

**THE VOICE OF PEOPLE LIVING WITH *MYCOBACTERIUM  
ULCERANS* (BURULI ULCER) DISEASE. A GROUNDED THEORY  
TO UNDERSTAND THE ILLNESS EXPERIENCE AND SUPPORT  
NEEDS OF PEOPLE LIVING WITH *MYCOBACTERIUM ULCERANS*  
DISEASE IN A RURAL DISTRICT OF CENTRAL GHANA.**

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## ABSTRACT

*Mycobacterium Ulcerans* (also known as Buruli Ulcer) is a rare skin disease which is prevalent in rural communities in the developing world mostly in Africa. Even though the mortality rate is low morbidity and consequent disabilities which affect the quality of life of sufferers is very high. If the disease is reported early treatment is available but many people receive help late in the disease process. Many reasons have been given in the literature why people receive treatment late. The aim of this study was to explore the experiences of people living with Buruli ulcer in a rural district in central Ghana in order to understand their diagnosis and support needs.

The study was qualitative in design and used Glaser's version of grounded theory. It consisted of semi-structured and unstructured interviews, participant observation, conversation with opinion leaders, traditional healers, people living with Buruli ulcer (who were not part of the study) and a focus group interview with six health care professionals. The Dermatology Life Quality Index (DLQI) tool was also used to determine the quality of life of people living with Buruli ulcer in the study area.

Three principal categories of *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* and a Basic Social Psychological Problem (BSPP) of *Reliving the trauma of my ulcer* were derived. These led to an encompassing core category of *My needs matter*. The theory explains the needs of people living with Buruli ulcer and that this followed a three stage process whereby *Delayed diagnosis* was the cause of the BSPP, *Quality of life as a mirage* the consequences and *Seeking to be myself* as the strategies required to deal with the BSPP of *Reliving the trauma of my ulcer*.

How to deal with the consequences of this disease and the approaches to dealing with the needs of this vulnerable group have also been explored. The outcome of this thesis and its contribution to knowledge is a theory which explains the needs of people in the early stages of and living with Buruli ulcer and why their needs matter.

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## ***CHAPTER 1: Introduction***

### ***1.0 Introduction***

The aim of this chapter is to provide a general introduction and overview of the study. It is therefore divided into four sections - the focus of the study, the significance and background information of Buruli ulcer, the research questions and the organisation of the thesis.

### ***1.1 The focus of the study***

Buruli ulcer is a rare dermatological and multi-organ disease caused by the bacterium known as *Mycobacterium Ulcerans*. It is a multi-organ pathology because the symptoms and effects are many as this study will show. The problems encountered by people living with Buruli ulcer in the study area have been recorded in previous studies, for example Asiedu and Etuaful, (1998). However with the exception of few studies (see the literature review in section 2.2) which used the qualitative approach to understand the illness experience of people living with Buruli ulcer my literature search revealed that all the previous studies on Buruli ulcer in West Africa used the biomedical approach which was based on the relationship between the host (patient) and the environment (soil and water bodies, aquatic insects and the ecology of the areas), case finding, laboratory confirmation of the causative organism, aetiology of the disease and so on. The few that sought to understand the illness experience of people living with Buruli ulcer such as the effects of the disease on the patients' lives, why patients delay in seeking medical intervention, relapse rate and so on have relied on the survey research (questionnaire) approach.

Therefore to understand the illness experience of people living with Buruli ulcer there is the need for a qualitative exploratory study to get closer to them and to get an in-depth understanding and meanings they attach to their condition. This will help to uncover any reasons for late presentation, the coping strategies they employ to deal with their (new) body image and (new) identity and any health-related quality of life and well-being concerns. This study was designed to address the weaknesses in the survey methodology approach which has been used in previous studies and the rationale for adopting this approach has been explained in the Methodology chapter (see section 3. 03). The approach will assist health professionals to identify the support needs of people living with Buruli ulcer.

## ***1.2 The significance of Buruli ulcer and its context***

The skin is the largest organ of the body (Rittie et al, 2010) and apart from its major function of protecting the internal organs of the body; its aesthetic and cosmetic functions are of equal importance due to the role it plays in our appearance. Appearance is one of the most powerful factors influencing social interactions with others (Rayner, 2000). Therefore one's physical appearance in the modern world is of considerable importance due to the media's portrayal of what constitutes beauty. The excessive media intrusion in our lives which shows 'thin smooth faces with no blemishes' as the perfect person, makes the 'social dimension of skin disease very important' (Walser 2010, pp: 96). The proliferation of skin products to enhance our skins to meet societal expectations makes an unblemished, flawless skin everything in our social lives, for it conjures attractiveness, good health and youthfulness. Not only does the skin become what Walser (2010, pp: 96) has described as 'the "open borderline" of the human being' but also the gateway to our personalities, which makes it look as if we don't own our skins and bodies but we hold them in trust for the people we meet and interact in our daily lives. Societal ideal of a flawless skin has become so important in our lives that 'it precipitates psychological morbidity especially in women (Parker et al 2011, pp: 45).

Therefore if one is unfortunate to be afflicted by a skin disorder the person does not only suffer from the physical problems the illness cause them or related symptoms such as the itchiness and pain but also the psychosocial difficulties due to the desire to avoid the stigma associated with the condition and the quest to satisfy societal ideal of what a perfect skin (and for that matter the desired appearance) should be.

One of such skin condition is the bacterial disease called Buruli ulcer which has been reported in over 30 countries in Africa, Southeast Asia, Australia and South America. It is mostly in rural tropical communities. According to Diaz et al (2006), the full extent of Buruli ulcer burden is unknown because it occurs primarily in remote and rural areas. This study was conducted in a rural district in central Ghana. The district was chosen for the following reasons: First it is the district with the highest incidence of Buruli ulcer in Africa. Hilty et al, (2006) analysed the genetic diversity of 72 African isolates of *Mycobacterium Ulcerans*, including 57 strains from Ghana and found two different genotypes demonstrating for the first time the genetic diversity of *Mycobacterium Ulcerans* in an African country. A third variant genotype known as C/BAA was found only in this district making this district different from other Buruli ulcer endemic areas. Secondly the researcher is bilingual and knows the



area, so it made sense to choose this area where I could understand the lives of people living with this condition.

Buruli ulcer was first detected in this rural district in Ghana in the late 1980s. The affected communities attributed the condition to mystical causes due to its uniqueness. Lack of knowledge of the disease coupled with the fear of contracting it led to widespread stigmatisation. By the middle of the 1990s *Mycobacterium Ulcerans* disease had received national attention in Ghana. While many of the patients were treated at the local hospital others depended on their traditional health practices of dealing with the condition. It was a major public health issue which led to preventive measures such as health education as well as outreach programmes to enable people report the disease on time to prevent the many deformities caused by the disease.

Buruli ulcer disease can be effectively managed and/or controlled if treated early (Muelder et al, 2008; Stienstra et al, 2002; Aujoulat et al, 2003). The World Health Organisation (W.H.O) has estimated that 80% of cases detected early can be cured with a combination of antibiotics and simple surgery which reduce the debilitating effects of the disease if it is delayed. But because the disease occurs mainly in less developed rural communities in Africa (and other few developing countries of the developing world) many sufferers keep long before seeking medical intervention. Many reasons have been given to the reasons of late presentation (Renzaho et al, 2007; Aujoulat et al, 2003; Stienstra et al, 2002; Asiedu and Etuaful 1998). If treatment is delayed sufferers go through a lot of physical and emotional difficulties including amputations and destruction of major organs which affect their activities of daily living and this is elaborated in the literature review section (see chapter 2 of this study). Therefore the W.H.O's approach to dealing with the disease is preventive in outlook – mainly to detect the disease early and get it treated to avoid the complications that sufferers go through so as 'to minimise the morbidity and disability associated with Buruli ulcer' (W.H.O, 2008).

The W.H.O's determination to control Buruli ulcer and its consequences led to the 2009 Cotonou Declaration on Buruli ulcer in Benin – West Africa. This was a meeting grouping together heads of states and high level officials of Buruli ulcer endemic countries in Africa. Among other things the leaders declared their 'concern about the heavy burden of Buruli ulcer on children and women in Africa'. They reaffirmed their 'determination to take all the

necessary measures to alleviate the suffering caused by Buruli ulcer and to contribute to further enhancement about the disease'. As well as 'making commitment to take the necessary measures to fully implement the W.H.O recommended strategies for Buruli ulcer control such as promoting social and economic rehabilitation of people negatively affected by the disease' (W.H.O, 2009, pp: 2-3).

The W.H.O continues to develop strategies to minimise the effects of the disease. Its main aim of 'minimising the morbidity and disability associated with Buruli ulcer' has led to three core areas to help it achieve this aim. Core area iii; Standardised management, deals with 'Prevention of disability (POD) and rehabilitation' (W.H.O, 2009) which is in line with the 2009 Cotonou Declaration. Apart from these there are six research priorities set out by the W.H.O one of which is the cultural and socio-economic studies selected by the W.H.O Advisory Group Meeting on Buruli ulcer held on 11-14 March in 2002 in Geneva. The Advisory Group recommended seven studies (see appendix 1 of the seven recommended studies under cultural and socio-economic studies).

Apart from that during the meeting on Buruli ulcer control and research held in Geneva between 25 -27 March 2013 four programmatic targets were agreed upon (see Appendix 2) The targets were silent on people living with the consequences of Buruli ulcer. The failure of the last Research Group meeting to incorporate research on the lives of people already disfigured by the disease explains researchers' desire towards the biomedical approach in dealing with the disease. It must be borne in mind that beyond morbidity and mortality, Buruli ulcer inflicts enormous physical, social and psychological costs to the individual sufferer, his/her family and the community, yet there is absence of a rigorous qualitative and quantitative research studies of the health-related quality of life impacts as well as the support needs of people living with Buruli ulcer.

To date research on Buruli ulcer as well as the main approach to managing people with the disease have focused on knowledge of the aetiology of the disease, treatment modalities, the relationship between the host and the environmental factors, transmission of the causative organisms and how to get patients to report the disease early to prevent disabilities. Early detection of the disease prevents disabilities (W.H.O, 2009), but it is important to note that the disease has already had its toll on many individuals in the affected communities. Apart from that those who have been treated and discharged continue (and will continue) to suffer

from other consequences such as recurrence of the disease and effects of carrying out their activities of daily living due to contracture and other physical deformities. People living with Buruli ulcer may also not be able to benefit from The UN Millenium Development Goal (UNMDG) aimed at eradicating extreme poverty and hunger and to achieve universal primary education (W. H. O, 2009) due to their varied disabilities which affect the work they can do to cater for themselves. While they live with the consequences of this chronic disease the W.H.O's cultural studies appears to be relegated to the periphery of the research priorities.

To address these issues this study adopted the qualitative research approach using the grounded theory methodology. Details of the essential features of the grounded theory methodology and the rationale for opting for this (and qualitative research in general) are described in the methodology chapter. This study is designed to address one of seven of W.H.O's research objectives on Buruli ulcer in Africa: ... *to reduce the morbidity, disabilities and socio-economic consequences caused by Buruli ulcer...* (WHO, 2007: 1-7) as well as the 2009 Cotonou Declaration which emphasised the rehabilitation needs of people living with Buruli ulcer. It should be noted that morbidity, disability and socio-economic consequences due to Buruli ulcer could be reduced if there were quality exploratory studies which would uncover the support needs, illness experiences and behaviour of people living with Buruli ulcer from the time of seeking diagnosis through treatment to rehabilitation which the existing studies have failed to address.

This study also looked at the nurses/carers understanding and perceptions of the respondents' support needs to identify any differences. In developing this study the intention at the outset was for the finding(s) from this comparison to inform the development of nursing practice for those supporting people living with the condition and potentially influence current policy on Buruli ulcer management related to their support needs of those in Africa in particular and other developing countries in general.

### ***1.3 Research Questions:***

This study therefore sought to contribute to meeting these needs by examining the following research questions using research methods which have not been applied to such problems:

1. What prevents people living with Buruli ulcer from seeking early medical treatment?
2. What are the experiences of people living with Buruli ulcer?

3. What health-related concerns do those living with Buruli ulcer have about managing their condition and
4. What are the support needs of people living with Buruli ulcer that may enhance their health-related quality of life and well being?

#### ***1.4 Organisation of the thesis***

The rest of the study is organised as follows: Chapter two reviews the literature related to Buruli ulcer making the case for the study. It reveals the gap in the literature related to the focus and significance of the study. The chapter also deals with the quality of life of people living with Buruli ulcer and the need to their diagnosis and support needs.

Chapter three deals with the methodology, methods and design of the study and the approach I used to collect the data relevant to the study. The rationales for adopting the approaches are explained and data from the various approaches are analysed and presented. The chapter ends with a section on reflection and reflexivity where I discuss the reflexive role I played in the research process.

Chapter four is the findings and discussion chapter. The chapter returns to the focus and objectives of the study and then presents with the over all findings of the study. The Basic Social Psychological Process (BSPP) leading to the core category is presented. In chapters 5, 6 and 7 the findings of each principal category is presented and then discussed with the relevant literature. In chapter 8 the core category and its relationship with the principal categories is presented and discussed with the extant literature.

The thesis ends with the final chapter of summary and conclusion where the study's contribution to knowledge, recommendations, limitations and areas for further research are discussed.

## **CHAPTER 2: Literature review**

### **2.0. Introduction**

This chapter provides a critical appraisal and summary of the literature related to the research focus, it commences with the search strategy. The literature review is organised into two sections. The first section deals with the biomedical approach to *Mycobacterium Ulcerans* (Buruli ulcer) disease and the second section deals with quality of life issues relating to people living with chronic illness and how this is applicable generally to skin disease and *Mycobacterium Ulcerans* (Buruli ulcer) in particular.

### **2.1 Search strategy**

In conducting the background to this study I conducted a search on both published and unpublished studies from 1990 (the period when Buruli ulcer broke out in the study area) to the present date. Due to my limited knowledge in French, literature in French which had been translated into English or had an English abstract were also assessed as well as two studies which had been translated from Japan. The rest were journals written in English. This has been acknowledged as a limitation and had been added to the weaknesses in the study in the last chapter. The following search terms and strategies used:

*Mycobacterium Ulcerans*; *Mycobacterium Ulcerans treatment*; Buruli Ulcer treatment; Buruli Ulcer and/or functional limitations; Buruli Ulcer and/or disfigurement; Buruli Ulcer and/ qualitative research and World Health Organisation and *Mycobacterium Ulcerans*.

The following strategies were used:

Searches of on-line data bases and catalogues, W.H.O website and the databases (from 1990 to-date), Global health; Cinahl; Medline; included in the search were British Nursing Index, PsyInfo and the Cochrane library.

### **2.2 The nature of *Mycobacterium Ulcer* disease**

The British physician Sir Robert Cook first described *Mycobacterium Ulcerans* in 1897 in Uganda. The local name Buruli ulcer originated from a geographical area in Uganda where the large group of patients were identified in the 1960's. It is a chronic necrotising disease of the skin and soft tissue caused by *Mycobacterium Ulcerans* which produces a toxic lipid *mycolactone* (Junichiro et al, 2008). *Mycolactone* has both immunosuppressive and cytotoxic properties, which explains the lack of host symptoms such as fever, malaise or adenopathy

(Ndobe and Ghotbi, 2008). The incubation period of the causative organism (*Mycobacterium Ulcerans*) has been estimated to be four to seven months (Lavendar et al 2011).

### ***2.2.1 Clinical presentation***

According to Duker et al (2006) Buruli ulcer presents three forms of lesions – one is the non-ulcerative form which appears as a papule or a nodule – which appears as a firm, non-tender, subcutaneous nodule 1-2 centimetres in diameter at the site of the trauma. These may eventually ulcerate and progress over months (Diaz et al, 2006) destroying cells in the subcutis leading to the development of large ulcers with undermined edges (Wansbrough-Jones and Philips 2006). The second is the ulcerative form characterised by ulcers of different sizes with undermined edges that tend to extend. Ulceration can be extensive and the infection can destroy nerves, appendages and blood vessels. The third is the end stage or healing form that may take several months to heal and which is sometimes punctuated by local recurrences of active disease. Bone lesions (damaged bone just under the lesion called contact bone lesion or the damaged bone may be remote called metastatic bone lesion) have also been reported (Ndobe and Ghotbi, 2008). Patients with bone lesions are prone to have the lesions spreading to multiple sites. An acute oedematous form of the disease which may involve a whole limb, side of the trunk or the entire face is also common (Debacker et al 2004). The disease also causes osteomyelitis; the severe form has been known to lead to amputation (Legarrigue et al, 2000).

### ***2.2.2 Impact of disease***

Though mortality of the disease is low, morbidity and subsequent disability are very high (Fletcher, 2008) if treatment is delayed which may lead to disabilities that have long term social and economic impacts. For instance it leads to loss of limbs (amputations), sight, breast, genitalia, contracture deformities and other physical impairments which may lead to functional limitations and incapacity (Asiedu and Etuaful 1998). In Chauty et al's (2007) study, functional limitations hampering daily activities were found in 22 per cent of patients. Strienstra et al (2005) used 19 items related to daily living and found that participants (median age 14 years) could not perform 23 per cent of their daily activities. Average limitation scores were 31 per cent in Benin and 15 per cent in Ghana. The mean limitation score in participants without visible contractures (n= 65) was 13 per cent while participants with visible contractures (n= 20) or an amputation (n= 3) had a score of greater than 50

percent. A selection bias cannot be ruled out in Stienstra et al's (2005) study as the authors reported that they omitted patients who had only traditional treatment. If many of the patients in endemic areas report late it follows that the number of limitations could have been less than what they reported because those who seek hospital treatment are those with extensive wounds and therefore are more likely to seek hospital intervention or treatment. Nonetheless in the Amansie West district Asiedu and Etuaful (1998) confirmed that among the 102 cases there were 10 limb amputations, 12 contracture deformities, two patients lost sight in each eye and two died of sepsis and tetanus. The rest had permanent disfiguring scars on their bodies.

Despite the extensive period of hospitalisation and the cost of treatment (see 2.03 below), recurrence rate of the disease is high. The W.H.O's definition of Buruli ulcer recurrence is that recurrence should appear within one year of completing treatment. In 2001 W.H.O came out that these rates vary from 16 per cent for patients whose conditions are diagnosed early to 28 per cent for those who seek treatment late (W.H.O 2001). In Ghana Amofa et al (1998) found a recurrence rate of 16 per cent at the same site within one year of follow-up. Telken et al (2003) compiled the recurrence rate of 78 Buruli ulcer patients in two different hospitals in Ghana and found that 35 per cent of ulcers were not healed when followed up to three years later. For one hospital the rate of those not healed was 18 per cent and 47 per cent in the other. The authors were however unable to differentiate between ulcers that had healed and then recurred. O'Brien et al (2013) found in their Australian study that out of the 192 patients there were 20 recurrences in 16 patients. The median time of recurrence was 50 days. Recurrence occurred less than three centimetres from original lesion in 13 cases and more than three centimetres in nine. Duration of symptoms was more than 75 days and was associated with treatment failure.

Recurrence rates have been found to be directly proportional to the length of follow-up (Debacker et al 2004). Using the 2,564 patients treated from 1989- 2001 at The Centre Sanitaire et Nutritionnel Gbemoten (CSNG) in Benin, the researchers found recurrence rate to be 6.1 per cent. Muelder and Nourou (1990) did a follow-up of 28 patients for 42 months and found that the longer the follow-up period the higher the cumulative recurrence rate.

Debacker et al (2004) have also found that bone lesions are susceptible to spreading to multiple sites and to have recurrences more than one year after hospital discharge. Debacker

et al (2004) therefore are of the view that detecting these spread lesions should also imply a follow-up period of over one year and therefore suggested that The W.H.O's (2002) definition of recurrence needs to be revised to include a follow-up period longer than one year ('delayed recurrence').

As a result of these and the due to the absence of effective tools to control Buruli ulcer disease, the WHO's current control strategies are preventive in outlook. The annual meeting of the WHO Global Buruli Ulcer Initiative held in 2005 agreed on seven control strategies chiefly among them was the early detection of cases at the community level, and information, education and communication.

### ***2.3 Epidemiology***

The disease has been reported in over 30 countries in Africa, Southeast Asia, Australia and South America. It is mostly in rural tropical communities. According to Diaz et al (2006), the full extent of Buruli Ulcer burden is unknown because it occurs primarily in remote and rural areas. Therefore not much can be known about the global burden of the disease. Hayman and Asiedu (2000) for instance have suggested that nearly all available data come from passive case-finding and are therefore underestimates of the true prevalence rates. Sarfo et al (2013) have also reported that Buruli ulcer is found in rural areas of West Africa in numbers that sometimes exceed those reported for leprosy.

The W.H.O (2013) reported that between 5000-6000 cases were reported in 2012 from 15 of the 33 endemic countries of the world. Children are the main casualties. For example in Amansie West district, three studies - Hospers et al (2005), Amofa et al (2002) and Asiedu and Etuaful (1998) reported that 70 per cent of cases were children up to 15 years old. The W.H.O (2013) Report found that in Africa 48 per cent of those affected were children under 15 years old whereas the corresponding figures in Australia and Japan were 10 per cent and 19 respectively. This means that more adults have contracted the disease in Africa in the last decade. The number of cases in some West Africa countries in the last decade however is substantial- 5,700 cases between 1989-2003 in Benin; 17,000 cases between 1978 -2003 in Cote d'Ivoire, and 5,619 cases in 1999 in Ghana (Kwer and Ampadu, 2006). In Ghana, more than 20,000 cases of Buruli ulcer disease were reported from 1994- 2003 and outbreaks were reported in at least 90 of the country's 138 administrative districts (Kwyer & Ampadu 2006),



with Amansie West as the most endemic area with point prevalent estimate of 150-280/100,000 population (Raghunathan et al, 2005).

There are discrepancies regarding the distribution of the ulcer on the body. In Chauty et al's (2007) Benin study the lesions were localised on the lower limbs. Debacker et al's (2005) study supported Chauty et al's (2007) study, noting that lower limbs were 3.2 times more frequently involved than the upper limbs in older patients. Hamzat and Boakye-Afram (2011) on the other hand found that upper limbs were mostly affected followed by lower limbs while Asiedu et al (2000) were specific that upper limb lesions were more prevalent among children while lower limb lesions were common among adults in their Amansie West study. However Hospers et al (2005) observed that Buruli ulcer lesions on arms and legs showed bilateral symmetrical distribution and that upper and lower limbs are affected equally. The W.H.O (2013) Report has confirmed that in general 35 per cent of lesions occur on the upper limbs, 55 on the lower limbs and 10 per cent on the other parts of the body.

#### ***2.4 Public health, costs and economic implications of Buruli ulcer***

After Tuberculosis and Leprosy, *Mycobacterium Ulcerans* is the third most common mycobacterial disease in humans (Qi et al, 2009; Ortiz et al, 2009). Therefore the main focus of public health efforts has been on early detection and treatment to reduce morbidity and costs of treatment (Debacker et al, 2004; Evans et al, 2003), emphasising the need for early presentation.

Without early detection The WHO (2007), has estimated that in Ghana between 1994 and 1998 the average cost of treating a Buruli ulcer case was US\$ 780 per patient, while in 2001 – 2003 the median annual total cost of Buruli ulcer to a household by stage of disease ranged from US\$ 76.20 (16 % of a work year) per patient with a nodule to US\$ 428 (89 per cent of a work year) per patient who had undergone amputation.

In Ghana Niyama (2012) found that the National Health Insurance Scheme (NHIS) of 2003 was aimed to ease and improve the health situation of the people. However endemic diseases such as Buruli ulcer were excluded from the scheme. Therefore while the NHIS remained ineffective to Buruli ulcer, the burden of treatment costs lie on National Buruli Ulcer Control

Programme (NBUCP). Niyama (2012) found that the budgets provided by the NBUCP often failed to cover the fundamental medical supplies like bandages.

In Ghana in the three years (1994-1996), Asiedu and Etuaful (1998), computed the total treatment cost of Buruli ulcer in Amansie West district as US\$ 79,893.11 compared with the district's health budget (excluding salaries) of US\$ 58, 835. These figures far exceed per capita Ghana government spending on health. For example in 1994 alone they found out that 83 per cent of the district's budget was used on 36 Buruli ulcer patients in a population of 130,000. This would have a negative impact on the delivery of other health programmes and emphasises the importance of preventing the disease as well as its early detection.

Apart from the direct costs such as those enumerated above Buruli ulceration also leads to indirect costs to the individual and his/her household. The indirect costs include the opportunity cost of time lost to the patient seeking health care as well as the accompanying caretaker, cost of change in accommodation or dietary pattern due to Buruli ulcer (Adamba and Owusu, 2011). The authors suggested that any cost calculation should include the indirect costs of the accompanying carers as these persons would be unavailable for household productivity. In Ghana Asiedu and Etuaful (1998) and Asante and Asenso-Okyere (2003) noted that the indirect costs of an illness such as Buruli ulcer is more than half of the total cost of the illness itself.

Many of the affected communities are purely rural and because of the high cost of treatment, the associated stigma and its disabling consequences Buruli ulcer can impoverish and worsen the already difficult economic hardships of affected households. Adamba and Owusu (2011) found that disability due to Buruli ulceration leads to loss of productive man-hours and loss of income. In their study in the endemic district of Ga West in Ghana they found that the average patient spent 205 days for treatment including hospitalisation and time as an outpatient receiving sore dressing. The average patient with a nodule was hospitalised for 67 days and was likely to lose 78 days of productive work time. An ulcer patient spent a total of 301 days receiving treatment, hospitalised for nearly 251 days and lost 265 days of productive work time. A patient with a plaque spent approximately 169 days for treatment, hospitalised for 131 days and likely to lose 165 days of productive work days; while a patient with oedematous stage spent 182 days for treatment and was likely to be hospitalised for 182 days and more likely to lose 225 of productive work days for treatment. It must be realised

that these computations do not include the opportunity costs such as that of the accompanying carers and loss of education due to the extended periods of hospitalisation (both to the patients and the carers).

### **2.5 Mode of transmission**

Although it is clear from epidemiological studies that proximity to wetlands is a risk factor for *Mycobacterium Ulcerans* infection, the exact mode of transmission is not clear ( Johnson et al, 2005; Etuaful et al, 2005). Field studies however, have shown that the disease is associated with aquatic and swampy environments with the *mycobacterium* occurring in bio-films, soils, aquatic insects, field and wild life in the transmission of the pathogen even though the mode of transmission to humans remains unclear (Wilson et al 2011; Marsollieur, 2002). It is however widely believed that inoculation of the causative agent into the subcutaneous tissue of the skin likely occurs through environmental contact although this mechanism too has not been proved (Merritt et al 2010). The hypothesis surrounding the mode of transmission such as bites from predatory water bugs and mosquitoes have not been proved save a recent study by Lavenda et al (2011). The authors tested for the association between the detection of *Mycobacterium Ulcerans* in mosquitoes and the risk of Buruli ulcer disease in humans in an endemic area in South Eastern Australia. Their findings have strengthened the long held hypothesis that mosquitoes are involved in the transmission of *Mycobacterium Ulcerans* in South East Australia. Poor wound care, failure to wear protective clothing and living and working near infected water bodies coupled with poor hygiene have been found to be the risk factors (Jacobson et al, 2010).

Duker (2004) and Duker et al (2006) used analysis of detailed geographical information about rivers and streams and physio-chemical data in Amansie West to implicate arsenic content in the soil and its exposure as a confounding immunosuppressant. Both studies concluded that both arsenic in the natural environment and gold mining influences Buruli ulcer infection. ‘Galamsay’ (surface gold mining along river banks) activities where vast lands have been turned to artificial lakes have been implicated in Merritt et al (2005) and Johnson et al (2005) studies. Similar studies have been confirmed in Angola and the Democratic Republic of Congo (Kibadi et al, 2008) but the findings in these studies have not been conclusively proved. For example in Ghana there are other Buruli ulcer areas such as Ga West district in Accra where gold mining is not carried out yet Buruli ulcer is endemic.

## ***2.6 Diagnosis and Treatment of Mycobacterium Ulcerans disease***

The mode of transmission of the disease remains unclear so a simple surgery to remove the nodule has been found to be the only option to control Buruli ulcer; that is if the nodule has been reported early. Direct examination has been found to be unreliable and culture is long and difficult (Abgueguen et al, 2010). The result is that confirmed Buruli ulcer diagnosis has always been late, inefficient, time consuming or very expensive in many areas. Current diagnosis of Buruli Ulcer therefore depends on clinical presentation and microscopy which are usually carried out by Polymerase Chain Reaction (PCR) and other tests in laboratories (Souza et al 2012) which has been found to be difficult in developing countries. The W.H.O (2013) recommends that at least 70 per cent of cases reported need to be confirmed by PCR. A recent technique by Souza et al (2012) called Loop Mediated Isothermal Amplification (LAMP) has been found to be cheaper and simpler and ten times more sensitive capable of given results in one hour. The technique is deemed to help in resourced-poor facilities in the developing world. Work on this is still ongoing to be confirmed by the W.H.O.

In terms of therapy there is no established effective anti microbial therapy (Kwyer & Ampadu, 2006), except Rifampicin and Streptomycin for four weeks or more which has remained the antimicrobial choice of treatment because the combination (on patients with nodules or plaques) was found by Etuaful et al (2005) to render the disease tissue culture negative within four weeks. On the basis of Etuaful et al's (2005) findings The World Health Organisation (WHO, 2006) issued preliminary guidelines recommending streptomycin in combination with rifampicin as standard treatment for *Mycobacterium Ulcerans* infection with or without additional surgical debridement or skin grafting.

The use of Rifampicin-Streptomycin combination has been very controversial in different settings. This is because while the combination has been found to be ineffective without surgical support others have found it effective as far as the disease is determined early (Nienhuis et al 2010), even though a Cochrane review by Constatine et al (2009), found no consensus about their clinical efficacy. The review stated that 'although it is becoming common practice to implement the WHO recommendation, there are no systematic reviews to our knowledge to support the use of the rifampicin-streptomycin combination therapy in the treatment of Buruli Ulcers at the early stage'. Nevertheless the W.H.O (2013) has recommended the following treatment regimen:

1, different combination of antibiotics given for eight weeks to treat Buruli ulcer and these are:

a, a combination of *rifampicin* (10mg/kg once daily) and *streptomycin* (15mg/kg once daily) or;

b, a combination of *rifampicin* and *clarithromycin* (25mg/kg twice daily) has been used though effectiveness not proven by a randomised trial. Since *streptomycin* is contraindicated in pregnancy, the combination of *rifampicin* and *clarithromycin* is also considered the safer option for this group of patients; or

c, a combination of *rifampicin* and *moxifloxacin* (400mg/kg once daily) has also been used though effectiveness not proven by randomised trial.

2, Complementary treatment such as wound care, surgery (mainly debridement and skin grafting) and interventions to minimise or prevent disabilities are necessary depending on the stage of the disease.

Sarfo et al (2013) have found that *streptomycin-rifampicin* combination for eight weeks rapidly reduced gross lesions, bacterial numbers and *mycolactone* production. At the same time lack of treatment resulted in extracellular infection, destruction of host cells, and ultimately lesion ulceration. However, the use of the standard antibiotic treatment has led to the controversial ‘paradox reactions’ in patients. When the *streptomycin-rifampicin* combination or any of the antibiotic combinations recommended by the W.H.O (2013) is used they lead to worsening clinical condition after an initial response to therapy (O’Brien et al, 2009). This deterioration (known as paradoxical reaction) are most common in patients with extensive wounds and can take a variety of forms including increased size, ulceration or previously non-ulcerative papules or the development of new lesions not detectable before antibiotics, and can occur four to eight weeks after antibiotic therapy (Nienhuis et al, 2012). Ruf et al (2011) also found that skin lesions emerging several months after completion of antibiotic therapy were associated with *Mycobacterium Ulcerans*. The authors were of the view that during antibiotic therapy of Buruli ulcer development of lesions may be caused by immune response-mediated paradoxical reactions.

Several researchers have attempted to circumvent paradoxical reactions by the use of corticosteroids (Martins et al, 2012; Friedman et al, 2012; Ruf et al, 2011; and Trevillyan, 2013). The over all findings and conclusions from these studies are that there were marked

improvements in the appearances of the lesions when steroids were used for paradoxical reactions but the patients conditions deteriorated when steroid therapy were weaned. Although there are established guidelines for the management of paradoxical reactions in *Mycobacterium Tuberculosis* (American Thoracic Society, 2003) and while pre-emptive steroid therapy may have a role in preventing paradoxical reactions, there is no randomised evidence to support its use in Buruli ulcer. These new developments have implications for health seeking behaviours of people living with Buruli ulcer in the study area which will be discussed at the discussion chapter. All these notwithstanding, clinical management of advanced stages are still based on the surgical resection of the infected skin (Trigo et al, 2013).

Other treatment involves topical nitrogen oxide (Phillips et al 2004), and recently effective use of two weeks of ozone therapy has been reported in Central Africa (Betolotti et al 2012). If successful in a large scale trial the authors are hopeful that it could become an effective option for managing Buruli ulcer as an alternative to antibiotic or surgical treatment. Trigo et al (2013) have also demonstrated the potential of bacteriophage therapy against *Mycobacterium Ulcerans* infection paving the way for future studies aiming at the development of a novel phage-related therapeutic approach against Buruli ulcer. Others are repeated surgical debridement and skin grafting (Wansbrough-Jones and Philips et al 2006; Muelder et al, 2008; Pszolla et al, 2003). Active treatment by excision and skin grafting necessitates long hospital stays. Asiedu and Etuaful (1998) confirmed that the average hospital stay in Ghana was 186 days in 1994, 103 days in 1995 and 102 days in 1996. This limits hospital bed capacity and further limits the number of patients who can be seen.

The active treatment notwithstanding relapse after surgery may occur in between 18 percent and 47 percent of cases (Teelken et al, 2003). Therefore in many West African countries a major focus has been public health campaign to inform the affected communities about the importance of early detection of Buruli ulcer followed by timely treatment (Aujoulat et al, 2003).

## ***2.7 Disease prevention***

In terms of protection there is no proven vaccine for primary prevention of Buruli ulcer although there have been reports that Bacilli Calmette-Guerin (BCG) vaccination might confer protection against the disease or delay the onset of symptoms (Walsh et al, 2008;

Portaels et al, 2004). An Amansie West study (Ragnathan et al, 2004) and a Benin study (Nackers et al 2006) found that BCG vaccination does not provide lasting protection against Buruli ulcer disease. A recent study by Fraga et al (2012) confirmed that BCG vaccination delayed the onset of *Mycobacterium Ulcerans* growth and also resulted in cell-mediated immunity in *Mycobacterium Ulcerans*-infected footpads. Yet despite these BCG protective responses, ‘BCG vaccination did not avoid the later progression of *Mycobacterium Ulcerans* infection, regardless of challenge dose’ (pp: 33405). The researchers also found that immunisation with *mycolactone*-deficient *Mycobacterium Ulcerans* also significantly delayed the progression of footpad infection, swelling and ulceration, but ultimately *Mycobacterium Ulcerans* pathogenic mechanisms prevailed.

### **2.8 Delays in treatment**

Mortality due to Buruli ulcer is low (Fleischer, 2008), so it is the morbidity and its consequent disfigurement and disabilities which are of grave concern to governments and the individuals of affected countries. Therefore the need for preventing long term disabilities has been seen as an important ‘end point at time of healing and cure’ (W.H.O, 2005). Morbidity, disfigurement and disabilities due to Buruli ulcer can be prevented if treatment is sought in the early stages of the disease, yet several reasons have been given for the delay in the affecting communities in seeking early medical intervention. The reasons vary and all seem to revolve round economics, such as cost of treatment (Muelder et al 2008; Stienstra et al 2002) and socio-cultural factors such as reliance on traditional medicine (Muelder et al, 2008; Etuaful et al, 2000). What is worthy of note is that many of these widely published researches or findings were carried out through structured surveys and questionnaires. They are worth looking at and therefore are presented in the following sections. The various reasons are interrelated because in some instances one study could produce two or more reasons.

Muelder et al (2008) and Stienstra et al (2002) found that fear of surgery and the mutilating consequences after surgery was the most important factor why their research participants refused to seek early medical intervention. This reason presupposes that the participants were fully aware of the diagnosis of Buruli ulcer but the fear of the surgical procedures (apparently what they had seen from other sufferers) and perhaps its devastating aesthetic consequences put considerable amount of fear into them, necessitating their decision to seek intervention where there would be no scarring. While this reason may be true in some circumstances it might not be the major reason. This is because majority of the Buruli ulcer patients are

minors under the age of 15 years (Hospers 2005; Amofa et al 2002 and Asiedu and Etuaful 1998), it is therefore reasonable to assume that the decision to seek medical intervention will be taken by their parents or responsible adults. We should therefore look further for more plausible reasons from both parents and sufferers points of view.

The fore going will then lead us to more reasonable and perhaps convincing causes for delaying treatment; which are economic and financial reasons. These are the reasons that many of the researchers have alluded to (Muelder et al 2008; Stienstra et al 2002; Asiedu and Etuaful 1998 and Etuaful et al 2000). The cost of treating Buruli ulcer has been found to be expensive and beyond the reach of the ordinary rural dweller in Africa (see section 2.03 above on the Public health, costs and economic implications). This reason seems very convincing given the direct and indirect cost involved in the treatment of Buruli ulcer. Indirect costs such as loss of earnings and work opportunities associated with parents or carers attending to their children's hospitalisation over an extended period of time has been found by Ndobe and Ghotbi (2008) in their study in Cameroon. Similar findings have been found in Ghana by Adamba and Owusu (2011) and Adoma (2003). Other related costs that have been implicated by other researchers are the cost of transportation to the nearest health facility since in most of the affected communities the health care facilities are far away and with deplorable road conditions (Debacker et al (2004).

### ***2.9 Traditional medicine***

The decision to seek other forms of treatment has been attributed to such reasons as cultural and social stigmas of the disease (Stienstra et al 2002; Aujoulat et al 2003; Awusabo-Asare and Anarfi 1997). If social stigma is attached to the disease the individual will try to 'deny' the disease by seeking help from herbalist or resort to over-the counter treatment. Yet other researchers have attributed the decision to either self medicate or seek the services of traditional healers and spiritualists to lack of knowledge of a 'strange' disease (Kibadi et al 2008; Renzanho et al 2007; Aujoulat et al 2003).

The ordinary rural dweller faced with such financial difficulties will ordinarily seek other means for treating the ulcer; and this leads to other related reasons such as preference of having treatment in their traditional setting or using their own traditional means of treating diseases such as relying on traditional medicine or spiritualists due to widespread beliefs that the disease is due to curses or divine retribution.



With regard to skin problems Ryan et al (2011), have stated that up to 80 per cent of the world's population use traditional systems as the first entry point for their conditions. In others traditional medicine of whatever form is used as a back-up of biomedicine. Traditional health practitioners are useful and will continue to be used by many in the developing world for skin diseases because they are accessible, available and affordable as well as a cultural imperative to consult them (Hay and Fuller 2011). They are also client-centred, culturally appropriate, holistic and offer a form of family counselling and most of them are opinion leaders with credibility and often more knowledgeable than village health workers so they will be there for the foreseeable future (Ryan et al 2011).

The W.H.O (2008) defines traditional medicine as the sum total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures that are used to maintain health, as well as to prevent, diagnose, improve or treat physical and mental illness. It means for a group of people to rely on their traditional medicine it would have been handed down from generations orally or in written form. Turner (1996) categorises treatment for any illness into three categories: first, some treatments such as the use of herbs and acupuncture can be classified as folk medicine - treatments believed to work because they have a long tradition of use by a given group. The second is the Western medicine which is based on cause and effect demonstrated by clinical trials. The third treatment he identifies is magical medicine which is also based on cause and effect relationship. According to Klein (1979), in magical medicine the cause of both acute and chronic disease is seen as a metaphysical one and thus the treatment is also metaphysical. Magical treatment is exemplified by the use of new age crystals and religious rituals such as prayer, voodoo and witchcraft and according to Turner (1996), the practitioners of both folk and medical medicine often seek to gain a balance within the individual and/or between the individual and nature and both are intertwined. For example Kleiman et al (1995), describes how Chinese epileptics consult Taoist priests, Buddhist adepts, or Muslim Imams but also take Chinese herbs and other medicines.

Turner (1996) gives anecdotal and research based evidence to show that combining Western medicine and traditional approaches to healing may have some beneficial outcomes. For example the use of dual medicine approach in Africa to treat chronic illness such as Schizophrenia led to positive outcomes in follow-up studies in Nigeria. A psychiatric outpatient facility in Aro in Nigeria demonstrated that the use of traditional healing –

including local rituals – and Western psychiatry led to lower cost, reduced recidivism and need for aftercare and a lessened length of stay (roughly a third of the average stay in other facilities). Due to the success of the programme it was expanded to other areas of Nigeria and other African countries (Lambo, 1978). For 50 months Kaiser (1993), followed a group of HIV infected men who use folk medicines (including herbs and stress reduction) as well as Western medical treatment such as antiretrovirals. He concluded that a blend of both alternative and standard medical therapies provide an optimal approach to treatment. Hemmersley (1988), a psychiatrist who worked with traditional healers in India realised that Western medicine did not always work, or work alone, in healing physical and psychological illness and both medicine men and medical practitioners admitted their respective practices strengths and limitations.

