information, is an important tool for interactive communication and education. About 89% of Ghanaians have access to radio and most regions and municipalities operate their private frequency modulation (FM) stations (The Intermediate Knowledge Center, 2010). Furthermore, all TV channels in Ghana and many of the radio stations have a health programme segment. The National Buruli Ulcer Control Programme (NBUCP) in collaboration with municipal health workers should use these resources to raise awareness of the clinical features of BU and medical treatment.

8.5.2 Inclusion of Buruli ulcer in medical school curricula

Ghana has made significant strides to control BU by establishing a NBUCP to reduce the national burden of BU through effective public health interventions. As already mentioned in chapter one, the NBUCP collaborates with certain medical institutions and laboratories to achieve this goal. However these institutions are woefully inadequate considering the magnitude of the national burden of BU. (World Health Organization, 2008). Buruli ulcer should be included in training programmes of all medical institutions in the country. This is likely to increase awareness about BU among health professionals from the outset, strengthen health systems' capacity to improve access and deliver effective services, and strengthen BU research and control initiatives in the country. Consequently, BU should be included in the curriculum of primary and secondary schools in the country.

8.5.3 Health system strengthening for BU control

Findings from chapter 7 show the importance of collaboration and networking among stakeholders to achieve the BUPaT goals of increased awareness and timely and appropriate help-seeking for BU. Building upon lessons from the BUPaT phase 1 programme, and considering the unresolved issues (chapter 7 and section 8.4 of this chapter), a stronger consensus of existing stakeholders is needed with new partners to strengthen and scale-up existing initiatives to improve access to BU treatment.

There are private health practitioners in our study municipalities. Although they have not been included in the health system, our findings show that their services are being used extensively by the local people, indicating their acceptance (chapters 5 and 6). It is important that they are trained to provide antibiotic treatment according to strict guidelines. They provide prospects of improving access to antibiotic treatment which should not be ignored

For consensus building, stakeholder forums should be convened quarterly to review programme strategies and to exchange and consolidate ideas. Bringing all stakeholders together allows faster planning, implementation and allocation of resources.

Studies have indicated that BU is often underreported because of difficulties with identifying early forms of infection, seasonal variations and poor access to endemic communities (Amofah et al., 2002; Webb et al., 2009). Statistics from the NBUCP, 2010, (unpublished report) showed cases from communities that were not endemic previously. This indicates a need to scale-up community based surveillance and to raise awareness about BU. More importantly, it underscores the need for a functioning health information system at the municipal level and an integrated health system at regional and national levels.

Among the 6 building blocks of the health system, it is often argued that the information sub-system is the most neglected. Information gaps and flows are the common cause of malfunctioning of the health system. (de Savigny et al., 2009). Field observations confirm the use of manual records and incomplete patients' records. However, use of personal digital assistants (PDAs) produces higher efficiency and accuracy of information. Furthermore, PDAs do not add to the burden of an already over-stretched health staff. Although some may argue that the initial costs of setting-up an integrated information system is high, it has been reported to be less cost-effective in the long term, after taking into consideration the savings on paper, computer ink for printing, hiring of data-entry clerks etc. (de Savigny et al., 2009; Seebregts et al., 2009)

Apart from efficient record management that provides up-to-date information on prevalence data, information systems are also useful for providing up-to-date information on other sub-systems. This enables the system to manage procurement and supply of antibiotics, on-going BU health programmes, staff shortages and needs, and to use global positioning systems (GPS) for mapping cases in endemic communities. GPS mapping is critical for effective planning, allocation of human and financial resources, and community programme interventions for BU control.

Additionally, the use of telecommunication and information technologies to improve access to health services, commonly referred to as telemedicine should be considered. The importance of telemedicine to improve access to medical services, and improve disease outcomes has been documented in a study in Ghana (Andreatta et al., 2011).

By using short message service (SMS) and imaging, traditional healers, teachers, community-based surveillance volunteers and other residents of the community could use cell phones to relay BU information to health professionals and receive prompt feed-back. This is likely to clear ambiguities about suspicious lesions, improve management of BU, and foster provider-patient interaction which is necessary to improve adherence to treatment regimens. Tele-medicine has been proven to improve supervision of health services from a distance, particularly in geographically dispersed communities such as our study areas, at a minimum cost.

8.5 Conclusions

Since the KAP study in 2005, Buruli ulcer awareness has increased. There is evidence of improved treatment outcomes with minimal recurrence if medical treatment is initiated early, when there is awareness of infection. However, findings indicate gaps in local knowledge of disease aetiology which raise doubts about public health messages and establish local notions of witchcraft as a possible cause of infection. Findings highlight the impact of impoverished environments, cultural concepts and notions, and health system factors that influence timely treatment and adherence to treatment regimes and suggests pragmatic public health approaches to address these issues. More importantly the study draws attention to the importance of health programme awareness and consideration of the socio-cultural features of BU illness, meaning, experience and behaviour, when designing programmes.

8.6 Areas for further research

Because the mode of transmission is unknown, future research should clarify possible host interactions with the environment. Ethnographic studies of human behaviour and BU transmission are also required. A range of credible explanations of transmission patterns will instil confidence in the health system, health professionals and health messages.

Recognising the impact of social change from urbanising and globalising technologies, more attention to social and cultural contexts of control in needed. Awareness of socio-cultural features of illness meaning, experiences and behaviour should be conducted regularly.

The influence of enacted stigma and social exclusion on timely treatment and treatment adherence requires attention. Clarifying the relationship between social stigma and personal share of deformities would contribute to other areas of public health that are concerned with the impact of stigma.

Adherence to antimicrobial treatment is important. Clarifying socio-cultural features of treatment adherence would contribute to control strategies and enhance treatment outcomes in Ghana.

The extensive use of herbalists, particularly as a first-help provider, delays medical treatment. Considering the research finding that herbalists are family members, explains their influence on affected persons. It also presents opportunities for their training and integration into the health system as advocates for timely medical treatment. This approach needs to be researched as findings would be of interest to other public health programmes in Ghana

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Curriculum vitae

Personal information

Full name	Mercy Mawufenya Ackumey
Contact address	Department of Social and Behavioural Science, School of Public Health, College of Health Sciences, University of Ghana, P. O. Box LG 13, Legon, Accra, Ghana .
E-mail	Mercy.Ackumey@unibas.ch, jekammy@yahoo.com
Nationality	Ghanaian
Date and place of birth	16th July, 1964, Dzodze, Volta region, Ghana.

Education

1985-1988	BA (Hons), Sociology with Psychology, University of Ghana, Legon
1991-1992	MA (Population Studies), University of Ghana, Legon.
2000-2001	MPH (Master of Public Health), University of Ghana, Legon
2008-2011	Swiss Tropical and Public Health Institute, University of Basel, Switzerland.

Work experience

1989-1991	Research assistant, Institute of African Studies, University of Ghana
1992-1995	Sociologist/Demographer, World Vision International, Ghana.
1998-2005	Monitoring and Evaluation Officer, Centre for Social Policy Studies, University of Ghana, Legon.
2002-2005	Part-time Lecturer, School of Public Health, University of Ghana, Legon.
2005-	Lecturer, Dept. of Social and Behavioural Science, School of Public Health, University of Ghana, Legon

Oral presentations

1999	‘The state of the Ghanaian social situation’. Paper presented at a seminar for Parliamentarians in Accra
May 21,1998	‘The transport burdens of rural women’. Paper presented at an international conference on long distance education and development, Accra.

July. 28,1999.	‘The role and importance of socio-cultural factors in the formulation of population policies and programmes’. Paper presented at the regional workshop on the socio-cultural Impact of demographic behaviour on population policies and programmes in Africa, Douala, Cameroon
November 26, 1999	‘Ageing in Ghana’ - Paper presented at a workshop on socio-economic implications of population ageing, Malta.
2000	‘Family Health: Findings from the 1998 Ghana Demographic and Health Survey (GDHS)’ Paper presented at a media sensitisation seminar organised by the Centre for Social Policy Studies, University of Ghana, Legon.
November 13, 2001	‘Migration and Child Welfare’ Paper presented at a conference on migration and livelihoods at the Institute of Statistical Social and Economic Research (ISSER), University of Ghana, Legon.
October 22, 2002	‘Local perceptions of Buruli Ulcer in the Ga district, Greater Accra region’. Paper presented at an in-house seminar at the Centre for Social Policy Studies (CSPS), University of Ghana, Legon.

Poster presentation

October 3-8, 2011	‘Help-seeking for pre-ulcer and ulcer conditions of *Mycobacterium ulcerans* disease (Buruli ulcer) in Ghana’. Poster presented at the 7th European Congress on Tropical Medicine and International Health, Barcelona, Spain.