Aujoulat et al (2003) discovered two types of traditional healers that their Buruli ulcer participants in Benin normally sought help from- Phytotherapist (healers who use traditional plants) and those who rely on divination and behavioural prescriptions to free patients from the disease which resonate with Turner's (1996) account. The reliance on traditional healers for Buruli ulcer has been found in other studies such as Renzaho et al (2007), Asiedu and Etuaful (1998), Etuaful et al (200), Muelder et al (2008) and recently Grietens et al (2012). Other studies have also found that many of the affected individuals depended or relied on over-the- counter medications in addition to seeking help from traditionalists and spiritualists (Adoma 2003; Ackumey et al 2011; Adamba and Owusu 2011).

### ***2.10 Quality of life and chronic skin diseases***

This section touches on the concepts of quality of life and health related quality of life and how they affect people living with Buruli ulcer. Quality of life could be explained based on the individual's subjective well-being, satisfaction and fulfilment, or it could be seen or concerned with both individual needs and the collective notions of social capital and social cohesion (Philips, 2006). Therefore the term pertains to the individual satisfaction with life and his/her health and when on reflection he/she feels satisfied that he/she meets his desires and needs (Fayers and Machin, 2000; Moons et al 2006). The implication of this subjective meaning of the term is that for people living with Buruli ulcer their quality of life could change as their circumstances change.

The term can also be seen as an objective construct which can be measured by objective indicators such as ones ability to perform his/her normal duties uninterrupted by illness or the ability to lead a normal life and contributing to society (Moons, 2006 and Bowling, 2005). The position of this paper (thesis) is that the subjective and objective meanings of quality of life are not mutually exclusive as far as the respondents in this study are concerned. This is because firstly, the objective explanation assumes a direct relationship between for example the respondents' symptoms and their functional abilities in respect to their quality of life; and secondly the respondents' quality of life is determined by themselves upon reflecting on their lives.

To avoid the distinction between the objective and subjective explanations of the generic term this study will adhere to the specific term health related quality of life, which is, the quality of life (as explained above) related to the individual's health and treatment. There are two aspects of health related quality of life – the global areas which typically are the physical, social and emotional which are relevant to all patients (Bowling, 2001; DeGest and Moons, 2000; Mandzuk and McMillan, 2005) whereas the disease specific measures refer to areas that are particularly relevant to the condition being explained (DeCivita et al, 2005). So for a condition such as Buruli ulcer there may be specific quality of life domains which have a greater importance for the health-related quality of life of the patients than the general population.

In terms of the quality of life impact of skin diseases, Finlay (2000) an authority in the field, has argued that virtually all aspects of the patient's lives can be affected. This can range from the effects of symptoms such as itch, pain and discomfort to the effects of undertaking simple everyday tasks or choice of clothes as well as engaging in social activities such as going out with friends or enjoying one's hobbies. Finlay (2004) goes on to provide empirical evidence to show that the biomedical approach assumes that doctors and nurses are aware and knowledgeable enough about the impact that a particular skin disease has on its patients which may not necessarily be the case. Therefore according to Finlay (2000), knowledge of the patients' quality of life has the potential to inform health professionals' understanding of individual patient's needs so that health professionals can plan towards these and can also provide powerful ammunition when arguing for resources for dermatology.

Several approaches have been designed to assess the quality of life of people with skin diseases. The general measures such as the Short Form – 36 (SF-36), Euroqol-5 or Sickness Impact Profile are designed to be used across all diseases. According to Finlay (2004), information for their use allows for the comparison of the effect of the skin to the effect of non-skin disease to be made. Finlay (2004) however concedes that they are normally not as sensitive to change as disease specific measures when used to measure change after an intervention.

Inflammatory skin diseases affects individuals in similar ways and to avoid repetition of creating disease specific measures for every skin disease a dermatology specific measure which could be used across all skin disease was devised by The Cardiff School of Dermatology called The Dermatology Life Quality Index (DLQI). The DLQI tool has been described in at least 36 skin diseases. Use of the DLQI tool has allowed new insights into several aspects of clinical dermatology (Finlay and Khan 1994). If quality of life is severely impaired, patients become depressed or demotivated to treat themselves effectively (Finlay, 2004).

The DLQI tool is a simple self administered, easy and user friendly validated questionnaire used to measure the health related quality of life of patients suffering from a skin disease. It was developed in 1994 and it is the first dermatology-specific quality of life instrument. It consists of 10 questions concerning the patients' perception of the impact of the skin disease in different aspects of their health-related quality of life over the last week (see appendix 3). There is also a Children's version (see appendix4). The nature and application of the DLQI tool is described in detail in section 3.6.14 in the methodology and methods chapter.

The DLQI tool has been used in many countries in the developing world on diseases such as *Leprosy, Psoriasis, Podoconiosis* and general dermatology. Unfortunately the literature review reveals that the tool has not been used anywhere on Buruli ulcer patients. In dermatology, patients' needs arise from the disease itself and from the effects of the disease... (Finlay, 2000). These needs can be met if health professionals are able to assess the effects of the disease on the peoples' quality of life. While we can use antibiotic therapy to determine the effect and or the severity of the disease, we cannot use it to evaluate the impact the disease has on the patients' quality of life. So an assessment of the patient's quality of life is important in identifying their needs so that we can help them manage the effect the condition

has on them. The only study that has made an attempt to determine the quality of life of Buruli ulcer patients was that of Hamzat and Boakye- Afram (2011). However the authors used the Nottingham Health Profile Questionnaire (NHPQ). The NHPQ has two parts: Part I comprises of 38 questions divided into six domains of Pain, Emotional reaction, Sleep, Social isolation, Physical abilities and Energy levels; which is an indication of a person's perceived emotional, social and physical health status. Part II on the other hand contains six items dealing with the effects of health problems on occupation, jobs, personal relationships, social life, hobbies and holidays. The authors found that the respondents' quality of life was adversely affected compared with controls and the area most affected was Pain. The authors' based their assessments on patients who had attended clinic or whose ulcers were still sore. Therefore just as I stated in the introduction section there is a gap in the literature with regard to the methods available for the valid assessment of the quality of life of people living with Buruli ulcer and thus their needs as they live a life of disfigurement. This study therefore appears to be the first study to look into this aspect of living with the disease.

### ***2.11 Chapter summary***

I began the chapter with how the literature was searched. I have attempted to look at what appears to be the biomedical approach to Buruli ulcer – the nature/aetiology of the disease, the epidemiology, mode of transmission, diagnosis and treatment, cost and public health implications. I then looked at the social aspects of the disease such as the reasons why people report late and went on to identify the different types of health seeking behaviour among people living with Buruli ulcer in the study area. The chapter ended with the quality of life of people living with Buruli ulcer.

The literature review has confirmed the lack of studies in the important area of the support needs of people living with Buruli ulcer. The only study that was identified to have made an attempt to assess the quality of life of people living Buruli ulcer was identified but it was found that the authors concentrated on the quality of life of Buruli ulcer patients but not those living with the condition. How I approached the study to assess the respondents' quality of life, their coping strategies and their support needs is presented in the next chapter (chapter 3).

## ***CHAPTER 3: Methodology and methods***

### ***3.0 Introduction***

In the previous chapter I discussed the literature in relation to *Mycobacterium ulcerans*. The paucity of information regarding the quality of life issues and the needs of people living with Buruli ulcer became evident. This chapter looks at my approach to the methodology in answering the four research questions. The chapter is organized under the following sections: Introduction; objectives of the study; theoretical and methodological context; rationale for using qualitative research; rationale for using Grounded theory methodology; negotiating access and selection of informants; overview of data collected; ethical considerations/issues; data analysis; reflections and reflexivity and rigour in qualitative research as applied to this study.

### ***3.1 Objectives:***

The specific objectives of the study which sought to answer the research questions (see section 1.3) are as follows:

- i, To explore respondents beliefs regarding those factors which prevented them from seeking early medical treatment for Buruli ulcer and to explore if they hold on to these reasons/beliefs;
- ii, To generate analytic descriptions of the respondents' experiences from the time diagnosis of Buruli ulcer was confirmed through their hospitalisation for surgery, the care they received and their lives during rehabilitation;
- iii, To explore and analyse the coping strategies the respondents employ to manage their body image and disfigurement, the impact on their self-esteem and their identity;
- iv, To understand the impact of Buruli ulcer on the respondents' health and examine and discuss their health- related quality of life and any concerns;
- v, To explore what those living with Buruli ulcer report/express about their social, psychological, educational and spiritual support needs and their beliefs about how these needs can or have been met and;
- vi, To compare (v) above with the health professionals' perceived understanding of the respondents' support needs.

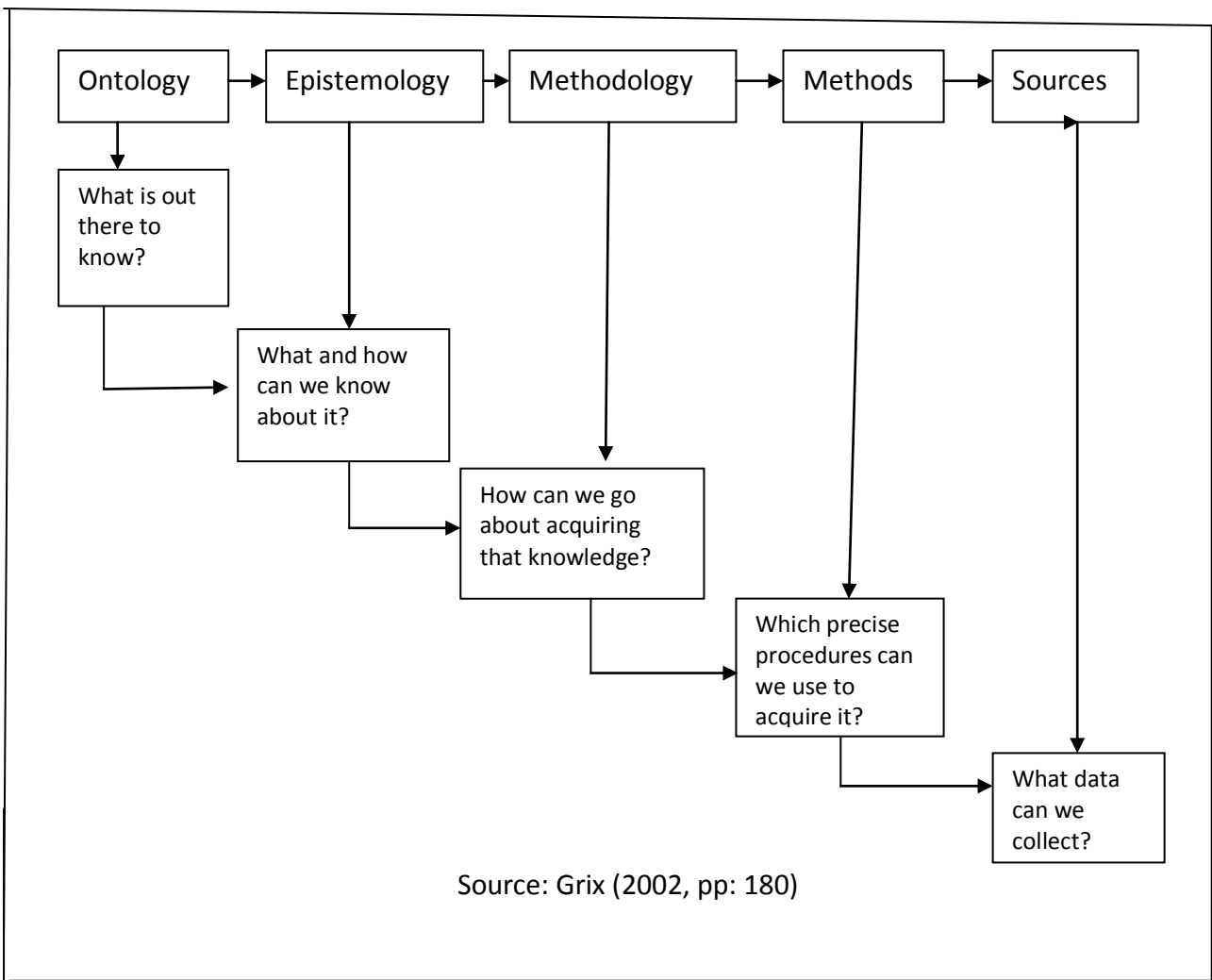
### ***3.2 Theoretical and methodological context***

Creswell (1998) emphasises how important it is for all researchers to recognise the basic set of beliefs or assumptions that guide human and social research in general. These basic beliefs, which constitute the building blocks of social research, begin with acknowledging the different views of what constitute social reality (ontology) and the nature of knowledge or how that reality can be known (epistemology) in social research (Holloway 2005).

Researchers can gain knowledge of the social world through ‘tenacity’ (what people have always believed to be true), authority (which is generally based on tradition and belief from trusted sources such as our parents and teachers), ‘priory’ or intuition (a belief that something is true because it is “self-evident”), and through a ‘scientific’ method (objective testing, independently verified and scrutinised approach) Kerlinger (1986; pp: 6-7). Kerlinger (1986) points out that the “scientific method” of obtaining knowledge is unique because of the checks that can be carried out at every stage of the process that was used to obtain that knowledge. Grix (2002) however, argued that obtaining whatever is regarded as an acceptable ‘scientific knowledge’ about reality should be underpinned by ontological and epistemological ideas; and that ontology should be seen as the starting point of all research, after which one’s epistemological and methodological position will logically flow’ (pp: 177) Therefore from Grix’s (2002) perspective, ontological ideas are the image or reflection of social reality upon which a theory can be based. As far as this study is concerned the ontological consideration is the claims and assumptions about why people living with *Mycobacterium Ulcerans* (Buruli ulcer) delay in seeking medical intervention and their illness experience. The epistemological position adopted for this ontological consideration is the Grounded theory approach developed by Glaser and Strauss (1967) [see section 3.4 below].

Therefore ontology and epistemology influenced the methodology employed in gaining knowledge about the nature of the social reality about Buruli ulcer and where that reality (or knowledge) should be sought. This is because when social scientists do a study they are making assumptions about what we will study and its place in the world (ontological assumption) and what that knowledge will look like once we have produced it (Newman, 2011). The relationship between these concepts is depicted by Figure 1 below.

*Figure 1: The interrelationships between the building blocks of research*



These ontological, epistemological and methodological views of social research have led to the two main paradigms in social research known as positivism and naturalistic enquiry. While the positivist paradigm contains an objective, realist ontology and an empiricist epistemology, the naturalistic enquiry or philosophy (which was adopted in this study) questions the fundamental nature of reality.

Kant is noted to have proposed that perception was more than the act of observation and therefore reality cannot be explained by cause and effect and that ‘nature was not independent of thought or reason’ (Hamilton, 1994: 23). These early debates offers the opportunity to focus on finding answers to questions centred on social experience, how it is created and how it gives meaning to human life. Therefore it is appropriate for social scientists to engage in exploring ways of knowing and understanding the experience of people living with a chronic



condition such as Buruli ulcer in order that their support needs for example can be effectively addressed. Understanding such human phenomenon needs subjectivity and interpretation and should not 'be reduced to mathematical formulas' (Krasner, 2000: 44) as proposed by the positivists.

The naturalistic epistemology uses 'social actors' (human researchers) to interact with the object of study (research participants) to construct meanings about their social world (Grix, 2002). So for example it is through my interactions with the respondents' in this study who have experienced Buruli ulcer that the real meanings of their experience could be constructed. Furthermore the naturalistic philosophy uses inductive form of thinking at the early stages of the research in order to arrive at the findings (Descombe, 2010), suggesting that theory is not derived from any pre-existing knowledge in the literature but through 'the discovery of patterns, themes, and categories that emerge from the researcher's data' (Patton 2000, pp. 453). However because the approach uses social actors to gain knowledge about the social world it has been criticised as having implications for bias. In order to reduce the potential for bias researchers are advised to include a reflective account of their study (Grix, 2002). This study is of no exception and therefore a reflexive account is provided at section 3.9 of this chapter.

This study was not devoid of the on-going paradigmatic debate. In deciding an approach for this study I found that both approaches were applicable or suitable. First it enabled me to approach the respondents' in their natural settings and then analyze the data inductively. Then the resulting framework was analyzed deductively (a feature of the Grounded Theory methodology), thus allowing some elements of the positivism in the analysis.

The literature review revealed that previous studies on people living with Buruli ulcer revealed a leaning towards a positivist paradigmatic stance. Therefore, opting for a methodology that was subjective, exploratory, and in the respondents own natural setting was deemed appropriate to enhance the quality of the results and the rationale for this is discussed next.

### ***3.3 Rationale for using the Qualitative Approach***

The qualitative approach was chosen for this study because of the suitability of such methods for the research questions being investigated. The research questions of this study are well suited to the qualitative approach as they seek to explore the illness experiences and attitudes, the perspectives and the behaviour of people living with Buruli ulcer. The qualitative enquiry is particularly suited to exploring a previously little researched topic, offers in-depth enquiry and in naturalistic settings (Creswell, 1998).

The qualitative approach was chosen because its strength lies in the provision of rich information, for example, of patients' experiences, making it more holistic (Crombie & Davies, 1996). It strives for an understanding of the whole and it involves a merging together of various data collection strategies (Polit & Beck, 2005). In this study for example both the inductive and deductive approaches (a feature of the Grounded Theory methodology) were used to analyse the data which enabled me to ascertain the interrelationship between the variables identified. This cannot be achieved using the quantitative approach. Yet another feature is that it is used when the research question does not involve a clear and measurable framework or where observations need to be interpreted in context (Thompson, 1998). Thus a qualitative enquiry is particularly well suited for research that is exploratory or descriptive, that assumes the value of context and setting and that searches for a deeper understanding of the respondents' lived experiences of the phenomenon under investigation (Marshall and Rossman 1995). The perspectives, attitudes, experiences and the meanings that people living with Buruli ulcer attach to their condition cannot be explained through the survey method which has been used in most of the researches on Buruli ulcer. These attributes need to be observed, described and explored in order to understand how they live their lives and the meanings they attach to what are both obvious and peculiar to the observer. Thus, Creswell (1998, pp.17), argued that qualitative research is suited for examining areas in which 'variables cannot be identified; theories are not available to explain behaviour of participants...' It in effect, locates the observer in the world of the observed (Denzin and Lincoln, 2000).

Therefore choosing a qualitative approach to answer the research questions of this study was based on the strength of the qualitative methods and the weaknesses inherent in the quantitative/survey approach. The survey approach lacks flexibility and incapable to extract the 'hows', 'whys' and meanings respondents attach to their condition. This is because

respondents receive the same set of questions which are asked in the same manner or sequence. Thus according to Silverman (2001), structured interviews capture precise data of a codable nature in order to explain behaviour within pre-established categories.

In overview, this study involved 21 adults and six children living with Buruli ulcer using narratives, conversations, observations, documentary sources and semi-structured interviews. The sample size and the characteristics of the sample will be discussed later in the chapter.

### ***3.4 Rationale for Using Grounded Theory Methodology***

There is no single approach to qualitative research as there appears to be different typologies in the qualitative paradigm. Therefore Patton (2002, pp. 78), posits that ‘understanding the divergent theoretical and philosophical traditions that have influenced qualitative inquiry is especially important in the design stage...’

In particular this study was informed by the Grounded theory method, which was first developed by Glaser and Strauss (1967) and later refined by Strauss and Corbin (1990). The essential features of Grounded theory methods are the systematic inductive guidelines aimed at collecting and analysing unbiased data which is then used to build middle-range theoretical frameworks that explain the collected data (Charmaz, 2000). This refers to the method consisting of simultaneous data collection and analysis with each informing and focussing on the other throughout the research process – as an iterative process. This enables the researcher to generate concepts and hypotheses which are then developed into a substantive or formal theory through systematic analysis of the data.

Another feature of Grounded theory (in its original stance) assumes an objective external reality, making it positivist in outlook. This positivist underpinnings assumed by its proponents have, over the years, come under increasing attack by postmodernist and poststructuralists (Denzin, 1998; Van Manen, 1998). Strauss and Corbin (1990 and 1998), moved into post positivism, that is, reality cannot be fully apprehended, but can only be approximated (Guba, 1990), as they tried to give voice to their respondents and recognising the importance of incorporating art and science in their analysis.

A middle way approach is that of *constructivist* grounded theory with Charmaz (2000, 1998 and 2006) as one of its proponents. The constructivists recognise that the empirical world is

made up of 'relative multiple social realities' and therefore calls for the need to appreciate the views of the researcher and the researched. This view reaffirms studying people in their natural setting and redirects qualitative research away from positivism (Charmaz, 2000). The views of people living with Buruli ulcer as they see it cannot be apprehended by the researcher neither can it be assumed. Therefore a leaning towards the constructivist paradigm informed this research because according to Guba and Lincoln (1989), 'it provides the best fit whenever it is a human enquiry that is being considered. With this approach individuals do not find or discover knowledge but knowledge is socially constructed in relation to shared understandings, practices and language (Schwandts, 2000).

Guba and Lincoln (1989), posit that the basic belief system of the constructivist paradigm is reflected in the answers to the following questions:

- a, What is there to be known?
- b, What is the relationship of the knower to the known (or knowable) and
- c, What are the ways of finding out the knowledge?

These questions together with the philosophy of qualitative research guided the design of this study.

Using the constructivist grounded theory the first step was to study the data. Strauss and Corbin (1990) have suggested that the grounded theory approach invariably consist of a comparative method with repeated movement between data and analysis. The idea is to reveal what is happening or what the participants are doing. In this study these comparisons led to incorporating younger respondents who had initially been excluded from the study. It also led to the need for multiple interviews to enable the respondents to explore in some considerable detail some of the themes which arose; for example why respondents decided to abandon Western orthodox medical treatment for the African traditional approach. To answer the research questions using the constructionist grounded theory approach required a holistic knowledge of the lives of people living with Buruli ulcer which included their social world, their hospital experiences as well as the meanings and significance individuals gave to their well being as people living with disfigurement.

The approach I used in collecting the data was therefore based on Glaser and Strauss original work in 1967 and the constructivist approach particularly Charmaz's works (2000, 2002 and 2006). Because Glaser and Strauss later on had divergent views about how to analyse

grounded theory data leading to two traditions of grounded theory – Glaserian and Straussian - it was necessary for me to make a decision about which of the approaches to use in my study. It is not the intention of this study to arbitrate on Charmaz's (2006), Bryandt and Charmaz (2007) critiques of the two versions as well as Melia's (1996) description as war of words between friends but to consider both approaches in the light of the current study and make a decision whether to choose the Straussian full description approach or Glaser's abstract-conceptualisation process approach. Glaser's (1992) work and Strauss versions (based on Strauss and Corbin's 1990 work) as well as Charmaz's (2006) and Melia's (1996) critical analyses of their works assisted my choice- making. My decision to choose Glaser's version is based precisely on the following reasons.

From purely methodological point of view I realised that Glaser's approach is more suitable for studies which are exploratory in nature as opposed to Strauss' full descriptive approach. This study was aimed at exploring the experience of people living with Buruli ulcer and thus it was in line with Glaser's abstract-conceptualisation approach. Glaser (1992) was emphatic about how the research focus should emerge contrary to Strauss and Corbin's (1990) more definitive approach about what to study and what needs to be known. Apart from this Glaser's constant comparative method of analysis has structure and not as directive as that of Strauss. According to Glaser (1992) being directive may lead the researcher to 'force data to fit a preconceived theoretical framework' on the study thus compromising the outcome of the work. This will result in a conceptual description of the work and not a grounded theory as both of them originally conceived. In this study my aim was to make sure that the respondents' views were of paramount importance and because I wanted my grounded theory to reflect the perspectives of the respondents allowing the data to emerge from the study but not to be forced to 'fit a preconceived theoretical framework' (Glaser, 1998 and 2001), I chose Glaser's approach. Glaser's approach focuses on abstract conceptualisation that are not concerned with people, time and place but tied to the substantive area of inquiry which is more useful and applicable to my study's particular goal. This study is meant to explore the lives of people living with Buruli Ulcer and so it makes sense to maximise the potential benefit from Glaser's approach.

Lehman (2001, pp: 9) observed that the Straussian approach appears more useful for studies involving individuals than studies involving organisational, political and technical issues. This study involves individuals living with a chronic condition which should have

encouraged me to adopt the Straussian approach. But I was not swayed by Lehman's (2001) observation because my preliminary literature search revealed the potential practical problems reported by earlier researchers who had used the Straussian coding paradigm approach (Kendall, 1999; Urquhart, 2001; Bryandt and Charmaz, 2007; Charmaz, 2006 and Sarker et al, 2001), and because I did not want to encounter similar problems while analysing the data I decided to follow Glaser's abstract conceptualisation approach.

### ***3.5 Philosophical basis of the Grounded Theory approach***

This study used the grounded theory approach as its methodology and this section outlines its evolutionary development, assumptions and the philosophical and intellectual basis of the approach. The philosophical basis of Grounded theory has been traced to symbolic interactionism by many writers (Goulding, 1999; Bryant and Chamaz, 2007; Crooks, 2001; Hutchinson and Wilson, 2001), although Glaser and Strauss (1967) said very little about this in their original book, *The Discovery of Grounded Theory*. Later on Strauss (1987) discussed the philosophical traditions underpinning the development of grounded theory emphasizing the influence of the Chicago School of Sociology and pragmatism with the following assumptions:

- a, that change is a feature of social life that needs to be accounted for by means of social interaction and process and;
- b, interaction, process and social change can only be understood if the researcher is able to grasp the actor's viewpoint.

Glaser (1992) on the other hand, stated how human beings shape the worlds they live in and how life is characterized by variability, complexity, change and process. In his later writings Glaser (1998) conceded that through his colleague Anselm Strauss, he started learning the social construction of realities by symbolic interaction making meanings through self indications to self and others. In the process he learned that man was a meaning making animal and that there was no need to force meaning on a participant, but rather there was 'a need to listen to his genuine meanings, to grasp his perspectives, to study his concerns and to study his motivational drivers' (pp: 32).

Symbolic interactionism can be traced to the works of Charles Cooley (1864 – 1929) and George Herbert Mead (1863 – 1931). According to this view there is no distinction between

the individual and the society that he/she lives in because a person's self identity grows out or is shaped by the relationship he has with others in his immediate environment. Thus Mead proposed that symbolism is the most profound aspect of human conduct, and that an individual's career or lifestyle is shaped by linguistics the greatest of which is language. So for example to seek the meaning of different experiences within our environment one needs to engage in exploring that culture (Crotty, 1998).

Blumer (1969) then identified what has become the focus or the bedrock of symbolic interactionism:

- a, that people act towards things and people on the basis of the meanings they have for them,
- b, meanings stem from interaction with others and;
- c, people's meanings are modified through an interpretive process used to make sense of and manage their social worlds.

In attempting to expand and to put Blumer's (1969) assumptions into context Snow (2001) argued that symbolic interactionism requires reflexive interaction and therefore people act and react to environmental cues and objects according to the meaning these hold for them. These meanings do evolve through interacting with others in the form of communication such as language, gestures and the significance of objects. So taking the role of others is a central notion of symbolic interactionism - that is putting oneself in the place of the other. Symbolic interactionism then becomes a theoretical perspective which informs the methodologies of social research; as it directs the investigator to take, to the best of his ability, the standpoint of those studied (Crotty, 1998). This role taking is an interaction – symbolic interaction – for it is possible only because of the 'significant symbols' ... that we humans share and through which we communicate' Denzin (1978, pp: 99) and 'It is only through dialogue that one becomes aware of the perceptions, feelings and attitudes of others and interprets their meanings and intent' (Crotty, 1978 pp: 75). It is this central notion of putting oneself in the place of the other and to see things from the others perspective that classical cultural anthropologists' idea of "going native", over the years has led to the belief that the research methodology - ethnography also took its root from symbolic interactionism. By means of in-depth interviewing, participant observation, collection of artefacts and documents the ethnographer learns from the observed the meanings they attach to every aspects of their lifestyles.

In terms of the methodology therefore, both the symbolic interactionist and the ethnographer enter into the world of their respondents to observe the interactions that go on in their environment, interpret their actions beyond mere descriptions by making meanings based on their “self, language, social setting and social object” (Schwandt, 1994 pp: 124). Grounded theory can therefore be viewed as a specific form of both symbolic interactionism and ethnography because it uses systematic procedures to collect and analyse qualitative data, the resultant theory could be traced to the behaviour, language, social setting and the overall environment in which the research took place. What makes grounded theory more distinct from other forms of qualitative research is that the substantive theory is a product of ‘continuous interplay between data collection and analysis’ (Glaser and Strauss, 1967), taking into consideration what goes on in the environment - a basis of symbolic interaction.

### ***3.6 Design of the Inquiry***

The preceding can be said to be the methodological groundwork of the inquiry and in this section I will explain the research design which outlines the strategy of sampling, the data collection and analysis I chose to explore the lives of people living with Buruli ulcer and their support needs. The over all research framework/ methodology of the study followed the schema outlined in Figure 2 below.



**Figure 2: The schema of the overall Methodology for the study**

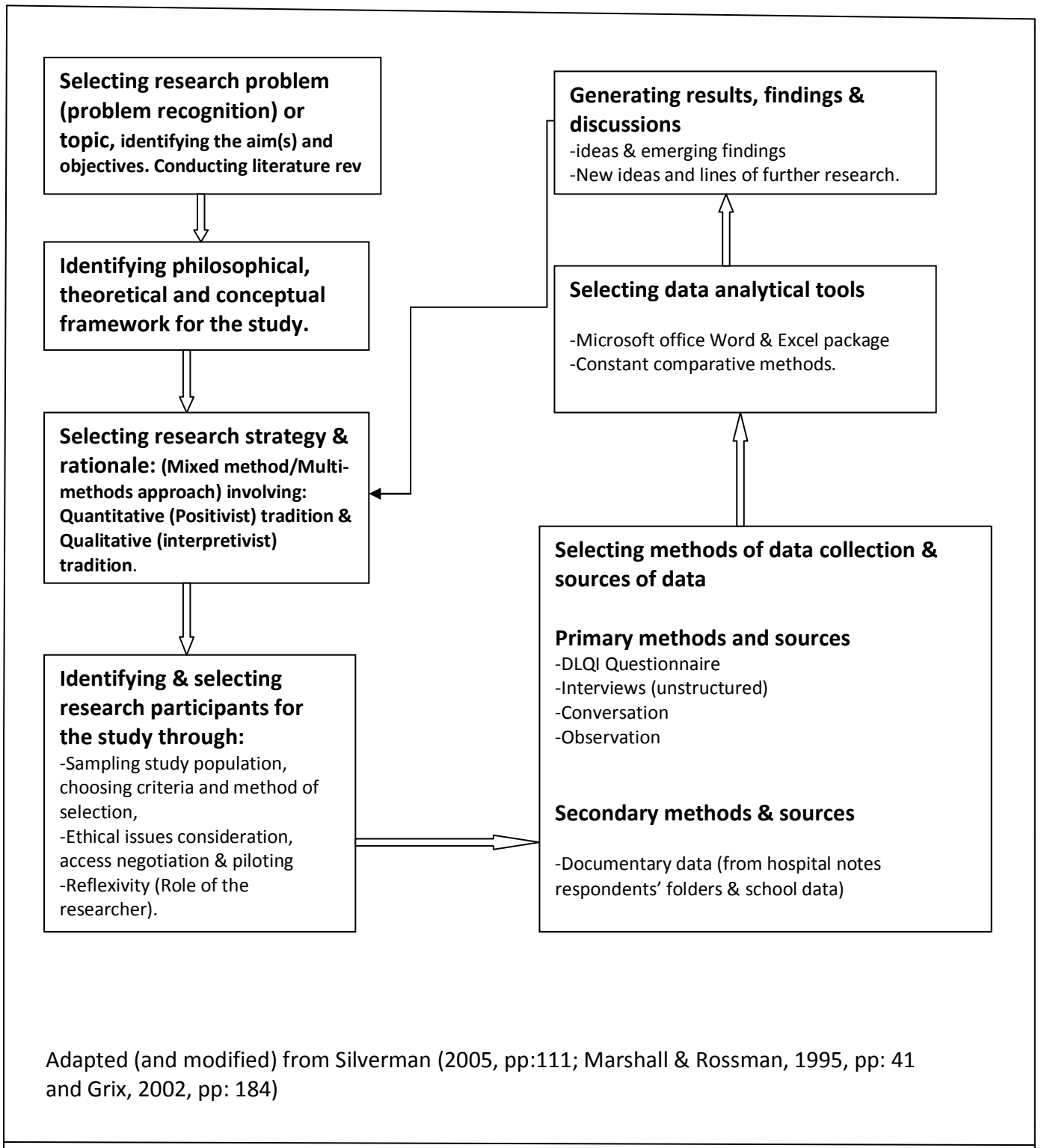


Figure 2 shows that depending on the focus of study the researcher is faced with different options – a qualitative, quantitative approach or a combination of both (mixed methods). As already explained in the preceding sections this study employed qualitative methods to gain knowledge on the social reality of the life of people living with *Mycobacterium Ulcerans* (Buruli ulcer) disease. The following sections will be about the study area and how it was approached, data collection methods, selection /sampling strategies and data analysis methods.

### **3.6.1 The Study Area:**

The study was conducted in a rural district in central Ghana. The rationale for choosing this district has been explained in section 1.2 in chapter one. The district has one hospital, four health centres, six clinics and five maternity homes. Agriculture is the main stay of the people in terms of output, employment and income with a population of 130,000 (2006 census). In terms of agriculture cocoa production is the dominant activity but the local farmers produce other food crops and vegetables at subsistence level for their own consumption having realised the dangers of monoculture. Poultry and animal farming on small scale could be found in many of the villages.

During the time of this field study, surface gold mining using simple tools (locally called *galamsay*) along river banks had become one of the major income generating activities in the district and it has attracted a lot of the youth from other parts of the country. Many foreign companies mainly from South East Asia were actively involved in the mining sector and they employed many of the youth. There are two main rivers which due to *galamsay* have transformed the landscape of the district. There are a lot of other smaller rivers and streams which overflow their banks during the rainy seasons but some of them become either misfit or dwindle in size during the hot dry season. Nonetheless these smaller rivers are not spared of the *galamsay* operators. Many of the communities drink from these streams but there has been a sudden change recently as The Millennium Development Project in its effort of poverty alleviation has constructed a lot of bore holes to provide safe drinking water for the people.

In terms of housing many of the houses are built with mud with thatch roofs. The few affluent ones have houses completed with cement and roofed with corrugated aluminium sheets. The

houses are mostly the compound type typical of *Akans* due to the extended family system. It is therefore not uncommon to see other members of the extended family – brothers, sisters, nieces, aunties, grand parents and others living together and other siblings sharing a room with cousins and friends. The houses are mostly detached with big compounds explaining the communal spirits among the inhabitants.

The main language spoken is the *Twi* dialect of the *Akans*. English as a second language is taught in schools. Therefore it takes an educated person in the district to speak English. Other tribes from other parts of Ghana live in the district but their languages have not had any influence on the locals. It is therefore common to hear almost every person in the district speaking *Twi*.

The district experiences a tropical humid climate with two almost imperceptible seasons – the rainy and dry seasons. The former starts from April till the middle of November and this is when the people in the district become busy with farming activities until the dry season takes over till the end of March.

### ***3.6.2 Negotiating access and selection of informants***

Gaining access to the community was not a straight forward procedure. It involved first of all where to locate the ‘gatekeepers’ who would direct me to the potential respondents, and negotiating with opinion leaders and key informants within the communities. This will be discussed in the following sections.

### ***3.6.3 Locating the potential respondents:***

Hammersley and Atkinson (1995), consider personal networks to be a legitimate source in gaining access to research sites. So contacts were made with the district hospital’s Matron to meet the potential ‘gatekeepers’. This first meeting was significant: first, to strike the needed acquaintance with the hospital authorities and to locate the potential respondents. The Matron introduced me to the staff and the nature of my study. I visited the records department to enable me get the individual patients’ records. Unfortunately, the period that records were available for the potential respondents were from 2001 to date (2010) and they were not in any chronological order. There were no individual records. I decided to do my best in the circumstances by constructing a composite record which consisted of any information I found

necessary and relevant to the work. This information was extracted manually as the hospital was now in the process of computerising their records. It is also worthy to note that at the time of the study there were only nine Buruli ulcer patients at the hospital. All the patients had been treated and discharged to the communities. This had not been planned for in the proposal before leaving for Ghana. Nevertheless Hammersley and Atkinson (1995), found that it was not unusual for processes to evolve as the study progresses, and Burges's (2000) advice that field researchers should be prepared to accommodate unforeseeable encounters in their studies.

All potential respondents were identified from the hospital records. I analysed the data using settlements as a criterion and a large-scale map of the area enabled me to identify the endemic area within the district. In terms of epidemiology the disease was concentrated around the south western part of the district.

#### ***3.6.4 Access to the community***

Hornsby-Smith (1993, p.53) and Walsh (1998, p.224), distinguish between two kinds of research settings: 'closed' or 'private' settings where access is controlled by 'gate-keepers' and 'open' or 'public' settings where access is freely available. This study fell in the latter category as all the potential respondents were located within sixteen communities with their own peculiar practical and ethical difficulties.

Access to this remote community was not a straight forward procedure. It involved different approaches with both the traditional and statutory authorities at different levels. It also involved knowing the traditions, customs and the traditional set up of the *Akan* people. This was to my advantage as an *Akan*. Descombe (2010) has suggested that the researcher's identity and 'self' can sometimes become a crucial resource that can enhance data collection. This will be discussed at the reflexive section.

I got a young man who knew the area very well to assist me to meet the potential respondents and the traditional authorities for the first time. I had to go to the local Chief's palace as *Akan* custom demanded to introduce myself to him and his elders to find out who the "key informants" would be. These are the individuals who provide useful insights into the group and can steer the researcher to information and contacts (Creswell, 1998). As an *Akan*, I knew

that if I won the support of the chief I would win the support of the entire community. Therefore reliable “key informants” would be obtained with the active support of the Chief and his council of elders. But I had to make sure that I avoided ‘giving an impression that might pose as an obstacle to access’ (Silverman 2000, p.199) while more positively ‘conveying an impression appropriate to the situation’ (Hamersley and Atkinson 1995, pp: 78-88). I did my best by maintaining my *Akan* identity by dressing as one and making sure that I had carefully chosen the right vocabulary.

My meeting with the Chief and his elders was full of surprises. The Chief (*Nana*) was represented by the head of the Royal Family (*Abusuapanin*), who appeared to me as the official spokesman of the entire community and its surrounds. I told the community the purpose of my study which would necessitate my stay in the community for a while.

The *Abusuapanin* appeared to me as someone who was enlightened and urbane. He had served as a linguist to the King of the *Ashantis* in Kumasi (the second largest city in Ghana) and therefore was well connected too. After the official meeting my discussion with him became very informal. He told me a lot about Buruli ulcer, its effect and impact on the community and why he thought the government of Ghana had failed the people.

The issue of ethical approval became contentious as the community questioned the legality of The Health Service Ethical Review Committee to grant me access before the study commenced. In the opinion leaders’ view my ethical obligation lied with the community representatives and the people living with Buruli ulcer and not the Administrators and the Professionals in Accra. This issue was carefully surmounted before the study commenced which raises a lot of ethical dilemmas as to who actually has the final say in granting access to respondents who do not reside in institutions. This is discussed at the reflection and reflexivity section.

The community provided me with a free accommodation which I used throughout my stay. I continued to have relationship with the opinion leaders as a way of deepening my relationship with them and the communities in general. I was introduced to the Chairman of the Buruli ulcer Association in the area. He had a list of all who had suffered from the disease in the area. I compared his list with that of the hospital and found a lot of differences, that is, whilst he had omitted the names of children below eighteen years from his list the hospital had not

deleted names of patients who had died. This notwithstanding was to my advantage as both records/ list constituted a potential sample frame for my study. The chairman agreed to be my aide-de-camp and my first key informant.

I left the community to the city to get prepared for my stay with them and also to work on the official ethical approval letter from Accra. I had to also complete my negotiation with the Director of Buruli Ulcer Control Programme in Accra as a potential local supervisor for my work which was one of the requirements by the Ethical Review Committee.

### ***3.6.5. Entering the community and identification of key informants.***

On arrival in the community for the second time I realised that the Buruli ulcer Association Chairman had made my work far easier for me. He had visited all the sixteen communities and informed them of my research. He had informed me of the additional task of alleviating the suspicions of the potential respondents as they had had promises in the past from previous researchers. Upon his advice I contacted the district director of health who in consultation with the opinion leaders was able to alleviate the suspicions of the potential respondents. The verbal approval from the District Director of health paved the way for me to proceed without hindrance, confirming Burges (2000), view that entering unstructured settings involves ‘negotiations and renegotiations’. *Nana* (The chief) and *Abusuapanin* (head of the royal family) assured me of their continued support for my stay there. After a while a key informant from each community was purposively selected on the basis of ‘relevance to the topic and privileged knowledge’ (Patton 2002) or experience of Buruli ulcer.