National and international consultation

1990	Baseline study and report on water and sanitation in the Volta Region, Ghana. Prepared with consultants from the Royal Danish Embassy, Accra, Ghana
1998	Consultant to prepare a report on ‘Stakeholders interventions on the plight of Street Children’, for the World Bank, Ghana.
2001	Consultant for a study on the ‘Situation of street children in Madina, Accra’, commissioned by ActionAid, an NGO.
2001-2003	Consultant for a study on ‘Challenging global forces on a local level: An advocacy-centred study of the ways in which Ghanaian traders of global consumer items are constrained by the trade policies under which they operate’. Funded by the Third World Network (TWN) and Gender Reforms in Africa (GERA)
2001-2004	Facilitator for an HIV/AIDS workshop for out-of-school youth at Ashaiman, Accra,
2004	Consultant for the African Youth Alliance (AYA) in-School reproductive health programme, end-of-project survey, Ghana.
2005	Consultant for a baseline survey of the ‘stepping stones’ programme – an HIV/AIDS awareness programme for the Christian Council of Ghana.
2005	Consultant on an end-of-programme evaluation ‘strengthening the participation of religious groups in reproductive health, commissioned by UNFPA,
2005	Consultant for a baseline survey for a Buruli ulcer prevention and treatment programme, Ga-West District, commissioned by World Vision Ghana.
2007	End-of-programme evaluation – Buruli ulcer prevention and treatment programme, commissioned by World Vision Ghana.

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1. **Ackumey, M.M**. (2002). Local Perceptions of Buruli ulcer in the Ga District, Greater Accra Region**.** *Social Policy*, *2*(2), 44-57.

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6. Yirenya-Tawiah, D., Amoah, C., Apea-Kubi, K.A., Dade, M., **Ackumey, M**., Annang, T., Mensah, D.Y., & Bosompem, K.M. (2011). A survey of female genital schistosomiasis of the lower reproductive tract in the Volta basin of Ghana**.** *Ghana.Med J.*, *45*(1), 16-21.

7. **Ackumey, M.M**., Gyapong, M., Pappoe, M., Kwakye-Maclean, C., & Weiss, M.G. (2012). Socio-cultural determinants of timely and delayed treatment of Buruli ulcer: Implications for disease control**.** *Infectious Diseases of Poverty*, *1*(6).

8. **Ackumey, M.M**., Gyapong, M., Pappoe, M., Kwakye-Maclean, C., & Weiss, M.G. (2012). Illness meanings and experiences for pre-ulcer and ulcer conditions of Buruli ulcer in the Ga-West and Ga-South Municipalities of Ghana. *BMC.Public Health*, *12*(1), 264.

Appendix A – The Explanatory Model Interview Catalogues

Buruli Ulcer: Socio-cultural Priorities for Treatment and Control in Ghana

Semi-Structured Interview Schedule for Affected Adults in the Community

Respondent No/Interview no: **MUIN-PtA ___ ___ ___**

Region:

District:

Sub – district:

Community:

Illness status:

Nodule	
Plaque	
Amputee	

Oedema	
Ulcer	

Date of interview: dd\mm\yy

Time Start: ……………………………………………………

INTRODUCTION

Greetings in local language). My name is……………… and I am conducting a study on behalf of the District Health Management Team and the University of Ghana. We would like to understand a health problem affecting people in this district so that we may be more helpful. We are interviewing everyone in the community who has the problem to learn more about how it affects people who have it. Thank you for agreeing to talk to me. Please bear in mind that it is your experiences of the problem I am interested in, not what you think, or what doctors or other professionals might say. I will therefore appreciate your candid responses to the questions I will ask.

1 IDENTIFICATION OF THE CONDITION

1.1 "What is the name of your condition? What do you call it? (What name would you use to describe it to someone else?) Tick ✓ *the appropriate cells based on respondent's account*

(Tick all that apply)

No.	**Name**	**Tick**
1	Odontihela	
2	Helagbonyo	
3	Aboagbonyo	

No.	**Name**	**Tick**
4	Detsifudolele	
5	Detsifufofoe	
6	Dovor	

No.	**Name**	**Tick**
7	Kukruam	
8	Other (specify)	

1.2 "How long ago did you first notice your ***current*** condition?" *(Against the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	Can't remember

1.3 **Respondent's with Ulcers: Pre-ulcer condition**
"What was your condition before it became a sore?"
(Code the appropriate name and category: whether nodule, plaque or oedema)
(Fill one box only)

No.	**Condition**	**Tick**
1	Nodule (boil)	
2	Plaque (firmness)	
3	Oedema (swelling)	
4.	Healed but scarred	
5.	Reoccurrence	
98	Other specify	

1.4 "When did you first notice the pre-ulcer ***(name)*** condition? How long ago was it" *(Against the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	Can't remember

PATTERNS OF DISTRESS
Current condition

2.1 "How does your **current condition** affect you? *Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick.'✓' Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.*

No	Patterns of Distress	Spon	Probe
Physical conditions			
1.	Fever		
2.	Pain in the affected part		
3.	Stench (smell) from affected part		
4.	Weight loss		
5.	Loss of appetite		
6.	Weakness		
7.	Problems with mobility and use of affected limb		
8.	Condition is ugly		
Social problems			
9	Rejection/isolation from family		
10	Rejection by friends/ peers		

No	Patterns of Distress	Spon	Probe
11.	Disrupted education		
12.	Loss of income		
Psychological – Emotional			
13	Anxiety regarding course of illness		
14.	Fear of surgery		
15.	Embarrassment as a result of condition		
16	Unable to marry		
17	Separation /divorce		
Miscellaneous			
98	Other, specify		▨
			▨
99	Cannot say/ uncertain		▨

(Narrative) ....

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Most troubling symptom of current condition

Code most troubling symptom of condition from the above list of patterns of distress in the box below:

2.2 "Which among these problems that you have just mentioned would you consider the most important cause of anxiety or worry for you?"

☐

"Why do you consider this as the most troubling feature?" *(Narrative)*

....

....

………

Seriousness of current condition and effect on others

2.3 "How serious do you think your ***current condition*** is?"

(Tick one box only)

Usually fatal 4	Sometimes fatal 3	Serious but not fatal 2	Cannot say 1	Not serious 0

(Narrative) ………

………

………

………

2.4 "Do you think that you might infect other members of your family with this current condition?"

(Tick one box only)

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ………

………

………

………

2.5 "From your observation, how has your condition affected members of your family? Does the condition create any particular problem for them?" *(Probe for impact of condition on social life, family life, economic well-being, general welfare etc.,)*

(Narrative) ………

………

………

………

………

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

No.	**Effect on Family**	**Spon.**	**Probe**
1.	Loss of income		
2.	Sadness, anxiety or worry		
3.	Concern about course of illness (future situation/ progression of illness)		
4.	Miss work for care-taking		

No.	**Effect on Family**	**Spon.**	**Probe**
5.	None		
98.	Other (specify)		▨
			▨
99	Cannot say/ uncertain		▨

Absence from work:

If 'Miss work for care-taking' (option 4)is reported, ***from table 2.5*** *inquire further:*

2.6 "Who is that person most likely to be?" (*Code the single most likely person)* ***(Tick one box only)***

Mother 1	Father 2	Daughter 3	Son 4	Brother 5	Sister 6	Spouse 7	Other blood relation 8	Other (specify) 98	Cannot say 99

(Narrative) ....

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2.7 "How long did you stay away from ***school/work*** since this condition began?" (A*gainst the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	N/A

3.0 PERCEIVED CAUSES

Open-Ended Query

3.1 "People explain their problems in many different ways, I would like to know what you think may be the cause(s) of your **current condition?"**(*Remember it is your personal observation of the condition that I am interested in). (Summarise respondent's ideas about cause in his/her own words)*

(Narrative) ....

....

....

………

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

No.	**Perceived cause**	**Spon**	**Probe**
Ingestion			
1.	Drinking bad water from ponds, rivers and dams		
Illness/ injury			
2.	Prone to illness		
3.	Insect bite (s)		
4.	Scratches on skin		
5.	Strength of blood		
Environmental			
6.	Poor sanitation/dirty environment		
7.	Poor personal hygiene		
8.	Exposure to sand (playing/working)		

No.	**Perceived cause**	**Spon**	**Probe**
Behaviour			
9.	Swimming in ponds/rivers/ lakes		
10.	Domestic water work (washing, cooking etc.,)		
11.	Contact with animals (cattle, dogs, goats etc.,)		
Climate			
12.	Rains		
Spiritual			
13.	Witchcraft		
Miscellaneous			
98.	Other (specify)		▨
			▨
99.	Cannot say / uncertain		▨

Most important perceived cause

Code 'most important cause' in the box below giving the number from the above table.

3.2 Among all that you have mentioned (or something else), which do you think is the most important cause of your current condition?

☐

(Narrative) ....

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4. HELP-SEEKING

Home-based care for PRE-ULCER (Nodule, plaque or oedema)

4.1 "What did you or family do for your pre-ulcer condition ***at home***?"

(Narrative) ....

....

....

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. Probe for the level of effectiveness and mark appropriately.

Tick as many as apply

NO.	**Home-based care**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Drank herbal concoctions at home					
2	Placed herbal dressing on pre-ulcer					
3	Placed herbal dressing on ulcer	▨	▨	▨	▨	▨
4	Pills and other drugs available at home					
5	Offer prayers at home					
6.	Nothing					
98	Other (specify)		▨			
			▨			
99	Uncertain/ Can't say		▨			

4.2 “How soon after the awareness of the pre-ulcer condition did you or family do anything at home?”*(Against the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	N/A

Outside – care for pre-ulcer condition

4.3 “Where did you go for help outside the home for your pre-ulcer condition [**NAME**]? Tell me about all the different providers you may have seen?”

Tick ’✓’the appropriate cells based on respondent's account. Mark all boxes that apply with a tick ’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. Probe for the level of effectiveness and mark appropriately.

Tick as many as apply

NO.	**Outside- help**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Herbalist (NM)					
2	Fetish/Spiritualist (NM)					
3	Prayer camp (NM)					
4	Health worker (minimal training) (NM)					
5	Private practitioner (trained) (M)					
6.	Health Centre (Obom/Amasaman) (M)					
7.	Gov't Hospital outside the district (M)					
8.	Nothing					
98	Other (specify)		▨			
			▨			
99	Uncertain/ Can't say		▨			

(Narrative) ....

....

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....

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Most helpful outside-help

4.4 "Of all these places/providers that you have just mentioned, which of these was most helpful?"

Code most helpful outside-help from the above list in the box

Only one answer ☐

First – help Seeking (FHS)

Inquire about first-help excluding home-based care.

4.5 "Which of these places/providers did you visit/use first?"

(With reference to the table in ***Q4.3****, write the corresponding code in answer to the question in the box)*

Only one answer ☐

4.6 "Was the treatment medical or non medical?"

Using the codes in brackets from table 4.3 as a guide (NM representing 'non-medical' and M representing 'medical') indicate the appropriate response.

Medical (M) 1	Non-medical (NM) 2

(Continue if ***FHS*** *is non-medical, otherwise skip to* ***Q 4.8****)*

4.7 **Still on place/provider for FHS** "Did this provider, suggest, discourage or not mention the need for medical help at a clinic?" **(*Fill one box only)***

Referral 1	No referral 2	Discouraged medical treatment 3	Cannot say 4

(Narrative) ....

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4.8 "When you first noticed the nodule, plaque or oedema, how long after was it that you first went to this first outside source of help?" *(Against the appropriate box, write the corresponding figure)*

(Fill only one box only)

Day (s)	Week (s)	Month (s)	Year (s)

4.9 "What were the reason(s) that led you to decide to get help from this place you went to first, for your ***pre-ulcer*** condition, rather than some other place?"

(Narrative) ....

....

....

....

Tick '✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

Tick as many as apply

NO	Reasons	Spon	Probe
1.	Treatment offered is very effective		
2.	Closeness to home/residence, convenient		
3.	Affordable		
4.	Self referral		
5.	Referral by family/ friends		
6.	Referral by health worker (professional)		
7.	Referral by CBSV		

NO	Reasons	Spon	Probe
8.	Education through IEC activities		
9.	Medical treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

Medical Care for pre-ulcer condition

4.10 "When you first noticed the nodule, plaque or oedema, how long after that was it that you sought medical care for your ***pre-ulcer*** condition?" (*Against the appropriate box, write the corresponding figure)*

(Fill one box only)

Day (s)	Week (s)	Month (s)	Year (s)	N/A

(Narrative) ....

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....

If ‘N/A’ to Q 4.10 then skip to Q 4.22 otherwise continue with following questions

4.11 “What was/were the main reason(s) that led you to seek medical care for your ***pre-ulcer*** condition?”

(Narrative) ....

....

....

....

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***Tick as many as apply***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

4.12 “Was there any reason you decided to get medical help, for your ***pre-ulcer*** condition, when you did rather than earlier or later?”

(Narrative) ....

....

....

....

Tick ’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick ’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***Tick as many as apply***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

Most important reason for medical-help seeking for pre-ulcer condition

NO.	**Medical Treatment**	**Spon.**	**Probe**	**Effectiveness**		
				Effective **3**	**Uncertain/ Mixed** **2**	**Ineffective** **1**
1	Pills					
2	Injection					
3	Wound dressing	■	■	■	■	■
4	Operation (surgery)					
5.	Nothing					
98	Other (specify)		■			
			■			
99	Uncertain/ Can't say		■			

4.13 "Of all these reason (s) that you have just mentioned, which of these is the most important reason for medical-help seeking for your ***pre-ulcer*** condition?"

Code most important reason from the above list in the box ☐

4.14 "Did the nurse or other health staff usually talk to you nicely? Did he/she care/ treat you nicely?
(Against the appropriate box, write the corresponding figure)

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0

(Narrative) ....

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....

4.15 "What medical treatment was given for your ***pre-ulcer*** condition? How effective was it?"
Tick '✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe to explore levels of effectiveness of medical treatment as indicated by respondent and indicate responses accordingly. ***Tick as many as apply***

(Narrative) ....

....

....

....

4.16 “Did the medicines/pills cause any problems or side effects?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

....

....

....

....

4.17 “Did the injections cause any problems or side effects?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

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....

....

4.18 “Do you think the surgery was more of a problem than a help?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

....

....

....

4.19 “Have you missed any doses of pills or shots of injection?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0

(Narrative) ....

....

....

....

4.20 "If yes or possibly, what is the frequency?" ***(Tick one box only)***

1-2 times	3-5 times	More than 5 times

4.21 "If yes or possibly to **Q 4.19**, what difficulties did you encounter that made you skip medication for the ***pre-ulcer*** condition?"

Tick' ✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick' ✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

(Mark all that apply)

NO	Reasons for non-compliance	Spon	Probe
1.	Health centre is far away		
2.	High transportation cost		
3.	Difficulty in obtaining transport		
5.	Long waiting time at health centre		
6.	Fear of injections		

NO	Reasons for non-compliance	Spon	Probe
7.	Medical treatment heals condition slowly		
8.	BU is caused by witchcraft, medical treatment is not the solution		
9.	Advised against medicines by family and friends		
10	Advised against medicines by traditional healer		
98	Other (specify)		▨
			▨
99	Cannot say/ uncertain		▨

(Narrative) ....

....

....

....

....

NO.	**Home-based care**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Drank herbal concoctions at home					
2	Placed herbal dressing on pre-ulcer					
3	Placed herbal dressing on ulcer					
4	Pills and other drugs available at home					
5	Offer prayers at home					
6.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

Home-based care for ULCER

Continue with persons with ulcers, if respondent ***does not have an ulcer, then*** skip to **Q 4.38**

4.22 "What did you or family do for your **ulcer** condition at home?"

(Narrative) ....

....

....

....

....

*Tick'✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe to explore levels of effectiveness of medical treatment as indicated by respondent and indicate responses accordingly. (**Mark all that apply)***

4.23 "How soon after the awareness of your ***ulcer condition*** did you or family do anything at home?"

(Tick one box only)

Day (s)	Week (s)	Month (s)	Year (s)	N/A

Outside – care for ulcer condition

4.24 "Where did you go for help outside the home for your ***ulcer*** condition? Tell me about all the different providers you may have seen?"

Tick'✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe for levels of effectiveness and tick k'✓' accordingly.

(Mark all that apply)

NO.	**Outside- help**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Herbalist (NM)					
2	Fetish/Spiritualist (NM)					
3	Prayer camp (NM)					
4	Health worker (minimal training) (NM)					
5	Private practitioner (trained) (M)					
6.	Health Centre (Obom/Amasaman) (M)					
7.	Gov't Hospital outside the district (M)					
8.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

(Narrative) ....

....

....

....

....

Most helpful outside-help

4.25 "Of all these places/providers that you have just mentioned, which of these was most helpful for your ***ulcer*** condition?"

Code most troubling symptom of condition from the above list in the box

☐

First – help Seeking (FHS)

(Inquire about first-help excluding home-based care.

4.26 "Which of these places/providers did you visit/use first?"

*(With reference to the table in **Q4.24**, write the corresponding code in answer to the question in the box)*

Only one answer ☐

4.27 "Was the treatment medical or non medical?"
Using the codes in brackets from table 4.3 as a guide (NM representing 'non-medical' and M representing 'medical')indicate the appropriate response).

Medical (M) 1	Non-medical (NM) 2

*(If response to **Q4.27** is 'medical' skip to **Q 4.31** otherwise continue with **Q4.28)***

4.28 **Still on place/provider for FHS** "Did this provider, suggest, discourage or not mention the need for medical help at a health centre?" ***(Tick one box only)***

Referral 1	No referral 2	Discouraged medical treatment 3	Cannot say 4

(Narrative) ....