From this time on I stayed in the community. I tried to get as close to them as possible, to understand their ways of life and to socialise with them. I achieved this by observing and having conversations with the people as well as visiting some of the people living with Buruli ulcer in their homes, farms, ‘*galamsay*’ (mining) sites, in the market, boarding public transport with them, attending funerals on Saturdays, Church services and out door ceremonies such as child naming typical of *Akans* on Sundays. I sought permission from the various Primary and Junior Secondary School Head teachers to visit them to familiarise myself with the life of children living with Buruli ulcer. These were used to capture what actually went on in the communities. These would be discussed in the appropriate sections below.

### ***3.6.6 Sampling: Selection and recruitment of respondents***

One of the basic tasks of every qualitative researcher is the sampling method to select the respondents from the population of interest. This is because it is not easy to gain detailed knowledge of all the people affected by the topic/subject of interest. Marshall and Rossman (1995) pointed out that it is possible to make a choice to focus the study on people within a particular population through sampling of which there are two main types- probability sampling and non-probability sampling methods.

In probability sampling ‘nothing but chance determines which elements are included in the sample’ (Schutt 2009, pp: 158). Usually when the aim of the research is to generalise the results to the larger population this method becomes more desirable and has the advantage of reducing sample selection biases and thereby increasing representativeness. However real world research conducted using this method tends to be very difficult and often impossible to fulfil due to such factors as cost, poor response rate, data attrition and time involved in obtaining and selecting the sample population (Robson, 2011).

With the non-probability method the probability of selecting the respondents is unknown but the small sample allows the researcher to conduct intensive study on the selected respondents using a variety of methods to collect rich and varied information (Schutt, 2009). Peoples’ values, attitudes, beliefs and opinions are not normally distributed so the probability approach was found to be inappropriate in this study. Again I realised that not all the potential respondents were on my “sampling frame” (the Buruli ulcer Chairman’s list and the hospital records) so a combination of purposive sampling and snowballing was used to select the respondents from sixteen communities (that is cases of all ages of 16 years old and above who were affected by Buruli ulcer and had had surgery). These are explained next.

In Purposive sampling the respondents’ or ‘elements are selected for a purpose usually because of their unique position’ (Schutt 2009. p.173). Rubin and Rubin (1995, pp. 66) suggest that researchers using purposive sampling strategy should know that their informants are:

- a, knowledgeable about the cultural arena or situation or experience being studied;
- b, are willing to talk; and
- c, representative of the range of points of view.

With regard to snowballing the potential respondents who are interested to take part in the study are asked if they know of anyone else with similar characteristics who would be interested to take part in the study. The nominated individuals are then interviewed in turn and are asked to identify further sample members (Descombe, 2010).

With this kind of (purposive) sampling the sample is ‘hand-picked’ ... on the basis of relevance (to the issue being investigated) or knowledge (experience or privileged knowledge about the topic) (Descombe, 2010, p. 34). This formed the basis of establishing the inclusion and exclusion criteria in the selection of the respondents.

Conducting several interviews should contribute to a deeper understanding of the phenomenon under study (Stoltz, et al 2006) and help to make generalisations of the findings (Moon et al 2000). Apart from the sample size being sufficient to reach data saturation the sample also needed to be sufficiently diverse to ensure the transferability of the data/findings. Therefore there was the need to cover a wide range of disabilities, ages and gender within the sample. Eventually thirty five respondents were purposefully selected and agreed to take part in the study. The actual number (21 adults and six children) was determined at the point of ‘theoretical saturation’.

Those who agreed to participate were required to sign/thumbprint a consent form (see appendix 5), which had been read to them in the local language. For respondents’ below 16 years of age an appropriate adult’s consent (thumbprint or signature) was sought. When all the consent forms had been received, I met the thirty five respondents for the second time. Entering the field should be seen as a learning process (Flick 2009) and ‘to build trusting relationships’ (Marshall and Rossman 2006, p.62). Closeness to the respondents in this way was to ensure that I had been able to strike sufficient rapport and empathy and to allay any fears and suspicions.

During this second meeting the nature of the interview (one-to-one and tape recorded) was emphasised. The respondents were given the opportunity to ask any questions. The respondents below the age of 16 years were assured that an appropriate adult (parent/guardian) would be present during the interview to give them the necessary emotional support.



### ***3.6.6.1 Theoretical Sampling***

A basic feature of the inductive process in grounded theory is that data collection, analysis and generation of substantive theory occur simultaneously. Glaser and Strauss (1967) originally defined theoretical sampling as:

‘the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges’ (pp: 45).

Birks and Mills (2011, pp: 69) put the original definition in focus as ‘the process of identifying and pursuing clues that arise during analysis in grounded theory study’.

The difference between theoretical sampling and other sampling techniques or strategies in research is that while in other sampling techniques the researcher makes decisions at the outset as to who, what, where, when and how to sample based mostly on finding a representative data, in theoretical sampling ‘the aim is to build theory through the construction of categories directly from data’ (Birks and Miles, 2012, pp: 70). In essence sampling is directed by the emerging theory as the researcher keeps on asking questions to find out what is missing, obscured, obvious in the data; all raised through the application of the constant comparative method of analysis. According to Glaser (1978), as the grounded theory emerges the researcher considers what groups or subgroups should be approached next, where to find them in order to develop his theory as it emerges. Thus the group(s) to be studied are chosen on the basis of ‘theoretical purpose and relevance’ for developing the categories that are emerging (Glaser and Strauss 1967).

As the interview progressed this feature of grounded theory guided me to be aware of issues that required expansion or clarification as well as the next stage of data collection. In practice the technique led to the inclusion of younger respondents (below 16 years old) who had initially been excluded from the study due to their ages. The rationale was that there was the need to explore the perspectives, views and experiences of these ‘young ones’ as many of the ‘older ones’ had forgotten their experiences of the phenomenon under investigation.

Theoretical sampling also allowed me to re-interview some of the respondents to clarify issues that had theoretical relevance, that is, to ‘fill the gaps’ in the study as well as interviewing of the health care professionals in the hospital to identify what they perceived as the support needs of the respondents in the study. It also led to the use of the Dermatology

Life Quality Index (DLQI) to confirm the quality of life of the respondents which is discussed later.

### ***3.6.7 Inclusion and exclusion criteria***

The aim of sampling in qualitative research is to ensure that a wide range of experiences have been sampled in order to ensure the transferability of the findings (Marshall and Rossman 2006) that is, the findings can be applied to the wider community. To be included in the study (at the outset) I set out that the potential respondent should be at least 16 years old and should have suffered from Buruli ulcer with a disability or disfigurement. The sample needed to represent the diversity of the experiences.

The exclusion criteria were that children under the age of 16 years were initially excluded from the study as well as anyone with psychiatric impairment. This was revised to include younger children who were theoretically sampled into the study. Other people living with Buruli ulcer without a disability or disfigurement were also excluded from the study (This is because they had had a small nodule which did not develop into a serious ulcer).

### ***3.6.8 Participant Information Sheets: informed consent.***

The respondents were told to go and reflect on the study before the participant information sheet (see appendix 5) was read to them in *Twi*. ‘Participant information sheets should explain what is involved and the likely duration of the interview and should give assurances about confidentiality’ (Britten, 2000, pp.18). The purpose and academic nature of the study, its voluntary nature, the right to withdraw at any time and assurances about confidentiality and anonymity were elaborated to the respondents. I also explained how long each interview would take (approximately one hour with breaks as necessary) as well as its longitudinal nature whereby there would be further interviews to throw more light on issues that might emerge later (a feature of the theoretical sampling technique).

The respondents and their parents/legal guardians/carers were given the opportunity to ask questions to clarify any issues. When their concerns had been clarified the dates to visit them for the interviews were given. I assured them of my visit a day prior to the interview to remind them and that they were at liberty to withdraw during the day when they would sign the consent forms.

### 3.6.9 An Overview of Data Collected

The actual data collected from this field study were obtained from multiple sources and shown in the table 1 below.

**Table 1: Data Collected and Sources**

Data	Type of data	Source
<b>Primary data</b>	Participant Observation	<ul style="list-style-type: none"> <li>• Respondents' Activities of daily living</li> <li>• Church and other outdoor Programmes</li> <li>• Certain activities in the community such as Farming, 'galamsay' sites, Public places e.g. Markets etc</li> </ul>
	Questionnaire	<ul style="list-style-type: none"> <li>• DLQI Questionnaire</li> </ul>
	Informal Interview	<ul style="list-style-type: none"> <li>• One-to-one informal interviews with respondents</li> </ul>
	Conversation	<ul style="list-style-type: none"> <li>• With opinion leaders, Church leaders, Dispensers, Herbalists, Hospital staff, Parents, Respondents etc.</li> </ul>
<b>Secondary data</b>	Documents	<ul style="list-style-type: none"> <li>• Hospital records.</li> <li>• Respondents' clinical folders</li> <li>• Photos/Albums.</li> <li>• School register/Attendance records.</li> <li>• Literature as data.</li> </ul>

Source: Fieldwork, 2010

The importance of using multiple sources of information (such as observation, interviewing and document analysis) has been emphasised by Patton (2002) because no single source of

information can be trusted to provide a comprehensive perspective on the study. ‘Using a combination of data types – the method of triangulation – increases validity as the strengths of one approach can compensate for the weaknesses of another approach’ (Marshall and Rossman, 1989 pp. 79-111). Therefore the main data sources that influenced this study were or could be grouped under the following headings: interviews (including pilot interviews), participant observation, conversation, questionnaire and documents. These will be discussed under the appropriate sections which follow.

### ***3.6.10 Pilot exploratory interview***

Having obtained the clearance from the Ethics Committee and having stayed in the community for six days to familiarise myself with the people and the environment I decided to test my interview guide (see appendix 6) by selecting two potential respondents for a pilot interview. I chose one young man of twenty four years old with a disfigured right arm and a twenty six year old lady with a contracture to the right foot (all due to Buruli ulcer). The two were from villages which were five miles apart and had initially agreed to participate in the study.

I read the Participants Information Sheet to them. I discussed with them if they would be willing to take part in a pilot interview to enable me test my interview guide. I had become very familiar with them so they did not hesitate to agree to take part in the study. They were allowed to decide a convenient location and time for the interviews. The first interview was conducted under a tree at the back of the respondent’s house while the second interview was conducted in her house. The first interview lasted for 46 minutes while the second interview lasted for nearly one hour. Both interviews were tape recorded as already agreed with them.

The interview guide was used to ask them to tell me about themselves prior to the onset of Buruli ulcer. The next was to stimulate them to describe their experiences as inpatients at the hospital. The remainder was conversational in style. As far as possible interviews were respondent-led but a topic guide informed by literature on Buruli ulcer and my conversations and observations in the communities were used to prompt further discussions if necessary. Interview guides help to ensure that similar topics are explored with all participants and can be structured to a greater or lesser degree (Patton, 2002). Since semi-structured interviews were used the interview guide contained a list of topic guides to be covered but it did not

specify the order or specific questions to be asked or discussed. I had the option to probe for issues that needed more clarification.

I thanked them for their cooperation and assistance and gave each five cedis (the equivalent of £2 at the time) for their time. The pilot interview was helpful as it helped me to revise my interview guide (see appendix 7). The pilot interview was transcribed verbatim into my field notebook the same evening by hand as there was no electricity in the community.

### ***3.6.11 Informal Semi-structured Interviews***

#### ***36.11.1 Procedure***

The aim was to get the respondents' responses about their experiences, feelings, perceptions as well as their understanding and knowledge of Buruli ulcer. Interviews permit the observer to go beyond actual behaviour to explore feelings and thoughts (Patton, 2002). Patton (2002, pp: 342) has identified three qualitative approaches to in-depth exploratory interviewing which were of considerable importance to me at the time:

- a, the informal conversational interview;
- b, the general interview guide approach and
- c, the standard open-ended interview.

Therefore all the interviews were the semi-structured in-depth, (which included a variant of all three above), one-to-one and were conducted in *Twi* dialect and audio-taped. In-depth interviews 'allow us to enter into the other person's perspective' Patton (2002, pp: 34).

Therefore the interviews allowed the respondents viewpoints to be expressed freely. This mean that different types of questions were applied using an interview guide based on the research questions, my observations and conversations. The idea was to probe further on issues that I found relevant to the research questions and to allow the respondents' perspective on their lives as people living with Buruli ulcer to unfold as they viewed it (the emic perspective),but not as I (the researcher) viewed it (the etic perspective)' (Marshall and Rossman, 2005 pp: 101). The respondents' thus became 'experts and theoreticians of themselves' (Flick 2009, pp: 178).

I could have adopted a focus group discussion with the respondents to save time but I did not. This is because individual one-to-one interviews have been found to be better suited to studies which require explorations in depth (rather than breadth) of a topic (Lewis, 2003). Apart from this the informal atmosphere encourages respondents to be open and honest, and

secondly the qualitative data collected are well suited for locating the meanings people place on the events, processes and structures of their lives (Miles and Huberman (1994). Therefore the interviews were conducted in an informal way which encouraged the respondents to speak freely and to develop their own thoughts and viewpoints with minimum interruption. So in a way the conversations I had coupled with the observations helped to restructure the interviews. With some of the respondents it became necessary to re-interview them to throw light on issues which emerged later from my analyses.

The day before the actual interviews I contacted the respondents to make sure that they were still willing to participate in the research. The information sheet was recapped and they were asked again if they had any questions or concerns for clarifications. If no concerns or questions were raised they were requested to complete the consent forms. Many of the respondents were illiterates so they had to thumbprint to indicate their willingness to participate in the study, yet with some of them a mere nod or verbal consent was given.

The relationship between the interviewer and the interviewee has been found to be of paramount importance in fostering trust and making the interviewee feels safe (Gerson and Horowitz, 2002). Therefore in order that the respondents felt comfortable in their surroundings the order in which the interviews were conducted and the location were discussed with them. Ethical guidelines have also been found to be based on scenarios of unequal power, especially where researchers could abuse their superior power situations (Holstein and Gubrium 1995). To avoid this and to ensure that power was equalised I gave the respondents the choice to decide where they wanted to have the interviews. The interviews therefore took place in a variety of settings convenient for the respondents. Considering the sensitive nature of the topic it seemed appropriate for me at the time to begin by adopting an exploratory approach that considers how individuals construe what is happening to them and how this in turn, influences coping and adjustment. The respondents' answers and narratives were deeper and more exploratory. As the interview proceeded they told me their life story in their own words including their childhood, school and family, their experience with Buruli ulcer and their reaction when Buruli ulcer was first confirmed at the hospital/clinic. I achieved this by using open-ended questions such as, "can you give me an example"? "How did you feel"? "What were your thoughts"? "Can you tell me more"? And so on. In two separate instances the interviews had to stop as the respondents became upset

and emotional as they recounted their experiences with Buruli ulcer. The interviews resumed when they were emotionally prepared to continue.

There were also the issue of what I would describe as bi-vocal or shared interview which was never anticipated. This happened during the interview process when some of the respondents could not reconstruct or recount their experiences due to time factor and the fact that they were as young as four or five years old to remember their experiences during the onset of the disease. In these instances I discussed with them if they would allow their parents to take part in the interview to help them reconstruct their experiences.

Bi-vocal or shared interview was useful particularly when it came to the issue of late presentation of the disease as well as the respondents' lives at the Hospital. This notwithstanding it had its own difficulties. As the interview progressed the respondents were unwilling to disclose personal or private issues with their lives as disfigured individuals particularly issues bothering on their sexuality. This had to be overcome politely by asking the parent to leave and assuring them that if I found it necessary to invite them for more information I would let them know.

My twelve weeks stay in the community helped me to build the necessary rapport to convey to the respondents that the information they were disclosing were important to me. I ensured that extra time was needed to establish the needed relationship in a relaxed atmosphere so that no pressure was put on them. I made sure that I maintained a neutral stand throughout the deliberations as Patton (2002), has advised that the interviewer should focus on the interviewee's perspective, experience and opinions and it is therefore not a place to pass judgement on the respondent.

### ***3.6.12 Participant observation***

I combined the interviews with the role of a participant observer, using all my senses to note and capture what went on in the environment. Germain (1993, pp: 250) defined participant observation as 'immersion of the researcher in the cultural data of the field'. It means that the researcher finds any means possible to become part of the society or subculture s/he is studying without inducing any significant change in the people being researched. The researcher only becomes both 'a listener and a learner', while s/he uses both cognitive and behavioural conceptualisations to not only describe what he sees but also be able to assess

and offer explanation of what is going on (pp: 250). Lee (2000) sees participant observation as an unobstructive use of collecting data and suggested that one of the justifications for its use lies in the methodological weaknesses of interviews and questionnaires. As Webb et al. (1986, p.1) put it: ‘interviews and questionnaires intrude as foreign elements into the social setting ... they elicit atypical role and response, they are limited to those who are accessible and who will cooperate...’. Observing a social situation unobtrusively to capture what goes on everyday therefore yields quality results for the social researcher. This is sometimes combined with participating in the activities of the researched.

With regard to sensitive and personal behaviours, Lee (2000) found that the characteristics of the interviewers can under certain circumstances affect the answers respondents give to particular kinds of questions and respondents sometimes try to manage their impressions in order to maintain their standing in the eyes of the interviewer. Lee (1995) suggested that unobtrusive methods encourage researchers to innovate in order to find pathways around the obstacle certain topics put in their way. (Silverman (2001) shares this view that certain attitudes and behaviours within the environment cannot be identified by any form of survey research. Dabbs (1982) referred to this as ‘ephemeral traces’ within the social environment which needed to be captured by the researcher to complement other data collecting methods. These ephemeral traces ‘make up much of the ordinary behaviour of people and organisations’ but ‘unless someone or something is there to record, the ephemeral trace is lost’ (Dabbs 1982, pp: 34).

### ***3.6.12.1 Field roles***

In Junker’s (1960, pp: 35 – 38) study he put the participant-observation in a four stage continuum which researchers oscillate – from a complete observer, observer-as-participant, participant-as- observer to complete participant. Junker (1960) found that in the early stages of reconnaissance, the first activities of the field worker will be the role of complete observer. In the complete observer’s role the researcher does not hide his presence but s/he does not directly interact with the researched. After a while as s/he interacts with more and more people, s/he moves into observer-as-participant role. This is whereby the researcher’s role is well known in advance. The researcher may be permitted to a wide range of information. He has the choice to be selective in what s/he chooses to observe or participate. From here s/he moves into the participant-as- observer role whereby the researcher may participate as an employee of the organisation, or as a member of the group s/he is investigating. In this role



the researcher's flexibility in movement is limited and he may also be limited to access to certain kinds of information which fellow workers or the observed may be unwilling to share. In the extreme end of the continuum - the complete participant role in which Junker (1960) says that the participant-observer's identity is intentionally concealed because s/he tries to become a full-fledged member of the community or the culture he is researching. This role would be seen in today's research governance as unethical because it violates the core principles of informed consent and voluntary participation (see section 3.6 below). This role, according to Junker (1960) could be inadvertent particularly when there is reason to believe that it is unwise to interrupt the situation to explain the study, or when the identities of those researched are not in jeopardy. Silverman (2000), argues that 'we should not assume that 'covert' access always involves possible offence' (p.200).

Spradley (1980, p. 58-62) offered variations on Junker's (1960) version, and described five types of participant observation – nonparticipation, passive, moderate, active and complete participation and said that 'by means of participant observation you will observe the activities of people, the physical characteristics of the social situation, and what it feels like to be part of the scene' (p. 33). Given the nature of this study and the social stigma attached to Buruli ulcer, I initially planned to play the role of a moderate participant. Spradley (1980, pp. 60), describes the moderate participant as present at the scene of action 'to maintain a balance between being an insider and an outsider, between participation and observation'. While observing and talking with people I realised that it was not possible to adhere to Spradley's (1980) clear-cut delineation. Differences between real and verbal behaviour became apparent, therefore a combination of Spradley's (1980) variations and Junker's (1960) continuum (apart from complete participant) were employed at least inadvertently to collect the relevant data.

My approach reflected Bogdewic's (1999) observation that in participant observation the extent to which the researcher both chooses to participate and is allowed to participate depends on several factors. In this study the primary factors were the purpose of the study (to see how people living with Buruli ulcer interacted with the wider community) as well as the setting (which was highly unstructured which gave me the opportunity to observe a range of activities).

I varied my participant observer roles which provided me with clues and important questions for subsequent interviews. For example when the children were normally seen near the pools of water at the *galamsay* (mining) sites helped me to delve into the normal activities during the long school holidays. I watched how these children swam in these pools of water and the streams and if their parents were aware that the bacterium, *Mycobacterium Ulcerans* was prevalent in those streams as had been documented in the literature.

But Silverman (2001), warns that once people become aware that they are being watched they can ‘manage their appearances by controlling the impressions they give’ (p.52). So I tried to minimise this and to allow as near a natural scene as possible. To do this, I carefully considered and maintained a distance in relation to the people and the environment being observed to avoid influencing the activities going on in my presence.

In deciding what to observe I had to make strategic decisions which involved the deliberate selection of people so as not to ‘disrupt the naturalness of the setting’ (Descombe 2010, p.206). In the first week I decided to observe unguided by any framework, that is non-selective in terms of what to observe; what Descombe (2010), describes as ‘holistic observation’ in line with Junker’s (1960) first stage of complete observation. I was simply ‘learning the ropes’ (Bogdewick 1999) – observing the whole community: the socio-cultural organisation, the activities that go on and how people living with Buruli ulcer interacted with the general community.

From then on my observation began to take shape - became more focused and then selective based on areas of interest and of significance which needed more scrutiny. Therefore I attended social activities such as funerals (usually on Saturdays), church services (on Sundays), out-door ceremonies/engagements (usually on Sundays), as well as how they carried out their daily activities such as farming, trading, working as miners (*‘galamsay’* workers) and the lives of Buruli ulcer children in schools to see what actually went on and how people living with Buruli ulcer got on during such gatherings. This followed Spradley’s (1980) three levels of observation - descriptive, focused and selective.

The observed data were recorded in my field note. I chose my timing carefully. For example on Sundays I tried to be at the church before anyone arrived and I made sure I stood at the entrance. This way I will have the opportunity of observing how people come to church

(individually or in groups) and how they shared seats or not with people living with Buruli ulcer. Getting into the church premises early also gave me the opportunity to have informal conversations with the priest or his assistants about people living with Buruli ulcer.

Other information I observed were location of ulcer, mobility/restriction/contracture and interaction with the opposite sex. Observing the physical characteristics and appearances of the respondents this way was a prelude to the one-to-one interviews – to ask them questions about how they carried out their activities of daily living to enable me to make comparisons with other studies.

I must also admit that I did sometimes observe or intrude ‘covertly’, thereby compromising my ethical obligation with the respondents. This was when I visited the mining (*galamsay*) sites. People living with Buruli ulcer would always try to give wrong impressions whenever they saw me. Therefore I normally tried to avoid being seen at the site to enable me know how they actually carry out this activities with their disfigurement.

### **3.6.13 Conversational data:**

As part of my informal interviews I talked with ordinary people, opinion leaders as well as people living with Buruli ulcer and their parents/relations to solicit their views, opinions, perceptions, experiences, feelings and attitudes.

These conversations were recorded in my field note and research diary. The conversations I had particularly with the key informants/opinion leaders were important source of data because Patton (2002), observed that they give information about what the observer has not or cannot experience. Of particular use of such conversation was the attitude of the opinion leaders about the government’s decision on Buruli ulcer in the community and anger and frustration from parents and carers with parental responsibilities.

Other conversational data were obtained from key informants and they helped me to understand certain words and phrases which would have been difficult to understand. For example the use of the terms ‘*Kjobasia*’ (a derogatory name for transsexuals) and ‘*Mekondowuo*’ (I wish I were dead) would have escaped my attention had it not been the key informants some of whom were people living with Buruli ulcers. The diversity of the information I collected revealed that the information from the Buruli ulcer key informants

were not the whole truth; they could be perceptions yet I found them invaluable. Such information were clearly specified in the field notes so that, as Patton (2002), observed, “the researcher’s observations and those of the informants do not become confounded”. Different colours were used in my field notes to guide me on this varied information.

Another source of conversational data was from the ‘Ministers of God’ (the Priests and Catechists) of the various denominations. All but four of the respondents in the study professed to be regular church attendants, (although some of them admitted they combined church going with their traditional worship) and therefore I found it necessary to talk to these ‘Men of God’ as many of them had assumed the unofficial role of counsellors. These ‘Men of God’ were selected purposefully and they revealed a lot of rich information particularly about relationship, psychosocial problems and support needs of the respondents and people living with Buruli ulcer in general. All these were recorded in the field notes with comments which were highlighted in red colours.

I also had the opportunity to have conversations with traditional health practitioners. The selection of these important key informants was not based on any sampling technique but by pure chance. They told me about what they use to treat people living with Buruli ulcer, their faith and how they interacted with their patients. All these were recorded in the field notes in a different colour

#### ***3.6.14 Questionnaire:***

The only questionnaire which was used in the field was data derived from the Dermatology Life Quality Index (DLQI) questionnaire (see appendices 3 and 4). The information on the questionnaire had to be interpreted to the respondents in *Twi* to make it meaningful to them. Codes were used to identify each respondent. This source of data was combined with the qualitative data to determine the effect of Buruli ulcer on the patients’ quality of life.

The DLQI tool is a simple self administered, easy and user friendly validated questionnaire used to measure the health related quality of life of patients suffering from a skin disease. It was developed in 1994 and it is the first dermatology-specific quality of life instrument. It consists of 10 questions concerning the patients’ perception of the impact of the skin disease

in different aspects of their health-related quality of life over the last week (see appendix3). There is also a Children version (see appendix4).

Each question is scored on a four-point Likert scale:

Not at all/Not relevant =0;

A little = 1;

A lot = 2 and

Very much = 3.

Scores of individual items (0-3) are added to yield a total score (0-30); higher scores mean greater impairments on the patients' quality of life.

#### ***3.6.14.1 Meaning of the DLQI scores***

0-1 = no effect at all on the patient's life;

2-5 = small effect on the patient's life;

6-10 = moderate effect on the patient's life;

11-20 = very much effect on the patient's life and

21-30 = extremely large effect on the patient's life (Finlay and Khan, 1994).

#### ***3.6.14.2 Administration of the DLQI questionnaire***

The DLQI questionnaire was administered to 21 adults of 16 years and older respondents.

The questions were interpreted in the *Twi* dialect by the researcher to 14 of the respondents and the remaining seven were assisted to complete the questionnaires themselves in English.

The children's version was administered to the six minors.

For reasons of anonymity the respondents names were replaced with codes which were known to me only and these codes were recorded on the score sheet before analysing.

Microsoft office Excel was used to analyse the questionnaires. In the spread sheet codes were given to each question based on the key word(s) in the question. For example question one was coded *itchy/sore/painful* and the corresponding options weighted as follows:

Very much 3;

A lot 2;

A little 1 and

0, for Not at all.

To facilitate easy comparison between the gender, males and females were given codes 1 and 2 respectively. So for example M1 will indicate respondent number one who is a male and F5 will indicate respondent 5 who was a female. The total score for each respondent was then recorded and compared to the DLQI Scores. The outcome of this analysis is shown by figures 9-11 (inclusive) in the findings chapter.

### ***3.6.15 Documental data:***

Documents and records are necessary as they ‘provide a behind-the-scenes look of the study that may not be directly observable and about which the interviewer might not ask appropriate questions without the leads provided through documents’ (Patton, 2002:p.307). Personal data about the respondents (age, sex, home town) as well as treatment data (type of ulcer and the location, type of treatment, duration of treatment/length of hospital stay etc) were collected at the hospital. These were compared with the information on the clinic cards given to the patients when they were discharged. Some of them had photos of their wounds in their private folders or albums which were made available to me.

A visit to the local clinic where most of them attended for daily dressings also provided useful documentary data such as type of dressings, number of times of attendance, recurrence rates, referrals as well as any support that had been offered. Information from the Buruli ulcer Chairman’s personal folder such as minutes of their meetings, government officials they had interacted with were all noted. Personal data such as age, sex, marital and employment status and hometown, were confirmed in the field with the patients’ voters Identity Cards which contained every person of voting age personal data. The ages of respondents who were below 16 years of age and who had no voters ID cards were confirmed by their parents.

Data were also collected from the school authorities regarding number of days when the pupil/student did not attend school due to his/her condition, any assistance given, any form of bullying recorded and the effect of the Buruli ulcer on the pupils performance (if any) were all provided by the schools without hindrance.

Flick (2009, p.258) has suggested that once the sort of documents to use are known ‘a major step will be to construct a corpus of documents’ as well as ‘intertextuality of documents’; which is linking the documents to other related documents to enable the researcher to decide whether he will select a representative sample of them. Due to time and funding constraints I

prepared a table with the headings of each demographic data which were relevant to the study (such as age at the time of diagnosis, educational background, employment, treatment received and relationships). These were collected in a way which did not expose the identity of the individual patient. These documents would provide the key context to understand the respondents' illness experience and behaviour but this had to be relevant to their context and how typical they are vis-à-vis any findings that may be generated from the study.

### ***3.6.16 Data recording and preparation***

The interviews were audio taped using Olympus DS2200 Digital Voice Recorder. I had a back up Olympus VN-120 PC but this was never used. The recordings of the interviews were transcribed verbatim by hand as there was no electricity. The interviews in *Twi* were translated into English and transcribed verbatim. Marshall and Rossman (2006) have cautioned that transcribing and translating entail judgement and interpretation. Clues to meanings of pauses and unfinished sentences as well as the visual cues one would rely on to interpret certain meanings are likely to be misunderstood when one reads the transcribed data.

I anticipated the difficult task of generating accurate data when translating certain key words and phrases from *Twi* to English. To reduce these problems and to ensure that the translation was accurate and captured the meanings of the original language every third transcription was checked by an independent person (the Head teacher of the local JSS) with good knowledge in both languages to ensure that the transcripts were the exact translation (he listened to the original recording while reading the draft translation). We had few disagreements with the translation but eventually we were able to sort them out. Phrases and certain key words in *Twi* that do not translate easily into English were included in the final narratives. Due to time factor about a third of the final transcripts were shared with the respondents to verify that they agreed to their memory of the interviews. Few of them had to shed light on inferences and meanings to certain linguistic patterns whose meanings can only be explained by them.

### ***3.6.17 Field notes and research diary:***

Field notes became essential aspect of the research process. According to Fielding (2001 pp: 152), the production of field notes is the observer's *raison d'être*'. As an essential element I carried it with me throughout the research period to complement the observed data and the interviews. The field notes were written after every round of observation as well as at the end of every interview. I used it to record the general characteristics of everyday event making

sure that these were recorded in chronological order. Where it was not possible to write in detail while on the field I developed the capacity to take mental notes and as soon as possible transfer these into the field notes by using key words, phrases and sometimes quotations. I recorded my personal impressions and feelings in red pen because ‘field work entails emotional cost and therefore one needs data on one’s own attitude to document one’s evolving relationship to others in the setting’ (Fielding, 2001 pp: 153).

The field notes thus, contained the essential information related to the over all field research – observations, conversations, my visits and over all experiences. It captured the respondents’ answers as well as the proceedings of the interviews. Becker (1998) suggested that, one enters the field with concepts and ideas that direct our gaze and need to be recorded as fully as possible, as well as, seemingly unimportant actions or words that can become critical. The field notes were made immediately or as soon as possible after interviews and I repeatedly interrupted my observation to record important events.

The research diary documented and reflected on the on-going research process. It was continually updated with such issues as how the field was approached, my experiences with respondents and “gate keepers” as well as how I applied any particular methods and how I learnt from the whole process. Relevant pages of the research literature I carried with me were all recorded as I read to make sure that I could easily refer to them when I start to write up my report/field experience.

### ***3.6.18 Focus group interview:***

Interview with the professionals took the form of a focus group discussion. Cronin (2008) suggests that the group should not be more than 10. Therefore six nurses/carers were purposively selected. For a nurse/carer to participate in the study s/he should have worked with Buruli ulcer patients for at least one year.

According to Flick (2009), focus groups motivate the participants to clarify their views more frequently than one-to-one interviews. This view is shared by Kitzenger (2000, pp: 21) ‘using different forms of communication that people use in day-to-day interactions such as jokes, anecdotes, teases and arguing, focus group can reach those parts that other methods cannot reach, and that it works well if the group is homogenous because it helps to capitalise on their shared experiences. They are also quick, convenient to implement and economic to run



(Holloway, 1997). This was a self funded academic study and the advantages to be derived from the group dynamics far outweighed the one-to-one interview for this group.

A suitable venue was discussed with the Matron after I had completed the field research. I suggested to her that it should be one which was familiar to them with the minimum of distraction and interruptions and where they would feel comfortable enough to sit and talk for at least sixty minutes with breaks as appropriate. It was decided that the office next to the Hospital Administrator's office would be suitable. I visited the venue to ensure that it had a power supply to make recordings of the proceedings possible.

I approached the Matron again a day before the interview and told her that I would need between five – seven volunteers. Five nurses, three ward assistants, The Matron and a physiotherapist assistant agreed to take part in the study. I realised that the number was more than enough so I decided to allow three nurses, two ward assistants and the physiotherapy assistant to take part of the interview. All the three nurses and one of the ward assistants were women while the remaining two were men.

Before the interview I recapped the participant information sheet and they all agreed that they had read and understood it. They were then required to sign the consent forms. I intentionally dropped the Matron from the list because I realised how dominant she was and that she would not only dominate the proceedings but would overshadow her junior colleagues.

Refreshments in the form of soft drinks and biscuits were provided by the hospital to which I was grateful. The discussions were made as informal as possible by the use of a simple discussion guide (see appendix 8) which was centred round their own experiences with Buruli ulcer, any training they had received, issues that the Buruli ulcer respondents had raised with me, my personal observations as well as their own reflections. The guide was not used as a formal and sequential interview guide but purely as a check-list, ensuring all along that the discussions evolved naturally, reflecting on the group dynamics and interaction. I was conscious of the recording, so as the discussion went on I kept on writing what I could capture by way of their body language and facial expressions. As the facilitator I tried to maintain a neutral stand but occasionally interrupted to steer the discussion on course especially when the group using teases and their everyday jargon about Buruli ulcer patients were going out of line. The interview went on for seventy minutes and it was conducted in

*Twi* with some of them occasionally using English. It was so lively that we exceeded the one hour which had been planned.

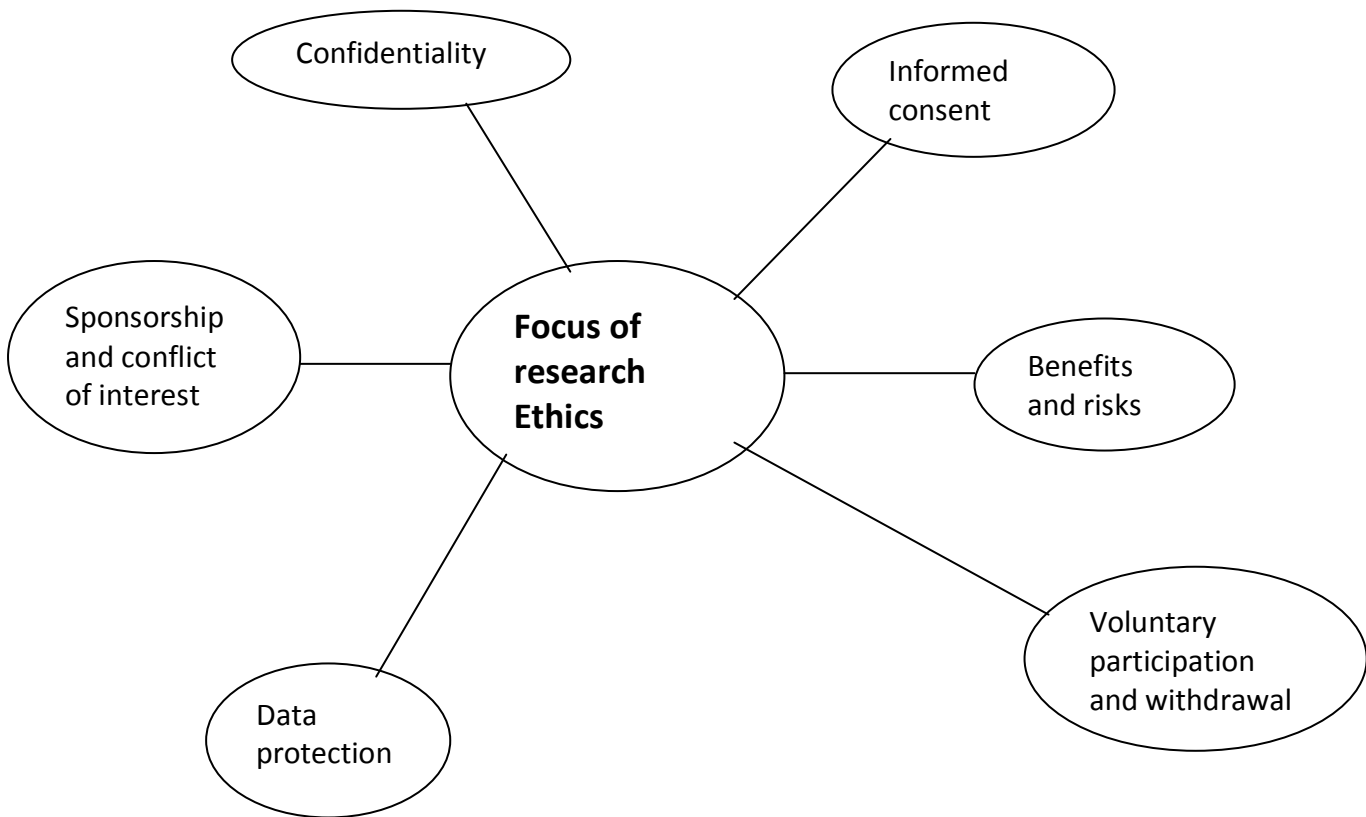
After the interview I thanked them for their cooperation. There were many information gaps related to government policies which they were either unsure or reluctant to discuss. These gaps were 'filled in' by the Matron after the interview.

### **3.6.19 Ethical Issues**

Ethical issues play a central role in all social research because "to become part of a social scene and participate in it requires that the researcher is accepted to some degree" May (2001, pp: 157). I could not have been accepted in the communities without first developing "pre-existing relations of trust" Lofland (1996, pp: 95). I had had informal discussions with the Director of Buruli ulcer Control Programme in Ghana and the Deputy Regional Director of Health in the Ashanti Region before I set off to Ghana. These officials became the initial "gate keepers" of my study. These contacts notwithstanding it is impossible these days to conduct social research without following the accepted norms of modern social research involving human subjects. Robson (2002, pp: 65) describes these norms as "the rules of conduct, typically to conformity to a code or set of principles".

In Ghana just as any other country, social research involving humans is governed by ethical considerations and therefore all researchers need to obtain ethical approval from their Local Research Committees. In Ghana just as in the UK, Local Research Committees have over the years developed the Nuremberg Code of 1947-1949 and the 1964 Declaration of Helsinki along four core principles in social research. These principles expect researchers to conduct their investigations in a way that 'protects the interests of the participants; ensures that participation is voluntary and based on informed consent; avoids deception and operates with scientific integrity and complies with the laws of the land' (Descombe, 2010 pp: 331). Other considerations such as: no harm to subjects; anonymity and confidentiality; avoiding deception and the way research is reported, including political considerations have been added (HMSO, 1998, quoted in Descombe, 2010). These basic principles or norms surrounding ethical situations are illustrated by Henn et al (2009 with modifications) in figure 3 below and how they were applied in practice is discussed in the sections that follow.

**Figure 3: Issues on research ethics**



Source: Adapted (and modified) from Henn, Weinstein & Ford (2009, pp: 80)

### ***3.6.19.1 Confidentiality and privacy***

The ethical principles which guided this research were based on the notion of beneficence and duty of care (Beauchamp and Childress, 2001). As a professional nurse I felt that I owed the respondents in this study a duty of care to ensure that their privacy was respected at all times. The issue of privacy went along with that of freedom and confidentiality. That is there was no undue intrusion or invasion of personal privacy and therefore when I visited the respondents in their homes I made sure that they were aware of my presence and I sought their permission before I interviewed or discussed any issue with them.

Confidentiality was given prominence throughout the study. Any information gathered from this research was treated in confidence so as not to expose the identity of the respondent. This involved both verbal information that was gathered from the respondents as well as documentary data that were obtained from the respondents' records at the hospital or from

themselves at home. To make this possible the respondents were given special codes which were known to me only.