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4.29 "When you first noticed your ***ulcer*** how long after was it that you first went to this first outside source of help?" ***Tick one box only***

Day (s)	Week (s)	Month (s)	Year (s)

4.30 "What were the reason(s) that led you to decide to get help from this place you went to first, rather than some other place?"

(Narrative) ....

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Tick' ✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick' ✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

(Mark all that apply)

NO	Reasons	Spon	Probe
1.	Treatment offered is very effective		
2.	Closeness to home/residence, convenient		
3.	Affordable		
4.	Self referral		
5.	Referral by family/ friends		
6.	Referral by health worker (professional)		
7.	Referral by CBSV		

NO	Reasons	Spon	Probe
8.	Education through IEC activities		
9.	Medical treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		▩
			▩
99	Cannot say/ uncertain		▩

Medical Care

4.31 "When you first noticed your ***ulcer*** how long after that was it that you sought medical care?"

(Fill one box only)

Day (s)	Week (s)	Month (s)	Year (s)

(Narrative) ....

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4.32 "What was/were the main reason(s) that led you to seek medical care for the ***ulcer***?"

(Narrative) ....

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Tick’✓’ the appropriate cells based on respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***(Mark all that apply)***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		
99	Cannot say/ uncertain		

4.33 “Was there any reason you decided to get medical help for your ***ulcer*** when you did, rather than earlier or later?”

(Narrative) ....

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Tick’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***(Mark all that apply)***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		
99	Cannot say/ uncertain		

Most important reason for medical-help seeking

4.34 “Of all these reason (s) that you have just mentioned, which of these is the most important?”

Code most important reason from the above list in the box

☐

4.35 “Did the nurse or other health staff usually talk nicely to you? Did he/she care treat you nicely? Was he/she caring? ***(Tick one box only)***

Yes	Possibly	Uncertain	No
3	2	1	0

(Narrative) ....

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4.36 "What medical treatment was given for the ***ulcer*** condition? How effective was it?"
Tick '✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. ***(Mark all that apply)***

NO.	**Medical Treatment**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Pills					
2	Injection					
3	Wound dressing					
4	Operation (surgery)					
5.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

(Narrative) ....

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....

4.37 "Did the medicines/pills cause any problems or side effects?"
(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

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4.38 "Did the injections cause any problems or side effects?" ***(Tick one box only)***

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative)..

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4.39 "Do you think the surgery was more of a problem than a help?" ***(Tick one box only)***

Yes	Possibly	Uncertain	No	N/A
3	2	1	0	

(Narrative) ....

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4.40 "Have you missed any doses of pills or shots of injection?" ***(Tick one box only)***

Yes	Possibly	Uncertain	No
3	2	1	0

4.41 "If yes or possibly, what is the frequency?" ***(Tick one box only)***

-2 times	3-5 times	More than 5 times

4.42 "If yes or possibly to **Q 4.40**, what difficulties did you encounter that made you skip medication for the condition?"

Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. ***(Mark all that apply)***

NO	**Reasons for non-compliance**	**Spon**	**Probe**
1.	Health centre is far away		
2.	High transportation cost		
3.	Difficulty in obtaining transport		
5.	Long waiting time at health centre		
6.	Fear of injections		

NO	**Reasons for non-compliance**	**Spon**	**Probe**
7.	Medical treatment heals condition slowly		
8.	BU is caused by witchcraft, medical treatment is not the solution		
9.	Advised against medicines by family and friends		
10	Advised against medicines by traditional healer		
98	Other (specify)		
99	Cannot say/ uncertain		

(Narrative) ....

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5 METHODS OF PREVENTION

5.1 Is there anything that could have been done to prevent this current condition?”

(Narrative) ……………….……………………………………………………………………………………

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Tick’✓’ the appropriate cells based on respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response.

NO.	**Prevention and control**	**Spon.**	**Prob**
1.	Personal hygiene		
2	Maintaining a clean environment		
3	Drinking clean water		
4.	Avoid swimming/bathing in rivers and ponds		

NO.	**Prevention and control**	**Spon.**	**Prob**
5.	Avoid cuts and bruises		
6	Avoid body contact with infected person		
7	Cannot be prevented		
98	Other (specify)		▨
99	Can’t tell/ Don’t know		▨

6. SOURCES OF INFORMATION

“Where did you learn what you know about your condition?“ *Tick’✓’ the appropriate cells based on respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response.*

NO.	**Source of information**	**Spon.**	**Prob**
1.	Health talks at school		
2.	Community health education programmes		
3.	Posters		
4.	Friends/colleagues		

N	**Source of information**	**Spon.**	**Prob**
5	Family		
98	Other (specify)		▨
99	Can't tell/ Don't know		▨

(Narrative) ....

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7. STIGMA

Self-directed (PRE-ULCER CONDITION)

7.1 "Have you thought less of yourself because of the ***(pre-ulcer)*** condition?"*(less self esteem/pride)?*

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.2 "Have you found it difficult to mingle with friends because you did not want them to find out about this ***pre-ulcer*** condition?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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....

7.3 "Have you found it difficult to attend public functions, board public transport or be seen in public with this ***pre-ulcer*** condition?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.4 “Has anyone in the family or at home spoken unkindly or teased you about the ***pre-ulcer*** condition?”

Tick one box only

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

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....

7.5a “Have any friends or neighbours who knew about your ***pre-ulcer*** condition lost respect for your family because of that?”**(Enacted)** ***Tick one box only***

Yes	Possibly	Cannot say	No	N/A
3	2	1	0	

(Narrative) ....

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7.5b “If any (more) neighbours or friends were to find out about your ***(pre-ulcer)*** condition, will they lose respect for your family?” **(Anticipated)** ***Tick one box only***

Yes	Possibly	Cannot say	No	N/A
3	2	1	0	

(Narrative) ....

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7.6 “Have you tried to conceal the ***pre-ulcer*** condition so that friends and neighbours will not find out?”

Tick one box only

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

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Influence of stigma on help-seeking

7.7 "Did you delay outside help-seeking for your ***pre-ulcer condition*** so that neighbours and others wouldn't find out?" ***Tick one box only***

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

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FOR QUESTIONS IN THIS SECTION, ASK RESPONDENT'S WITH ULCERS ONLY: (CURRENT CONDITION)

Family directed stigma at affected persons

7.8 "After you developed the sore did your family try to avoid being seen with you?"

Tick one box only

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

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7.9 " Has anyone in the family or at home ever spoken unkindly or teased you about the ***ulcer?***

Tick one box only

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

....

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Community directed stigma

7.10 "Do most, some or any of your friends know about the ***ulcer***?" ***Tick one box only***

Yes , most	Yes, some	Yes, few	None
3	2	1	0

(Narrative) ....

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....

7.11 “If your friends found out about the ***ulcer***, do you think they would continue to remain friendly and support you?”

Tick one box only

Yes 0	Possibly 1	Cannot say 2	No 3

(Narrative) ....

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7.12 “If your friends who don’t know about the condition were to find out, do you think they would continue to remain friendly and offer support”?

Tick one box only

Yes 0	Possibly 1	Cannot say 2	No 3

(Narrative) ....

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7.13 “If your friends knew about the ulcer condition, would they avoid you”?

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.14 “If any of your friends who don’t know about the ulcer condition were to find out, would they avoid you”?

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.15 "If any of your friends knew about the ulcer would they speak to or tease you unkindly?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.16 "If any of your friends who don't know about the ulcer condition were to find out would they speak to or tease you unkindly?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.17 "If others in the community have found out, or if they do find out about your condition will it be difficult for any of your relatives to marry?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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Stigma after cure

7.18 "Even after the ulcer is successfully treated and it heals, will you still face the possibility of separation or divorce as a result of the scar or because you had this condition?"

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.19 “After treatment and healing, would you consider avoiding school because (classmates or teachers) know/ knew you had this condition?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0	N/A

(Narrative) ....

....

....

....

7.20 “Do you think school authorities might try to keep you from school because they know/knew you had this condition?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

....

....

....

7.21 “After treatment and healing, would you avoid work because people (at the work place) know/knew you had this condition?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0	N/A

(Narrative) ....

....

....

....

7.22 “Do you think people at your work place might try to prevent you from continuing work because they know/knew you had this condition?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0	N/A

(Narrative) ....

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7.23 “**After you are healed,** are any of your friends likely to speak or tease you unkindly because of the scar or having had the condition?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.24 “Would it be more difficult for you to hold a social or political office, if you wanted to, because of the scar or having had the condition? “

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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8. SOCIO-DEMOGRAPHIC CHARACTERISTICS

8.1 **Sex**:

Male 1	Female 2

8.2Age: ☐ *Write age in completed years)*

8.3 **Name of Adult respondent**

First name	*Second (family) name*

8.4 **Name of parent/caretaker acting as proxy respondent**

First name	*Second (family) name*

(*Tick the corresponding number)*

No.	Religion (8.5)
1.	Christianity
2.	Islam
3.	Traditional Religion
4.	None
98.	Other (specify)

No.	Ethnicity (8.6)
1	Ga
2	Adangbe
3	Ewe
4	Akan
5	Northern ethnicity
6	Foreigner
98.	Other (specify)

No.	Marital Status (8.7)
1	Never married
2	Married
3	Separated/Divorced
4	Widowed
5	Remarried
98.	Other (Specify)

(*Tick the corresponding number)*

No.	Highest level of Education attained (8.8)
1	Primary
2	JSS
3	SSS
4.	Vocational
4.	Tertiary
5.	No education
98.	Other (specify)

No.	Relationship of Respondent to Head of Household (8.9) (i.e. What is the respondent to the head of household)
1.	Head of household
2.	Spouse
3.	Father
4.	Mother
5.	Sibling
6	Child
7.	Other relation (Cousin /Uncle /Aunt /Grandmother/ Grand father etc)
8	Non relation
98.	Other (specify)

(*Tick the corresponding number)*

No.	**Occupation (8.10)**
1	Pupil/student
2	Unskilled labour (Farmer/ fisherman/ woman/ fish mongerer/ private phone operator/ sand winning/ trader
3	Labourer skilled (seamstress/ tailor/ mechanic/ hairdresser/ cobbler/carpenter

4	Apprentice
5	Unemployed
98.	Other specify

8.11 Is your household income usually regular and dependable? *(Tick one box only)*

Yes	Possibly	Uncertain/ Don't Know	No
3	2	1	0

Concluding remarks **(Is there anything else you want to tell me about Buruli ulcer infection? Do you have any piece of advice or suggestions?**

....

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"Thank you very much for your patience and your candid responses. I appreciate all the time you have spent answering all these questions. We are hopeful that all that we have learnt from you will be useful in the management and control of *Mycobacterium Ulcerans* infection. Once again I say THANK YOU".

Interviewer's (Name) : ☐

Time of interview END: ....

Swiss Tropical Institute
Institut Tropical Suisse
Schweizerisches Tropeninstitut

INFORMED CONSENT FORM FOR AFFECTED ADULTS

Introduction

I am a student at the University of Basel/ I am an Environmental Health Officer (field assistant in this study) in the district. We are conducting a study on Buruli Ulcer, a disease which has affected so many people in this district and caused a lot of suffering and pain. We are particularly interested in views on the cause, impact on affected persons and family, health-seeking behaviour, medical treatment and access to medical treatment. Findings from this study will be helpful in understanding the socio-cultural impact of the disease on affected persons as well as in designing interventions for improved treatment.

Your participation in this study is entirely voluntary. It is your choice to participate or not and we will respect your decision; you will not be coerced to participate. If you decide to discontinue with the interview after it has began, you are at liberty to do so. We want to assure you that your responses will be kept confidential. That is, there will be no direct reference by name to any interview. However since study findings will be used to inform future interventions, findings of this study will be made public to researchers and health staff at the district and national levels and will be published in international journals for others to learn from. We solicit your permission in this regard.

Statement by participant

The content and purpose of the study has been read to me and I have been assured of confidentiality of responses. I have had the opportunity to ask questions. I agree to participate voluntarily in this study and give my consent to the publication of findings.

Thumb print of participant

Date: ________________________

Day/month/year

Statement by the researcher/person taking consent

I confirm that the affected person was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Name of Researcher/Field Assistant

Signature: ________________________ ***Date:*** ________________________

Day/month/year

Buruli Ulcer: Socio-cultural Priorities for Treatment and Control in Ghana

Semi-Structured Interview Schedule for Caretakers of Child Patients

Respondent No/Int314erview no: **MUIPtC ___ ___ ___**

Region:

District:

Sub – district:

Community:

Clinic:

Illness status:

Nodule	
Plaque	

Oedema	
Ulcer	
Amputee	

Date of interview: dd\mm\yy

Time Start: ………………………………………………………

INTRODUCTION

Greetings (in local language). My name is………………. and I am conducting a study on behalf of the District Health Management Team and the University of Ghana. We would like to understand a health problem affecting people in this district so that we may be more helpful. We are interviewing all patients at the health centre who have a condition like yours to learn more about how it affects people who have it. However, we reckon that child patients may have some difficulty recounting all their experiences of the problem. We have therefore decided to interview either parents or care-takers instead. Thank you for agreeing to talk to me. Please bear in mind that it is your child's/ward's experiences of the problem I am interested in, not what you think, or what doctors or other professionals might say. I will therefore appreciate your candid responses to my questions.

1 IDENTIFICATION OF THE CONDITION

1.1 "What is the name of your child's/ward's condition that brings you to the clinic? What do you call it? (What name would you use to describe it to someone else?)" *Tick✓ the appropriate cell(s) based on respondent's account. Tick all that apply.*

No.	**Name**	**Tick**
1	Odontihela	
2	Helagbonyo	
3	Aboagbonyo	

No.	**Name**	**Tick**
4	Detsifudolele	
5	Detsifufofoe	
6	Dovor	

No.	**Name**	**Tick**
7	Kukruam	
8	Other (specify)	

1.2 "How long ago did you first notice your child's/ward's ***current*** condition?" *(Against the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	Cannot remember

1.3 **Ulcer patients only: Pre-ulcer condition**

"What was your child's/ward's condition before it became a sore?" *Tick✓ the appropriate cell(s) based on respondent's account. Tick all that apply.*

No.	**Condition**	**Tick**
1	Nodule (boil)	
2	Plaque (firmness)	
3	Oedema (swelling)	
4.	Healed but scarred	
5.	Reoccurrence	
98	Other specify	

1.5 "When did you first notice your child's/ward's pre-ulcer ***(name)*** condition? How long ago was it" *(Against the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	Cannot remember

2. PATTERNS OF DISTRESS

Current condition

2.1 "How does your child's/ward's current condition affect him/her?" *Tick✓ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick ✓. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.*

No.	Patterns of distress	Spon	Probe
Physical conditions			
1.	Fever		
2.	Pain in affected part		
3.	Stench (smell) from affected part		
4.	Weight loss		
5.	Loss of appetite		
6.	Weakness		
7.	Problems with mobility and use of affected limb		
8.	Condition is ugly		
Social problems			
9.	Rejection/ isolation from family		

No.	Patterns of distress	Spon	Probe
10.	Rejection by friends / peers		
11.	Disrupted education		
12.	Loss of income	▨	▨
Psychological-Emotional			
13.	Anxiety regarding course of illness		
14.	Fear of surgery		
15.	Embarrassment as a result of condition		
16.	Unable to marry	▨	▨
17.	Separation/ divorce	▨	▨
Miscellaneous			
98.	Other, specify		▨
			▨
99.	Cannot say/ uncertain		▨

(Narrative) ....

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....

Most troubling symptom of current condition

Code most troubling symptom of condition from the above list of patterns of distress in the box below:

2.2 "Which among these problems that you have just mentioned would you consider the most important cause of anxiety or worry for your child/ward?"

☐

"Why do you consider this as the most troubling feature?" *(Narrative)* ....

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....

....

Seriousness of current condition and effect on others

2.3 “How serious do you think your child’s/ward’s current condition is?”

(Tick one box only)

Usually fatal	Sometimes fatal	Serious but not fatal	Cannot say	Not serious
4	3	2	1	0

(Narrative) ....

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....

2.4 “Do you think that your child/ward might infect other members of your family with this current condition?”

(Tick one box only)

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative) ....

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....

....

2.5 “From your observation, how has your child’s/ward’s condition affected members of your family? Does the condition create any particular problem for them?” *(Probe for impact of condition on social life, family life, economic well-being, general welfare etc.,)*

(Narrative) ....

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....

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response.

No.	**Effect on Family**	**Spon.**	**Probe**
1.	Loss of income		
2.	Sadness, anxiety or worry		
3.	Concern about course of illness (future situation/ progression of illness)		
4.	Miss work for care-taking		

No.	**Effect on Family**	**Spon.**	**Probe**
5.	None		
98.	Other (specify)		
99	Cannot say/ uncertain		

Absence from work:
If 'Miss work for care-taking' (option 4)is reported, ***from table 2.5*** *inquire further:*
2.6 "Who is that person most likely to be?" (*Code the single most likely person)* ***(Tick one box only)***

Mother	Father	Daughter	Son	Brother	Sister	Spouse	Other blood relation	Other (specify)	Cannot say
1	2	3	4	5	6	7	8	98	99

(Narrative) ....

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....

....

2.7 "How long did your child/ward stay away from school since this condition began?" (A*gainst the appropriate box, write the corresponding figure)* ***(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	N/A

3.0 PERCEIVED CAUSES
Open-Ended Query

3.1 "People explain their problems in many different ways, I would like to know what you think may be the cause(s) of your child's/ward's current condition?"(*Remember it is your personal observation of your child's/ward's condition that I am interested in). (Summarise parent's/caretaker's ideas about cause in his/her own words)*

(Narrative) ....