### ***3.6.19.2 Benefits and risks involved***

In every social or field research there is bound to be some form of risk to research respondents as well as some potential benefits. It is the duty of the researcher to identify the potential risks and find judicious means to minimise them. In this research for example theoretical sampling technique (see section 3.6.6.1) led to the inclusion of children respondents. I anticipated the complex ethical questions this was going to raise; whether it was ethical to use children in research which is for the 'social good' even if parents gave their permission (Silvermann, 2001). The issue of informed consent (see below) also raised a major ethical risk or dilemma which needed to be addressed. For example where written consent was required the risk of identification was increased. To reduce this risk no names were indicated on the participant information sheets and respondents were given the option to thumbprint which would be difficult to decipher.

### ***3.6.19.3 Informed consent***

Voluntary consent of the participants was absolutely essential in this study. Burgess, (1998), argues that the person involved should have legal capacity to give consent; should be so situated as to exercise free power of choice, without the intervention of any element of force, deceit, duress or any other ulterior form of constraint or coercion. He goes on to say that the participant should have sufficient knowledge and comprehension of the subject matter involved as to enable him/her to make an understanding and an enlightened decision. In addition to this there was no concealment of information, deceit, trickery or manipulation of any form on my part as a researcher taking advantage of my relatively superior position to coerce this vulnerable group to take part in the research.

Therefore before this study commenced I made sure that the participant information sheet was devoid of any jargon and was read to all the respondents in *Twi* to ensure that they had understood the principles involved. All potential respondents were made to understand that they did not have to participate if it were against their wish and that they could withdraw from the study at any time without repercussions. I made it known to them that any one who wanted to withdraw should inform his/her Assembly member in the locality who would then pass on the message to me on my next visit. This was because there was no means (example

telephone, email etc) of communicating with the respondents so I decided to rely on the Assembly Members who were very popular and prominent members of the communities.

I did not lose sight of the fact that minors (those below 16 years of age) were to be involved in the study. So it was very important to consider the ability of minors to make informed decisions. To surmount this problem the parent/legal guardians were given the opportunity to decide for their children. I impressed upon the parents/legal guardians to explain the purpose of the study as it has been explained to them to their children.

All these notwithstanding, there were few deviations from this ethical principles of informed consent which need to be discussed and reflected on. This was about power (or unequal power) relations in social research which has received prominence recently. Reynolds (2003) provides two dimensions where unequal power relations can exist between the researcher and the researched. The first dimension is where the research participants have the power and ability to withhold information they are willing to disclose to the researcher or setting out conditions for giving out the required information. This was evident in this study. Eleven of the respondents refused to sign or thumbprint for various reasons. Many thought that signing any document meant a contract with the government which they were unwilling to do because of previous encounters with government officials. My key informants suggested to me that a mere nod or verbal consent was all that was needed among some of the inhabitants. Yet there were others who wanted their names written on the consent form hoping that if ‘something good’ comes from the study later they would be the first to get their share. The latter problem was tactically resolved which raises a lot of ethical puzzles.

Searching through the literature I found that these were not peculiar to this study. For example in Reissman’s (2004) study in South India, a significant number of the rural women refused to sign due to a history of well-deserved suspicion such as government intrusion into property rights. In Ryen (2004), rural Tanzanian study interviewees requested that their names and titles be given due to a long standing tradition from Western donor projects whereby to be selected for funding requires that ones name is on the list.

The second condition that Reynolds (2003) identified is the power the researcher has in terms of control over the “selection, interpretation and analysis of the information provided” (pp:

303). I must admit that where this has been identified it has been reported at the section on reflexivity which is discussed later in this chapter.

#### ***3.6.19.4 Voluntary participation and withdrawal***

‘Covert research is bad science’ (Burgess, 1998) and that I knew that it was my responsibility to explain the object and implications of the study to the potential respondents. When this had been done the respondents were given enough time (at least one week) to deliberate on the information given in the participant information sheet before they made informed decision whether to take part in the study or not. The information made it clear that participation in the study was purely voluntary and that they were at liberty to withdraw from the study anytime without any repercussions and that withdrawal would not affect any services or treatment they were receiving in any way.

#### ***3.6.19.5 Sponsorship and conflict of interest***

Sponsorship of social research and field research in particular raises a lot of ethical questions. Sponsorship in this respect could be material and financial support from an institution/organisation which has a vested interest in the study. The researcher then has to be open and declare this conflict of interest. In discharging his professional duties s/he is obligated to be impartial and objective both in the data collection stage and the analysis stage (Descombe, 2010). This study was self sponsored and that my loyalty lied with my respondents. If any conflict of interest arose in course of the research I would have declared to the gatekeepers.

Sponsorship also involves how permission is sought from those who are in the higher reaches of the medical hierarchy who would grant permission for the research to be conducted. In this research it was more ethical and appropriate for the gatekeepers to request permission for me to use the research site to observe what went on. In this study gaining access to the site was not a straight forward issue as it did not follow the normal procedure. This will be discussed in the appropriate sections below. It therefore became evident that research sponsorship and access to situations/sites are defined by the institutionally powerful who not only grant access to research sites but also to individuals (Burgess 1998). Gaining access eventually involved negotiations with the Ghana Health Services Ethics Review Board, the District Director of Health Services in the study area, the opinion leaders in the communities, the hospital administrator and the medical superintendent at the hospital.

### ***3.6.19.6 Ethical Review Committee Comments:***

The ethical approval was granted by the Ghana Health Service Ethical Review Committee (GHSERC) in Accra. Before the approval was given The Research Administrator of GHSER went through the proposal with me and clarified what was to be included before submission. Among what was needed was a local supervisor who had knowledge of the subject area and a letter from the District Director of Health Services allowing me entry to the district. The Director of Buruli ulcer Control Programme in Accra agreed to be my local supervisor. Thirteen copies of the revised proposal were required and submitted but no interview was required. There were, however, few comments such as: a complete section on literature review of the topic, an explanation of the Dermatology Life Quality Index (DLQI) tool and a separate section on ethics in the proposal which I amended before submitting two copies. The two copies were submitted before the study was approved (see appendix 9 for all correspondence relating to Ethical approval).

### ***3.6.19.7 Data Protection:***

In order to protect the identity of the respondents each of them was given a code for the purposes of the transcription and this was known by me and was used in the analysis and discussion. Informed consent forms were kept in a secured desk and my door was all the time locked. When I left the field I kept these in my brief case. There were no means of identifying the respondents but the signatures of seven respondents who decided to sign could be easily read. These were clipped together and sealed in a special envelop. The consent forms were therefore kept in a secured part in my brief case and were not shown to any third party. The tapes were equally kept in my brief case and were not made available to any third party. On my return to England these were kept in an old brief case and kept at the top drawer of my wardrobe in my house. These will be destroyed in five years time.

## ***3. 7 Analysis of the data and building the Grounded Theory***

### ***3.7.1 Introduction***

In this section I will discuss how all the data were analysed. All the data sources used in used in collecting the information in this study (see table 1) were separately analysed and then integrated into the overall data to arrive at the categories.

A basic feature in Grounded theory methodology is that data analysis is a continuous process throughout the interview, discussion and observation period through the application of Constant Comparative Method (CCM) of data analysis. This method allows the researcher to organise the data into what Glaser and Strauss (1967) called categories (which form the conceptual element of the emerging theory) and their properties. In this study the identified categories (and their properties) included a core category which subsumed and integrated the other categories to form the basis of the substantive theory (Glaser and Strauss 1967; Glaser 1978). The principal categories identified fit the real world and remain relevant to what the respondents said and what they constructed. The strength of the principal categories is that they have all emerged from the data itself.

The approach I used is leaned more towards Glaser than Strauss and the rationale for opting for that approach has been explained in section 3.4 of this chapter. Glaser and Strauss original work in 1967 and Glaser's later works (1998, 2001 and 2003) were used as guides in my analysis. This enabled me to interpret his method and to provide my own critique of this approach as I go on. The processes involved in the data analysis and how I applied them in reaching the principal categories and their properties are explained in the following sections.

### ***3.7.2 Process of identifying the principal categories and building the theory.***

Constructivist grounded theory allows respondents to cast their stories in their own terms (Charmaz 2000). Therefore at the end of each interview the transcript was read several times to enable me get the real meanings of the respondents' accounts. I then wrote each as a story without quotes then a thorough reading of each 'story' was carried out which helped me to identify meanings in the 'stories' as they were told. I then tried to look for areas of convergence and divergence to enable me create themes that ran across each respondent's 'story'. These were noted to give me a clear idea of what the respondents actually meant before moving on to the next interview.

When I started analysing the data, I decided to follow the basic procedures in grounded theory – coding. Charmaz (2006) has suggested that 'coding gives the researcher the analytic scaffolding on which to build' (pp: 46). Therefore with the 'stories' in my mind I decided to code the original transcripts to enable me to make a close study of the data thus laying the foundation for its synthesis. 'Through coding, you define what is happening in the data and begin to grapple with what it means' (Charmaz 2006, p. 46). The two main phases of coding



in grounded theory (using Glaser's approach) were used – open and selective coding. In attempting to use these processes there were overlaps as 'grounded theory is not a neat process' (Glaser, 2003), and the processes used are explained next.

Through open coding I tried to be open minded or open to ideas. Therefore I tried to get closer to the original data as much as possible by asking the basic questions: What is this data a study of; what does it suggest and from whose point of view (Glaser 2001 and 1978; Glaser and Strauss 1967)? Approaches to open coding can be varied and there are no strict rules (Charmaz, 2006). It could be line-by-line, sentence-by-sentence, several phrases or sentences, paragraph- by- paragraph or a whole document. This approach helped me to approach and examine the data in minute detail. Therefore, I decided to start coding line-by-line but this produced some initial difficulties, such as incomplete sentences on a line and phrases that had no meanings. This however, assisted me in subsequent interviews when I was in the field. Therefore the line-by-line coding was followed by segment-by-segment and incident- by- incident coding on each document while at the same time asking pertinent questions on the data such as:

- 1, What is this data a study of?
- 2, What category does this incident indicate?
- 3, What is actually happening in the data (Glaser 1978, pp: 57)? And;
- 4, From whose point of view? (Chamaz 2006, pp: 47).

This way I was able to examine the text for salient concepts. I tried to avoid mere descriptions by looking for instances that were typical which ran through each document and putting the identified concepts together. 'Once a concept has been identified, its attributes may be explored in greater depth, and its characteristics dimensionalised in terms of their intensity or weakness' (Goulding 2009, p. 134). Therefore similar concepts were compared with like concepts through the process of constant comparative method of data analysis to generate properties. What I did was trying to maintain a close connection between the identified concepts and compared data coded in the same way to each other. Similar concepts that seemed to relate to the same phenomenon or 'made the most analytic sense' (Charmaz 2006, p: 47) were then subsumed to form a category. Thus a category pulled all similar concepts together in order to offer an explanation of its emergent. Glaser (1998), referred to this as the *conceptualisation process*. Every new data that was collected was compared with the emergent category and in the process new data meant revising the existing categories and their properties as well as revisiting and re-categorising 'old' data (Glaser, 1998). This

process was neither ‘linear nor neat’ as there were different conceptual levels within and between the categories.

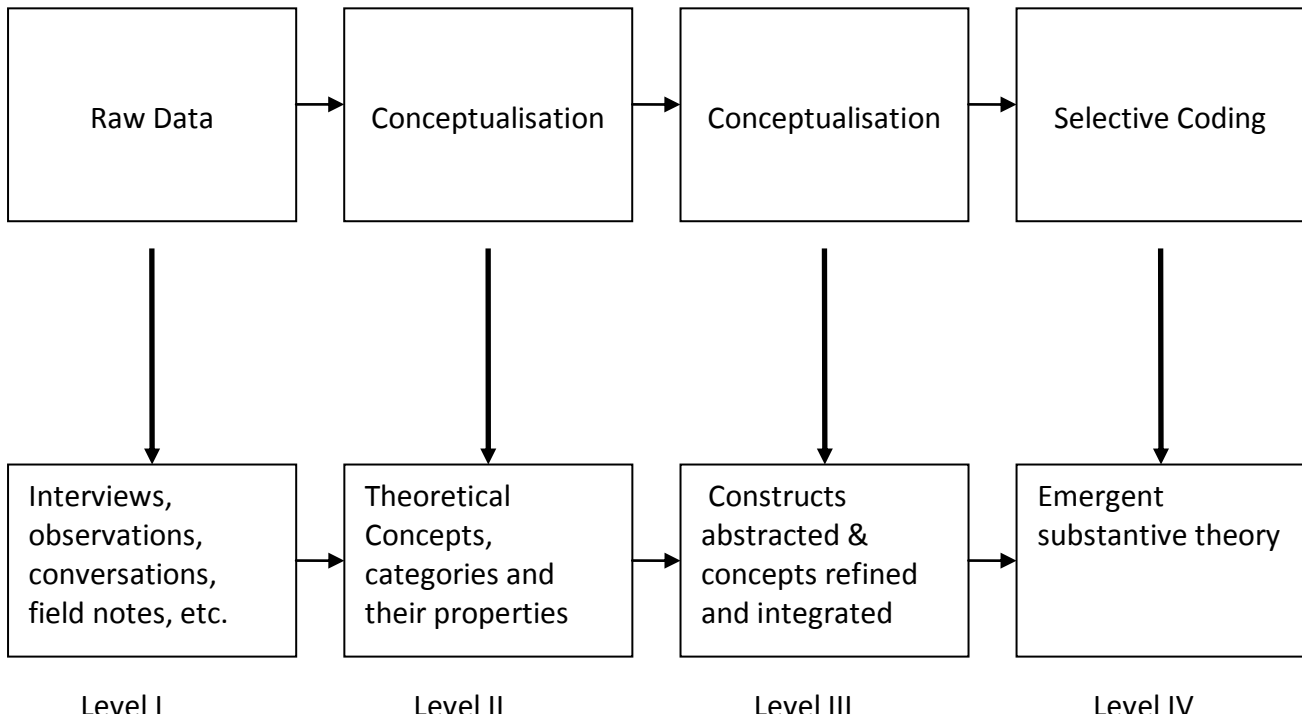
In naming a category two ideas were used. The first was trying to preserve or use respondents’ terms or meanings of their views; what Grounded theorists call *in vivo* codes. The term *in vivo* is Latin for ‘within the living’ and this type of code or category captures respondents’ words as representative of a broader concept in the data (Birks and Mills 2011, pp: 93). The second was based on ideas from the literature but I tried to avoid words that were theory-laden as I thought they could drive the analysis (example I tried to avoid the words denial and stigma even though they appeared several times in the data). Chamaz (2006), argues for the use of gerunds (verbs use as nouns that always end with ‘ing’) when coding as a way of identifying processes in the data as well as focusing on the respondents’ experiences as a source of conceptual analysis, and I used this to help me.

### **3.7.3 Saturation**

The constant comparative method and theoretical sampling continued until theoretical saturation was reached (Glaser and Strauss 1967). This stage occurs when after constant comparison and further sampling the researcher finds that the identified category has no new illuminations, no new data and it (the category) has well developed dimensions and properties and the relationship among them (the identified categories) are well established and validated (Glaser, 2001 and 2003).

After open coding and when theoretical saturation has been achieved the data is ‘moved’ through the process of *conceptualisation*. This process involves moving the data from one conceptual level to another (and higher) conceptual level all through the constant comparative method of data analysis. This is explained next and depicted in figure 4 based on Glaser’s views over time of what it comprises (Glaser 1998, 2001 and 2003).

**Figure 4. Glaser’s Conceptualisation Process (based on Glaser 1998; 2001 and 2003) showing the movement from raw data to the emergent theory**

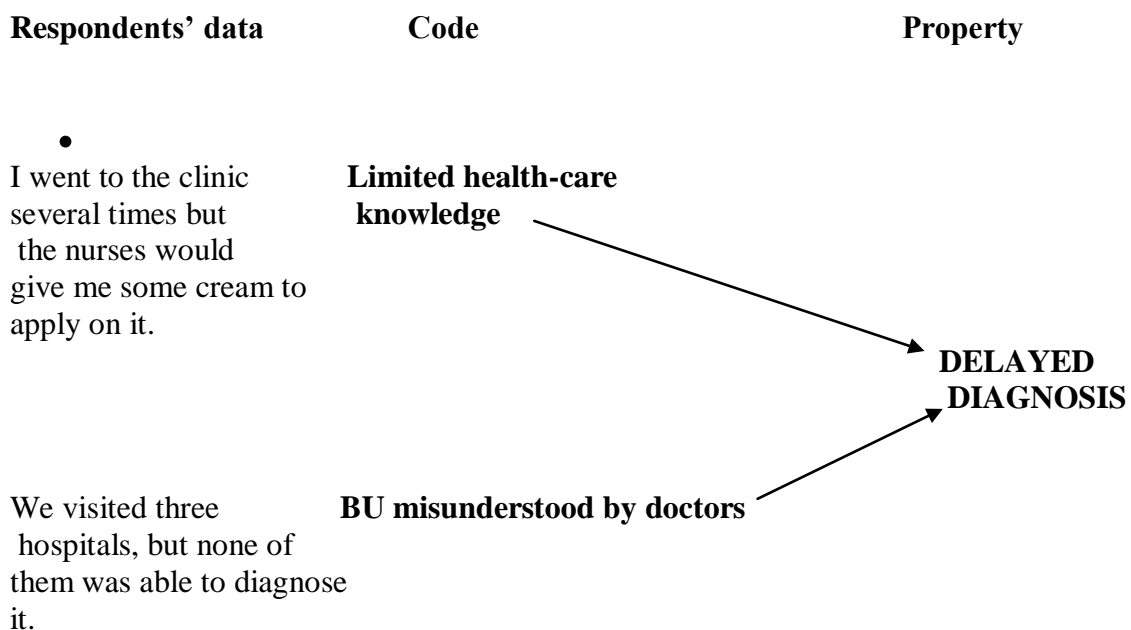
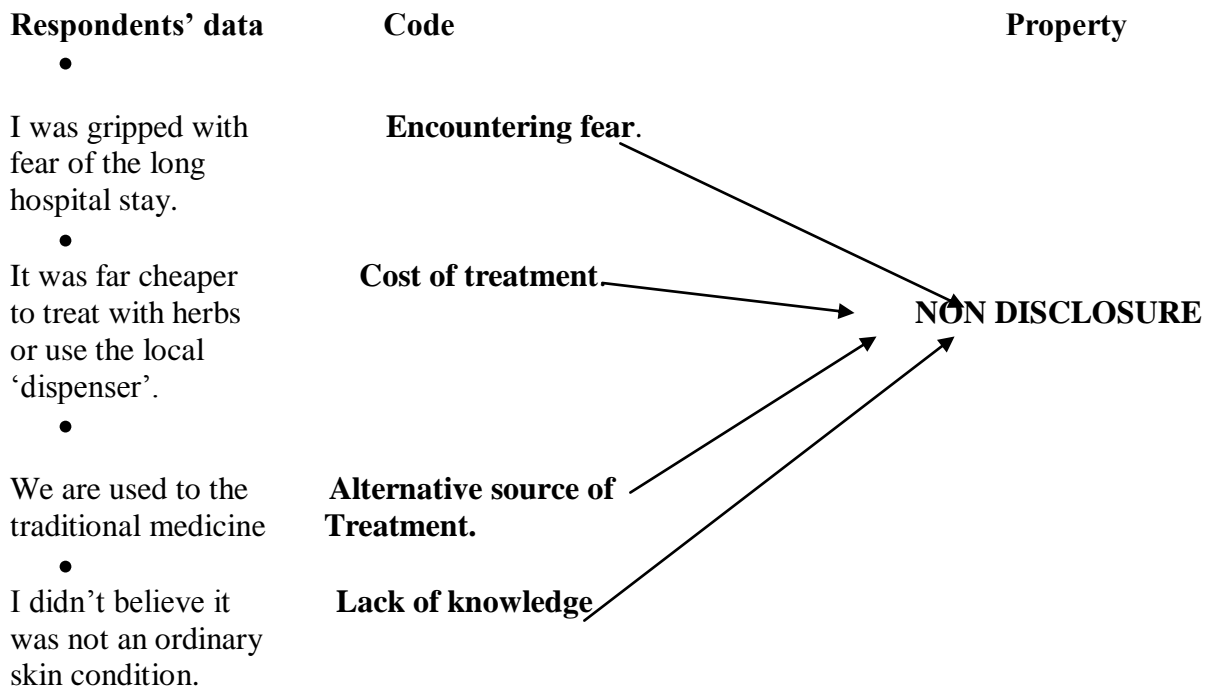


The figure depicts the conceptualisation process that will lead to the development of the substantive theory. Level I represents the ‘raw’ data (primary and secondary sources of data which included informal interviews, observations, conversations, field notes, DLQI questionnaire and documents). Through open coding (where similar incidents were grouped together to develop codes and categories), the refined data is moved to conceptual level II.

At this level, (level II) the coded concepts have been identified to form the main categories and their properties. Glaser (1998, p.136) admits that ‘there are sub-levels within this level’. Further analysis of the data through the constant comparative method will transform the data at Level II to move it to conceptual Level III, where identified concepts will be refined and integrated into the analysis. Glaser (1998, pp: 138) calls this ‘the level of overall integration through sorting in a theory’. The theory will then be derived from the identified categories. The fourth level perspective (Level IV) is the formalisation of a substantive theory which is arrived through the final stage of coding called Selective coding which has been used to ‘narrow’ the focus of the study.

A simplified conceptual ‘shift’ as an example in arriving at the properties ‘*Non-disclosure*’, and ‘*Poor diagnosis*’ as depicted by Figure 4 is demonstrated by Figure 5 below:

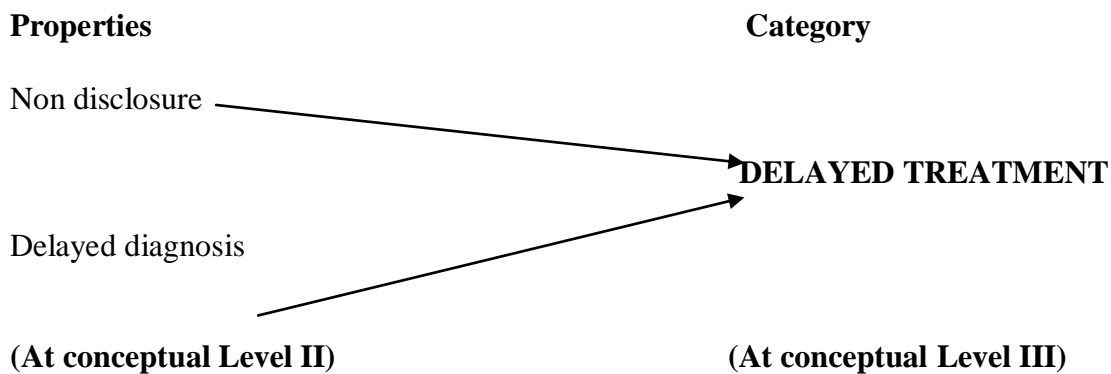
*Figure 5: A simple conceptual shift based on Glaser’s conceptualisation process*



The respondents' data have been culled from a combination of the interview transcripts, field notes and observation and therefore some of the data depicted here are typical instances which ran across the transcripts. I tried to get as close to the data as possible to ensure that the respondents' voices permeate throughout the data.

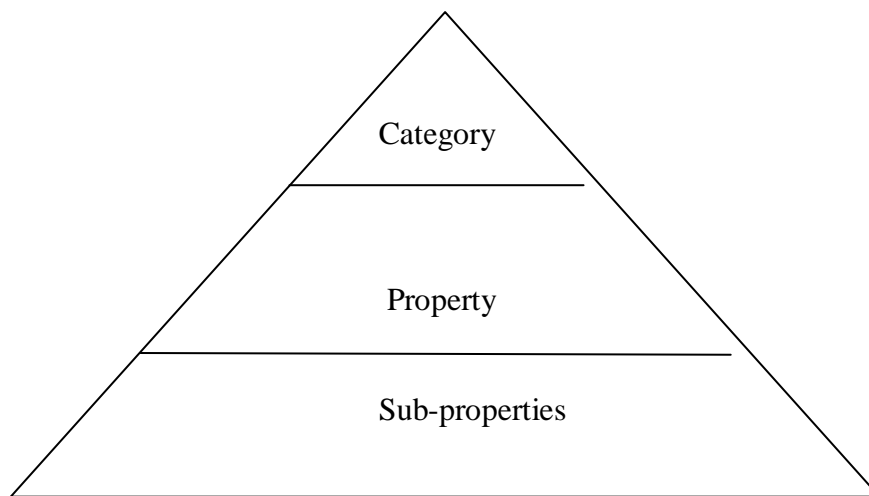
According to the conceptualisation process as depicted above *Non-disclosure* and *Delayed diagnosis* (as properties) are now at Level II of the conceptualisation process (see Figure 4) and are now 'ready to move' to conceptual level III where they will be subsumed to form the category *Delayed treatment*. This is depicted by Figure 6 below.

**Figure 6. Demonstration of conceptual shift from conceptual level II to level III**



In arriving at the categories in the way that I have demonstrated so far in the conceptualisation process the data have not only shifted from level I to Level III, there have been 'different conceptual levels within and between the categories' (Glaser, 1998, P. 63) that have been derived. In practical terms what it means is that these categories are at higher levels of theoretical hierarchy than their sub-categories and their properties. For example the category, *Delayed treatment* is seen at the top of the conceptual level because it has integrated the others which have now become subcategories or properties. This is depicted by Figure 7 below.

**Figure 7: Levels of Conceptual hierarchy**



The emergent category, *Delayed treatment* is at the abstract level and needs to move up to the final level (through interchangeable indices) where similar main categories will be subsumed to form the core category. By this stage similar categories have been formed through the same process and what is needed is to explore the relationship between them.

At this stage I had two options – either to use Strauss’s axial coding as a frame to ‘guide my analytic constructions’ of the respondents’ accounts or Glaser’s theoretical coding system. Glaser (1998) did not specifically subscribe to axial coding process prescribed by Strauss and Corbin (1998). Glaser (1992) had argued that the axial codes and the form that they should take should emerge from the data itself but not to be forced into a pre-determined format. Axial coding has also been attacked by many Glaserian grounded theorists (Charmaz, 2006; Clark, 2005 and Robrecht, 1995). Charmaz (2006) for example, intimated that axial coding ‘may limit what and how researchers learn about their studied worlds and, thus restricts the codes they construct’, and they ‘can make grounded theory cumbersome’ Robrecht (1995). Therefore in line with my earlier assertion to restrict myself to the Glaserian approach axial coding was discarded (even though I had made an attempt of it earlier on) for fear that it may ‘cast a technological overlay on the data and perhaps the final analysis’ (Charmaz, 2006, p. 63).

### 3.7.4 Theoretical Codes

Glaser (1992, 1998, and 2003) instead advocated for theoretical codes. The purpose of theoretical coding is ‘to conceptualise how the substantive codes may relate to each other as hypotheses to be integrated into a theory’ (Glaser, 1978, pp: 72). ‘Theoretical coding does not start anywhere in the data analysis but often begins during the open coding with constant comparison’ (Wuest 2011, pp: 240). I therefore grouped all the categories, and as data collection and analysis continued some of them expanded, while others collapsed and shifted to fit the data collected.

Some of these categories were *processes*, others had labels that were *nouns* which were likely to be the *problem, conditions or contexts*; and these were noted. I then had to sort all the data by categories manually as at the time I was not conversant with the latest computer software packages such as *InVivo 8*. Glaser (1978) uses a repertoire of theoretical coding families which I used to saturate the properties of the principal categories under the core category. So the data were manually sorted and resorted by category and then found out how the categories were related to each of Glaser’s (1978) 18 coding families especially his famous six Cs: *causes, contexts, contingencies, consequences, co- variances and conditions* to which, according to him, the researcher can rely on in proposing his/her theoretical links between his core category and the other categories which have been identified. These coding families, ‘act as a template of possible theoretical relationships that assist the researcher to move to more abstract level, away from descriptive understandings’ (Wuest 2011, p. 240). Glaser (2003) advises that describing the category is one thing and creating a substantive theory is yet another.

Since the aim of a theoretical coding is to integrate the other categories around the core (Glaser, 1978) and to show how it is happening in the data (Glaser, 2003), I systematically related the emergent categories to each other category and filled in other categories that needed further refinement. So a single (core) category was identified as the central phenomenon, that has the power to ‘elucidate lots of the aspects of the category’ I was looking at to enable me ‘to construct a story around this’ (Glaser and Strauss, 1967). This core category is at the highest conceptual level than the rest because it has integrated them. The core category is an essential requirement of the study which illuminates the “main theme” of the respondents’ by telling us ‘what is going on in the data’ (Glaser, 1978, p.94). This significant core category then becomes the basis for the generation of the substantive

theory because all the other identified categories and their properties become ‘inextricably related or linked to it’. In this study the forward and backward linkages of the data revealed the core category which was arrived at when it (the core category) was found to have become the central focus of their discussion which incorporated the other three categories.

### **3.7.5 Basic Social (Psychological) Process**

Glaser (1978, p. 100) then discusses what he referred to the Basic Social Process (BSP). He identifies two types of Basic Social Processes – Basic Social Psychological Process (BSPP) and Basic Social Structural Process (BSSP). While the former refers to the process of becoming and useful in understanding behaviours the latter is concerned with social structures in a process such as organisational growth or recruiting procedures (Glaser, 198). So far this study centred on properties of a process (conceptualisation process) but not properties of a unit, a person, a group or an organisation because I have been aiming at theoretical conceptualisation. Grounded theory deals with what is actually going on, not what ought to go on (Glaser, 1978, pp: 14) and so in this study what actually is going on is the core pattern of a Basic Social (Psychological) Problem that has engaged the respondents in a series of (pattern) of emotional recall about their condition. The principal categories of this Basic Social (Psychological) Problem with their interrelated properties and sub-properties explained the core pattern. In this study the basic social psychological problem of *Reliving the trauma of my ulcer* was identified as a **condition** (requiring strategies by the respondents to deal with) and also providing a **context** for dealing with their experiences while the other principal categories of *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* as a **cause**, a **consequence** and as a **strategy** respectively all in relation to the core category.

‘Several steps precede the selection of the Basic Social Process (BSP) which include different levels of coding, memoing (discussed below) theoretical sampling and sorting’ and ‘as a process it is independent on the structural unit in which it was discovered (Hutchinson, 1993; p.194). What is worthy of note is that *Reliving the trauma of my ulcer* may not necessarily be the only Basic Social Process (BSP) of theoretical importance in the lives of people living with *Mycobacterium Ulcerans* (Buruli ulcer) but it seeks to explain a lot of the ‘behavioural variation in the data’ in this study.



### 3.7.6 Selective Coding

In theory the emergence of a pattern that is, the Basic Social Process (in this instance the basic social psychological problem) marks the beginning of *selective coding* which is the final stage of coding (Glaser1998). It is used to narrow the focus (delimit) of the study by selectively coding on it and those data that relate to it. Glaser (1998) saw selective coding as ‘a crossing-over delimiting levelling’ (p.138); implying that the Basic Social Process then guides future data collection and analysis. Whilst this would lower the conceptual level of the study it would raise the conceptual level of the selective codes related to the core category (Glaser 1998, p.138). The process was not as straight forward as described. What happened in practical terms was that the constant comparative method of analysis has enabled the emergent categories to ‘settle’ around a core category.

The basic aim of selective coding is to generate the Basic Social Process and all the codes related to it. What the researcher does in selective coding is to search for the conditions, the consequences, the causes, the strategies, and so on by asking such questions as:

1. What is going on in the data?
2. What are these data a study of?
3. What is the basic social psychological problem with which these people must deal?
4. What basic social psychological process helps them to cope with the problem? (Glaser, 1998, p. 104).

Glaser (1978) suggests that the researcher should not go to theoretical places ‘by armchair’ and ‘logical drift’; and that theoretical codes are necessary to discourage the analyst from forcing his/her pet or professional theoretical frameworks on the data. It allows the researcher to be open minded in his/her approach so that the resultant theory that emerges ‘cuts across disciplines, comprehensive and abstract of time, place and people (2003, pp 112). Thus in my analysis I realised that not all the theoretical codes were relevant, nonetheless they guided me to refrain from deducing codes from my area of expertise and to allow them to emerge freely from the memo bank I had written and stored all this while. Glaser (1978) again advises the analyst to express these theoretical links in the form of hypotheses to enable him/her ‘weave the fractured story back together’ so that a coherent theory derived from the data can be formed. The theoretical links as well as the core category and its relationship with the emergent categories are shown by Figure 9 (page 94) and the corresponding hypotheses to help with the write up are depicted by Appendix10.

### 3.7.7 Memoing

Another feature of grounded theory which assisted me in the data conceptualisation process was memoing and it is appropriate to mention it at this stage; suffice to say that it has been applied from the very beginning as the whole conceptualisation process has not been ‘linear nor neat’. Memos were used to keep track of what was going on. According to Charmaz (2006), memo writing constitutes a crucial method in grounded theory because it prompts you to analyse your data and codes early in the research process. She asserts that certain codes will stand out and take form as theoretical categories as you write successive memos. Therefore my memos were not confined to the respondents or individual cases but were about codes, concepts and ideas that came to my mind. These were modified and ‘fine-tuned my subsequent data analysis’ (Charmaz, 2006).

When I wrote the memo on ‘*Delayed treatment*’ for example I looked at issues of disclosure, the effects of illness and hospitalisation and the role of the professions. In particular I drew on the psychological effects of hospitalisation and the works of Illich’s (1975) comprehensive writings on the concept of *iatrogenesis*. Then I kept asking myself; just what are the problems of these people and have other people misconstrued their plight? Have I encountered similar life experiences somewhere and how did I react to them? Then I realised that ‘all is data’, and that ‘if data are the building blocks of developing a theory, then memos are the mortar’ Stern (2007, pp.119). So in practice my memo writing went on unabated throughout the coding, conceptualisation and the constant comparative method of analysis

Similarly when writing the memo on the category *Quality of life as a mirage*, I explored the relationship between the attempts respondents made to achieve true quality of life and well being. Throughout the analysis stigma became a household term mentioned by almost all the respondents. I then drew on the work of Goffman’s (1963) analysis on the topic. The respondents talked about how they felt stigmatised in their daily lives. Even though few of the respondents made reference of the struggle to maintain quality of life and well-being their ‘stories’ were replete with it, and to me it made sense of their experiences.

I had encountered codes such as ‘feeling stigmatised’, ‘feeling worthless’, ‘loss of self and identity’, ‘feeling unloved’ and so on but never analysed them in relation to quality of life and well being. A forward and backward movement between the data by means of constant comparative method of analysis revealed numerous indications of the respondents’ desire to

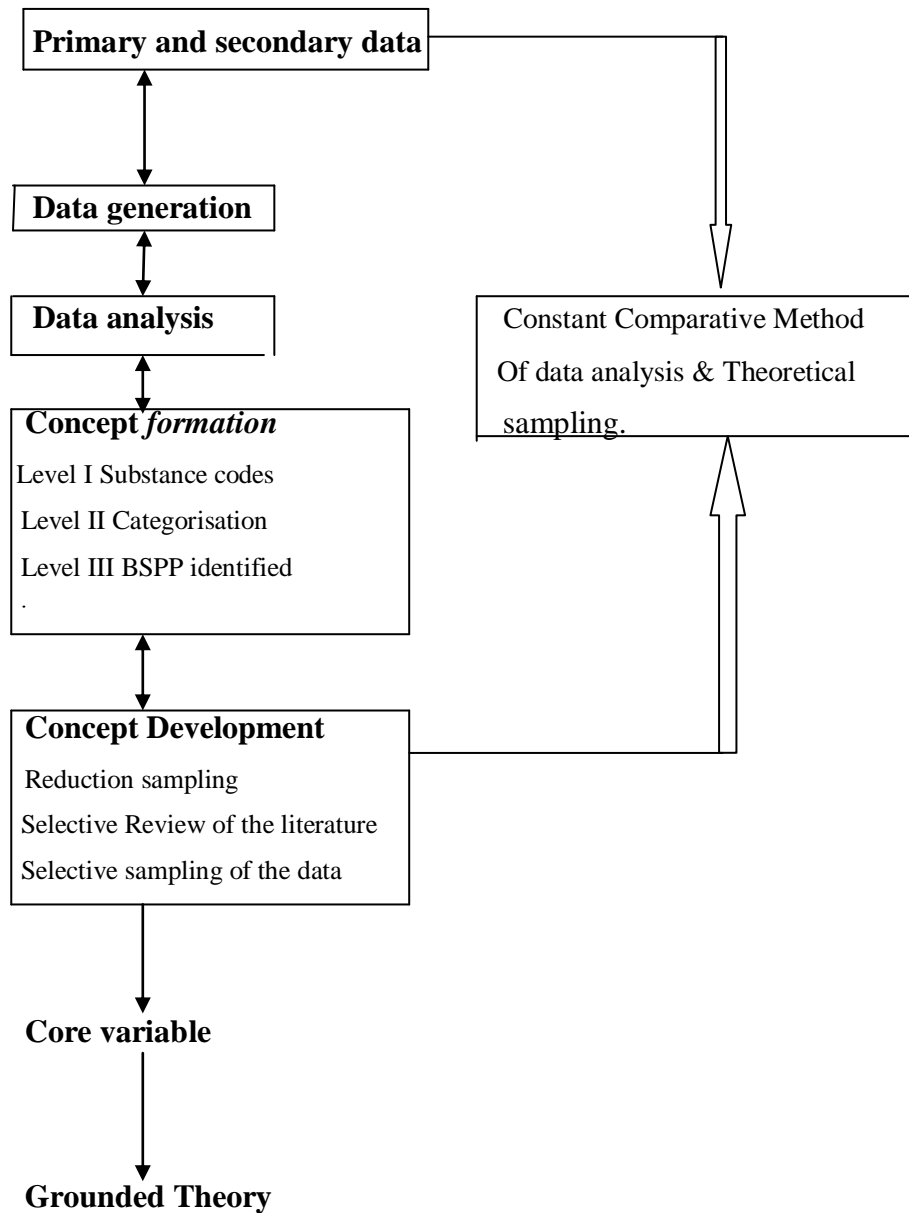
achieve the desired quality of life and well being. When this was confirmed by the Dermatology Quality of Life Index (DLQI) questionnaire it became necessary to incorporate this into the analysis. In my memo on this category I wrote all that I knew and had read about quality of life and well being and integrated the respondents' views into my memo. Therefore by raising *Quality of life as a mirage* as a category, I was able to raise the other codes 'to conceptual levels to treat analytically' (Charmaz 2006, pp: 46).

In the same vein looking at the respondents' data on their support needs and comparing this to the professionals' response (which became necessary because of theoretical sampling) I realised how important it was to incorporate issues of power relationship and power differentials as well as concepts of professionalization in my memo writing.

### **3.7.8 Use of extant literature**

The conceptualisation process described so far did not involve the use of the extant literature. At the beginning of the study, I decided to enter the field with a 'blank mind' that is, to free my mind from preconceived theoretical ideas so that whatever emerges from the study would be nothing but unadulterated data – data devoid of preconceived theoretical ideas and concepts from the literature. I realised that this approach was debatable as far as grounded theory is concerned. This is because Glaser and Strauss (1967; pp 3) had stated that: 'of course the researcher does not approach reality as a tabula rasa. He must have a perspective that will help him see relevant data and abstract significant categories from his scrutiny of the data'. Glaser (1992) goes on to suggest that, 'it is possible to identify and incorporate relevant literature once the substantive categories and their properties have emerged (pp.136). Thus the dictum; to discover grounded theory one needs 'theoretical sensitivity'. 'Indeed the trick is to line up what one takes as theoretically possible or probable with what one is finding in the field' (Glaser and Strauss, 1967; pp 253). Therefore when I realised that reconciling abstinence from preconceived theoretical concepts and the utilisation of theoretical sensitivity was difficult I decided to stick to my earlier assertion of waiting for the categories and concepts to emerge from my data before incorporating the relevant literature in writing my grounded theory. So what I did was to include all the literature that I found to be relevant and related to the issues that had arisen from the data and incorporated this in writing my grounded theory. The conceptual journey I have followed so far is shown by the schema blow.

Figure 8: Schema leading to the formation of Grounded theory.



Adapted and modified from Stern (1980) and Carpenter (2003)

### 3.7.9 Writing conceptually

Finally Glaser (1978) advises that the substantive grounded theory should not be written descriptively but in a conceptually theoretical manner. This means that writing the substantive grounded theory should be in a form that is ‘abstract of people, place and time’ because the conceptualisation process described so far ‘would have transformed the data’ because the findings represent the theoretical hypotheses which have been generated from the data (Glaser 2001). Wuest (2012) reinforces this view: ‘the grounded theory report is a

theoretical account of the study domain identifying the basic problem and discussing how the core category addresses the basic problem'. As far as this thesis is concerned, in writing up the theory based on the conceptualisation process I have been careful in making sure that I do not lose the core data that had given rise to the categories which eventually cumulated in deriving the substantive theory. In order to achieve this therefore means I had to defy Glaser's (1972, 1978, 2001 and 2003) advice to write conceptually. According to him Grounded theory 'is not the voice of the participants but it is a generated abstraction from their doings and its meaning which are taken as data for the generation of the substantive theory (2001, pp: 11). I have been very mindful of this maxim but for the purpose of this thesis I have presented the 'raw findings' based on each principal category and their properties (and sub properties) that gave rise to them and where they emanated from. I use direct quotes which are typical to reinforce the respondents' concern about the Basic Social (Psychological) Problem. These are presented in a way to show that they are the properties of the principal category. I then write conceptually when I discuss the findings by incorporating the extant literature found to be relevant to the categories and their properties as well as the hypotheses that had emerged from the study.