....

....

……

Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

No.	Perceived cause	Spon	Probe
Ingestion			
1.	Drinking bad water from ponds, rivers and dams		
Illness/ injury			
2.	Prone to illness		
3.	Insect bite (s)		
4.	Scratches on skin		
5.	Strength of blood		
Environmental			
6.	Poor sanitation/dirty environment		
7.	Poor personal hygiene		
8.	Exposure to sand (playing/working)		

No.	Perceived cause	Spon	Probe
Behaviour			
9.	Swimming in ponds/rivers/ lakes		
10.	Domestic water work (washing, cooking etc.,)		
11.	Contact with animals (cattle, dogs, goats etc.,)		
Climate			
12.	Rains		
Spiritual			
13.	Witchcraft		
Miscellaneous			
98.	Other (specify)		
99.	Cannot say / uncertain		

Most important perceived cause

Code 'most important cause' in the box below giving the number from the above table.

3.2 Among all that you have mentioned (or something else), which do you think is the most important cause of your child's/ward's current condition? ☐

(Narrative) ....

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4. HELP-SEEKING

Home-based care for PRE-ULCER (Nodule, plaque or oedema)

4.1 "What did you or family do for your child's/ward's pre-ulcer condition ***at home***?"

(Narrative) ....

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Tick the appropriate cells based on respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. Probe for the level of effectiveness and mark appropriately.

Tick as many as apply

NO.	**Home-based care**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Drank herbal concoctions at home					
2	Placed herbal dressing on pre-ulcer					
3	Placed herbal dressing on ulcer	▨	▨	▨	▨	▨
4	Pills and other drugs available at home					
5	Offer prayers at home					
6.	Nothing					
98	Other (specify)		▨			
			▨			
99	Uncertain/ Can't say		▨			

4.2 “How soon after the awareness of the pre-ulcer condition did you or family do anything for your child/ward at home?”*(Against the appropriate box, write the corresponding figure)****(Fill one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	N/A

Outside – care for pre-ulcer condition

4.3 “Where did you go for help outside the home for your child’s/ward’s pre-ulcer condition [**NAME**]? Tell me about all the different providers your child/ward may have seen?”

Tick ’✓’the appropriate cells based on respondent's account. Mark all boxes that apply with a tick ’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. Probe for the level of effectiveness and mark appropriately.

Tick as many as apply

NO.	**Outside- help**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain / Mixed 2**	**Ineffective 1**
1	Herbalist (NM)					
2	Fetish/Spiritualist (NM)					
3	Prayer camp (NM)					
4	Health worker (minimal training) (NM)					
5	Private practitioner (trained) (M)					
6.	Health Centre (Obom/Amasaman) (M)					
7.	Gov't Hospital outside the district (M)					
8.	Nothing					
98	Other (specify)		▨			
			▨			
99	Uncertain/ Can't say		▨			

(Narrative) ....

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Most helpful outside-help

4.4 "Of all these places/providers that you have just mentioned, which of these was most helpful?"

Code most helpful outside-help from the above list in the box

Only one answer ☐

First – help Seeking (FHS)

Inquire about first-help excluding home-based care.

4.5 "Which of these places/providers did your child/ward visit/use first?"

*(With reference to the table in **Q4.3**, write the corresponding code in answer to the question in the box)*

Only one answer ☐

4.6 "Was the treatment medical or non medical?"

Using the codes in brackets from table 4.3 as a guide (NM representing 'non-medical' and M representing 'medical') indicate the appropriate response.

Medical (M) 1	Non-medical (NM) 2

*(Continue if **FHS** is non-medical, otherwise skip to **Q 4.8**)*

4.7 **Still on place/provider for FHS** "Did this provider, suggest, discourage or not mention the need for medical help at a health centre?" ***(Fill one box only)***

Referral 1	No referral 2	Discouraged medical treatment 3	Cannot say 4

(Narrative) ....

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4.8 "When you first noticed the nodule, plaque or oedema, how long after was it that you first went to this first outside source of help?" *(Against the appropriate box, write the corresponding figure)*

(Fill only one box only)

Day (s)	Week (s)	Month (s)	Year (s)

4.9 "What were the reason(s) that led you to decide to get help from this place you went to first, for your child's/ward's pre-ulcer condition, rather than some other place?"

(Narrative) ....

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....

Tick '✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. ***Tick as many as apply***

NO	**Reasons**	**Spon**	**Probe**
1.	Treatment offered is very effective		
2.	Closeness to home/residence, convenient		
3.	Affordable		
4.	Self referral		
5.	Referral by family/ friends		
6.	Referral by health worker (professional)		
7.	Referral by CBSV		

NO	**Reasons**	**Spon**	**Probe**
8.	Education through IEC activities		
9.	Medical treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		▨
			▨
99	Cannot say/ uncertain		▨

Medical Care for pre-ulcer condition

4.10 "When you first noticed the nodule, plaque or oedema, how long after that was it that you sought medical care for your child's /ward's condition?" (*Against the appropriate box, write the corresponding figure)*

(Fill one box only)

Day (s)	Week (s)	Month (s)	Year (s)	N/A

(Narrative) ....

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If ‘N/A’ to Q 4.10 then skip to Q 4.22 otherwise continue with following questions

4.11 “What was/were the main reason(s) that led you to seek medical care for your child’s/ward’s pre-ulcer condition?”

(Narrative) ....

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Tick the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***Tick as many as apply***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

4.12 “Was there any reason you decided to get medical help, for your child’s/ward’s pre-ulcer condition, when you did rather than earlier or later?”

(Narrative) ....

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Tick ’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick ’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***Tick as many as apply***

NO	Reasons for medical –help	Spon	Probe
1.	Easy access to health centre		
2.	Referral by CBSV		
3.	Referral by Traditional Healer		
4.	Referral by health worker (professional)		
5.	Self-referral		
6.	Referral by family/friends		
7.	Education through IEC activities		

NO	Reasons for medical – help	Spon	Probe
8.	Important to report early for quick recovery		
9.	Antibiotic treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

Most important reason for medical-help seeking for pre-ulcer condition

4.13 "Of all these reason (s) that you have just mentioned, which of these is the most important reason for medical-help seeking for your child's/ward's pre-ulcer condition?"

Code most important reason from the above list in the box

4.14 "Did the nurse or other health staff usually talk nicely to your child/ward? Did he/she care/ treat your child/ward nicely? *(Against the appropriate box, write the corresponding figure)*

(Tick one box only)

Yes	Possibly	Uncertain	No
3	2	1	0

(Narrative) ....

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4.15 "What medical treatment was given for your child's/ward's pre-ulcer condition? How effective was it?"

Tick '✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe to explore levels of effectiveness of medical treatment as indicated by parent/guardian/care-taker and record responses accordingly. ***Tick as many as apply***

NO.	**Medical Treatment**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Pills					
2	Injection					
3	Wound dressing					
4	Operation (surgery)					
5.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

(Narrative) ....

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4.16 "Did the medicines/pills cause any problems or side effects?"

(Tick one box only)

Yes	Possibly	Uncertain	No	N/A
3	2	1	0	

(Narrative)..

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4.17 “Did the injections cause any problems or side effects?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

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4.18 “Do you think the surgery was more of a problem than a help?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0	N/A

(Narrative) ....

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4.19 “Has your child/ward missed any doses of pills or shots of injection?”

(Tick one box only)

Yes 3	Possibly 2	Uncertain 1	No 0

(Narrative) ....

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4.20 “If yes or possibly, what is the frequency?” ***(Tick one box only)***

1-2 times	3-5 times	More than 5 times

4.21 “If yes or possibly to **Q 4.19**, what difficulties did your child/ward encounter that made him/her skip medication for the condition?”

Tick’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***(Mark all that apply)***

NO	**Reasons for non-compliance**	**Spon**	**Probe**
1.	Health centre is far away		
2.	High transportation cost		
3.	Difficulty in obtaining transport		
5.	Long waiting time at health centre		
6.	Fear of injections		

NO	**Reasons for non-compliance**	**Spon**	**Probe**
7.	Medical treatment heals condition slowly		
8.	BU is caused by witchcraft, medical treatment is not the solution		
9.	Advised against medicines by family and friends		
10	Advised against medicines by traditional healer		
98	Other (specify)		▨
			▨
99	Cannot say/ uncertain		▨

(Narrative) ....

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Home-based care for ULCER

Continue with ulcer respondent’s, if respondent does not have an ***ulcer***, skip to **Q 4.38**

4.22 “What did you or family do for your child’s/wad’s ulcer condition at home?”

(Narrative) ....