### ***3.8 Rigour in qualitative research as applied to this study***

In order to maintain the rigour in this study I made sure that the study was trustworthy. A study's trustworthiness can be confirmed if its readers can be assured that the findings are not questionable. Lincoln and Guba (1985, pp: 287) states: 'in the final analysis, the study is for naught if its trustworthiness is questionable' Lincoln and Guba (1985) set out the criteria for establishing the trustworthiness of a study which require, among other things such as; the maintenance of a field journal as a safeguard against common distortions; recognising the impact of the researcher's presence on site, his involvement with respondents, biases arising from personal issues and culture of both researcher and respondent; .... developing and maintaining an audit trail on both the process and product of the research. They argue that 'these are all directed either to increasing the probability that trustworthiness will result or to making it possible to assess the degree of trustworthiness after the fact' (p.289). These have been the guiding principles in rigour in qualitative research.

These are then fractionalised into a long list of which includes excessive details of the audit trail and a reflexive journal which apply specifically to the establishment of credibility,

transferability, dependability, relevance and confirmability” (Lincoln and Guba (1985) p.327). I have used these concepts with a consideration of their applicability to Grounded theory research and have provided my own critique of them because after all Lincoln and Guba (1985, pp: 295) eventually concede that, ‘they (the criteria) are not prescription of how inquiry must be done’.

### ***3.8.1 Credibility***

Credibility as a criterion looks at the truth value of the findings in the study. The credibility of the findings in this study could be attributable to or verified through my prolonged engagement with the respondents, their surroundings and the communities as a whole. I had sufficient time to build the necessary rapport with the respondents as well as having prolonged and persistent observation about what was happening around me; all of which were recorded in my reflective journal, field note book and research diary. “All is data”, a well known Glaser dictum was relevant in this study to provide the necessary credibility. This means that everything that went on in the research scene; whatever the source, including what I observed, was told, how it was told and so on were all included in the conceptualisation process. These were not meant for accurate description as prescribed by Lincoln and Guba (1985), but the data collected went through the conceptualisation process (coded, analysed, compared, through the constant comparative method) which put the focus on concepts that were ‘fit and relevant’ which led to a Grounded theory which is an ‘abstraction of time, place and people’.

### ***3.8.2 Transferability***

In deciding whether the data so presented is transferable, Silverman (2000) has suggested that we (researchers) are interested in the extent to which the findings of the research can be applied to other contexts. Whilst Lincoln and Guba (1985), argue that the judgement of transferability rests with the researcher to provide sufficient information in the form of an audit trail to allow the reader to make informed judgement, I have provided sufficient and detailed account of the context, the background of the respondents, how the interview was conducted as well as the step-by-step guide to the analysis. All these were a means to provide the reader with how transferable the study is. I will however concede that this does not mean that the results of the study should be generalisable due to certain issues such as culture of the people which will makes generalising the results somewhat controversial. But the audit trail

which this study provides makes it useful for the findings to be applicable to other Buruli ulcer endemic communities in the developing world.

### **3.8.3 *Relevance***

In assessing whether a Grounded theory study is trustworthy, Glaser (1978); Glaser and Strauss (1967) considered a different view which is the *relevance* of the study. In considering the relevance of a study Glaser and Strauss (1967), considered how ‘fit’ the data is naturally to the theory rather than being forced to correspond. In this study I used the constant comparative method of data analysis which allowed me to not only gather new data but also to review existing categories. The forward and backward movement of data collection through theoretical sampling meant that when data did not ‘fit’, categories had to be repeatedly changed to accommodate it. Because of this the study met the principle of ‘fit’ and trustworthiness.

### **3.8.4 *Dependability and confirmability***

Qualitative research also needs to be dependable, which means that any design-induced changes should be accounted for (Lincoln and Guba, 1985). Factors which need to be considered are credibility and confirmability . How credible this study is has been established in section 3.3.1 above. Confirmability also needs to be proven such that the research findings should be shown or proven to have emerged or grounded in the data and were not in any means influenced by the researcher’s background or profession. This study can assure its readers of its dependability and confirmability because a clear audit trail can be provided through the constant comparative method of analysis and the use of Glaser’s approach of analysing grounded theory. To prove this the findings section has provided adequate paraphrased quotes from the respondents in support of the identified categories and their properties.

Glaser (2001) argues against inviting the participants in a research to review what was said as a check or “test” on validity. He says that: ‘Grounded theory is generated from much data that many participants may be empirically unaware of. Grounded theory is not their voice: it is a generated abstraction from their doings and its meaning which are taken as data for the generation’ (p.11). He continues that ‘Most researchers have to argue their interpretation of the “voice”, their construction, perception... as to what was actually said by many participants as they heard it’ (p.50). But ‘the GT researcher listens to “what is going on” “as

is”, then he conceptualises it, the abstraction of which detaches him from precise descriptions as he generates categories. In the process the GT researcher begins to conceptualise the participants’ main concern then the core category that continually resolves it... The participants just act and talk a few if any really see the patterns involved in the prime mover of their behaviour. Their voice is abstracted and constantly compared and modified (p.51).

This study used multiple sources of data – primary and secondary sources (see section 3.032) which has been abstracted in generating the categories. This study again defied Glaser’s advice and invited a third of the respondents to clarify what was actually said or to throw light on what had been said through theoretical sampling. This was done to rid the transcripts of certain cultural and linguistic ambiguities whose meanings were not readily understood which I felt needed clarification from the respondents themselves. These clarifications were then fed into the data to make sure that no ambiguities were hidden in the data thus confirming the true value and the dependability of the findings.

### ***3.9 Reflections and reflexivity***

Reflexivity deals with the influence and the position the author has on the research respondents, the data collected as well as the analysis. The position of the researcher is therefore of paramount importance and need to be reported in the findings. Reflexivity may involve reflection but ‘while reflection demands thinking about something (Finlay and Gouch, 2003: ix), it does not require an ‘other’ (Chiseri-Strater, 1996 p.130).

Just like any other theoretical position there appears to be a wide array of views as to the usefulness of reflexivity and reflections in qualitative research. In ethnography for example, Wolger (1988) considers the problem of observing the observer being observed. Lynch (2000) outlines a myriad of forms of reflexivity until eventually settling on ethnomethodological reflexivity as the preferred kind, but Roulston (2010), intimates that ‘an ethnomethodological viewpoint of reflexivity has many competitors within the field of qualitative inquiry’ (p.117).

For a study like this I had to comb through the myriad of viewpoints on this issue and to settle on the one which is appropriate and relevant. Finlay (2002) outlines typology of five pathways to reflexivity of which the first form is considered relevant to this study. This is the



‘reflexive introspection’, - a form of self discovery that is accomplished through reflection and intuition (p.213-215). Her view shares similarities with that of Chamaz (2006, p188-189) who defined reflexivity as,

*‘the researcher’s scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how, and to what extent the researcher’s interests, positions, and assumptions influence inquiry. A reflexive stance informs how the researcher conducts his or her research, relates to the research participants, and represents them in written reports’.*

Despite the critiques of the five typologies of reflexivity that Finlay (2002) reviews, she asserts that reflexive practices are useful for researchers, and provides a way for researchers and readers to evaluate the research process (p.225).

This study relied on Glaser’s approach in analysing the data so it is worth looking at his view on reflexivity. Glaser (2001) has a different view about reflexivity. According to him, the constant quest for qualitative researchers to collect “real data” as a means to counter the critiques of the hard positivistic sciences is ‘self centred to the degree it causes “reflexivity paralysis” among QDA researchers’ (p.47). Thus according to Glaser (2001) reflexivity is irrelevant in generating categories and their properties. In addition, that ‘the constant fitting of categories and their saturation to the data, modification of hypotheses, theoretical sampling, delimiting, and memoing of theoretical conceptualization provided the constant verification needed’ (p.47). Glaser however concedes that ‘a reflexive account of how the description was obtained helps but not completely and that conceptualization transcends these problems’ (p.48).

I disagree with Glaser on this occasion. It has been shown how coding of the data to arrive at the categories and their properties through the conceptualization process help to arrive at the substantive theory. There is a caveat – and that is - how important it is for readers of this thesis to recognise that the research process could not be without potential biases albeit unintentional from its inception. This is because the subjective nature of the social environment in which the data were collected [was] and is always under social construction by many of its actors. I therefore had to be cautious in acknowledging that biases in the study

would be unavoidable and therefore try to minimise any form of bias that might affect the credibility and transferability of the findings. This could not be achieved by relying solely on the conceptualization process.

I need to recognise how the different facets of me (the ‘self’) went into the research and how I might have unwittingly affected the research process and to address them accordingly instead of recognizing them by post ad hoc evaluation. This reflexivity helped me to realise that I entered the field with my *Akan* identity shaping and directing the course of events and I cannot omit this from my field account. As an *Akan* researching in a predominantly *Akan* community I did not encounter what Germain (1993) referred to as ‘a cultural shock’ and so I cannot fail to discuss the emotional feelings I had any time I got so close to the people in an effort to understand them. I saw the respondents as my compatriots and ‘myself’ as a concerned, enlightened and a potential spokesperson eager for their cause. As a result, I wanted to know more than what the research entailed. Therefore as I sat in my room in the night with my lantern writing my field notes and experience and analyzing the data I could not hide my emotions, frustrations, desperations and anger yet I felt powerless. I could identify myself with them as a fellow *Akan*. With hind sight, I believe this might have influenced my data collection approach, a warning which Descombe (2010) gives to researchers that: ‘researchers’ should distance themselves from their normal everyday beliefs and enter the field with an open mind’ (pp: 45). In spite of this, I believe that my identity as an *Akan*, values and beliefs were helpful in collecting rich data and also gave me a ‘privilege insight’ into the cultural and social issues (Burgess, 1998) which I, not only utilized to the full but exploited to my advantage to get to areas that might remain barred to researchers with different cultural identities.

Throughout the interview and my contact with the community I never disclosed my other ‘identity’ as a nurse but made my other biographical details known to them, to feel as a fellow *Akan* who was interested in their predicament and willing to know more about their lives. My background and training as a nurse might also have had an influence on the data collection approach. I realise that at some stage I became judgemental particularly when the respondents unveiled to me their incessant quest to rely on their traditional forms of treatment as against the Western orthodox form of medication on which my training as a nurse in England was based. This led to a complex dilemma which I will explain next.

I have been brought up as an *Akan* to cherish and believe (albeit with some exceptions) in the traditional health seeking behaviour of my people. Although some of the community's health seeking behaviours were at odds with my urbane upbringing and education as well as my training and experience as a nurse from England. In some instances I could see myself in a compromising situation. For example I had, as a child, seen how local herbs and local soap had been used to treat eczema and other childhood dermatological conditions when Western orthodox creams had failed. These experiences were gradually creeping into my judgement and in my desperation not to condemn them for not seeking proper medical intervention I was at a certain stage finding it difficult to determine where my 'allegiance' was. Nonetheless I was able to take a stand when I realised that Buruli ulcer was a 'different' skin disease with devastating consequences which cannot be compared with other dermatological disease I had known and seen being treated with herbs and 'our' local soaps. That is when my nursing background reigned over my own beliefs as an *Akan*. As my nursing 'self' came to the fore, I, on several occasions saw myself assisting, teaching and demonstrating to some of the patients (some of who were not respondents) and their carers the best ways of dressing their ulcers that had recurred which with hindsight should not be the case. It is the same nursing background that led me to drive some children and their families to the hospital in my car for treatment even though they were not part of my study. Information from these sources were incorporated into the study. I realised that once a nurse one will always be a nurse and I performed this role to the admiration of the community. Nevertheless, my experience of desperation highlighted my understanding of what it means to live a life of disability and disfigurement and about a society, a nation and a government where the disabled is left on their own yet there is abundance in the cities. As a passionate advocate for women and children emancipation and empowerment in all spheres of life in sub- Sahara Africa I could not come to terms with myself seeing so many young girls abandoning their education because of Buruli ulcer.

With regard to reflection I would say that it has not been easy interviewing twenty-seven respondents with varying physical disabilities and emotional/psychological problems. In conducting these interviews I had to manage a number of roles such as managing the pace of the interview, ensuring that the respondents felt comfortable to enable them feel relaxed to disclose personal experiences, ensuring that whatever the respondents said was accurately recorded as well as recording facial expressions and body language so that quality data sufficient for analysis had been collected. Kvale (1996), has said that interviewing is a craft

that requires a skilled researcher and that the skills of interviewing must be developed. Therefore, I agree with Patton (2002), that the popularity of interviewing as a ‘quick and easy’ data collection tool belies the skill and time that is required to conduct a good interview.

The interview with the respondents highlighted what I termed a bi-vocal interview. Due to the nature of the Buruli ulcer and its effect on the respondents, many had had the condition when they were as young as four years old and had forgotten a lot of information crucial for the study and I had no choice but to involve their parents to be part of the interview process. This was unethical as many of the respondents sometimes felt uneasy trying to divulge important information to me. Particularly important was sensitive issues such as that bothering on their sexuality. For example in page 21 of my reflective diary I wrote;

*‘In the presence of her mum F6 was unwilling to say anything about her sex life. I have to contact her again with an excuse that there are few issues that would need clarification but without her mum’s presence’.*

On page 24 I continued;

*‘This is an interesting revelation from respondent F6 and I think I need to be careful what questions to ask in the presence of their parents and what to ask in later conversations without their mums’.*

I have had the experience of conducting qualitative interview in the past but this field experience has helped me to build on my previous experience. I tried to achieve this by listening to the interviews of the day and reflecting on them and then looking at areas where my skill needed improvement. I would then go out the following day to make sure that I had improved on my interview skill.

This was my first experience in conducting a focus group interview and I felt satisfied when I went home and listened to the tape. With hindsight, I realized that the trained nurses dominated the discussion and I had to occasionally intervene by prompting the other participants to make their views known. I also had to direct the participants away from more mundane issues to issues that were relevant to the study. For example the participants were

more interested with issues affecting their practice vis-à-vis the care given to the Buruli ulcer patients at the time of the epidemic. Whilst this was important for policy and caring considerations I had to remind them to focus on what they felt were the support needs of Buruli ulcer patients post discharge. Nonetheless, I have noted areas where I can make improvement in the future.

The whole field experience was a learning process for me in that but for this field study, I would not have understood this community as an *Akan* just as Van Manen (1998) intimated that 'being there offers a sense of omnipotent authority'. I can now tell it as it is.

This fieldwork experience has demonstrated to me what social research actually entails. Before I left for Ghana, I had a planned agenda, which I knew I was going to follow to the letter and return as planned. It did not work that way. In fact, I have come to realise that field research does not follow any neat, planned process, but it 'entails a social process involving the research and the researcher and it is this interaction, which will influence the course of the research programme' Burgess (2000 pp: 58). Nonetheless, the flexibility, which can be built into field research such as this, makes it an experience worth having.

As I went about the process of collecting the data, I found that interviewing alone could not generate the required information needed to understand the complex nature of humans. I had to incorporate other forms of data collection such as observing the communities as a whole and having conversation with opinion leaders, church leaders, traditional healers and others. These sometimes led to me compromising my ethical obligations. For example, I could not observe the ways of life of the communities I visited without visiting the illegal mining (locally called *galamsay*) sites. These were illegal gold mining sites but most of the communities spent most of their days scouring for gold as a means of earning a decent income. I realized that I could not clearly understand their ways of life without visiting these illegal sites, which means compromising my ethical standing, which I cannot hide from my readers. What about the respondents who were dealing in illegal substances such as sale of Marijuana? I have given them the assurance of keeping their illegal trade under wraps. As a former substance misuse worker with Portsmouth City Council should I have reported them to the authorities after the field work or keep my guilt to myself?

The preceding brought to the fore the issue of the nature of qualitative approach in collecting rich and varied data. I realized that qualitative research as a discipline enables the researcher to build other forms of data collection into what had been originally anticipated. Glaser (2001, pp: 44) says that ‘qualitative research crosscuts disciplines, fields and subject matter’. For example, I planned to use Grounded theory methodology in this study. Prior to entering the field, I held the view that Grounded theory was a distinct qualitative approach. It has emerged that it had evolved from ethnography and symbolic interactionism and it is time to concede that there were certain degree of ethnography and symbolic interactionism in the data collection process. As Patton (2002, pp: 81) has shown, ‘... ethnography is the earliest distinct tradition of qualitative inquiry’. This is clear enough to suggest that any delineation between these forms would be inappropriate and practically misleading. They are interwoven. This field experience has demonstrated that it is the analyses of the data (repeated movement between data and analysis in grounded theory) that any distinction can be made. Thus confirming Patton’s (2002, p125) view that ‘grounded theory focuses on the process of generating theory rather than a particular theoretical content’. In addition, the ‘goal is substantive theory to be applied as explanations of behaviour and not accurate description (Glaser, 2001 p.51).

One important observation that needs discussion is that of gaining ethical approval for a study such as this. The respondents in this study did not come directly under any institutional control at the time of the field study. This raised a very important fundamental question, that is; under whose authority would I, as a researcher, obtain ethical approval to enable me commence the research? Would I have been accused of covert research if I had decided to conduct the research whereby the opinion leaders in the communities felt that a formal ethical approval from the Ghana Ethical Health Review Committee was unnecessary and would have nothing to do with me if I relied on the Committee as planned? This study led to a lot of ethical puzzles, which needed tact to resolve particularly where the respondents felt that they had the mental capacity to make informed decisions and the opinion leaders questioning the rationality of having to surrender their ethical obligations to a higher authority residing some miles away from them. This study will leave this issue unresolved as I was still unsure if my decision to seek ethical approval from the authorities in Accra did not jeopardize the trust the respondents had in any potential researcher and me in the future. But as an academic exercise I had to rely on the official ethical approval letter to satisfy my faculty’s requirement.

Whichever way one looks at these issues it is clear from the field research that the myth surrounding the issue of ethical approval led to a complex set of informal rules in gaining access to the sites. Gaining access to the respondents took various forms and it involved series of ‘negotiations and renegotiations’ (Burgess, 1998) with different personalities which could be formal or informal. For example whilst waiting for the formal approval from the Ghana Ethical Health Committee, I still had the informal task of negotiating with the Chiefs and the opinion leaders in the communities. This was where I exploited my identity as an *Akan* to my advantage.

There were also no ‘rules of thumb’ with regard to informed consent as far as this study was concerned. The Western form of gaining respondents consent was not, in totality, appropriate in this study. In the communities, that I visited an ordinary nod of the head was all right for a respondent’s consent and approval to take part in the study due to a well-established fear in the past of dealing with government officials. This leads to the question whether researchers have to rigidly apply this to other settings or whether the Western ethical moral principles can be rigidly ‘exported’ and applied without any modifications in other less developed communities such as the study area. This is an issue, which might need further investigation in the future, but as far as this study was concerned informed consent came in varying dimensions. Potential researchers therefore need to understand in advance the complex nature of the social processes and their inter-relationships before they enter the site. Failure to recognize these may lead to confusion, disappointments and delays.

### ***3.10 Chapter Summary***

The chapter did not only analyse the data but demonstrated the steps taken to collect all the data and how they were analysed. The rationale for using every approach was clearly explained to provide the reader the background of these theories. The data were rigorously collected and where my ‘self’ impacted on the findings has been accounted for in the reflection and reflexivity section. The data collected has been presented in the next chapter.

## **CHAPTER4: Findings of the study**

### **4.1 Introduction**

In this chapter I will present the key findings of the study. This will reconsider how the core category was arrived and how the principal categories were built up as they are presented. The focus, the research questions and the objectives of the study will also be revisited to put the data in context. The core pattern – the Basic Social Psychological Process (BSPP) of *Reliving the trauma of my ulcer* which led to the core category of *My needs matter* and how it is linked to the three principal categories of *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* will be explained. The other three sub chapters - chapters 5, 6 and 7 will be devoted to the findings of each principal category and discuss these in relation to the existing literature by comparing what confirms, disagrees or challenges what we know and then explores what is new and the implications for the lives of the respondents in this study. The last sub chapter - chapter 8 will focus on the core category of *My needs matter*, its relationship with the three principal categories and then discussed these with the extant literature.

### **4.2 Focus of the study**

This study sought to explore the lives of people living with *Mycobacterium Ulcerans* locally known as Buruli ulcer in a rural district in central Ghana in order to understand their health and illness behaviour to better address their support needs. The qualitative grounded theory approach was used to achieve this.

### **4.3 Research questions**

The analysis of the data using the Grounded theory methodology sought to answer the four research questions of:

- a, What prevents people living with Buruli Ulcer from seeking early medical treatment?
- b, What are the experiences of people living with Buruli Ulcer?
- c, What health- related concerns do those living with Buruli Ulcer have about managing their condition and
- d, What are the support needs of people living with Buruli Ulcer that may enhance their health-related quality of life and well-being?



#### ***4.4 Objectives of the study***

The specific objectives of the study aimed at answering the above four research questions are:

- i, To explore the respondents' beliefs regarding those factors which prevented them from seeking early medical treatment for Buruli ulcer and to explore if they hold on to these reasons/beliefs;
- ii, To generate analytic descriptions of the respondents' experiences from the time diagnosis of Buruli ulcer was confirmed, through their hospitalisation for surgery, the care they received and their lives during rehabilitation;
- iii, To explore and analyse the coping strategies the respondents employ to manage their body image and disfigurement, the impact on their self- esteem and their identity;
- iv, To understand the impact of Buruli ulcer on the respondents' health and examine and discuss their health- related quality of life and any concerns;
- v, To explore what those living with Buruli ulcer report/express about their social, psychological, educational and spiritual support needs and their beliefs about how these needs can or have been met and;
- vi, To compare (v) above with the health professionals' perceived understanding of the respondents' support needs.

The analysis and the findings which follow have shown that by exploring their experiences, people living with Buruli ulcer were able to help answer the remaining three research questions and these will be discussed at the appropriate sections.

In this section therefore the experiences of the 27 people (21 adults and six children) living with Buruli ulcer as described by them as well as my personal experiences through observations, conversations and field notes will be described in detail.

#### ***4.5 Sample of data collected and sample obtained***

As explained in the methodology and methods chapter (Table 1) the data for this study were collected from both primary and secondary sources. The former included 27 respondents (21 adults and six children) living with Buruli ulcer. This data was obtained through a combination of purposive, snowballing and theoretical sampling techniques. There was also a focus group discussion with six health professionals from the local hospital who were theoretically sampled into the study. The information from this second source cannot be said to be representative of all the health professionals from the hospital, health centres and

dressings stations in the district. This is because the information/data were collected through convenience sampling due to cost and time constraints. Other primary data sources included my personal observations (recorded in my field notes and research diary) as well as discussions with opinion leaders in the communities, school teachers, ‘dispensers’, church leaders/spiritualists and traditional healers such as herbalists and *Mallams*. The only quantitative data as a primary source of data was the application of the Dermatology Life Quality Index (DLQI) tool used to identify the impact of Buruli ulcer on the lives of the respondents in the study. Data from secondary sources were obtained from the hospital (from respondents’ hospital notes, respondents’ personal hospital folders and photos) as well as documentary information from school authorities. Table 2 below depicts the characteristics of the respondents. The other characteristics of the respondents and treatment received are shown by appendix 11.

**Table 2: Characteristics of Respondents**

Respondent	Age	Gender	Age at Onset	Back To School Post Treatment	Contracture/ Disability Present
AM	22	M	13	Yes	Yes
BMM	14	M	10	Yes	No
CF	47	F	18	N/A	Yes
DM	26	M	9	No	Yes
EMM	15	M	11	Yes	No
FM	25	M	8	No	Yes
GFM	13	F	9	Yes	No
HF	27	F	7	No	Yes
IF	18	F	7	No	No
JM	24	M	10	Yes	No
KM	31	M	7	Yes Then Stopped	Yes
LM	19	M	10	Yes	No
MM	20	M	14	Yes	Yes
NF	32	F	21	N/A	Yes
OF	20	F	10	Yes Then Stopped	Yes
PF	31	F	10	No	No
QF	20	F	8	No	Yes
RF	23	F	18	N/A	No
SF	22	F	6	No	Yes
TM	29	M	12	Yes	Yes
UFM	12	F	5	Yes	Yes
VF	41	F	12	Yes	No
WFM	13	F	6	Yes	No
XFM	14	F	8	Yes	No
YF	26	F	9	No	Yes
ZM	23	M	12	Yes Then Stopped	Yes
BAM	27	M	11	No	No

Source: Field work 2010

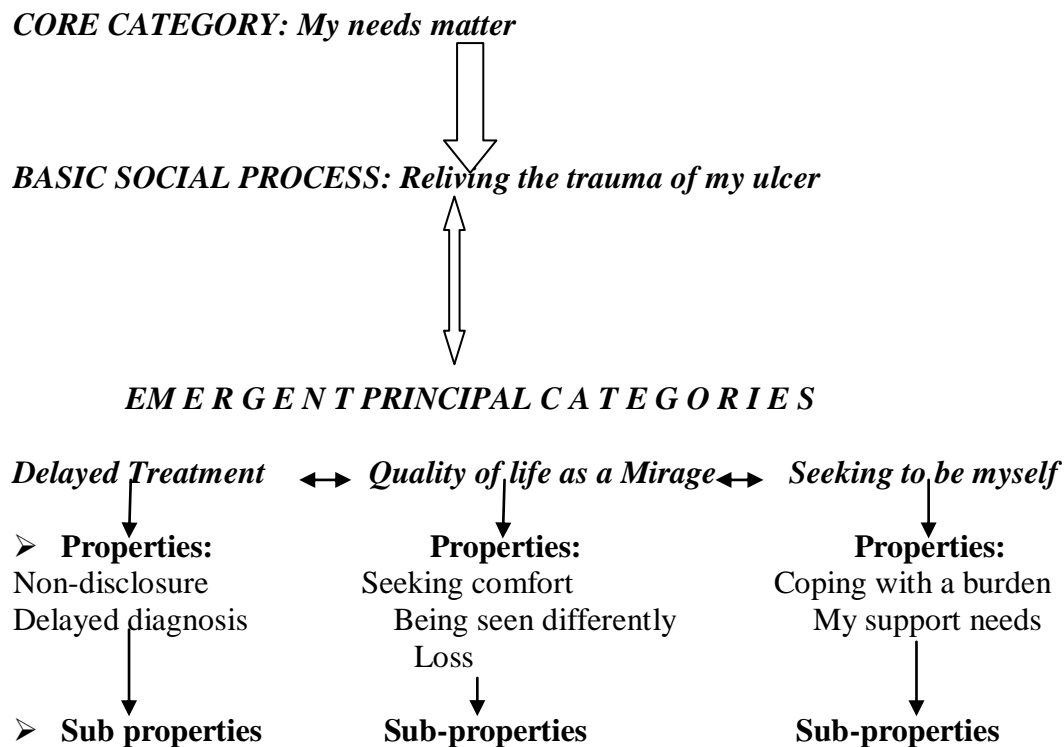
#### ***4.6 Overview of the grounded theory derived***

The principal categories and the core category reflect the data as a whole which were collected through different research methods. Grounded theory derives or generates key grounded concepts and propositions explaining the relationships between them and these are the building blocks of the emergent grounded theory. The relationship between some elements can be described as a process which Glaser refer to as Basic Social Psychological Process (BSPP). The analysis of the various data sources led to the identification of a core pattern consistent with grounded theory analysis - Basic Social Process of *Reliving the*

*trauma of my ulcer* which led to the three interrelated principal categories of; *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* and their properties and sub properties (shown in Figure 9 below). These were subsumed to form the core category of *My needs matter*.

Glaser introduced (what he referred to as) 18 theoretical codes to help understand the relationships between the emergent concepts. Glaser's six famous theoretical codes of: causes, contexts, contingencies, conditions, consequences, co-variances were applied to this study. The core category of *My needs matter* provides the **context** for dealing with the respondents experiences while *Delayed treatment* was found to be the **cause** of the BSPP, *Quality of life as a mirage* as a **consequence** of the BSPP and *Seeking to be myself* as the **strategies** adopted by the respondents to achieve the core pattern. The theoretical links as well as the core category and its relationship with the emergent categories are shown by Figure 9 below, while appendix 12 demonstrates the core category, the principal categories, their properties and sub-properties.

**Figure 9: Core category and its relationship with the principal categories and their properties.**



Glaser (1978) again advises the analyst to express these theoretical links in the form of hypotheses to enable them ‘weave the fractured story back together’ so that a coherent theory derived from the data can be formed. The hypothesis which helped with the write up is depicted by Appendix 10.

#### **4.7 Summary**

This chapter has pulled together all the data sources, the focus of the study, the characteristics of the respondents as well as an overview of the grounded theory leading to the identification of the three principal categories and the core category of *My needs matter*. In the chapters which follow (chapters 5, 6 and 7) each principal category is presented in greater depth and then discussed in relation with the existing literature as appropriate to provide the discussion element of the thesis. This will be followed by the findings of the core category (chapter 8) and how it is related with the other principal categories. This is then discussed with the existing literature where appropriate to put the concerns of the respondents in context.

## **CHAPTER5. Findings - Delayed treatment**

### **5.0 Introduction**

The first principal category to emerge from the study is *Delayed treatment* which has two properties of *Non-disclosure* and *Delayed diagnosis*. These properties explain the delay in seeking medical treatment on time. Whilst *Non-disclosure* refers to the reasons why the respondents delayed in seeking medical intervention, *Delayed diagnosis* is the part health professionals played in *Delayed treatment*. In this section the respondents' voices in support of these properties will be elaborated.

In order to capture the phenomenon of *Delayed treatment* from the emic perspective the voices of the respondents have been presented in quotes in data excerpts in support of the categories identified. The quotes are followed by the age and gender of the respondent (in parentheses) as a way of providing the reader with additional contextual information and help authenticate the findings. These quotes reflect the codes in the grounded theory.

### **5.1 Non- disclosure**

This is the first property under *Delayed treatment*. It outlines the specific reasons the respondents gave for delaying in seeking medical intervention for their condition at the time. These were varied and involved issues of culture, behaviour and economics. They are illustrated by the respondents' voices below using various data sources.

#### **5.1.1 Encountering fear**

For many of the respondents it was not the fear of the disease itself but the fear of the long hospital stay. Eleven respondents expressed this (and other reasons) as the major reason why they delayed in seeking early medical intervention. A mother of a fifteen year old respondent said during a bi-vocal interview:

*'I was gripped with fear of the long hospital stay and the consequences. I had to, emm, decide carefully. If I went to the hospital with her for err... say err... three months will mean leaving the little ones with nobody. It was a hard decision to take and, umm... I paid dearly for it'. (Mother of a fifteen year old boy).*

And;

*'I was thirteen at the time when I discovered this small nodule. Err; I was not sure what it was so I showed it to my dad. He said it looked like Buruli ulcer but it was too small a nodule to spend about four months in the hospital for it. He therefore got some local herbs to apply on it there and then. I wasn't taken to the clinic until about ten months later. If my parents had taken an early decision I wouldn't have gone through all that'. (Male, 23 years old).*

And;

*'When I showed my swollen arm to my mum she wasn't sure what to say. It was the farming season and I remember her saying, "Let's try the chemist because it will not be an outpatient treatment at the hospital. You have to be there for months and I wouldn't get a carer to be with you". (Female, 26 years old).*

The long hospital stay was captured succinctly by this young respondent whose sister had to abandon her education to be with her at the hospital for nineteen months.

*'I owe sister.... a lot because err... she had to be with me at the hospital for nearly nineteen months. I don't want to talk about what we went through. She had missed two academic years in school so she eventually gave up her education'. (Male, 20 years old).*

Apart from the fear of long hospital stay there was also the fear of surgery and its consequences. This included the cost of the surgery and the fear of amputation, mutilation and disfigurement following the surgery as the following data quotes will show.

*'A lot was said about the surgery at the hospital. People came back from the hospital with ugly scars and I didn't want my daughter to look so horrible following surgery so I decided to rely on local treatment which involved the use of herbalist and dispensers' (Father of 19 year old male respondent).*

Many respondents decided to find other means of treatment. My discussions revealed that in most cases the decisions were made by the parents at the time as many of the respondents were too young at the time to make their own decisions.

### **5.1.2 Cost of treatment**

Another reason why many of the respondents did not seek medical treatment on time was due to economic factors. I found that treatment of Buruli ulcer at the time of the epidemic (in the late 1980s and early 1990's) was not free and the cost was beyond the reach of the ordinary patient and his/her family. In addition the hospital provided the facilities for patients to prepare their own meals. The carer would have to look for his/her own accommodation as well. Due to these reasons many of the respondents at the time sought other means of treatment. The economic reasons for the delay in treatment shared similarities with fear of the long hospital stay as the following quotes show.

*'I remember vividly when my dad realised that he had no choice but to take me to the hospital. My mum and my sister rotated the shift in my care. There was the cost of feeding ourselves as the hospital didn't provide meals. Sometimes the funds were not there to buy ourselves the basics that a patient would need. In fact there were a lot of problems that is why my going to the hospital was delayed'. (Male, 24 years old).*

And;

*'My mum had to look for a menial job to support our stay at the hospital. Sometimes she would not be back from work till 5pm to take care of me. For the first two months she had to sleep on the floor at the same ward with us because we didn't know anybody in the town for her to put up with and she couldn't afford to rent a room'. (Female, 26 years old).*

As well as;

*'My sister had to come every other day with foodstuff and go back. Sometimes she will miss school for days. The nurses kept on telling me how poor my diet was. They said things like umm... it will delay the healing and some stuff. That wasn't all. Raising funds for the operation became a burden because the cocoa season was over when I was due for my operation'. (Female, 39 years old).*

For these and other economic reasons many parents delayed treatment and gambled by resorting to other means of treatment which were cheaper and with less hassle albeit less effective as the following quotation shows:



*'It was far cheaper and convenient to try with herbs or rely on a "dispenser". I eventually went to the hospital when these failed but I had no choice at the time. I mean umm... the funds were not there'. (Male 29 years old).*

Some of the respondents also relied on local chemical sellers (locally called dispensers). The 'dispenser' will normally administer antibiotics orally, topically or intramuscularly. The most popular oral antibiotic was *Ciprofloxacin* (which the locals called *Sapro*). *Sapro* was very common and could be bought at any chemical shop without prescription. The Buruli ulcer site would normally be washed with warm water (with varying temperature depending on the degree of hotness the patient can endure) and then the powdered *Sapro* would be sprinkled on the wound. The wound would then be dressed with a gauze and bandage. For economic reasons the bandages are washed for reuse. In all cases *Sapro* was administered orally between twice daily to three times a day depending on the condition of the ulcer. In addition the dispensers will give his patients sleeping tablets which were to be taken at night to help them settle well and the most popular was *diazepam* which could also be bought without prescription. All these normally gave the patient a temporary relief of up to eight months or even more. The ordinary rural folk did not know the difference between a doctor and a dispenser so the services of the latter were well sought because of their readiness to see the patient at any time.

Some few quotations will suffice to illustrate;

*'Sapro and the herbs were a relief in the first two years so I didn't umm... see the need of seeking expensive medical treatment, or should I say help? Even before I went to the hospital my parents tried the herbalist'. (Female 27 years old).*

My discussion with some of the dispensers also confirmed that intramuscular antibiotics were given in severe cases only and the syringes sterilised in *Akpeteshie* (a local alcohol similar to *Gin*) and hot water. There were other related economic problems similar to the sentiments expressed by these respondents such as transportation cost to the nearest health facility located about twelve miles from the community. This is captured by the following quotation:

*'There was no clinic here at the time. The nearest was 'A' health centre and to get there you had be ready before 5 o'clock in the morning to get into the only 'bus'. If you missed it then you have to wait for the next day. If you had other children to look*

*after who would you leave them with at that time of the day? You see we had to make conscious decisions with your limited time. So in the end you just decide to rely on a dispenser or an herbalist who were always prepared to come to you.* (Mother of a 22 year old respondent).

### **5.1.3 Alternative source of treatment**

Related to the cost of treatment was the decision to seek alternative source of treatment such as an herbalist, a *Mallam* (usually a Muslim believed to have spiritual powers who consults a medium similar to traditional healers) a traditional healer (who consults a medium) or a ‘prophet’/spiritualist (they consult medium through prayers). It was when these sources had failed that the patient would try Western orthodox form of treatment. The search for these forms of treatment did not come as a surprise to me giving that Buruli ulcer was seen as a strange disease in the communities with spiritual significance and origins at the time. In illnesses believed to be spiritual in nature the ordinary *Akan* will first seek spiritual assistance before turning to western medical treatment. Surprisingly some of the respondents confirmed that some Buruli ulcer patients were treated this way. Many of the respondents also combined the services of a dispenser or over the counter medication with the traditional medicine. For example there were respondents who confirmed that Buruli ulcer caused them to lose appetite so they would normally buy all kinds of multivitamins and vitamin B Complex tablets (locally called *biiko*) to enhance their appetite while at the same time using all kinds of herbs to treat the condition.

The following statements from the respondents will explain these;

*‘We are used to the traditional medicine particularly when Buruli ulcer was seen as a curse at the time’.* (Female, 41 years old).

And,

*‘I don’t think Western orthodox medicine can treat a condition caused by a curse or divine retribution. I believed that the doctors can come in when the curse has been removed. That was my parents’ belief at the time. I still have that belief’.* (Male, 31 years old).

A mother explaining why she sought help of a spiritualist had this to say;

*'Removing the curse is very important. If you initiate a hospital treatment while you are still under the curse the patient will incur the wrath of the gods and I didn't want to do that for my daughter'.*

A young woman vehemently defended the traditional system and has not regretted it.

*'First I was told it was a curse and I had to go through all the rituals before the lady will give me the concoction. I took it regularly and err... applied the herbs on the arm. I was ok for umm... say six months, err... maybe more than that, err... not sure. I might have eaten something I was told not to.... that is why the ulcer recurred'.*

(Female, 29 years old).

Although many of the respondents will report to the hospital if confronted with the same condition, they will combine the use of spiritualist/ herbalist due to their belief as this lady told me;

*You cannot divorce the two (she is referring to Western orthodox form and the traditional belief systems). Yes you need to see if you have done something wrong while you go for a treatment at the hospital. Certain things are beyond the knowledge of doctors'. (Female, 31 years old).*

#### **5.1.4 Lack of knowledge of Buruli ulcer**

Another reason which emerged for late presentation was lack of knowledge of the disease in the community at the time. Much about this have been outlined in the preceding sections but it must be added that it was this lack of knowledge of Buruli ulcer and its causation that led to the reliance on herbal treatment, dispensers and *Mallams* .The following quotations from respondents will suffice to explain this lack of knowledge at the time.

*'No one believed that it wasn't an ordinary skin condition. If I knew that it was curable I would have sought assistance from the hospital'.* (Male, 27 years old).

And,

*'The lack of knowledge of Buruli ulcer was widespread. My parents were torn between seeking help from the hospital and going the traditional way. Since the latter was cheaper it made sense at the time to stick to it for a while. By the time we went to the hospital it appeared that I was alive but dead, umm..., but I don't blame them for my disfigurement'. (Male, 22 years old).*

A matured female respondent with a deformed right arm and blind in one eye had this to say;

*'There were so many theories at the time. I think the popular view won the day; that it was a curse by the river because of the way we had defiled it. There are certain days that women are barred from going to the river but because of 'Galamsay'(small scale mining) nobody cares. The gods are angry with us and we are paying for our stubbornness (Female, 47 years old).*

Then turning to me and pointing towards the direction of the river she continued;

*'All the signs for the anger of the gods were there so the first choice was err... to seek to ... you know... pacify the gods before going to the hospital'.*

Another young woman shared the same view when she said that the rivers are responsible for their predicament.

*'The widespread recurrence of the ulcers points to this fact. Yes we have had hospital treatment but why the recurrence? Mine has recurred four times this year alone. You see my point? (Female 28 years old).*

Lack of knowledge of Buruli ulcer was expressed by almost all the respondents as well as their parents. This could be the driving force for the other reasons.

## **5.2 Delayed diagnosis**

The second property that was identified under *Delayed treatment* was *Delayed diagnosis*. Under this property the reasons for late presentation did not emanate from the respondents as preceding sections have shown but from either the professionals' lack of knowledge of the disease at the time or their failure to refer the patients to the right hospital. Nearly fifty five

percent of the respondents (n=12) stated delayed diagnosis and other reasons as the cause for their disfigurement. *Delayed diagnosis* will be discussed under its two sub-properties of *Limited healthcare knowledge* and *Buruli ulcer misunderstood by doctors*.

### **5.2.1 Limited healthcare knowledge**

Few of the respondents said that their parents first sought treatment from the local clinic not because they did not believe in the traditional treatment but it has always been their practice. The nurses would examine the nodule or the oedematous part of the body and would give the patient a cream to apply on it. Unfortunately the health professionals at the local clinic could not confirm the type of creams the respondents were referring to as they were not at post at the time of the epidemic. But it appears these topical treatments were ineffective. The respondents claim they had no idea what these creams were. In some cases they will be prescribed with a sedative to enable them sleep at night. When the creams failed some of them relied on dispensers which were helpful until the ‘temporary relief’ were over. By the time they decided to go to a hospital to be seen by a doctor the disease had ‘got out of hand’ and (some) needed surgery.

A local teacher whose nineteen year old son had a lower limb amputation recalled his experience;

*‘I went to the clinic and all that the nurse gave him was a cream to apply on it, which we did. He was nine years at the time. It was sort of, umm ... on and off for nearly two years. After a while I was inclined to believe that it was a curse because all the treatments from the clinic proved futile before I decided to go to the hospital. It was a race against time’.* (Father of 20 year old respondent).

Another eighteen year old girl replied to my question as follows;

*‘Mine was rare because there was no nodule. I woke up with a swollen arm. It was not painful but err... had become umm... warm and I...I ...err... was feeling feverish in the afternoon. My dad arrived from the farm and took me to see the nurse. I was given a cream to apply on it with some painkillers even though I had no pain anywhere.’*

Another woman explained how her cream was changed several times by the nurse followed by injections but there was no sign of the swollen getting better. She continues;

*'Eventually somebody recommended the dispenser so we had to walk the three miles to see him. I was given some capsules which were helpful, and err... I was on it for err... about a year or so. Then all of a sudden my right leg began to swell. So my dad decided that we should go to the hospital'. (Female 27 years old).*

Another male respondent who was twelve years at the time blames the clinic.

*'I knew the nurses would be able to provide a treatment when we err... I mean err... me and mum- went to see her. I had no nodule; my legs were swollen and I was very feverish. She gave me an injection.(Respondent claims he had no idea what the injection was). I err... think umm... I had seven in all in addition to the cream but it didn't help. Later on I went to see a herbalist who helped me for a while but it was just temporary'. (Male, 28 years old).*

If the clinic could not provide treatment then the patient would then decide whether to seek treatment elsewhere or continue to seek medical intervention. In all cases the condition would have worsened before the patient would go to the hospital for surgery or surgical debridement.

### **5.2.2 Buruli ulcer misunderstood by doctors**

Related to the foregoing is how Buruli ulcer was misunderstood by doctors but the respondents saw this as the lack of knowledge of the disease or Buruli ulcer was not known (or unfamiliar) to doctors at the time. Even though the respondents who expressed this as a reason for their disfigurement were few (n=9; about a third of the respondents) these reasons cannot be discounted. What is worthy of note is that only two of these respondents lived in the study area at the time they had Buruli ulcer. The respondents had reported their condition to government hospitals in different parts of the country but no solution was found and they were not referred to experts.

A twenty six year old respondent who was a student at the time of contracting the disease said he visited three government hospitals (including a regional hospital) yet Buruli ulcer was

not diagnosed. Therefore faced with no hope and choice his parents decided to seek the services of a *Mallam*.

He had this to tell me during the interview;

*'We visited three government hospitals including a regional hospital in .... but none of their experts was able to diagnose it. Eventually my parents had to go to see a Mallam'. (Male, 26 years old).*

This respondent recalls how he nearly died of Buruli ulcer. He said that by the time somebody alerted his parents to this local hospital he was bloated beyond recognition.

*'I had bloated umm... I was smelly and there were flies all over me. I had lost appetite. It was the timely visit of my dad's cousin which saved me. By the time I got to the... hospital I knew I couldn't make it. A lot of tests were carried out and umm... err... I had blood transfusions in the first three days... '.*

Another twenty year old woman describes how she spent seventeen months in a regional hospital where the doctors could not diagnose that it was Buruli ulcer. She told me of her anguish, suffering and the number of tests which were performed on her and how much her parents spent for her stay at the hospital. Eventually out of desperation the family requested for self discharge. Interestingly she was told of this small district hospital which saved her life.

*'I was like a living but as a dead woman. I was smelly and nobody could come near me. I lost one on my breasts and my right arm severely disfigured. I thought I was in the hands of professionals but I was wrong. They let me down (Female, 31 years old).*

These and other experiences suggest that the hopes of these respondents were dashed as Western orthodox medicine could not provide the solutions to their medical conditions even though they were the first port of call when they had the disease.

### ***5.3 Discussion - Delayed treatment***

#### ***5.3.1 Introduction***

Objective 1 of the study sought to explore the reasons why the respondents delayed in seeking early medical intervention as this problem is well established (example Ajoulat et al, 2003; Asiedu and Etuaful 2000). The key findings relating to this objective are under the principal category of *Delayed treatment*. As far as this category is concerned I drew on issues of disclosure, health seeking behaviour pertaining to *Akans*, the misdiagnosis and/or misunderstanding of Buruli ulcer by the health professionals, vis-à-vis the respondents' accounts which prolonged their illness and suffering. This category also revolved around issues of culture, behaviour and economics which are discussed in relation to the existing literature. *Delayed treatment* was shaped by the different factors which influenced the respondents' decision making process and these are discussed below.

#### ***5.3.2 Encountering fear***

The study found that fear of surgery and fear of the long hospital stay and their consequences were some of the reasons why the respondents sought hospital treatment late. This resonates with what has been documented in the literature (see section 2.06). The difference between this study and the others described in the literature is that while the literature provided studies that used survey approaches with structured questionnaire interviews (where the questions were pre-coded for the respondents to choose) this study adopted the exploratory approach which was more open ended where the fear was explained by the respondents from their perspective and/or the appropriate adult and were usually shaped by my questions.

What is significant about this category is that in a farming community such as in the study area 'wasting' an average of three months in a hospital environment would mean that one of the parents (usually the mother) would have to give up their main source of income and livelihood to be with the patient about 15 miles away. In a situation where the mother decided to stay at home to take care of the larger family, in addition to supplying foodstuff to the patient at the hospital (patients had to provide their own meals), a female carer (by tradition) would have to be chosen by the family to be with the patient. This arrangement led to a number of school-going teenage girls to abandon their education to fulfil their traditional caring duties. If the child was the patient the fear of losing their education became an inhibiting factor an issue which is supported by Hamzat and Boakye-Afram's (2011) study.



The authors found that some school-going children had to curtail their education either because of Buruli ulcer or their parents suffered from the disease. In this study 44 per cent of the respondents (n=12) stopped school because of Buruli ulcer. This finding reinforces the stereotypical African role of the woman. Feminists will argue that this is made possible because of male dominance which perpetuates the unfairness, repression and lack of women empowerment, an issue which is beyond the scope of this study but which is highlighted by the findings.

In situations where there were harmonious marital relations the decision making process would be made by both parents of the child with the disease which most of the time led to the woman leaving the house to be the main carer for the child in the hospital. The man's role will be to ensure that adequate resources in the form of foodstuff, money and other essentials are supplied to the sick child and the mother. My discussions with the families resonated what has been found in previous studies on chronic illness (McCullum and Gibson, 1971; Burton, 1975; McCrum, 2000). My findings therefore confirm that family strength (rather than weakness) is a catalyst for families dealing with chronic illness.

Illich (1995) referred to clinical *iatrogenesis*, which is, doctor inflicted disease. According to Illich (1995) this occurs in various forms which the ignorant patient will find difficult to detect. In the context of this study there was evidence of clinical *iatrogenesis*. Apart from this there were ignorant treatments such as the use of unidentified creams and injections which were found to be ineffective but which were used by health professionals at the local clinics. These findings have not been reported in previous studies. For instance a Buruli ulcer respondent contracted the equally serious disease of Tuberculosis while at the hospital. There were other accounts where another woman lost a pregnancy; two people contracted Hepatitis C, three others complained of other complications, and how three Buruli ulcer patients (a teenager and two children) died in hospital and how many children suffered from bed wetting following their surgeries. Accordingly stories of personal experiences such as these either put fear in some parents or put them off completely from seeking medical intervention for their children as it was thought to often fail. Similarly in Evans et al's (2003), Stienstra et al's (2002) and Muelder et al (2008) studies, fear of mutilation and fear of surgery respectively and other clinical difficulties were reasons found for the delay in seeking early medical treatment which support the accounts given by the respondents in this study. Therefore in addition to perceived threat of fear, clinical *iatrogenesis* is a further factor or

issue that prevents Buruli ulcer patients from seeking early medical intervention. So there is clear evidence from this study that people living with Buruli ulcer believed that many health problems were caused by conventional Western hospital treatment a finding that has never been reported in the literature. In Evans et al (2003) and Stienstra et al (2002) studies the participants had chosen this fear from a structured questionnaire. In this study this kind of fear and other clinical problems were obtained through repeated interrogation and exploration with the respondents and their parents once again highlighting the importance of exploratory studies and confirming the rigour in this study. The clinical and policy implications of this are addressed under the recommendations section.

### ***5.3.3 Cost of treatment/ Alternative forms of treatment***

These two properties are discussed together because they seem to have the same basis for explaining the reasons for delayed treatment. At the time of the Buruli ulcer epidemic in the study area (in the early 1990s) treatment of the disease was not free. Therefore the patients resorted to the use of traditional health practice which was cheaper and in line with their beliefs. Every culture perceives disease differently and people's beliefs about health and illness are woven together from personal and shared experiences, folk beliefs and stories Jones (1994). According to Turner (1996) cultural beliefs and behaviours influence individual's perception of disease aetiology, illness and disease labels. Turner's (1996) treatment categories – folk medicine, Western medicine and magical medicine (see section 2.06) as well as Ryan et al (2011) typologies of traditional medicine –herbalists, divine healers and faith healers are found to be consistent and support the findings of this study. This study however found a fourth type of treatment category which combines self – medication with what the locals call Dispensers (sellers who use Western medicine bought over the counter to treat and dress wounds but with limited medical knowledge). In all cases analgesics bought over the counter as well as oral and topical antibiotics are used to ease pain and reduce inflammation.

This finding is significant for policy in that despite years of public education on Buruli ulcer (there has not been any policy review by the government of Ghana at the time of the study) the respondents in the study area find the use of traditional health practices very useful in their health seeking behaviour. There could be two reasons for this. The first is that even though treatment of Buruli ulcer is free at the time of the study many people are not aware of

this which highlights the lack of information dissemination in rural communities in Ghana. The second is the ease with which the various traditional health practice is accessible (because of transportation problems), affordable in terms of costs and the inconvenience of leaving home to attend to a health facility at a distance. Apart from these the traditional health practitioners approach are in tune with their beliefs and culturally appropriate at a time when Buruli ulcer was seen as a curse or divine retribution. In many of the rural villages the people have knowledge of the common herbs to treat skin diseases which I as an *Akan* was aware of. Knowledge of these herbs is shared by word of mouth and has been handed down from generations so there was a cultural commitment to the use of these herbs and other forms of traditional health practices. Whilst the health professionals insisted that the government messages about free treatment of Buruli ulcer has been around for a while many of the respondents' and opinion leaders denied any knowledge of this.

The economic drivers for these decision-making approaches is highlighted by Donovan and Blake (1992) and Down et al (1994) whose studies (although not specifically focus on Buruli ulcer) suggest that seeking these traditional treatments from purely economic point of view is part of a rational decision-making process. It is clearly evident in these accounts that families would seek Western medical treatment when the other sources had failed by which time the disease had progressed leading to extensive ulcers which take a long time to heal.

This study has therefore found the importance of incorporating the peoples' belief systems and the understanding how this shapes their health seeking behaviour and affects their effective interaction with the health care delivery system in the treatment of Buruli ulcer.

#### ***5.3.4 Delayed diagnosis***

Lack of knowledge of the disease by both the respondents and the professionals is discussed together under this section because they seem to have the same basis for explaining the reasons for diagnosis. The lack of knowledge of Buruli ulcer could also be seen in the light of the nature and the clinical presentation of Buruli Ulcer itself. In this study it was found that the condition appeared in various and in disguised forms which made it difficult for the doctors to diagnose. Traditionally Buruli Ulcer would appear as a nodule (a small painless swelling under the skin), an oedema (a large painless swelling which often involves the legs or the arms) or a plaque (a large painless swelling with clearly marked borders) ( Nienhuis et

al, 2008; Wansborough-Jones and Philips, 2003). This study revealed that Buruli ulcer could appear in diverse forms occasionally with symptoms mimicking that of other ulcers, malaria or even rheumatism. For example there were respondents who had reported what they suspected to be mosquito bites, or the swellings or scratches were play or work-related (especially in the farm). These findings appear to be at odds with Ackumey et al (2011) Ga study in Ghana. While their respondents felt that the nodules were ordinary boils that will burst in time (and thus doing nothing about them) and ointments and balms bought from chemists were used to reduce unexplained swellings; in the present study the respondents would initially either use herbal treatment for such unexplained swellings or scratches before turning to ‘dispensers’, herbalists, divine and faith healers. The findings of these two studies however have implications for public health education in helping in the early detection and understanding of the disease because while the Ga district is more urbane the study area for the present study was a typical rural community.

### ***5.3.5 Buruli ulcer misunderstood by doctors***

This study appears to have uncovered the failure to diagnose Buruli ulcer by doctors and the fact that they were not referring the patient to appropriate specialists as one of the major reasons for delaying treatment. This major finding has eluded previous researchers. It is however reasonable to admit that at the time of the epidemic (in the early 1990s) Buruli ulcer was not a reportable disease in Ghana. My discussions with health professionals indicate that Buruli ulcer is now a reportable dermatological disease and that many health facilities have professionals who have had training in dealing with the disease. The major obstacle is that majority of the people living in the affected areas still are not aware that treatment of Buruli ulcer is free which is still affecting government’s efforts of getting people to report the disease on time.

### ***5.3.6 Summary***

This chapter has discussed the findings related to the delay in seeking medical intervention on time. The various reasons have centred on cost of treatment which pushed the respondents to seek treatment late although the decision to rely on the peoples’ own health seeking behaviour cannot be discounted. The contribution of health professionals has been discussed. This principal category is the cause of the BSPP. In the next chapter the consequences of delay in treatment will be presented and discussed.

## ***CHAPTER 6 Findings - Quality of life as a mirage***

### ***6.0 Introduction***

The second principal category is *Quality of Life* as mirage. The respondents used words and phrases in *Twi* dialect when referring to their health in which they use the metaphor of a mirage. A mirage, according to the Oxford Advanced Learner's Dictionary is a 'hope or wish that you cannot make happen because it is not realistic'. In other words the desire to achieve or enjoy quality of life is an illusion to most of the respondents of this study because of widespread stigma associated with the condition. In this first category the respondents narrate and describe their lives as people living with Buruli ulcer in a 'world' of their own. The three properties: *Being seen differently*, *Loss* and *Seeking Comfort* will be described next and I will attempt to explain how they are linked to the core category of *Quality of life as a mirage*.

### ***6.1 Being seen differently***

Under this property the respondents tell what I have described as 'a tortuous journey of everyday embarrassment'. They give vivid accounts about how they have been subjected to all forms of stigma – by health professionals, in school, the general public and at home for which a satisfactory quality of life will remain a mirage to them.

According to many of the respondents there were overt as well as subtle forms of stigma which affected their daily lives which made them feel and be seen as different from others in society. Yet no matter how one sees it the respondents saw such behaviour and attitudes very embarrassing which had profound effects on their self esteem and perceptions of society.

#### ***6.1.1 Compliments***

This was the first sub-property identified under *Being seen differently*. One respondent recalled her student days when anytime he answered or gave a constructive contribution in class the teacher will say something like;

*“oh you see, even with all her problems... I'm thrilled by your answer”*; suggesting that he wasn't expecting a disfigured girl to know the answer or make such a contribution in class' (Female, 18 years old).

Another male respondent recalled similar incidents in school when a teacher remarked something like;

*'I know that had it not been your problems you would have done more than this'* Male 20 years old).

He went on to say that,

*'Such unwelcome comments will put you off from being active in classes'*.

One male respondent commented that;

*'Because of this I stopped answering questions in class and the teachers never asked why I became a mere passenger in classes'* (Male 24 years old).

Such unnecessary compliments were experienced at home as well as in public places. At home, one respondent said that,

*'When my mum says "well done" to a daily routine I have carried out but will not say the same to my siblings it makes me feel inferior among my own brothers and sisters; and makes me think it's is due to my condition'*. (Female, 14 years old).

In public places and in public transport such unnecessary compliments are encountered by Buruli ulcer patients on daily basis. Compliments such as,

*'Oh! So you've been standing in the bus all along eh? You might be tired... Well done'*. (Male 19 years old).

The respondents felt that what appeared to be unnecessary compliments led to feelings of being pitied by people around them. In some instances this led to embarrassment which made them think less of themselves.

*'Why should people feel pity for me all the time? I want to feel normal and to go along my daily life without any one feeling sorry for me. It leads to embarrassment and sometimes feelings of worthlessness'* (Female 14 years old).

### **6.1.2 Patronising**

Apart from the unnecessary compliments, patronising was another form of stigma that most of the respondents reported in this study. This form of stigma occurred in schools, at homes and in public places (including public transport).

Patronising came in different forms. One respondent said,

*'It mainly took the form of someone smiling at you which would normally not be necessary'. (Male 19 years old).*

And,

*'Imagine a complete stranger smiling at you in a way that suggest "well done" when you have managed to board a "trotro"(a form of public transport in Ghana) unaided with one arm. It makes me self-conscious anytime I leave the house as I have to work out the impression I have to put on in areas where 'normals' will not'.(Male, 23 years old)*

A young lady remarked that,

*'Others will also try to assist you when you have not asked for their help... Such patronising acts make you angry and sometimes spoil your day'. (Female, 18 years old).*

One young man recalled similar experience in school. He asked me,

*'If a teacher looked at you all the time and kept asking you "are you ok, are you sure you are all right?" throughout the period, what did it suggest? I wouldn't mind if the teacher was doing this to every one in the class. I get worried if I feel that i'm being singled out because of my ulcer (Male 19 years old.).*

Yet another teenage girl angrily said,

*'Suppose the teacher entered the class and came to your table straight away and whispered in your ear if you had taken your medication. It makes you feel that somebody is policing you. (Female 14 years old).*

These patronising acts were not limited to schools and public places but also in the house where they were supposed to have some sympathy. Patronising at home was an everyday occurrence to some of the respondents and took many forms which were either overt or covertly carried out by parents and siblings. One young lady recalled that,

*'Phrases such as "can you do it by yourself" or "did you do that by yourself" occurred every minute in the house'. (Female 14 years old).*

And,

*'If I carried out a task anyone of my age will do in the house, my parents will assess it as something remarkably noteworthy. I will then become a normal person, for an accomplishment that will not raise a brow if performed by my other siblings. It makes me feel that I am the only one of my kind in the house and that everybody is being nice to me because of my disfigurement' (Male 14 years old).*

Throughout my discussions with the respondents I found that feeling of inferior, insignificance and unintelligible just about sum up their reactions to patronising as the following show.

*'I want to be seen as any other teenager in the community but not someone who is daft and doesn't know what he's doing. I hate it when people always seem to agree with whatever you say because they don't want to be seen to offend you because of your ulcer' (Male 20 years old reacting to peoples reaction to him when he sometimes knows that he might be wrong).*

In most instances the feeling of being patronised led to such cognitive events as being vigilant and this was mostly about the female respondents. For example;



*'I am always vigilant and looking round myself if someone is looking at me because of my disfigurement. I am conscious of visual bullying' (Female, 14 years old).*

And;

*'Sometimes I get the feeling that someone is staring at me. I then become self-conscious particularly when I'm in public; and that is why I try to conceal my disfigurement by covering my body with clothes without worrying about the weather' (Female, 19 years old).*

### **6.1.3 Name- calling**

Another way that made the respondents felt different from others in society was name-calling. Name-calling emotionally affected some of the respondents which also affected their everyday lives. This is because to some of the respondents it took them by surprise that they were called by socially derogatory names because of the way some of them had to dress to 'hide' their disfigurement. One respondent said to me;

*'I nearly fainted the first time I heard that err... "Kojobasia" (a transsexual) was the name given to Buruli ulcer patients'. (Female 26 years old).*

Another young woman disappointingly remarked,

*'I wished I could fly away from the scene when this bloke told me the polo neck I have been wearing is called "mekondowuo". ('I wish I were dead') (Female, 18 years old).*

She admitted that it was not only inconvenient to wear a polo neck in the hot tropical weather but it is meant to cover the horrific scars on her neck and chest.

Name calling led to antisocial behaviour to some of the respondents. One young respondent recalled how the name calling affected her social life. She recalls,

*'I became very antisocial and lived a life of a hermit. I couldn't be with my friends who were suspicious of contracting the disease so I became suicidal and angry with the world'. (Female, 22 years old).*

When I asked another young lady how she managed to cope with that tag she replied,

*'Who told you I coped? I have not been able to feel comfortable with it and anytime I hear that label in anybody's conversation I sort of coil back to my old self'. (Female, 20 years old).*

The name calling led to depression, loneliness and suicidal attempts particularly among the female respondents. One respondent confided in me that,

*'I became depressed, lonely and umm, didn't even think of my appearance anymore as err, young girl. In fact, umm, ... but for Father ... who noticed my absence from church and called to our house that afternoon, I would have done something nasty'. (Female 22 years old).*

In response to the name-calling some of the respondents feel in some cases that they do not deserve to live and it would have been better if they had died on the theatre table as this young man repeatedly told me;

*'Sometimes I feel that I don't deserve to live. I don't really fit- in. Umm .... I should have died at the hospital' (Male, 25 years old).*

When I asked him to clarify this he replied;

*'Certain specific dehumanising words such as 'apakye' (a lame person), 'oyarefo' (a sick person) and the like are used in peoples' daily conversations as a metaphor without a second thought and its effect on you. It makes you feel unfit to live in the community. It's like you are not one of them. It would have been better if the doctors had ended it all on the theatre table. I am a human being with feelings and I hope you know what I mean'.*

Due to the name calling some of the respondents have had to change the way they dressed 'to please' society at the expense of exposing their horrific scars.

#### **6.1.4 Battling with my culture**

The respondents also felt different as they came face-to-face with battling with their *Akan* culture; and it took various forms. As *Akans*, the respondents' felt that fitting into the *Akan* culture was conditional on their conforming to societal rules and regulations including the way they should dress even with their disfigurement. This 'cultural survival instinct' to dress to fit into the orthodox norms of the *Akan* culture became an uphill struggle and challenge everyday. They would be seen as deviants if they did not conform. Their quest to conform was not easy for majority of the respondents due to their varied disfigurements which prevented them from conforming to the norms of society.

One such difficulty to conform to societal norms was greetings (which take the form of hand-shaking) with the right hand. One of the taboos among the *Akans* is to greet /shake hands with the left hand. *Buruli Ulcer* respondents who had had their right hands/arms amputated or severely disfigured found it extremely difficult to conform to this norm. There were few in the present study. One respondent said,

*'I can't greet with my left hand which makes me feel awkward in my own society'.*  
(Male 31 years old).

And,

*'Most of the time I don't greet at all when I arrive at a social gathering which is odd'.*  
(Female 47 years old).

The following conversation I had with a twenty seven year old man will highlight the controversy surrounding this property of *Being seen differently*:

Me: *With just your left arm how do you greet at social gatherings?*

Respondent: *'People in this community have got used to me not shaking hands. I just bow and say good afternoon or good day and walk away'.*

Me: *What about if there are new faces at a funeral for example?*

Respondent: *I raise my voice to all as usual and will say “kafra” oo, (I’m sorry) I have a left arm, and people seem to sympathise or understand, and I just walk past them.*

Me: *What about when you are seated and it is your turn to receive the greetings?*

Respondent: *There you go! I keep reminding people “kafra” oo, I have a left arm only. They will then walk past me to shake the next person’s hand. It is not easy, very embarrassing but I have got used to it’. (Male 27 years old).*

Their need to conform and fit into this accepted tradition is normally driven by the desire or concern about what others will judge them to be if they fail to comply with this basic societal norm. To some of the respondents therefore, such demands by society have forced them not to attend social gatherings and when they meet people they refuse to shake hands in order not to offend them. They will prefer to say, ‘hi’!, or something similar and walk away, as this young lady told me;

*‘I try not to embarrass people so I wouldn’t put my left hand out at all to greet. Then they will look at you twice to find out why you are behaving in that manner. A local person would know but the problem you have is with strangers. Before I meet the stranger I will just say Hi! And just walk away regardless of what they would feel (Female 32 years old).*

*Battling with my culture* leads to feelings of rejection *which comes about* when the respondents cannot conform to certain societal norms which require the use of the left hand. For example in many *Akan* homes the extended family system is still very active and paramount where siblings and cousins from the same extended family eat together from the same bowl signifying the communal spirit among the people. But due to the stigma attached to Buruli ulcer, the belief that the condition is either a curse or as a result of divine retribution and the suspicion that the condition is contagious, people living with Buruli ulcer are not permitted to share in this ‘communal eating’. They have to eat in social isolation.

In the words of this twenty two year old woman,

*'Nothing is more emotionally painful than to see all of them eating together while you sit somewhere eating your food in tears which is concealed'.*

Another woman remarked,

*'The first feeling of rejection came about the first day I was discharged. For the first time in my life my food was placed some feet away from the rest while I ate with amazement and disbelief. I said to myself that if that is how I was going to face the world then how would I survive? That fear and worry started there and then to lock inside me'* (Female, 23 years old).

As well as;

*'The rejection, err, I mean err, the stigma among your own family devalues you, err... in fact, it kills you more than the disease itself'* (Male, 22 years old).

Another form of rejection that was uncovered was that by loved ones as this man recalls how his three years relationship collapsed after he was discharged from hospital,

*'She has always told me that she will be there for me and I trusted her. Then err, out of the blue came the shock that she could not cope with the pressure from her friends and family. Hmm... and that was it, she was gone for good'* (Male, 26 years old).

Feeling of rejection by loved ones were not limited to male respondents alone as this woman recounted her experience with her boy friend after her discharge;

*'My boyfriend came to see me at the hospital after my operation... Then I had the grafting three months after that. I had lost my right breast and my torso was badly disfigured. I went to see him several times after my discharge but his attitude had changed. I think he didn't want to see my disfigured body'* (Female, 25 years old).

### **6.1.5 Prejudice**

Yet there was *prejudice* as another property of *Being seen differently*. Prejudice and discrimination have been applied to Buruli Ulcer patients in many situations.

Whichever way one looks at the treatment and the experience of the respondents in the study it is obvious that many of the patients encountered a lot of institutional prejudice which led to feelings of worthlessness and marginalisation in their own community. Many of the patients were of the opinion that society at large had little knowledge of the disease at the time and therefore fear of contracting the disease led to this kind of stereotype. What made it worrisome was when this stereotypical behaviour was reinforced by the health professionals in whom they had entrusted their hopes.

One patient recounted his experience at the hospital when he realised that his status suddenly changed as soon as the laboratory results confirmed that he had Buruli ulcer. He recalls,

*‘The result of my test suddenly changed my status from a welcome patient to an undesirable and perhaps an unwanted one. The friendly faces of the nurses I had become acquainted with in the last two days had all of a sudden become strangers to me. It appeared strange to me at first but I had to try to forget about them and focus my attention on err... my treatment and recovery’.* (Male, 24 years old).

Another respondent complained that,

*‘There were negative attitudes and maltreatment, raising their voices when you would least expected them to. Sometimes it took the nurses’ time to answer my call-bell. On many occasions I didn’t bother to call them even though I might be in pain or wanted to use the toilet’.* (Female, 41 years old).

Due to prejudice this patient was kept in the same ward with Tuberculosis patients until he contracted the disease. He recounts,

*‘While I was suffering from Buruli ulcer I was kept in a male isolation ward with a Tuberculosis patient. After my sixth operation I had become weak err... and lean, then err... I started coughing profusely.... I had no strength and had to be careful to manage the scarce energy left in me. Oh, hmm... the incessant cough affected my right arm, I was dying from the cough but no matter how hard I complained nobody seemed to listen to me. My mum, oh err... shared tears with me. She err... was in err....I don’t know; err... and took the courage to complain to the doctor that the*

*cough was unusual. A test confirmed that I had contracted Tuberculosis and had to be treated for this as well. This was followed by skin grafting before I was transferred to the main ward'. (Male, 26 years old).*

Another male patient recapped his experience with institutional prejudice when he recalled,

*'I was neglected by staff and shunned by other patients; in fact, I was treated like a pariah.. Err... I kept asking myself if it was worth the while being there in the first place'. (Female, 23 years old).*

A twenty four year old respondent who was a student at the time describes how the media contributed to this unsavoury situation. He recounts,

*'In the face of this indifference, hostility and hate, prejudice was made worse by the media who twisted stories of Buruli ulcer during the period to their advantage. The media were allowed to interview patients sometimes without your consent and staff and the resultant publications and the news sparked prejudice. Because of this I err... wasn't prepared for the rejection and stigma that laid in wait for me outside the hospital. Even before I was discharged I felt vulnerable because the conscious self was not prepared for my borrowed identity' (Male, 24 years old).*

Outside the hospital corridors similar attitudes were encountered when they were discharged into the communities. Such prejudice led to loneliness and soling as well as misunderstanding among some of the respondents as this young woman recounted;

*'Because of the widespread prejudice I kept myself to myself and didn't want to have anything to do with the outside world. This didn't suit my personality as I have always been extroverted but because no one seemed to understand what it is like to live with Buruli ulcer I could stay at home all day as a stranger in my own community' (Female, 23 years old).*

Similar attitudes were encountered at home and it has not been easy beating the stigma that still lingers on the minds of many. The prejudice that occurred at home took the form of over-

protection from their over-caring and anxiety-filled parents. According to some of the respondents such attitudes have led to lack of independence and confidence in their lives. This stemmed from the widely held belief among over zealous parents that disfigured children are susceptible to bullying (physically and emotionally) and therefore they had to be there to 'protect' them. Due to this perception parents restricted their children living with Buruli ulcer from going out to play with their peers 'unsupervised'. Those who were lucky to be allowed to go out were constantly monitored by their parents. Accordingly these 'abnormal supervisions' had rendered them physically and emotionally dependent on their parents thereby finding it difficult to act or take decisions on their own. It has also affected their confidence and self-esteem.

A young respondent recalls such moments,

*'Even at the age of fifteen my mum still followed me to the playground to make sure that I was ok. Can you imagine that? It has affected me a lot because I cannot take decisions on my own, and err... I have no confidence in myself. It is all down to prejudice'* (Female, 27 years old).

Similar sentiments were expressed particularly among the male participants who felt that such over protection has affected their confidence in approaching the opposite sex. One young man tells me of his experience,

*'My mum had to decide who I should play with and who I should avoid. Eventually I realised that I couldn't approach members of the opposite sex. No wonder I am still a virgin at my age. I have no confidence and I don't know when, err.... What has become of me then? A hermit, err... unsociable member of my society and, err... perhaps a virgin for ever'* (he sobs) (Male 23 years old).

## **6.2 Loss**

The second property under *Quality of Life as a mirage* was *Loss*. This category revealed significant patterns of similarities and contradictions in the transcripts, therefore field notes and personal observations became part of analysing this sub-category. What is worthy of note however is that, two prominent issues became significant in dealing with loss as feature of the patients' discourse. The first one is of losses which were seen as tangible, physical or



materialistic in nature and the second kind of loss was how the respondents' constructed their perception of loss. These two were however seen to be inseparable as for example while the former involved loss of bodily organs such as limbs or eyes leading to inability to perform certain basic tasks the latter involved the effects of disfigurement in the daily lives of the respondents and how these affected their lives as individuals. These two issues were more significant to respondents' of working age than the younger respondents and these are discussed next.

### ***6.2.1 Loss of physical abilities***

This was the most obvious form of loss that the respondents have experienced – the loss of bodily parts such as arms, eyes and limbs which affected and interfered with their daily activities. Some of the losses under this property were obvious as the interview went on, and therefore what I did was leading the respondents on to tell me in their own words the effects of these losses on their daily lives. Contracture/disability affected 56% (n=15) of the respondents' activities of daily living. Therefore care was taken to avoid embarrassing questions.

Apart from the obvious physical losses due to amputation which affected their daily activities the respondents suffered other physical hardships such as loss of sensation and numbness on the affected parts as is narrated by the following respondents;

*'I have to be careful when I go near any cold or hot object because there is no sensation to my left hand'* (Male 29 years old).

Another respondent admitted that;

*'I have to be cautious when I go to the farm in case something pricks my left leg because I will not feel it. This constant reminder of my surroundings in itself is a big worry. I need to dress appropriately before I venture into the bush irrespective of the weather'* (Male 29 years old).

Yet there were other respondents who, for fear of the disease recurring (due to loss of sensation), have to be anxious all the time about their environs. One respondent said the only avoidance strategy is to remind herself of her environment. She said,

*'I will stop to remind myself of where I am; err, if my surroundings are ok. I'm all the time scared something nasty is going to prick my leg or something like that'* (Female 24 years old).

This means that due to the fear of recurrence (because of lack of sensation and numbness) Buruli ulcer restricts the respondents' movement such as where they could go to shop because they have to avoid crowded places, who and where they have to play with, what footwear to use and what work to engage in to earn a living. This is encapsulated by this young woman;

*'I spent about four to five hours daily thinking about recurrence and then try to think about how best to minimise any activity that will cause recurrence. If I decide to go to the shop I have to choose my timing carefully because my condition has a profound effect on when and where to shop. It's even worse when I want to travel by a public transport'* (Female 26 years old).

Another female respondent who I questioned about the effect of her condition on her quality of life told me;

*'If I cannot wear these high heel shoes like any other girl because of contracture and a mini skirt because of a disfigured thigh how do I say that I have a quality of life, it means I'm deceiving myself'?* (Female, 18 years old).

The thinking of recurrence affects their daily activities and this coupled with the intermittent pain affect their sleep patterns as well. One young man said,

*'Buruli ulcer itself is not a painful disease but the bones and muscles become painful and sometimes stiff when you stand for a long time or carry out any strenuous activity. But I have no choice; I have to stand on the leg to work in the farm to survive'* (Male 28 years old).

Another young woman recalled when she is awake most of the night due to phantom pain:

*'You feel pain in the amputated leg and wake up to take your medication only to realise that it was a dream'* (Female 22 years old).

This experience cut across all the respondents who have had amputation and they say that they have not got use to it. A teenage girl said,

*'It is a nightmare especially when you are sleeping with someone, hahaha...'*  
(Female, 20 years old).

Apart from the loss of sensation other effects from the physical loss of bodily organs or deformities have subjected some of them to restrictions. This has come about from contractures of the affected parts of the body. Various forms of contracture were experienced among all the respondents. While it affected how some walked, to some it was carrying out basic tasks such as carrying a baby, pounding "fufu", holding a basket or bucket on the head to even feeding themselves as the following respondents recall;

*'I always need someone to bath and cream my back because I can't use my left hand'*  
(Female 32 years old).

And;

*'I can't perform my normal daily routine due to contracture. In fact, contracture has restricted anything that I used to do. Even feeding my self is a task'* (Male, 28 years old).

And,

*'Contracture affecting my left arm is the most difficult problem I have had since I was discharged five years ago. Sometimes the arm gets swollen and I have to put it in a sling or put it on my head. Thanks to Sapro (ciproxine) and Para (paracetamol) which help to release the pain'* (Male 29 years old).

Another young mother said;

*'As for the contracture and the pain they are going to be with you all the time. Err... I don't see any solution to them. I can't hold my baby in my arms for long without getting tired. I can't even put her on my lap because the legs will give way'* (Female, 41 years old).

Losing a leg or an arm has a lot of psychological effects as well;

*'I feel all right and healthy inside until I look into a mirror; then I will ask myself if that person starring at me is me. That unconscious thought then suddenly changes me and then I would feel worthless'* (Male 22 years old).

Another young woman who was popularly called Princess Diana by her teachers (because of her long beautiful legs before she contracted the disease) said to me;

*'I was thirteen at the time and all the guys loved to be hanging round with me.... I can't wear a skirt any longer. And sometimes when I take my trousers off my self refuses to accept what I see under the clothes. Then I would ask myself if I have unintentionally disguised myself'* (Female 22years old).

### **6.2.2 Loss of Identity**

Many of the respondents discussed their loss in terms of their self and identity in reference to their tribe – as *Akans*. That is, the obvious loss of a physical nature such as loss of a limb for example, led to a perception of a loss of their *Akan* identity. This pertains to such issues such as dressing which were not akin to *Akans* (similar to *Battling with my culture* (see section 6.1.4). This issue was raised by the more matured respondents, as one man remarked,

*'I don't see myself as an Akan any longer'* (Male 24 years old).

This respondent said that having lost one eye and a deformed right hand has actually defined who he is. He said to me that,

*'It is the conscious thought of 'me' and not 'us' .... Err... because at the end of the day it is me that suffers the new identity of "oyarefo"(a sick person) or "Apakye" (a lame person)'* (Male 28 years old).

The issue of identity formation went beyond what was physically seen due to stigma as this respondent intimated regarding her gender,

*‘I have even lost my gender identity because of the way I have to dress following my amputation. I need to hide my disfigurement behind these bulky clothes and as a result people mistake me to be a man’* (Female 27 years old).

Another young woman suggested that;

*‘If your appearance goes contrary to that of your own people because of an illness you unconsciously become an alien; you begin to accept your newly found identity’* (Female 32 years old).

It would be recalled under *Name calling* (section 4.41.2) that most of the respondents expressed disapproval of being labelled as “*Kojobasia*”(a transsexual) because of the way they dressed or “*apakye*” (a lame person) because of the way they walked. Nonetheless many of the respondents succumbed to societal pressure to dress to ‘satisfy’ the needs of society.

Another dimension of the loss of the respondents’ identity could be seen in their struggle to recapture their loss of childhood moments. For these respondents they seem to oscillate between adulthood, adolescence and infancy as they seem to be going back and forth in their lives. Many of the respondents contracted the disease at a very early age. The onset of the disease, the time spent as in-patient at the hospital and the period spent recuperating from the illness robbed them of the joys of childhood and adolescence. As a consequence many of them felt the need to make up for the lost time by indulging in childhood activities albeit unknowingly. Many of them do not know and not sure of what triggers these unpredictable and erratic behaviours. To some of the respondents it was part of the recovery period to attain normalcy and doing these things help them get over the feeling of being cheated of the unique experiences of childhood as the following quotations demonstrate.

*‘I don’t know what triggers my behaviour. Sometimes before I realise I would be playing ‘ampe’ with the nine to twelve year olds. I guess sometimes I feel like I was cheated of my childhood moments* (Female 18 years old).

And;

*It all started one day when the kids came from school. I picked one of their books and saw these beautiful drawings and paintings. Then before I realised I went to the shop, bought myself a drawing book and started drawing there and then. Sometimes I use chalk to draw on the walls as a child would do. I do take delight in what I do but my partner gets angry with me and thinks I'm odd (Male 23 years old).*

When I asked this man why he thinks he does that he could not explain. He said that he was very good in art and drawing in school and had always dreamt to be an artist. Unfortunately he had to struggle with Buruli ulcer for almost seven years. After his discharge from hospital he couldn't go back to school due to constant recurrence of the ulcer and that might explain why he feels he had to catch up with what he lost as a child. Similar experiences were captured by four other women and a young man of twenty two years old

### **6.2.3 Loss of Loved ones**

Another perception of loss discussed by many of the respondents was with regard to love and belonging. This involved friendship, intimacy and family, the absence of which the respondents became susceptible or prone to anxiety, loneliness and depression. This was expressed by over a third of the respondents in the study. The issue of losing lovers were very complicated as it ranged from love in terms of physical attraction to the opposite sex, loss of significant others in their lives to not being loved by friends any longer after their surgeries. In my discussions with some of the respondents' statements such as the following became clearer;

*'I lost all of my friends'* (Male, 28 years old).

And;

*'I don't think any woman loves me'*. (Male 24 years old)

Such statements were common among the respondents.

The experience of a young woman captured some of the feelings of loss when she said,

*'I was fifteen years old in school with a great circle of friends and a boy friend. He adored me so much we were inseparable. But then it all came crashing down when I was diagnosed with Buruli Ulcer. He stopped seeing me even before the operation'* (Female 23 years old).

Another young man who spent six years battling with Buruli ulcer said,

*'Losing my girl friend was the shock of my life as my mind just went blur. I had all these emotions going through me – betrayal, confusion, hurt and anger. I haven't had one since then and it is almost five years ago. Sad life isn't it?'* (Male 31 years old).

Not being loved led to periods of depression, sleeplessness and anxiety and this was common among the male respondents.

Feelings of not being love also intensified their feelings of isolation. One respondent shared with me the moment he plugged the courage to ask a lady out for the first time in his life. He said he came close showing her how much he was in love with her and he thought that all the signs were there for him to break the 'news' to her. Then he had the shock of his life;

*'Little did I realise that she was being nice to me because of my disfigurement; she wasn't interested in me in any way. I felt ashamed and couldn't go out for a while. I lost a long time friend and it took me a while to come to terms with that loss'* (Male 22 years old).