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Tick'✓' the appropriate cells based on respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe to explore levels of effectiveness of medical treatment as indicated by parent/guardian/care-taker and indicate responses accordingly. ***(Mark all that apply)***

NO.	**Home-based care**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Drank herbal concoctions at home					
2	Placed herbal dressing on pre-ulcer					
3	Placed herbal dressing on ulcer					
4	Pills and other drugs available at home					
5	Offer prayers at home					
6.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

4.23 "How soon after the awareness of your child's/ward's ulcer condition did you or family do anything at home?" ***(Tick one box only)***

Day (s)	Week (s)	Month (s)	Year (s)	N/A

Outside – care for ulcer condition

4.24 "Where did you go for help outside the home for your child's/ward's ulcer condition? Tell me about all the different providers you may have seen?"

Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. Probe for levels of effectiveness and tick k'✓' accordingly ***(Mark all that apply)***

NO.	**Outside- help**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Herbalist (NM)					
2	Fetish/Spiritualist (NM)					
3	Prayer camp (NM)					
4	Health worker (minimal training) (NM)					
5	Private practitioner (trained) (M)					
6.	Health Centre (Obom/Amasaman) (M)					
7.	Gov't Hospital outside the district (M)					
8.	Nothing					
98	Other (specify)					
99	Uncertain/ Can't say					

(Narrative) ....

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Most helpful outside-help

4.25 "Of all these places/providers that you have just mentioned, which of these was most helpful for your child's/ ward's condition?"

Code most troubling symptom of condition from the above list in the box ☐

First – help Seeking (FHS)

(Inquire about first-help excluding home-based care.

4.26 "Which of these places/providers did you visit/use first?"

(With reference to the table in ***Q4.24****, write the corresponding code in answer to the question in the box)*

Only one answer ☐

4.27 *"*Was the treatment medical or non medical?"

Using the codes in brackets from table 4.3 as a guide (NM representing 'non-medical' and M representing 'medical')indicate the appropriate response).

Medical (M) 1	Non-medical (NM) 2

(If response to ***Q4.27*** *is 'medical' skip to* ***Q 4.31*** *otherwise continue with* ***Q4.28)***

4.28 **Still on place/provider for FHS** "Did this provider, suggest, discourage or not mention the need for medical help at a health centre?" ***(Tick one box only)***

Referral 1	No referral 2	Discouraged medical treatment 3	Cannot say 4

(Narrative) ....

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4.29 “When you first noticed your child’s/ward’s sore how long after was it that you first went to this first outside source of help?”

Tick one box only

Day (s)	Week (s)	Month (s)	Year (s)

4.30 “What were the reason(s) that led you to decide to get help from this place you went to first, rather than some other place?”

(Narrative) ....

....

....

....

....

Tick’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***(Mark all that apply)***

NO	**Reasons**	**Spon**	**Probe**
1.	Treatment offered is very effective		
2.	Closeness to home/residence, convenient		
3.	Affordable		
4.	Self referral		
5.	Referral by family/ friends		
6.	Referral by health worker (professional)		
7.	Referral by CBSV		

NO	**Reasons**	**Spon**	**Probe**
8.	Education through IEC activities		
9.	Medical treatment is effective		
10.	Transportation costs will be refunded		
11.	Herbal treatment not effective		
98	Other (specify)		■
			■
99	Cannot say/ uncertain		■

Medical Care

4.31 “When you first noticed your child’s/ward’s sore, how long after that was it that you sought medical care?”

(Fill one box only)

Day (s)	Week (s)	Month (s)	Year (s)

(Narrative) ....

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4.32 “What was/were the main reason(s) that led you to seek medical care for the ulcer?”

(Narrative) ....

....

....

....

Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

(Mark all that apply)

NO	**Reasons for medical –help**	**Spon**	**Probe**	**NO**	**Reasons for medical – help**	**Spon**	**Probe**
1.	Easy access to health centre			8.	Important to report early for quick recovery		
2.	Referral by CBSV			9.	Antibiotic treatment is effective		
3.	Referral by Traditional Healer			10.	Transportation costs will be refunded		
4.	Referral by health worker (professional)			11.	Herbal treatment not effective		
5.	Self-referral			98	Other (specify)		
6.	Referral by family/friends						
7.	Education through IEC activities			99	Cannot say/ uncertain		

4.33 “Was there any reason you decided to get medical help for your child's/ward's ulcer when you did, rather than earlier or later?”

(Narrative) ....

....

....

Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response. ***(Mark all that apply)***

NO	**Reasons for medical –help**	**Spon**	**Probe**	**NO**	**Reasons for medical – help**	**Spon**	**Probe**
1.	Easy access to health centre			8.	Important to report early for quick recovery		
2.	Referral by CBSV			9.	Antibiotic treatment is effective		
3.	Referral by Traditional Healer			10.	Transportation costs will be refunded		
4.	Referral by health worker (professional)			11.	Herbal treatment not effective		
5.	Self-referral			98	Other (specify)		
6.	Referral by family/friends						
7.	Education through IEC activities			99	Cannot say/ uncertain		

Most important reason for medical-help seeking

4.34 “Of all these reason (s) that you have just mentioned, which of these is the most important?”

Code most important reason from the above list in the box

☐

4.35 "Did the nurse or other health staff usually talk to your child/ward nicely? Did he/she care/ treat your child/ward nicely? ***(Tick one box only)***

Yes	Possibly	Uncertain	No
3	2	1	0

(Narrative) ....

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....

4.36 "What medical treatment was given for the ulcer condition? How effective was it?"

Tick '✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick '✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

(Mark all that apply)

NO.	**Medical Treatment**	**Spon.**	**Probe**	**Effectiveness**		
				Effective 3	**Uncertain/ Mixed 2**	**Ineffective 1**
1	Pills					
2	Injection					
3	Wound dressing					
4	Operation (surgery)					
5.	Nothing					
98	Other (specify)		▨			
			▨			
99	Uncertain/ Can't say		▨			

(Narrative) ....

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4.37 "Did the medicines/pills cause any problems or side effects?" ***(Tick one box only)***

Yes	Possibly	Uncertain	No	N/A
3	2	1	0	

(Narrative) ....

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....

4.38 “Did the injections cause any problems or side effects?” ***(Tick one box only)***

Yes	Possibly	Uncertain	No	N/A
3	2	1	0	

(Narrative) ....

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....

4.39 “Do you think the surgery was more of a problem than a help?” ***(Tick one box only)***

Yes	Possibly	Uncertain	No	N/A
3	2	1	0	

(Narrative) ....

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....

4.40 “Has your child/ward missed any doses of pills or shots of injection?” ***(Tick one box only)***

Yes	Possibly	Uncertain	No
3	2	1	0

4.41 “If yes or possibly, what is the frequency?” ***(Tick one box only)***

-2 times	3-5 times	More than 5 times

4.42 “If yes or possibly to **Q 4.40**, what difficulties did your child/ward encounter that made him/her skip medication for the condition?”

Tick’✓’ the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick’✓’. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an ‘x’ when respondent responds ‘no’ or ‘cannot say’ to any probed response. ***(Mark all that apply)***

NO	Reasons for non-compliance	Spon	Probe
1.	Health centre is far away		
2.	High transportation cost		
3.	Difficulty in obtaining transport		
5.	Long waiting time at health centre		
6.	Fear of injections		

NO	Reasons for non-compliance	Spon	Probe
7.	Medical treatment heals condition slowly		
8.	BU is caused by witchcraft, medical treatment is not the solution		
9.	Advised against medicines by family and friends		
10	Advised against medicines by traditional healer		
98	Other (specify)		
99	Cannot say/ uncertain		

(Narrative) ....

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5 METHODS OF PREVENTION

5.1 Is there anything that could have been done to prevent your child's/ward's current condition?"

(Narrative) ....

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Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.

NO.	**Prevention and control**	**Spo**	**Probe**
1.	Personal hygiene		
2	Maintaining a clean environment		
3	Drinking clean water		
4.	Avoid swimming/bathing in rivers and ponds		

NO	**Prevention and control**	**Spon.**	**Probe**
5.	Avoid cuts and bruises		
6	Avoid body contact with infected person		
7	Cannot be prevented		
98	Other (specify)		▨
99	Can't tell/ Don't know		▨

6. SOURCES OF INFORMATION

"Where did you learn what you know about your child's/ward's condition?" *Tick'✓' the appropriate cells based on the respondent's account. Mark all boxes that apply with a tick'✓'. Continue by probing for any category not yet mentioned and tick them in the probe column. Mark an 'x' when respondent responds 'no' or 'cannot say' to any probed response.*

NO.	**Source of information**	**Spon.**	**Probe**
1.	Health talks at school		
2.	Community health education programmes		
3.	Posters		
4.	Friends/colleagues		

NO.	**Source of information**	**Spon.**	**Probe**
5	Family		
98	Other (specify)		▨
99	Can't tell/ Don't know		▨

(Narrative) ....