This form of 'rejection' made people living with Buruli ulcer vulnerable to all forms of mental distress ranging from self harm to depression. This is evidenced by this young man who had a similar experience with a lady he had been 'hanging around' with for a long time. He said;

*'I became confused, err, and kept myself to myself for a long time. I became isolated from the community and it masked the hunger for food. I didn't bother about the outside world'* (Male 26 years old).

This also affected the outward appearance of some of the respondents. For example this is what a young man said to me;

*'Basically I lost a lot of interest in my looks. No one loves you so you basically let yourself go'* (Male 27 years old).

The interview process revealed to me that, to some, this created an internal struggle for them to come to terms with their condition.

Apart from the loss of loved ones and the rejection there were other forms of loss related to significant others in the respondents' lives who due perhaps to, personal and domestic strains the long hospital stays put them through died 'prematurely'. Caught in the spiral of frustration and disappointment these significant others in their lives passed away before some of them were discharged. Five respondents had such losses as the following quotations indicate.

*'I think my mother had enough of my suffering. She couldn't cope any longer. Her death devastated me and I think it affected my recovery'* (Female 13 years old).

Another young man lost his father and was not informed of it for almost thirteen months. He had this to say,

*'I was his only son and when he found me in coma at the hospital he went home and couldn't recover from the shock. It was a good thing his death was kept a secret until I was fit enough to be discharged'* (Male, 26 years old).

They praised these loved ones for their altruism and support.

Yet there were other forms of (indirectly though) losing significant others as this young man recalled,

*'My mum had to be with me at the hospital for nearly two years. By the time I was discharged my step-dad had left her for another woman. I blame myself for her 'loss'* (Male 14 years old).



What is significant about these revelations is that apart from these young people living with Buruli ulcer struggling to come to terms with their disfigurement and varied disabilities they had this additional uphill struggle to cope with life without the support of these significant others in their lives in a country where there are no welfare benefits. It was a blow in their quest for survival.

#### ***6.2.4 Loss of education and self-worth***

Even though the word worthless was used several times and on many occasions by many of the respondents it is captured here to reflect one important aspect of their future life, which is their education. Many of them felt that their future looked bleak without any formal education because Buruli ulcer ‘robbed’ some of the respondents of their primary school years and by the time they were discharged they were too old to go back to school. Some of them were in the Junior Secondary School and could also not go back to school after many months of hospitalisation and the discomfort coupled with the stigma of going back to school. To these respondents (n=12) therefore, without any form of education meant losing out on the job market when they become adults, hence the feeling of worthlessness. One 15 year old boy remarked,

*‘You are worth nothing these days without any form of education; more so when you are disfigured’* (Male, 15 years old).

Another young woman said,

*‘I felt worthless having ended my education at such a crucial time. No responsible man will marry an illiterate who is disfigured. It is some of these thoughts that make me feel worthless’* (Female 27 years old).

To some of them even if the clock were to be reversed they could not bring themselves back to the classroom to face the humiliation of being the oldest member of the class and the stigma of being a disfigured pupil. The effects of these sentiments and the transition to adulthood in the face of the wider community prejudice led to moments of anger, desperation and lack or absence of sense of direction in life, as this young girl said,

*'Where do I go from here without any formal education? I have lost my sense of direction in life and basically you just look up to God for the unexpected to happen. If it does, well and good, but if it doesn't, you take it as your destiny'* (Female, 20 years old).

The lack of direction in life without a formal education was a typical sentiment expressed by many of the respondents.

*'If you lack formal education these days you lack direction in life'* (Male, 19 years old who ended his education at primary 6).

When I enquired further he explained;

*'Education gives you a lot of opportunities and life chances. You see, err... even if you work for yourself (he meant self employment) without basic education you will face problems; you will be stuck! You can't go to places and err... you basically keep on marking time. Err... education is the key for your self worth.'*

Yet few of them expressed the desire to go back to school (on part time basis) if given the opportunity.

*'If there was a part time course around here I would take advantage of it. Who knows what will come out of it'* (Female, 18 years old who stopped school at Junior Secondary School 1).

Six teenage respondents expressed the desire to go back to school if they had another chance.

### **6.2.5 Loss of recreation**

Many of the respondents had the ambition to become sporting heroes in future while some had fulfilling recreational activities before Buruli ulcer struck. To these respondents, not only have they lost seemingly fulfilling future careers but they had also lost the pleasures of everyday pastimes which have had tremendous effects on their quality of life.

A respondent with below right knee amputation who had his medical expenses paid for by the football team he played for recalls the despair of ending a game of which he was a past master.

*'I had err, all the qualities of becoming hmm, err, football star at the tender age of fifteen. When people call me Pele, hmm, oh! Umm... it brings back sad memories'*  
(Male, 22 years old).

Another young respondent who went back to secondary school after his operation with a deformed torso and a disfigured left arm recounted his swimming abilities and how he missed his favourite hobby,

*'For the first time after my discharge, I left the village and went back to secondary school. I tried to have a go at the school swimming pool. Umm, as soon as I took my top off, every one left the pool. I was so embarrassed that it damped my spirit so I never had the courage to retry'* (Male, 26 years old).

His experience was a combination of discrimination from his fellow students and lack of support from the school authorities. He said to me that if he had had the support of the school in dispelling the prejudice and help in regaining his strength and dexterity, he would still be enjoying his favourite hobby today.

Another young girl recounted how she finds it difficult to enjoy her break time in school with her mates due to contracture in her leg.

*'How I wish I could run and play "ampe" during break time in school. I just stand there and watch them. Life is like err... on hold for me when you can't play with you mates apart from indoor games like "oware" and ludo'* (School girl, 12 years old).

This property - loss of recreation - was very typical and was mentioned by almost every respondent *ad nauseam*, I cannot continue to recount all their experiences. It did not surprise me when leisure or lack of it was the respondents' quality of life most affected on the Dermatology Life Quality Index (see section 6.02 below)

### **6.2.6 Loss of occupational skills**

Loss of skill was common among the more matured respondents. Five of these respondents had secured skills or jobs acquired through on-the-job training before they were struck by Buruli ulcer. After their discharge they could not continue with their skills due to contracture. There were other respondents who had the opportunity to gain various forms of apprenticeship training such as dress making, shoe making, carpentry, masonry and others through the benevolence of the Roman Catholic Church. Due to recurrence of their ulcers some of which has become chronic they cannot practice the skills they acquired. This has not only affected their quality of life but also their sources of livelihood.

One young respondent said that,

*'I could weave basket, umm... I did shoe making as well and these were my only source of income; but look at me now (He shows me his disfigured right arm). I have to rely on my family and friends for my upkeep. This is not life' (Male, 27 years old).*

Another young man lost his long time girl friend because he lost his job due to Buruli ulcer.

*'The only source of income that was coming in was the bricklaying job which I had acquired. With Buruli ulcer I can't use one hand to work so she left me for another man. If I should rely on my parents and other relations for my survival at my age do I have any quality of life? That will be an illusion (Male, 31 years old).*

It is disheartening to hear of such frustrations in a country where there are no welfare services. Had it not been the spirit of communal oneness among the *Akans* where each one is his brother's keeper one would have wondered what survival strategies these respondents would have relied on.

Another young dress maker who went through the apprenticeship scheme had her sewing machine bought for her by the Catholic Church. She has a right above knee amputation and a disfigured right arm. She says she works an average of four days a week due to pain and contracture in her right arm. She is a single mother and at the time of the interview the ulcer on the stump had recurred and was oozing. She goes to the local clinic every day to get it dressed.

I had this conversation with her;

Me: *So you work every day?*

Respondent (R): *I wish I could.*

Me: *Why is that?*

R: *Umm err... just have a look at my right hand. The sewing machine is the manual type so I have to stop occasionally to rest my arm in a sling. At the same time I need to be mindful of my stump. You see, it's recurred and oozing.*

Me: *Yes, I can see that; and it is dressed. What have you got on it now?*

R: *I've got it dressed at the clinic but today I've applied Sapro. And err... I have taken some Para (paracetamol tablets) as well. They help to ease the pain but it will recur. If I sit to sew for a whole day or two days the right hand will get swollen beyond recognition. So I work four – five hours every other day on average.*

Me: *How do you survive on that?*

R: *That's how it has been all these years. Well, I live with my parents and they support me. But I guess I am better off with nothing. My only problem is during the Christmas period when I have so many customers. Sometimes I will try to work for longer hours but that will come with a price; err ... a painful swollen stump and a swollen right arm which take some time to ease off.*

Me: *So what is the future like?*

R: *I might give up because the pain seems to get worse as I'm getting older. Sometimes I stay home for over a week or so and use all my earnings to buy drugs, then err... then I start all over again. I might as well stay home without any pain and look up to my parents' (Female 25 years old)*

Among the younger respondents, there were concerns of their inability to put their potential skills to the test due to their disfigurement.

### **6.3 Seeking comfort**

The third property under *Quality of life* as a mirage is *Seeking comfort* which has two properties of: *Painful moments* and *Feeling unattractive*. These will be discussed in turn.

#### **6.3.1 Painful moments**

In painful moments the respondents share with me problems which they encounter every day. Apart from the contracture which has been discussed at length, *Painful moments* refer to moments where the respondents have excruciating pains in the legs and arms particularly when they have been standing for long hours either in the farm or at the *galamsey* site as one forty one year old lady described to me,

*‘My right arm and left foot get swollen all the time and there appears to be no solution in sight’* (Female 41 years old).

The respondents tell a situation where they have to lie down for a while or put the affected leg up at least one hour to ease the pain in the affected area. This is made worse if the respondent is a mother with a child. This is captured in the following statement from a young woman,

*‘You get home from the farm with a swollen foot and instead of resting to ease the pain you have the additional responsibilities of fetching water, preparing the evening meal, caring for the child and standing on the same swollen foot to pound the “fufu”. You have no one to complain to. It is with you all the time.... When you manage to go to bed you have the phantom pain too to deal with. You don’t stop thinking: it’s about pain, pain and nothing else. It seems to occupy your mind throughout the day’*  
(Female, 31 years old).

Apart from the swollen feet and arms there were other painful moments the respondents disclosed. Some of the respondents said that for the most part of their lives following surgery they have had nightmares at night and yet some of them had suffered from bed wetting (three

children and five adult). All these were confirmed by their parents and partners. These were painful moments they have kept from previous researchers. To some of the respondents bed wetting and nightmares went on for over five years or more and was seen as uncomfortable experience not only to the respondent but the family as a whole, as one mother told me;

*'He stopped bed wetting at the age of five or thereabout. But after the surgery he started to wet his bed for nearly five years or even more. I had to keep close eye on him all night because he would scream, wake up and there he goes. You have to hold him and talk him back to bed'* (Mother of a 13 years old respondent).

The mechanism of bedwetting following surgery is unclear but it might have something to do with the type of surgery. In a situation where a young boy of five or six years had had an amputation it will appear reasonable to suggest that s/he might find it physically and psychologically painful getting out of bed unaccompanied to get to the loo. However, the physiological mechanism cannot be discounted and may need further investigation.

Yet another painful moment which was disclosed was the remains of the amputated leg/arm. One respondent said that he was told of the amputation so it never came to him as a shock when he woke up in the operating room but have continually thought about the whereabouts of the decapitated arm.

He told me,

*'I have been mourning my arm all this while. Sometimes I would dream about it; seeing so many decapitated arms and limbs being buried in a mass grave. Occasionally I feel, oh! err..., it might have been fed to some vultures. Sometimes I get close to asking the nurses, but then I say to myself, they might think I'm going mental or something like that. I still think about it. Yes, and all the time* (Male, 15 years old).

A class four pupil sobbingly asked me,

*'We were told at catechism lessons that if you live a good life you will be in heaven when you die. He also said that life in heaven is eternal and full of happiness, but how will I enjoy life in heaven with disfigured legs'* (Female 12 years old).

The mother expressed shock as this was the first time her daughter had raised this issue. I didn't have an immediate answer but it gave me the opportunity to explore this in subsequent interviews. Fortunately this issue came up again with six other respondents.

The interview therefore revealed one of the biggest worries among these "little ones". As children who have been brought up in the Christian faith, and who believe in eternal life I thought it prudent to do my best to get them the necessary reassurance and support in this area. Thus my 'message' was meant to give these little ones the hope and confidence they needed in life and to reinforce their belief in a happy life after death. I found it a relief having put smiles back on the faces of these little ones and their families.

Another painful moments that was mentioned, even though not typical (n=7) was difficulty of walking as a normal adult would, following months of being bed ridden and learning to use the other hand in writing for those who went back to school. This young man said he spent twenty one months in bed following his admission and went through different kinds of operations. He spent two weeks in the hospital following discharge to learn how to walk again.

*'I have been bed-ridden for twenty one months. I told the nurses that I couldn't stand on my own but no one would believe that. I was weak, emaciated and pale looking. I have to spend nearly two more weeks following my discharge to learn how to stand to walk again with crutches, and err... another two weeks to be on my feet unaided'*  
(Male, 26 years old).

And;

*'I told the nurses that I felt weak in my legs. As I tried to stand for the first time after fifteen months in bed, my feet gave way. I had physio and they gave me crutches and with the help of the nurses I learnt how to walk again. That one week of learning how to walk seemed an unpleasant experience but the nurses were very kind and helpful. It was a crucial turning point in my life after almost fifteen months'* (Female 20 years old).



Yet there were few painful moments relating to life back in school (Junior High School and Senior High School) after many months in the hospital.

This young man had to learn how to use his left hand to write following his amputation.

*'I have always been right –handed; err... so err... the first few weeks after my discharge, I went to school and little did I realise how I was going to fit in. I had to learn how to use my left hand to write for the first time. The teachers were not helpful either as sometimes they had to dictate the notes without considering whether I was catching up or not'* (Male 22 years old).

Another young woman went through the same difficulties when she went back to school.

*'In the first few weeks I had a friend who will copy the notes for me. Then I realised that I had to learn to write with my left hand because she won't be there for me during the exams; it wasn't easy but I went through'* (Female, 22 years old).

And another left-handed young woman who didn't have an amputation had a similar experience;

*'Both hands were skin-grafted. My left hand was severely disfigured, err... bent, stiff and numb. I couldn't open my fingers to hold a pen so I was forced to write with my right hand. Some of the teachers were very supportive but others didn't bother. It took a while mastering with the right hand'* (Female, 20 years old).

The last painful moments discussed by the respondents were their reactions when they found that they had got Buruli ulcer. Confirmation or a mere suspicion of Buruli ulcer stirred up different kinds of feelings which ranged from shock, stress, worry, fear, anxiety, sadness, depression, loneliness, feelings of loss and confusion. A representative remark by this 26 year old lady sums up such reactions.

*'I was shocked when my sister suggested that it looked like Buruli ulcer. The next moment I was filled with anxiety as what will happen to me; I became lonely, felt loss,*

*depressed and confused. Much of my feelings centred on if I had done anything wrong. I started looking back and then did a thorough search within myself where I went wrong. I was filled with sadness, couldn't sleep and lost appetite for food'.*

Despite the variety of feelings two intentions represent the strategies which were used by the respondents to face the 'reality'. Some of the respondents used one or two of these strategies but others used a combination of all of them.

The first strategy was the realisation of not being alone as this young man told me:

*'It wasn't easy to accept the reality but then looking round me my consolation was that after all I was not the only one with the condition. That helped me to calm down to face the reality of the situation' (Male 26 years old).*

And;

*'It was initially scary looking at the others who were going through the same condition. But I said to my self that once they have been able to go through it I should manage to sail through unscathed' (Male, 22 years old).*

The second one was the myth surrounding the availability of the treatment options.

According to many of the respondents the uncertainty of the treatment options occupied their minds and the decision relating to the treatment options took their minds off the reality. They were then faced with how to fund the treatment and how long each option will take. This is captured by this woman's experience:

*'The anxiety and worry about this strange disease all of a sudden gave way to the uncertainty of the treatment available. As my parents kept on discussing how to fund the treatment my whole mind was geared towards this. This realisation in a way became a strategy to deal with the condition itself' (Female 23 years old).*

### 6.3.2 *Feeling unattractive*

Feeling unattractive was identified as a property of *Seeking comfort*. This was common among the teenage girls. Due to the contracture and the hot weather Buruli ulcer patients are advised to apply Vaseline cream on the affected parts possibly to avoid getting dry and sore. They find Shea butter (the fruit from the Shea tree found in Northern Ghana) as an alternative because it is economical and easily available in the community. But it comes with a price – the ‘cream’ has a funny and a repugnant smell which repels people. This is what one teenage girl had to say about her experience:

*‘Shea butter has a funny smell but I have no option but to use it everyday to protect my skin. It makes you feel unwanted and unattractive to the guys but what can one do? You can’t let the skin go dry and sore’* (Female, 18 years old).

And,

*‘The first thing that comes to my mind in the morning is to make sure that I have checked if my body needs to be creamed with Shea butter. You get worried if you are getting in a public transport or leaving home. You can’t hide it because of the smell. When you see people looking the other way because of the way you smell it makes you feel unattractive. But I have to make sure that my skin doesn’t get dry for the ulcer to recur’* (Male, 20 years old).

Another young woman had the shock of her life when a friend introduces her to a young boy she had a crush on. She said,

*‘This bloke asked me if I cream with Shea butter, and I said sometimes; but before I could explain he puked and walked away’* (Female 22 years old).

Young women want to feel attractive generally and be loved but not with Shea butter. This was a very serious issue which the young girls had to endure.

Apart from feeling unattractive due to the application of Shea butter on their skins Buruli ulcer patients had the additional embarrassment of wearing uncomfortable clothes all year

round obviously to hide their disfigurement. This leads to discomfort as the temperature can be as high as 80 degrees Fahrenheit in Ghana as this young woman said,

*'I have to wear these bulky clothes to hide my disfigurement in this weather all the time. You always pray that the day ends quickly so that you can change into something comfortable at night'* (Female, 23 years old).

Another young man with disfigured legs had this to say,

*'I can only wear pair of trousers and long sleeve shirts. I can feel the heat during the day and how I wish I have the courage to wear pair of shorts to get some fresh air. Occasionally the heat make the ulcer worse and become sore even if you have Shea butter on it'* (Male 14 years old).

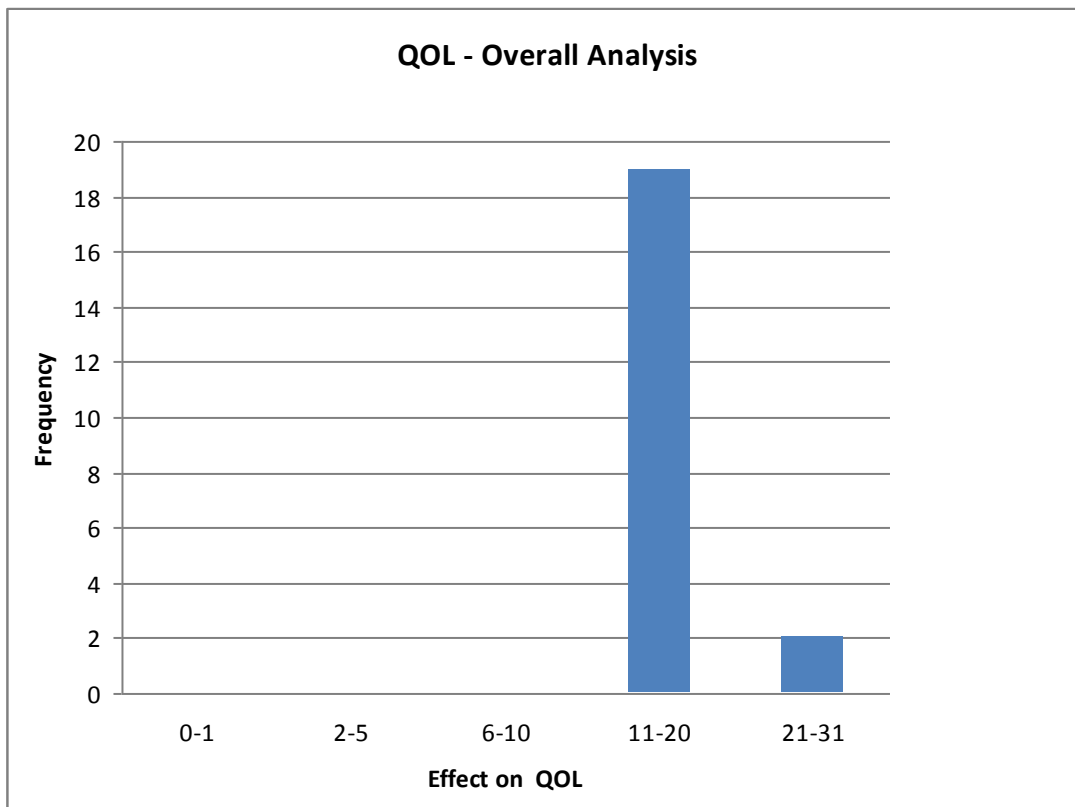
This is but one of the many problems people living with Buruli ulcer in the study area have been enduring. Wearing such bulky clothes does not only lead to discomfort but it intensifies their fear of being called by all sorts of socially derogatory names.

#### ***6.4 Findings from the Dermatology Life Quality Index (DLQI) questionnaire***

This was an add on quantitative method to determine the effects of Buruli ulcer on the quality of life of the respondents in the study and to enable comparisons with other groups living with chronic dermatological conditions to be made. The DLQI data revealed interesting findings. In this section I will present these findings and reserve my critique of the DLQI questionnaire to the discussion section in the next chapter.

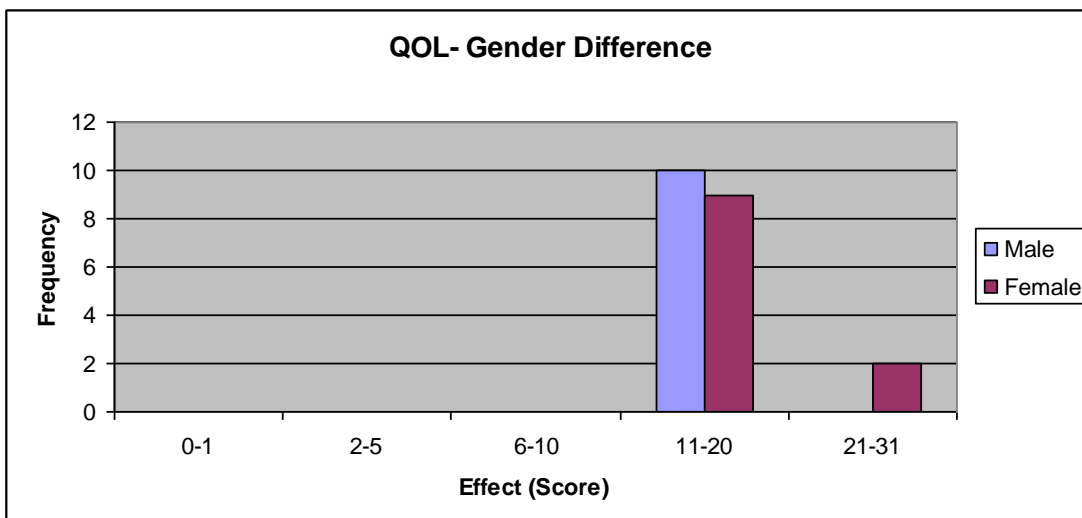
Among the adult respondents (n= 21) the main finding from the analysis was that Buruli ulcer had a very large effect on 19 of the respondents' quality of life (with a score of 11-20). This represents 90 per cent of the adult respondents in the study with two respondents (10 per cent) scoring 21-31 (extremely large effect). This is depicted by Figure 10 below.

**Figure 10 : Effect on quality of life of Buruli ulceration amongst the adult sub-sample**



The analysis further revealed that there was no significant difference on the effect of Buruli ulcer on the gender as shown by Figure 11 below.

**Figure 11: Quality of life – Gender difference**



The DLQI questionnaire was further analysed under six headings of:

Symptoms and feelings;

Daily activities;

Leisure;

Work and school;

Personal relations; and

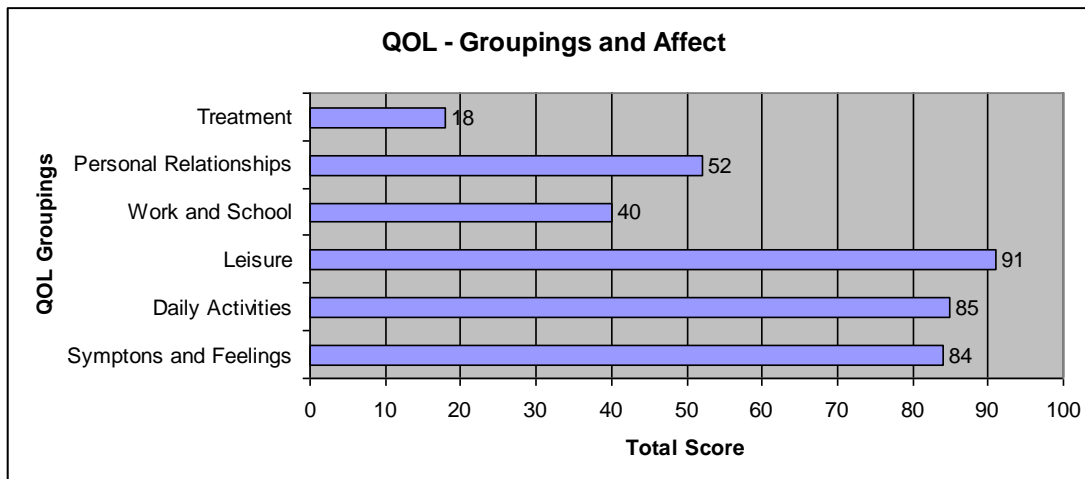
Treatment.

This was undertaken to reveal which areas of the respondents' quality of life were most affected. The analysis revealed that the areas of *Leisure*, *daily activities* and *symptoms and feelings* respectively were the most affected. This finding is depicted by Table 3 and Figure 12 below. This finding has a lot of implications for policy on patient care and treatment and this will be discussed at the discussion and critique sections.

**Table 3: Quality of life Groupings**

<b>QOL Groupings</b>	<b>Total score</b>
Symptoms and Feelings	84
Daily Activities	85
Leisure	91
Work and School	40
Personal Relationships	52
Treatment	18

**Figure 12: Quality of life Groupings and affect**

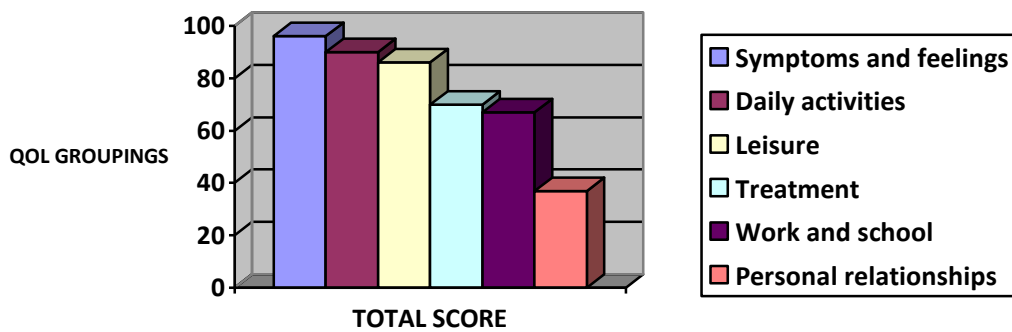


I further analysed the individual questionnaire in an attempt to examine if there were any correlations and/or associations. For example, I tried to use the data to find out if being embarrassed or self conscious of Buruli ulcer affected the choice of clothing a respondent would put on. This revealed a positive association but among the female respondents. I however, had to be cautious with this as the female population was greater than the males. I have indicated in the discussion section that this is an area which might need further research as my data revealed an association but was too small to make a generalisation about causation.

#### ***6.4.1 Children's Dermatology Life Quality Index (CDLQI) data***

The findings from the children's DLQI questionnaire revealed higher scores than that of the adult patients. This might be due to the fact that all the six children in the study had Buruli ulcers which were still sore. Among the six children Buruli ulcer had a very large effect on the quality of life of four of them (score of 11-20) with two children scoring 21-31 (extremely large effect). The sites that led to higher scores were the exposed parts of their bodies and these affected the scores on choice of clothing as well as treatment. When the data was further analysed under the six headings Figure 13 shows the areas most affected.

**Figure 13 Children’s QOL groupings and scores**



The over all findings from the DLQI questionnaire was that Buruli ulcer have a very large effect on the patients quality of life. Among the adult respondents the greatest effects are on areas of leisure, daily activities and symptoms and feelings of the disease and the mean score was found to be 17.6. Among the children however the greatest effects are on areas of Symptoms and feelings, Daily activities, Leisure and the mean score was 18.0.

## **6.5 Discussion – Quality of life as mirage**

### **6.5.0 Introduction**

The principal category, *Quality of life as a mirage* (and its properties) addresses objectives 2 and 3 and this is discussed in this section. This category is discussed in relation to the respondents’ qualitative accounts, combined with the quantitative data from the Dermatology Life Quality Index (DLQI) tool and the literature where appropriate. The quantitative data will be discussed after the qualitative data.

### **6.5.1 Being seen differently**

The effects of Buruli ulcer on the Dermatology Life Quality Index scores (discussed later in this section) revealed the health related quality of life of people living with Buruli Ulcer. The property, *Being seen differently* - and its sub-properties of *Unnecessary compliments*, *Discrimination*, *Patronising* and *Battling with my culture* could be summed up in one word – stigma. Stigma was found as a serious consequence of Buruli ulcer by previous researchers on Buruli ulcer (Stiensra et al, 2002; Aujoulat et al, 2003; Renzaho et al, 2007) which supports the findings in this study. However these were survey research studies which could



not go beyond the generic term stigma which is a drawback of using a survey research approach. This study went further to explore the extent to which living with Buruli ulcer led to both felt stigma and enacted stigma. The respondents felt prejudiced, patronised, discriminated against as well as issues with their *Akan* identity and culture, all of which revealed subtle forms of stigma which previous research have not discussed. This revelation is significant to enable health professionals to know which type of stigma is operating and how to intervene to enable the respondents to regain their confidence.

This study found similarities with Jones et al (1984) and Goffman's (1963) proposal or dimensions on which different stigmas can be ordered. These similarities are now discussed.

The first is that of concealment (stigma's *concealability*) that is, the ease with which the condition can be concealed. This suggests that if the manifestation of the condition given rise to the stigma cannot be hidden it is more likely for the stigma to be perpetuated. This study revealed that Buruli ulcer affected mostly the extremities of the body making it impossible for the affected individual to hide the condition.

The second dimension of *disruptiveness* (Jones et al, 1984) or *obtrusiveness* (Goffman, 1963) refers to how the condition interferes with the person's relationships with people close to them. As far as this study is concerned the respondents' accounts fit this dimension and were seen in the areas of personal relationships with peers as well as members of the opposite sex. The Dermatology Life Quality Index scale confirmed this dimension when the effects of Buruli ulcer with personal relationships were ranked fourth.

The third closely related type of dimension is that of *aesthetic qualities*. That is, the more others in society or close to the stigmatised person see the condition as 'repellent, ugly, or even upsetting' (Herek, 1990; pp: 109) the more stigma is attached to it. This dimension was found to be applicable to the respondents in this study who in their attempt to protect their scars from the vagaries of the hot tropical climate (if the scars get dry they are liable to open causing recurrence) apply Shea Butter the scent of which repels people close to them. This provides the basis for certain kinds of stigma, something previous studies have failed to reveal.

A fourth dimension is the circumstance of the conditions *origin*. Much has been said about the origin and peculiarity of Buruli ulcer. This dimension has perpetuated public stigma related to the condition.

A fifth dimension is the *course* of the stigma over time. The accounts of the respondents in this study seem to challenge this dimension because the study found that severity of stigma has waned with the passage of time within the Buruli ulcer communities. This is however not so with the general public or people living outside these communities. A similar finding of people living with *Onchocerciasis* was found in Tchouankeu et al (2012) study in Africa where although stigma persisted, avoidance with people with the condition decreased from 32.7 percent to as low as 4.3 percent over a seven to 10 year period. The findings in this study appear to reinforce what was found in the *Onchocerciasis* study, but similar study on Buruli ulcer does not exist for a comparison to be made.

The last dimension identified is the *perceived peril* from the stigmatised condition. That is the fear of contracting the disease. Despite the revelation that the severity of stigma has decreased over the years in the communities the fear of contracting the disease still lingers on in the mind of some few people in the communities as well as the general public which perpetuates stigma.

The dimensions of stigma proposed by Jones et al (1984) and Goffman (1963) were initially developed to define the stages that stigmatised individuals move through. As far as this study is concerned it appears that these dimensions represent a real process which is applicable to people living with Buruli ulcer in the study area.

The findings of this study however, appear to challenge Goffman's (1968) view that stigma originates in a hostile public. In this study the respondents felt that stigma from their immediate family as well as institutionalised stigma (derogatory remarks by health professionals) was rife. The reason for the felt stigma (where for example children living with Buruli ulcer were not allowed 'communal eating' which is the normal practice in *Akan* homes, as well as the use of personal domestic items such as cups, bowls and plates) was the irrational fear of spreading the disease. Scambler and Hopkins (1986) finding that "felt" stigma could predominate, and sometimes even predate "enacted" stigma gives credence and support to the findings in this study.

Therefore in order to understand forms of stigma associated with Buruli ulcer the present study followed Kent's (2000) suggestion regarding the stigma associated with skin diseases: firstly the characteristics of the condition that provides the basis for the stigma and secondly the culture and the perceptions of the communities towards the cause of the illness that brought about the stigma. As far as the former is concerned Buruli ulcer was construed as a 'strange disease' and the fear of contracting it formed the basis of the stigma. The second condition is about peoples' attitude towards a strange skin disease such as Buruli ulcer.

From my observations and discussions in the communities the indiscriminate attacks of Buruli ulcer (with few homes spared during the epidemic) brought a sense of unity and a strong communal spirit in supporting each other, something which has not been reported in previous studies. Therefore many of the stigmas identified in the communities were self-stigma (I will refer to it as self inflicted stigma) which becomes intense when the person is away from home.

#### ***6.5.1.1 Respondents' experiences in the context of theories of Body image, Social anxiety and phobia***

The respondents' experiences could be seen to be consistent with some of the theories of Body image disturbances (Cash, 1996, Cash & Grant 1996) and Social anxiety and phobia (Leary and Kowalski, 1995) which could be used to understand the respondents' experiences of stigma. The respondents' experiences of stigma were that almost invariably they felt worried, troubled and insecure through other peoples' reactions to their disfigurements. Therefore different kinds of emotional reactions such as being overtly vigilant, self-consciousness, and concealing the cause of the perceived stigma (by dressing to cover the body) as described by the respondents were seen as the triggering events. These cognitive actions and reactions were found to be consistent with Goffman's (1968) notion of felt-stigma as well as Cash (1996) and Cash and Grant's (1996) psychological view of body image. Attempts at 'passing' (Goffman 1968) or 'defensive reactions' (Cash, 1996) due possibly to enacted stigma were not limited to keeping the skin covered by clothes (as reported by the respondents) but also making excuses either to the opposite sex or peers, avoid playing with their peers or avoiding hobbies that require exposing the 'covered' body and not wanting any physical relationship with anybody.

## **6.5.2 Loss**

### **6.5.2.0 Introduction**

To avoid repetition only *Loss of identity* and *Loss of recreation* will be discussed in this section. The other sub-properties will be discussed in relation to the support needs as they appear to be more relevant and have implications for responding to those support needs identified by the respondents.

#### **6.5.2.1 Loss of identity**

Buruli ulcer provided an identity to the respondents which affected and suppressed both their *Akan* and their gender identities with the data revealing a lack of sense of belonging to a homogenous society. Sharing an identity suggests some active engagement on our part; which requires some element of choice where the individual seeks to identify with a particular group (Woodward, 2000). The respondents' accounts suggest that their *Akan* identity has been suppressed or taken over by Buruli ulcer a finding which has not been documented in the literature. A typical example is their inability to shake hands and dressings which are 'un-*Akan*'. When an identity is seen to be suppressed people try to explore other avenues to legitimise their new identities (Woodward 2004). These observations were found to be applicable to the respondents in this study as the respondents unconsciously justified their identities by the clothes that they wore or who they choose to associate with. The length of time that the respondents had had Buruli ulcer contributed to the strength of their Buruli ulcer identity, a finding similar to what has been found in studies involving people with *anorexia nervosa* (Steinhausen, 2002 and Pike, 1998). These new revelations have not been reported in the Buruli ulcer literature but they are relevant because policies on Buruli ulcer in the study area have concentrated on treating the disease but not the whole person.

In terms of identity our sense of self has been found to be synonymous with our identity, of which there are two aspects – personal and social (Stevens 1995). Our personal identities are derived from our experiences and reflections upon them, which reflects the symbolic interactionists' views about how individuals interact with the societies we live in which is the philosophical basis of the Grounded theory approach used in this study. Therefore Stevens (1995) view of identity provides empirical evidence to support this category – *Loss of identity* – in that this category reflects the respondents' individual or personal experiences of feeling

of a loss of their *Akan* identities. The loss of identity was based on individuals' personal experience shaped through social interaction.

Our social identity on the hand is derived from our interaction with the social world that we interact with including others attributes and contributions to it (Stevens, 1995). The respondents' social identity therefore, is seen in the light of their feeling of having a loss of their gender identity based on their interactions with their social world. This loss of social identity is mainly due to the media's portrayal of what constitute a perfect skin. When the respondents' feel that they no longer fit societal expectations of the perfect or normal skin, they try to defy the hot tropical weather and dress to 'please' society. It was therefore not uncommon to see women dressing as men; thus justifying their feeling of loss of gender identity to satisfy the needs of society.

Another dimension of the loss of the respondents' identity not captured in the literature on Buruli ulcer could be seen in their struggle to recapture their loss of childhood moments. These respondents seem to oscillate between adulthood, adolescence and infancy as they seem to be going back and forth in their lives. Many of the respondents contracted the disease at a very early age. The onset of the disease, the time spent at the hospital and the period spent recuperating from the illness robbed them of the joys of childhood and adolescence. As a consequence many of them felt the need to make up for the lost time by indulging in unexplained childhood activities discussed in the findings section above. A similar experience was found by Beck's (1993) study of postpartum depressed women. Coining the category *Mourning lost time*, Beck (1993) found that as the mothers progressed in their recovery from postpartum depression they began to mourn the lost time that they would not be able to recapture with their infants which is similar to what some of the respondents have gone through.

#### **6.5.2.2 Loss of recreation/leisure**

Another aspect of loss which affected the respondents' quality of life was *Loss of recreation and leisure* which ranked as the highest item on the adult's DLQI tool. This could be due to self stigma<sup>1</sup> that is, how the respondent felt about his/her body and others reaction to it. The

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1. Self stigma occurs when the person affected becomes ashamed of his/her condition because of what s/he thinks others will feel about him/her. The affected person therefore may start applying the negative stereotypes that people hold to him/her self and develop a negative self-image.

literature revealed two comparable studies regarding people living with skin diseases. Kazeem and Adegun (2011) found that due to self-stigma people with leprosy were found to be less likely to socialise with other people and De Groot et al's (2011) Netherlands study also found that people with visible skin conditions were found to be house-bound and frequently had to give up hobbies and other recreational pursuits.

Apart from stigma the present study reinforces what has been found in the literature (Asiedu and Etuafu 1998; Stienstra et al 2004; Chauty et al 2007) that is, contracture or restrictions and loss of sensation in the affected areas hinder people living with Buruli ulcer from enjoying or participating in recreational activities. Given that lack of inactivity has been found to be linked to high blood pressure (Weaver et al 2007; Din-Dzietham et al, 2007), obesity and other complications such as diabetes mellitus (Hu et al 2003), this finding is significant in that it has revealed the other health consequences faced by people living with Buruli ulcer.

#### ***6.5.2.3 Dermatology Life Quality Index (DLQI)***

The Dermatology Life Quality Index (DLQI) tool has been used to study the impact of several skin diseases on quality of life in developing countries including Africa but not Buruli ulcer thus making any comparative studies and analysis difficult. The only study that has investigated the quality of life of people living with Buruli ulcer is the recent study in the Ga West District by Hamzat and Boakye-Afram (2011); but the authors used the Nottingham Health Profile Questionnaire (NHPQ). The authors' found that the quality of life of their respondents' were adversely affected and the area most affected was pain. In the present study the three important areas most affected among the adult respondents were leisure, daily activities and symptoms and feelings (see figure 9). Among the six minors the Children's Dermatology Quality of Life (CDLQI) revealed the three most important areas which affect their quality of lives were symptoms and feelings, daily activities and lack of recreation. Whilst it is beyond the scope of this study to provide a critical appraisal of both tools they provide the basis for understanding the effect of quality of life of people living with Buruli ulceration but in different domains. The tool has again not been used on children living with Buruli ulcer thus making any comparative study difficult.