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7. STIGMA

Self-directed (PRE-ULCER CONDITION)

7.1 "Has your child/ward thought less of himself/herself because of the (***pre-ulcer)*** condition?"*(Did he/she experience less self esteem/pride)?* ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.2 "Has he/she found it difficult to mingle with friends because he/she did not want them to find out about this ***pre-ulcer*** condition?" ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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....

7.3 "Has he/she found it difficult to attend public functions, board public transport or be seen in public with this ***pre-ulcer*** condition?" ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

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7.4 "Has anyone in the family or at home spoken unkindly or teased your child/ward about the ***pre-ulcer*** condition?" ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative) ....

....

....

7.5a “Have any friends or neighbours who knew about your child’s/ward’s ***pre-ulcer*** condition lost respect for your family because of that?”**(Enacted)** ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0	N/A

(Narrative) ....

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....

7.5b “If any (more) neighbours or friends were to find out about your child’s/ward’s *(pre-ulcer)* condition, will they lose respect for your family?” **(Anticipated)**

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0	N/A

(Narrative) ....

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....

7.6 “Has your child/ward try to conceal the ***pre-ulcer*** condition so that friends and neighbours will not find out?”

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)..

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Influence of stigma on help-seeking

7.7 “Did you delay outside help-seeking for your child’s/ward’s ***pre-ulcer condition*** so that neighbours and others wouldn’t find out?” ***Tick one box only***

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)..

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....

FOR QUESTIONS IN THIS SECTION, ASK FOR CHILDREN WITH ULCERS ONLY: (CURRENT CONDITION)

Family directed stigma at affected persons

7.8 "After your child/ward developed the sore did your family try to avoid being seen with him/her?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)...

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....

7.9 " Has anyone in the family or at home ever spoken unkindly or teased your child/ward about the ulcer?

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)...

....

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....

Community directed stigma

7.10 "Do most, some or any of your child/ward's friends know about the ulcer?" ***Tick one box only***

Yes , most 3	Yes, some 2	Yes, few 1	None 0

(Narrative)...

....

....

....

7.11 “If your child’s/ward’s friends found out about the ulcer, do you think they would continue to remain friendly and support your child/ward?”

Tick one box only

Yes 0	Possibly 1	Cannot say 2	No 3

(Narrative)..

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....

....

7.12 “If your child’s/wards friends who don’t know about the condition were to find out, do you think they would continue to remain friendly and offer support”?

Tick one box only

Yes 0	Possibly 1	Cannot say 2	No 3

(Narrative)..

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7.13 “If your child’s/ward’s friends knew about the ulcer condition, would they avoid him/her”?

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)..

....

....

....

7.14 “If any of your child’s/wards friends who don’t know about the ulcer condition were to find out, would they avoid him/her”?

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)..

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....

7.15 "If any of your child's/ward's friends knew about the ulcer would they speak to or tease him/her unkindly?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)...

....

....

....

7.16 "If any of your child's/ward's friends who don't know about the ulcer condition were to find out would they speak to or tease him/her unkindly?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)...

....

....

....

7.17 "If others in the community have found out, or if they do find out about your child's/ward's condition will it be difficult for any of your relatives to marry?"

Tick one box only

Yes 3	Possibly 2	Cannot say 1	No 0

(Narrative)...

....

....

....

Stigma after cure

7.18 "Even after the ulcer is successfully treated and it heals, will you still face the possibility of separation or divorce as a result of the scar or because you had this condition?"

Yes 3	Possibly 2	Cannot say 1	No 0

7.19 “After treatment and healing, would your child ward consider avoiding school because (classmates or teachers) know/ knew he/she had this condition?” ***Tick one box only***

Yes	Possibly	Cannot say	No	N/A
3	2	1	0	

(Narrative)..

....

....

....

7.20 “Do you think school authorities might try to keep your child/ward from school because they know/knew he/she had this condition?” ***Tick one box only***

Yes	Possibly	Cannot say	No	N/A
3	2	1	0	

(Narrative)..

....

....

....

7.21 “After treatment and healing, would you avoid work because people (at the work place) know/knew you had this condition?”

Yes	Possibly	Cannot say	No
3	2	1	0

7.22 “Do you think people at your work place might try to prevent you from continuing work because they know/knew you had this condition?”

Yes	Possibly	Cannot say	No
3	2	1	0

7.23 “**After your child is healed,** are any of your child’s/ward’s friends likely to speak unkindly or tease him/her because of the scar or having had the condition?” ***Tick one box only***

Yes	Possibly	Cannot say	No
3	2	1	0

(Narrative)..

....

....

....

7.24 “Would it be more difficult for your child/ward to hold a social or political office, if he/she wanted to, because of the scar or having had the condition? “

Yes	Possibly	Cannot say	No
3	2	1	0

8. SOCIO-DEMOGRAPHIC CHARACTERISTICS

8.1 **Sex**:

Male 1	Female 2

8.2Age: ☐ *(Write age in completed years)*

8.3 **Name of Child respondent**

First name	Second (family) name

8.4 **Name of parent/caretaker acting as proxy respondent**

First name	Second (family) name

(*Tick the corresponding number)*

No.	Religion (8.5)
1.	Christianity
2.	Islam
3.	Traditional Religion
4.	None
98.	Other (specify)

No.	Ethnicity (8.6)
1	Ga
2	Adangbe
3	Ewe
4	Akan
5	Northern ethnicity
6	Foreigner
98.	Other (specify)

No.	Marital Status (8.7)
1	Never married
2	Married
3	Separated/Divorced
4	Widowed
5	Remarried
98.	Other (Specify)

(*Tick the corresponding number)*

No.	Highest level of Education attained (8.8)
1	Primary
2	JSS
3	SSS
4.	Vocational
4.	Tertiary
5.	No education
98.	Other (specify)

No.	Relationship of Respondent to Head of Household (8.9) (i.e. What is the child (patient) to the head of household)
1.	Head of household
2.	Spouse
3.	Father
4.	Mother
5.	Sibling
6	Child
7.	Other relation (Cousin /Uncle /Aunt /Grandmother/ Grand father etc)
8	Non relation
98.	Other (specify)

(*Tick the corresponding number)*

No.	**Occupation (8.10)**
1	Pupil/student
2	Unskilled labour (Farmer/ fisherman/ woman/ fish mongerer/ private phone operator/ sand winning/ trader
3	Labourer skilled (seamstress/ tailor/ mechanic/ hairdresser/ cobbler/carpenter

4	Apprentice
5	Unemployed
98.	Other specify

8.11 Is your household income usually regular and dependable? *(Tick one box only)*

Yes 3	Possibly 2	Uncertain/ Don't Know 1	No 0

Concluding remarks **(Is there anything else you want to tell me about *Mycobacterium ulcerans infection? Do you have any piece of advice or suggestions?*** ....

....

....

....

"Thank you very much for your patience and your candid responses. I appreciate all the time you have spent answering all these questions. We are hopeful that all that we have learnt from you will be useful in the management and control of *Mycobacterium Ulcerans* infection. Once again I say THANK YOU".

Interviewer's (Name) : ☐

Time of interview END: ....

Swiss Tropical Institute
Institut Tropical Suisse
Schweizerisches Tropeninstitut

INFORMED CONSENT FORM FOR PARENTS/GUARDIANS OF CHILD-PATIENTS

Introduction

I am a student at the University of Basel/ I am an Environmental Health Officer (field assistant in this study) in the district. We are conducting a study on Buruli Ulcer, a disease which has affected so many people in this district, particularly children and caused a lot of suffering and pain. We are particularly interested in views on the cause, impact on affected persons and family, health-seeking behaviour, medical treatment and access to medical treatment. Findings from this study will be helpful in understanding the socio-cultural impact of the disease on affected persons as well as in designing interventions for improved treatment.

We realize that children might not be able to give accurate responses to some of the questions (for eg. Places visited for treatment, reasons for choice of treatment and details of treatment and effect of disease on family, and secondly because they are minors). It is for this reason that we want to interview parents/guardians. Your participation in this study is entirely voluntary. It is your choice to participate and we will respect your decision. You will not be coerced to participate and your decision will not affect your child's medical treatment. However you are at liberty to discontinue with the interview after it has begun.

We want to assure you that your responses will be kept confidential. That is, there will be no direct reference by name of parent/guardian or child/ward to any interview. However since study findings will be used to inform future interventions, findings of this study will be made public to researchers and health staff at the district and national levels and will be published in international journals for others to learn from. We solicit your permission in this regard.

Statement by Parent/Guardian

The content and purpose of the study has been read to me and I have been assured of confidentiality of responses. I have had the opportunity to ask questions. I agree to participate voluntarily in this study on behalf of my child/ward and give my consent to the publication of findings.

Thumb print of Parent/Guardian

Date: ________________________

Day/month/year

Statement by the researcher/person taking consent

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Name of Researcher:

Signature: ________________________

Date: ________________________

Day/month/year