The DLQI tool has been shown to have universal applicability to almost all skin diseases (Finlay and Khan, 1994) it has not been used with populations living with Buruli ulcer. Although the quantitative data is limited, when integrated with the qualitative data they portray a congruent picture which has enabled me to identify the needs of the people living with the effects of Buruli ulcer.

#### **6.5.2.4 Well-being**

The findings of the category *Quality of life as a mirage* have implications for the well-being of the respondents in the study and it will be appropriate at this stage to explore the link between the quality of life of the respondents and their well-being. I will however limit the discussion to an examination of the findings in the context of hedonistic and eudemonistic concepts of wellbeing. This is because both philosophers and psychologists provide a lot of conceptions about the meanings of well-being but Ryan and Deci (2001) and McMahan et al (2011) have found that all the different conceptions revolve around hedonism and eudemonism.

Hedonism equates well-being with pleasure and happiness (Ryan and Deci 2001; Kahneman et al, 1999). In applying these to the respondents in this study it will be recalled from the DLQI tool and the preceding section that leisure had the greatest effect on the respondents' quality of life. Happiness and/or pleasures have not been experienced fully by the respondents in this study. This is because living with Buruli ulcer has deprived them of simple recreational childhood activities and games common among *Akan* societies leaving them with only indoor games such as ludo or *oware*. The lack of experience of hedonistic wellbeing explains why some of the respondents feel that they have become hermits in a society where outdoor activities are normative elements of the socialisation process.

This study and similar studies mentioned in section 2.0 have revealed that many of the respondents contracted the disease when they were children. Young people move through discrete stages - children, then becoming adolescents before developing into adults (Koblenzer, 1998) and that adolescence brings social and biological changes (Gross, 2005). These changes include the formation of independent identities of knowing and accepting who they are so that they too can enjoy the hedonistic pleasures ordinary and normal adolescents' experience. A child's self esteem depends upon an awareness of their identity (Burton, 1975); but for the respondents in this study this awareness was interrupted by the onset of the

disease thus disrupting their self esteem and confidence possibly due to self stigma. This arise from the way they express their identity: while ‘normal’ adolescents have no problem in choosing who to play with, people living with Buruli ulcer are restricted in the choice of play mates. Similarly there are respondents who wish they could enjoy the sun by choosing appropriate dress just as their friends’ do, and feel happy but their Buruli ulcer identity (see *Loss of identity*) restricts them of the pleasures and happiness their peers experience every day.

Eudemonic well-being conceptualises wellness in terms of the realisation of one’s true potential (Ryff and Keys, 1995). This type of well-being is achieved by meeting objectively-valid needs which are rooted in human nature and whose realisation is conducive to human growth (Fromm 1947 quoted in McMahan et al, 2011). The eudemonic well-being thus focuses on working to achieve ones potential. The lack of this kind of well-being among the respondents in this study became evident when they discussed their needs (see the property *My support needs* under the category *Seeking to be myself* below). The desire to achieve self development, competence and personal growth, were all seen as the very ingredients needed for their well-being. Unfortunately the category *Loss* and its properties identified in the study point to the fact that many of the respondents have not been able to achieve both the hedonistic and eudemonic dimensions of well- being because of their condition. While they are restricted and limited in their choice of recreational activities many of them have to give up the jobs they feel competent in because of either their contractures or a loss of a bodily organ or sensation. As a result they have limited choice in what they do for a living. What they do for their survival is not what they would normally do to achieve their potential and meet their satisfaction if they had any alternative.

Therefore from the practical point of view, some of the findings in this study do suggest that the wellbeing of these respondents is seriously impaired. This explains the numerous support needs identified in the study, the topic of the next section of this discussion chapter.

#### **6.5.2.5 Summary**

In this chapter the principal category *Quality of life as a mirage* has been shown to be the consequences of the BSPP of *Reliving the trauma of my ulcer*. Buruli ulcer has led to both enacted and self stigma. As a result different kinds of emotional defence mechanisms are employed by the respondents to deal with the consequences of such attitudes. The issue of



*Loss* has been discussed at length as it appeared to affect the respondents physically, emotionally as well as their identities. The congruence of both the qualitative and quantitative data has confirmed how Buruli ulcer has affected the quality of life and the well being of people living with Buruli ulcer for which they feel quality of life will continue to be a mirage to them. In the next chapter the strategies that the respondents use to deal with their numerous problems are presented and discussed and how this leads to their quest for support is highlighted.

## **CHAPTER7 Findings – Seeking to be myself**

### **7.0 Introduction**

*Seeking to be myself* is the last principal category identified in the study. This is a strategy adopted by most of the respondents to achieve normalisation but this was not without its difficulties. This category has two properties of: *Coping with a burden* and *My support needs*. These will be discussed in the following sections.

### **7.1 Coping with a burden**

Despite the problems which Buruli ulcer patients have been going through they share with me how they have been coping albeit with difficulties. They are coping under difficult circumstances that they find themselves. They cope through; *Seeking solace in the divine and the church, Family support, Unacceptable means, Music and Legitimising the condition*. These are discussed in the following sections.

#### **7.1.1 Seeking solace in the divine and the church.**

All but four of the respondents in the study see themselves as religious and practice their faith in various ways. Their belief in the omnipotent God was uppermost on their minds in helping them to cope. The belief in life after death and the hope of being in heaven for those who do ‘good’ while alive is a source of inspiration in helping them to cope in life. *Akans* by their nature and custom believe in the omnipotent God who they worship through different deities. The advent of Christianity has transformed this way of worshipping. At the time of the study many people in the communities were practicing Christians with a negligible percent being Muslims.

Some few quotes will suffice to throw light on the form of support.

*‘It is the prayers and hope in God that keep me going. I believe that God has a purpose for me and that alone motivates me’* (Male 15 years old).

And;

*‘I spent a lot of time praying and reading the “Book of Life”. In fact I read the Bible every day. I can’t live without it. It inspires me; gives me hope and a sense of belonging when I fellowship with my fellow brothers in Christ. I can’t live without my Bible and prayers; they take my mind off everything’* (Female, 47 years old).

And;

*'I have a supportive church. I know that the members will always be there for me. That assurance makes me feel the real me'* (Male, 22 years old).

There are few people who get a visit from the Priest any time he visits the community.

*'The Father will always look for you if you miss church service even for one Sunday. And that tells you that after all an important person cares about you'* (Female, 27 years old).

There are others who feel that discrimination and prejudice do not happen in the house of the Lord and wish every day was a Sunday.

*'The church atmosphere is different. Everybody treats you as a friend irrespective of your disfigurement. That kind of friendliness helps me to forget about Buruli ulcer. So every Sunday brings a new hope in my life and that helps me to cope generally'* (Female, 32 years old).

My observations during Sundays confirmed what the respondents told me. During church services there were no difference between a 'normal person' and those living with Buruli ulcer. The sense of belongingness and oneness was well demonstrated in the churches that I visited. There were no discrimination in the sitting arrangements and the people lived and worshipped happily together.

### **7.1.2 Family support**

The extended family system (where the mother, father and their children live side by side with other relatives such as cousins, nieces, uncles, aunties, nephews etc) is well developed and an integral part of the social structure of the *Akans*. The normal *Akan* family will therefore have a family head (usually the eldest male from the matrilineal line) who acts to see to it that the family lives in cohesion, unity and in peace and to promote the dignity of the whole family. Therefore when a member of the extended family is in 'trouble' (financially, in death or illness for example) it is the responsibility of the family head (*Abusuapanin*) to organise the other members to come to the need of the affected family member. The external family system is well organised such that no individual 'suffers' alone. Therefore support

from the extended family was seen as a major source of coping for almost all of the respondents. Support from family members which helped them to cope in life ranged from financial/material to social and psychological support.

*'My family members have always been there for me. They, in fact, help me to cope whenever I am down'* (Male, 26 years old).

*'I can't express the support I get from my family when my partner left me. They do everything for me and sometimes I tend to forget that I have a physical problem. They make me feel the real me'* (Male, 28 years old).

Family support for the younger respondents' was echoed with so much hope.

*'I wouldn't be alive without the support from my family.. They are the people who are always there for me and help me to cope in life'* (Female 14 years old).

*'I lost my mum three years ago. I wasn't sure how I was going to survive without her. But my dad and other family members have been able to make me achieve what I never suspected'* (Female 19 years old)

*'My greatest fear and worry are when I am outside home where visual abuse is the order of the day, I know I can take solace in my family members as soon as I get home'* (Male, 15 years old).

Others also get support in the form financial assistance and the hope and assurance that the extended family members will never let them down help others to cope.

*'If I need any financial assistance, I look up to any member of the family and every one seems willing to come to my aid. This assurance and hope help me to cope in life'* (Female 27 years old).

It is not only the financial assistance but the willingness to get help in their jobs/works from other friends and family members have been source of coping. In a rural community such as

the study area the peoples' main source of income is farming (and recently gold mining). People living with Buruli ulcer get the support from friends and family members during the farming season by assisting them in clearing their lands for them in the form of what is locally referred to as *nnoboa*. In the *nnoboa* system a group of friends come together in a communal spirit and work in each other members' farm in turns until every ones farm is cleared and ready for planting. The system goes on during harvest period as well. Thanks to the *nnoboa* system, many people living with Buruli ulcer own their farms as these two quotations show.

*'I haven't got much strength in my arms but thanks to my friends who allowed me to join the nnoboa, I have my own farm which supports my little family' (Male 31 years old).*

And;

*'I have been lucky to be in a nnoboa group. Apart from helping me clear the land, planting and harvesting I feel supported and I know I will never lack anything. The members of the group will always be there for each other' (Male 29 years old).*

The system is not limited to men only. The few women who belong to *nnoboa* (in the sample and the community at large) groups feel a sense of belonging and the assistance and support is enough for them to cope in life.

### **7.1.3 Coping through unacceptable means**

Apart from family support and the hope in the divine some of the respondents continue to cope in life by 'unacceptable and illegal means' (respondents' own phrase). All the respondents who expressed this as a source of coping mechanism knew the consequences but they told me that was one of the many ways to feel accepted and a sense of belonging. These 'unacceptable means' keep their minds off their predicament as people living with Buruli ulcer. Such unacceptable means of coping ranged from illegal small-scale gold mining (n=16) to selling and smoking Marijuana (N=9) as well as expressing their sexualities (n=7).

*'You can't survive in this community without a source of income so I do the "galamsay" now to keep me going and to cope financially' (Male 23 years old).*

The “galamsay” activity is carried out by both sexes.

*‘I can’t stay home and suffer loneliness. When you are in there concentrating on how many ounces of gold you will go home with, you make friends and this keeps your mind off your problems’ (Female 31 years old).*

In Marijuana selling and using this young man had this to say;

*‘It keeps me busy and put me in touch with a lot of people who would otherwise have nothing to do with a disfigured person. I use some of my earnings to meet some of my financial and material needs. Smoking the stuff also help me cope with my problems. Now I can’t cope without it’ (Male, 29 years old).*

And,

*‘There are few people who call me any time of the day when they need the stuff. There are others who will arrange for a secret meeting somewhere. When you sit down to talk and do “business” with normals... ha ha ha... it err... makes you feel a sense of belonging. To me that is one of main sources of coping (Male, 27 years old).*

There was but only one female in the illegal drug business. She said;

*‘I feel loved when men of all kinds know me and love the job I do in secret. I do feel proud as a woman engaged in a man’s job. I have had few relationships through this. When they get “high” they forget about my disfigurement and that help me to regain my womanhood’ (Female, 23 years old).*

Another source of coping to which some few respondents expressed as “unacceptable” is what would normally be described as expressing their sexualities. These few (n=7) cope with life though this means of expressing their sexualities but see it as unacceptable due to their culture. Homosexuality and masturbation are culturally unacceptable and considered abominable by *Akans*, but these respondents with varied forms of disfigurements defy these

taboos in order to satisfy their sexual needs. Three male respondents and four women expressed this as their main source of coping in life and feeling being loved.

*'I do it to myself to get the satisfaction that I need. I am not harming any one'* (Male, 19 years old).

*'It would've been a different thing if I were a virgin before I got the disease. It gives me a near satisfaction even though not as it would be with a woman. Am ok with it and it helps me to cope'* (Male 25 years old).

*'I find it difficult to stay calm without a man. I started doing it myself until I told this lady. One thing led to the other and before long we were doing it secretly. For the past two years I feel loved again'* (Female, 27 years old in a lesbian relationship with a 23 year old Buruli ulcer lady).

And;

*'My greatest worry was the joy I was missing in sex after my discharge. Then my friend will visit, we would talk about how we were missing out. When she started touching me I felt shocked but couldn't resist what I have been missing all these years. It's a taboo, yes I know, but err... as long as it helps us to cope and adjust to life I don't think about the consequences if I'm caught.'* (Female 26 years old in a secret a relationship with a 20 year old living with Buruli ulcer).

#### **7.1.4 Legitimising Buruli ulcer**

For the younger respondents the idea that Buruli ulcer has always been with them and as part of their lives in it self help them to cope. The Twi phrase "*Buruli ulcer nkoa na minim*", which literally means, all that I know is Buruli ulcer, much about summarises their attempts to legitimise the condition. The legitimisation took various forms such as accepting the condition as this teenager told me;

*'As for me Buruli ulcer is all that I have ever known. It is part of my life and that alone is enough for me to cope with life'* (Male 14 years old).

Others think that they are competent with it and that is their source of coping.

*'The condition, Buruli ulcer doesn't hold me back a bit. It is only when some one refers to me as "oyarefo" (a sick person) that my mind goes back to it; otherwise I feel competent with myself'* (Male 19 years old).

Yet others have tried to adjust to the condition and for them the ongoing adjustment helps them to cope.

*'I have come a long way, sir! It wasn't easy at first but I kept assuring myself not to sit down with self-pity because of Buruli ulcer. I had to make a decision; and that was to get on with my life.'* (Female 14 years old).

Others tried to shrug off the condition and tried to establish an identity of their self and Buruli ulcer.

*'To be honest with you after all these years I feel that I shouldn't allow my disfigurement to define who I am. This sense of feeling is what helps me to cope'* (Male, 16 years old).

Two young girls had the same feeling and viewing their condition as normal help them to cope.

*'The feeling that some people are begging because of their condition while I'm not gives me a hope that I'm disfigured but not disabled. Coping and managing my condition through this feeling has been a part and parcel of my life'* (Female, 14 years old).

*'Buruli ulcer is a normal thing to me. I can't remember a life without it. I have grown with it and its part of me now. I don't expect people to sympathise with me because that is how I have always been'* (Female, 13 years old who has had Buruli ulcer since the age of six).



It is interesting to note that the longer the respondents has had the condition the stronger their ability to cope. But surprisingly the matured respondents did not express this form of legitimacy as a coping mechanism.

## ***7.2 My support needs***

The last property under *Seeking to be myself* is *My support needs*. It must be mentioned that when the respondents' were asked to discuss what they felt their support needs were they were able to distinguish what they wanted as individuals from what they saw as their needs. Understanding the unmet needs of this vulnerable group of people is crucial to enable health care professionals and other stake holders to identify, develop and refine existing services in order to address these in meeting the over all support needs of people living with Buruli ulcer. Many of the respondents in this study reported unmet needs which ranged from being accepted as individuals belonging to a homogenous community to needs which were psychological, physical, disease specific and material/financial in nature. Therefore, *Acceptance, Fear of recurrence, Physical support Needs, Financial support and Education and retraining* were identified as needs which could help them not only to enjoy comfortable lives but also to enhance their qualities of life and well-being.

### ***7.2.1 Psychological need of acceptance***

The first psychological need expressed by many of the respondents was feeling accepted as a member of the community. This was an overwhelming need expressed by the respondents' (n=21). Many of these respondents felt that if the wider community could overcome the widespread stigma to enable them 'fit-in' (respondents own word) they could be able to adjust to their condition.

A young woman expressed this as;

*'I want to be seen as normal and accepted by all. That's the only way I can fit-in'*  
(Female 20 years old).

And;

*'I need to feel accepted and be loved in my society. I hate a situation when you approach some one and their first thought is, oh err... he is disfigured and... err... disabled and need some assistance or favours. Such feelings demoralise you; I need to be seen as a normal person who need acceptance and nothing else'* (Male 26 years old).

Another young woman had this to say,

*'If society could rid its mind of the prejudice about disfigured people and start to accept me, I would regain my confidence to approach people without a second thought. I do accept myself as disfigured but I'm not disabled and that I should not be seen as seeking favours'* (Female, 20 years old).

This young respondent had this to say;

*'I feel accepted by my family but even with that I still have doubts. You can see and feel unaccepted when you look at others faces. I don't want any one to pamper me but just to feel accepted by society and when I go to the hospital'* (Male 27 years old).

Feeling accepted was expressed differently by the younger respondents.

*'I want to enjoy my teenage years to the full if society will give me that opportunity by accepting me as who I am and capable of achieving my potential but not to be defined by what they see...'* (Male 15 years old).

### **7.2.2 Fear of recurrence**

Psychological needs expressed by the respondents were many and varied. Many of the respondents were of the view that their greatest need was the fear of the disease recurring. This fear led to anxiety and panic which affected their daily routines. Few quotations such as the following will explain these concerns.

*"The last time my ulcer recurred it took nearly one whole year for it to heal. I lost count of the number of days I had to visit the clinic for dressing"* (Male 24 years old).

And;

*“I have to be watching my immediate surroundings all the time because you never know what is going to happen next. The slightest prick on your skin can lead to the ulcer recurring”* (Female 18 years old).

As well as;

*“Because of the fear or recurrence you need to all the time cover your scars irrespective of the weather conditions. This fear keeps haunting you all the time”* (Female 23 years old).

### **7.2.3 Lack of sensation and numbness**

Lack of sensation to the affected parts was expressed as a need by almost all the respondents. This has already been discussed at length under *Loss of physical abilities* in section 6.2.1 and so to avoid repetition I will not discuss it here.

### **7.2.4 Lack of energy and feeling tired**

Respondents reported severe fatigue which they describe as feeling constantly tired with little improvement by resting and which interferes with their activities of daily living.

*‘I get overtly tired with the slightest activity. I don’t know why I get so tired with no energy so easily. This is something I think I need help with’* (Female 31 years old).

And,

*‘Any time I engage myself in any activity such as walking or doing normal domestic chores I get worn out which takes half an hour or so to improve when I stop to rest. Sometimes it doesn’t improve at all and I get to bed very exhausted. I have tried all sorts of herbs and concoctions but I have not seen any improvement* (Male 28 years old).

Getting tired with the slightest activity was interfering with others relationship and this was expressed by both sexes.

*'Any time I have sex it takes me two to three days to regain my strength and to recover. I feel burnt out, weak and unable to do anything for the next two or three days. I can feel all my muscles getting dull, weak and not having enough energy to support me. Sometimes I feel that I cannot recover at all. (Male, 31 years old).*

### **7.2.5 Sleeplessness**

Many of the respondents complained of sleeplessness at night and wished they could get help to enable them have a good night's rest after a day's work. Many of them recounted how they have become addicted to *Akpeteshie* (a local Gin) to overcome their insomnia while few take in the sleeping pill *diazepam*.

*'I can't sleep at night. It is not about being tired but I think the disease has affected my sleep pattern. I have resorted to drinking Akpeteshie before I go to bed but I am getting addicted now because I have to take more before it works for me. (Male 27 years old).*

As well, as,

*'I keep awake all night for no reason. I do all that I can to get enough sleep at night but no matter how hard I try the most I can sleep is about three hours the whole night. Then you wake up feeling tired as if I have been working all night (Female, 32 years).*

There were others who complained that not getting enough sleep at night was a worry to their partners and were having a strain in their relationships.

### **7.2.6 Need for prosthesis**

Some of the respondents (n=14) felt that they needed to feel normal and to achieve their potentials if they could be provided with prostheses. The need for prostheses ranged from artificial legs and arms (respondents' words), crutches, to protective clothing. Even though not typical (n=3) some expressed the need for a wheel chair.

*'My needs are many and varied but an artificial arm which can help with my daily routines will be desirable' (Female, 20 years old).*

And,

*'I need to be a little more mobile to ease my pain. If I could get an artificial leg many of my problems will be solved'* (Male 21 years old).

Few amputees narrated their ordeals as they have overgrown their crutches (the crutches have become too short for them as they the years wear on). A quotation such as this was typical:

*'The hospital gave me crutches during my discharge which were paid for by the Roman Father. But I have over grown them making life uncomfortable for me'* (Male, 24 years old).

He felt the crutches should have been seen to be a temporary measure to ease his problems during his discharge and that a wheel chair would have been the ideal. He continued;

*'If I had a choice I would have suggested, prior to my discharge that a wheel chair would be more appropriate for my condition. I can't go far... you see err... my whole world is limited. It's worse when it rains' A wheel chair can turn my world round'* (Male, 19 years old).

### **7.2.7 My sexual needs**

This need has already been touched upon under *Coping with a burden* (Section 4.04.13) where the respondents expressed how they have defied traditional taboos to express/meet their sexual feelings/needs in various ways. What many of the respondents added to this category as a need was the need to get a trusted health professional to discuss their sexual problems with. Of particular importance was the problem of getting tired after sex, the genitals getting sore after masturbation and getting addicted to the act.

A quotation from a young man captures few of the respondents' anxieties.

*'I visited the clinic with a sore penis following masturbation. The nurse told me to stop the act otherwise if I came there again she will ask me to go the hospital. I felt ashamed and guilty for disclosing this to her. I have not been able to visit the clinic for almost two years now because I thought I will be humiliated again by the nurses'* (Male 23 years old)

There were others (particularly the teenagers and adolescents) who expressed decreased confidence in approaching the opposite sex or their peers due to the media's intrusion into what constitute a perfect body.

*'I can't approach any normal girl because I feel that I haven't got the perfect skin type (Male 15 years old).*

And,

*'If a bloke looks at me twice I feel he's having a laugh at my body. Even among my peers I can't initiate a conversation because of this feeling of unnaturalness of my skin (Female 14 years old).*

### **7.2.8 Health information**

There was what others also referred to as lack of information from the health professionals following discharge. Many of the respondents said that they have been kept in the dark as far as new developments on Buruli ulcer are concerned. Others felt that the only information they get about Buruli ulcer are through sources they have doubts especially the media.

*'I was given a booklet about Buruli ulcer after discharge but that was all. I have no idea about how to manage my life following discharge and nobody has bothered to think of getting back to us about how to manage the many difficulties we have been going through, (Female, 41 years old).*

And:

*'Judging from the devastating nature of Buruli ulcer one would have thought the doctors would have a back-up plan for us following discharge. The system in place is like telling us to go home and then come back if it recurs. Who do we share our other problems with? (Male 23 years old).*

There were few who felt that information from the hospital could be passed to them through their Association or the traditional health practitioners. Their reasons were that they (the traditional health practitioners such as the local dispensers and herbalists) are the ones they hold in high esteem as far as their health needs are concerned.

A matured respondent commented thus:

*'No matter what the doctors tell me if the dispenser or herbalist tells me a different thing I will go for that. They are the ones we are used to. So why can't the hospital pass on any information on our well being or our needs through them'?* (Female, 27 years old).

### **7.2.9 Dietary requirements**

Many of the respondents expressed the feeling that they were told at the hospital about their poor dietary intake. They were informed about the importance of good diet in wound care. Many felt that the health professionals would have followed this up by advising them on issues of balanced diet to help wound care. Many believed that their immune system has been affected by Buruli ulcer and that account for the numerous recurrences. They thought a professional advice either through their Association or the traditional health practitioners on what to eat to boost their immune system could help prevent recurrence and promote wound healing. As it is they feel lack of information after discharge has been the cause of their numerous woes.

A young man had this to say:

*What is the point telling me you need proper diet to boost your immune system? You need good food to help heal your wound or prevent recurrence without telling me what is the good food?* (Male, 27 years old).

My personal observation on their nutritional intake was one of disappointment. The majority of the respondents rely solely on carbohydrates with little or no protein intake in their diet.

### **7.2.10 Transportation to clinic and back**

There were others who complained that walking long distances to the clinic was a drain not only on their finances but also on their health. When people get tired on exertion they expect to be seen by the nurses at home. Sometimes a respondent might feel it was not worth the while to wake up early in the morning to catch a public transport to go to the clinic to dress a recurrent ulcer.

*'Transportation to the clinic was a problem because after the dressing you can not wait till the lorry comes in the evening to bring you home. If you decide to walk back*

*the ulcer would be “weeping”; then you begin to ask yourself if it was worth the time going to the clinic at all’ (Female, 20 years old).*

Due to the difficulties in getting to the local clinic many of the respondents whose wounds have recurred resort to traditional health practitioners particularly the dispensers.

### **7.2.11 Financial needs**

Financial assistance was expressed by almost all the matured respondents (n=15) as a means for financial ‘freedom and independence’ (respondents words). To some of them a financial assistance will help them start a ‘small business’ (respondents’ words) in a kiosk for selling few basic things used in the home such as sweets, canned foods, sugar and bread or buying the requisite materials to commence their vocation such as cobbling, carpentry and dressmaking (which was acquired through the Catholic apprenticeship scheme).

*‘I can’t do any work. All that I need is financial assistance to put up a kiosk where I can sell basic things’ (Female, 27 years old)*

*‘If I can start a little support financially to enable me buy myself something like an artificial arm to support me daily chores I will be grateful (Female, 22 years old).*

These are but some of the few financial needs the respondents discussed with me. The needs ranged from setting up a small business to funds for buying over the counter medication to prostheses to assist them in their daily living.

### **7.2.12 Education and retraining**

Education and retraining were seen as stepping stones to achieve comfortable and noble life. While most of the respondents in the study expressed the need for a means of going back to school, others wished they could have the opportunity of a retraining programme which could help them secure a future job.

*‘I ended my education through Buruli ulcer. If there were any means of getting a formal education through a part time course for example I would be the first to register’ (Male, 20 years old).*



And the desire to retrain was uppermost on the mind of some of the respondents (n= 8).

*'I wish I could go back to Offinso for a retraining programme in shoe making' (Male, 31 years old).*

As well as;

*I stayed at Offinso for a while but had to drop out of the programme due to the constant recurrence of the ulcer. How I wish I could get a second chance' (Female 20 years old).*

To these respondents therefore, any form of education and a retraining programme would be welcome as a means of getting them back into the job market.

### ***7.3 Findings from the focus group discussions with the health professionals***

#### **7.3.0 Introduction**

Three main categories of *Institutional support needs; Personal support needs* and *Community support needs* emerged from the focus group discussion. In the professionals' view some of the identified categories and their properties had policy undertones that were far beyond their control and domain. Even though these categories have been presented separately they should be seen as interrelated. The voices of the professionals that were typical have been paraphrased and presented in quotes as a way of providing the reader with additional contextual information.

#### ***7.3.1 Institutional support needs***

The first main category to emerge from the focus group discussion was *Institutional support needs* which had four properties of *Adequate nutrition; Adequate space and Support for Buruli ulcer patients' carers*. These properties would be discussed at the appropriate sections and supported by the professionals' voices/narratives.

##### ***7.3.1.1 Adequate nutrition***

The issue of balanced diet became a major theme and a priority area for the discussion because as one nurse put it;

*'It was one of the most pressing issues that everyone was worried about at the time'.*

The diet of Buruli ulcer patients was discussed at length. It would be recalled from the respondents' data that they had to provide for their own meals at the hospital during the epidemic. According to the professionals this was one of the major reasons why most of the patients at the time spent weeks and months at the hospital because their diet was - in the voice of one professional- *'not good enough to facilitate proper wound healing'*. The discussion revealed that the professionals were aware that a good, adequate nutrition was a *sine qua non* for wound healing. One nurse suggested that:

*'Imagine a patient with an extensive wound being on a diet full of carbo with little or no vitamin or protein'.*

Some of the professionals had on a number of occasions bought fruits for some patients with their own monies in the past. They said they knew that the patients were malnourished but there was nothing they could do at the time.

She said;

*'I knew oranges were a good source of vitamin C so I would occasionally buy few of them on my way to work in the afternoon and share among them'.*

The consensus was that, with multiple wounds and occasionally on polymedication many of the Buruli ulcer patients confided in them that they had little or no appetite. To these professionals this prolonged their stay and suffering as healing of wounds were delayed.

One professional intimated that;

*'Sometimes you get stuck and don't know what to do as a caring professional. You get to the patient with the medication which needed to be taken with food and you are told that s/he had not eaten his/her meals. You ask them why and the usual response is "I've no appetite cos I've eaten the same food twice in the day" '.*

The professionals agreed that the hospital administration were aware of their concerns but because self feeding was a government policy at the time there was nothing any one could do. As far as the patients were concerned that was a normal thing and so no one ever complained.

### ***7.3.1.2 Adequate space in the ward***

Inadequate space in the ward was a second major category identified by the professionals. The professionals admitted that sometimes there were not enough beds at the wards for this group of patients and due to the seriousness of their conditions the professionals had no choice but to allow some of the patients to sleep on the floor (on blankets) at the ward. There were instances where their carers were also allowed to sleep at the wards because they had come from far and had no resources to rent a private accommodation. The professionals admitted that even though this could be a site –specific issue it needed to be reported as they (the professionals) saw it as an issue which affected patient care at the time because many of them had no access to personal space and privacy.

One professional jokingly asked a colleague;

*‘Do you remember the night of stampede’?*

A question which was accompanied with a huge laughter and giggling across the room. I found out that the professionals were on a night shift and the ward was unusually full so they had to stay on each side of the ward to avoid walking over patients and their carers. The situation became worse when deep in the night a patient shouted for help and the nurses had no choice but to tiptoe across the ward to discharge their duties.

Therefore the professionals felt that one of the major needs of the patients at the time was adequate space while they were recuperating. Fortunately this was not a problem at the time of this study.

### ***7.3.1.3 Support for Buruli ulcer patients’ carers***

Another important category that emerged from the discussion was the professionals concern for the carers of the Buruli ulcer patients some of whom were as young as thirteen years old. Their concern was that the carers had travelled from their villages with no adequate funds to rent a private accommodation so the hospital had no choice but to allow some of them to

sleep at the ward on blankets. These young carers had to leave the ward during the day and only came to the ward during meal times to serve their ill relatives. The hospital had provided them with kitchen facilities to prepare their meals.

One professional said;

*'some of them were in school, as young as fourteen years old and were doing the work of adults such as washing dirty bandages and clothes and cooking as well. They had no statutory support and some of them were not eating well just as the patients they were looking after'.*

There were others who had to leave the ward as early as 7am to go out to look for a manual job to supplement what they had come with. A ward assistant remarked that;

*'Sometimes the carer/worker would come from 'work' around 4pm suggesting that the patient had to be fed by one of the 'neighbours'.*

The 'informal neighbours' system which operated in the hospital was well recognised and benefitted both patients and the carers. With this system a carer could be away for a day (ostensibly to bring in foodstuff and some money from relatives) and the other carers would take care of his/her patient until s/he returned. They also shared the little that they had making sure that no one was left behind.

In an attempt to find out why the professionals felt this was a genuine need for the patients, I had a mixture of responses such as;

*'What does a fourteen year old girl know about caring?'*

And;

*'Some of the carers needed caring themselves. Many of them should be in school but because they had to fulfil their roles as women they had suspended their education to be with the patients'.*

And;

*'A motherly or fatherly figure would prepare the patient psychologically for his/her recovery. If a patient is left in the hands of a minor it signifies neglect and the patient feels isolated from his/her people'.*

This discussion on this property continued for a while until I decided to introduce a new topic.

### **7.3.2 Personal support needs**

Personal support needs was the second category identified in the discussion. This was the support the professionals thought the patients needed for their own good. When asked if these support needs were based on discussions they had had with the patients in the past the overall perception was that it was based on discussions, personal observation and experience. The personal support needs identified were:

*Lack of Prostheses/walking frames and vocational/educational support* and these are discussed next.

#### **7.3.2.1 Lack of prostheses and walking frames**

The need for prostheses and walking frames were identified as a major problem for people living with Buruli ulcer. The professionals were aware of the difficulties and challenges that the majority of the patients were going to face following their discharge. They admitted that they were concerned for the patients' needs for prostheses and frames but there were nothing they could do at the time. Sometimes some of the professionals became emotional seeing these young patients going to face the world without adequate support in the form of mobility as well as carrying out their activities of daily living. The following quotations will suffice to highlight the concern of the professionals as far as this property was concerned.

*'Some of the patients were as young as 14 years old or less. She/he had lost an arm or leg or going home with a severe disfigurement. You watch this child going to face the world without any support in the form of an artificial arm something similar. You feel guilty and ask yourself if as a professional you have done the right thing or not'.*

And as the discussion went on a nurse chipped in and asked a colleague to tell us the ordeal that led her to undergo counselling. As we listened she recounted her experience as follows:

*'I remember a fifteen year old girl with above knee amputation learning to walk for the first time after almost nineteen months at the hospital. She was hopping with her teenage carer by her side to the station to get public transport home following her discharge. I had her medication in a carrier bag with me and I felt like crying when we got to the station and sat down for a while. She was malnourished, pale looking and I could read what was going through her mind. She needed an ambulance or something similar to take her home in comfort. There was none and she had to struggle with a fellow teenager to get onto the public transport. She fell twice. I was demoralised; felt that I was in the wrong profession. I had sleepless nights after this incidence and it took me a while to get over it before I could return to normal duty'.*

Apart from a walking frame there were patients who according to the professionals were in dire need of wheel chairs. The professionals admitted that even though some of the patients had their wheel chairs and walking frames paid for them by churches and benevolent organisations the state should have taken over these support needs not as a privilege for the patients but as a right. One of the professionals said;

*'There were some lucky ones who had their walking frames paid for by the Catholic Church and other benevolent organisations. My concern is that this is a one off gesture; very soon these patients will overgrow these frames and it would be back to square one'.*

It appeared that the professionals had a genuine reason for the personal support needs of the patients they had cared for but the lack of statutory support seemed to thwart their efforts. Each of them recounted similar experiences which highlighted the paucity of basic support needs which these poor patients could not afford on their own. Therefore to these professionals the sufferings of Buruli ulcer patients did not end at the hospital but followed them home and would continue to be with them until they develop their own means of adjusting.

One professional ended this discussion on this property with her personal view that;

*'I feel that we haven't given these people the holistic care that they needed'.*

### **7.3.2.2 Vocational training and educational support needs**

The professionals in the focus group discussion did not limit the discussion only to the respondents' physical needs. They talked about their long term support needs as well which will help them to realise their potentials and to cope and adjust to the vagaries of life. One of such needs identified was the need to provide vocational educational training for these patients. This, according to them, should take the form of identifying the skills of the individual patient and provide them with the support to be able to find their feet in the competitive job market. We discussed the benefits of having a vocational training for these patients in a country where there are no statutory social services support in the form of disability allowance, income support and housing benefits.

One of the professionals recalled the training some of the patients had at Offinso which was provided by the Catholic Church;

*'I think it was a great relief when the scheme was introduced. Those who were able to complete and who had the necessary support were able to start their own vocation in the form of shoe making, carpentry and dress making'.*

There was however, some form of disagreement among the group. Some felt that the government should have collaborated with the initiators of the scheme, while others felt that the district council should have taken over the scheme and not the government. The second group felt that if this had been done the scheme would still be running today. In order to iron the differences I cut in and asked them if they felt the scheme had been of benefit to Buruli ulcer patients. They felt that it could not achieve its basic objectives because those who were too young at the time to undertake the training were left out of the scheme. One of the participants said that;

*'The scheme ran for a while. But there were those who were as young as 10 or 11 years old who could not be recruited into the scheme. These little ones would never be able to get the basic education as individuals to face the world. For how long will they continue to be at the mercy of their immediate family members and neighbours'?*

Following from this the discussion moved on to basic education. The consensus was that education is a right and not a privilege in Ghana but nobody felt the need to make sure that adequate provisions were made to enable the patients of school going-age return to the classroom to exercise this inalienable right. One participant suggested that;

*'Education is a right and for these children who had missed a year or so in school The Ghana Education Service working in collaboration with the Ministry of Health should have made provisions for these patients before they were discharged into the communities. As it is now they have not been supported to realise their basic rights and it appears that no one seems to feel that it is necessary. I feel that society has failed these patients'.*

The discussion on this generated a lot of debate but it appeared that the professionals knew what were indeed the needs of these vulnerable people in their society who they see every day.

### **7.3.3 Community and rehabilitation support needs**

#### **7.3.3.0 Introduction**

The third major category which emerged from the focus group discussion was the needs that the professionals perceived would help the patients cope with life in the community and which will help them to cope and adjust with life as disfigured individuals in the face of widespread stigma and lack of educational opportunities. This category had three properties of: *Psychotherapy, Educating the public and Formation of Buruli ulcer Association.*

#### **7.3.3.1 Psychotherapy**

The participants felt that the patients needed more psychotherapy in the form of counselling before they were discharged into the communities. They admitted that counselling was sometimes provided at the time of admission but felt that it should be provided at the time of discharge and should be on-going following discharge.

The professionals shared with me their concern of the emotional and psychological trauma that Buruli ulcer patients go through for which they felt adequate psychotherapy was needed to help them to cope in life after they have been discharged. While there was a debate as to



whether the patients received enough counselling on admission the general consensus was that majority of the patients were aware of the stigma associated with their condition before they were admitted and therefore more emphasis should be on counselling prior to discharge which should be on-going in the communities.

One nurse said that;

*'If we cannot help them to adjust and cope with their condition while in the community then we have not done enough because this is where they are going to live for the rest of their lives'.*

Following on from this I chipped in and asked them to explain in clear terms what kind of coping and adjustment they had in mind which they felt would help the patients in the community. This led to a number of issues which were discussed at length even though some of them were unachievable. This included the under mentioned properties of: *Formation of a Buruli ulcer Association* and *Educating the public*. These are discussed next.

#### **7.3.3.2 Formation of Buruli ulcer Association**

Some of the professionals suggested that in order for the respondents to cope there was the urgent need to assist them to form an association with the active support of the District Council. They felt that the Association could be assisted to meet regularly to enable them discuss and share their problems needs. With the mention of the formation of an Association I enquired if they were aware that such an association existed of which all but one answered in the negative. Unfortunately the Association which this professional was aware of was The Buruli Ulcer Victims Association (BUVA) which has a website. This came as a surprise to the professionals.

I told them about my discussion with the President of BUVA. I also discussed with them that BUVA was established by an individual who had had the opportunity to be educated to a Diploma level by the Ghana Buruli Ulcer Control Programme as well as some philanthropic organisations and that BUVA is not known by the respondents in the communities. This revelation changed the discussion into how the dormant Buruli Ulcer Association in the community could be incorporated with BUVA and how ludicrous it was for just one person to think for the majority of sufferers.

One participant suggested;

*'There is the need to facilitate a merger between the two. The one in the city with a website is for an individual and I suspect he is reaping benefits at the expense of the majority'.*

The formation and merging of the two associations drifted the discussion to the issue of a meeting place for the patients in the form of a walk-in centre where the patients could meet weekly or as needed to have discussions, play games such as *oware*, ludo, cards and to meet professionals and to discuss their concerns.

One of the participants suggested;

*'I feel that if we have such a walk-in centre for them it will be a place for them to meet to share ideas, play games and where they know they could go and have fun away from the wider community. They will feel at home, feel recognised and be each others neighbour in times of need'.*

The discussion went on for a while about the benefits of having an Association which will fight for their common good.

### **7.3.3.3 Educating the public**

Under this property the discussion centred on how to beat the stigma in peoples' mind to enable Buruli ulcer patients feel accepted while coping and adjusting in the community. Two of the participants suggested that the education should take the form of flyers on Buruli ulcer and how it was not contagious. The issue of whether Buruli ulcer was contagious or not nearly disrupted the proceedings as I wanted to know from them if they were aware that the respondents had accused them of contributing to the prejudice. The general consensus was that at the time of the epidemic (over two decades ago) not much was known about Buruli ulcer and whether it was contagious or not and so they had to be cautious at the time. They expressed remorse if they had behaved in any stigmatising way towards the patients at the time. During the discussion it became evident that the ulcer was not contagious but the bacterium lives in the environment.

I drew their attention back on what form of education was the best to beat the stigma to enable people living with Buruli ulcer feel accepted to enable them to cope. There were suggestions such as radio and TV adverts, using the churches and flyers on public transport and in schools. There were suggestions that school teachers should be educated in the understanding the disease and how to support pupils suffering from the ulcer.

## **7.4 Discussion – Seeking to be myself**

### **7.4.0 Introduction**

This is the last principal category identified in the study and it seeks to address objectives 3, 4, 5 and 6. *Seeking to be myself* was identified as a *strategy* to deal with the core category of *My needs matter*

### **7.4.1 Coping**

*Coping with a burden* highlights the various strategies the respondents use to cope with their condition albeit without difficulties and it has four sub-properties of *Seeking solace in the divine and the Church, Family support, Unacceptable means, Legitimising the condition* and *Music*.

The literature revealed three studies that have investigated the coping mechanisms employed by people living with Buruli ulcer (Adoma 2003, Stienstra et al 2008 and Adamba and Owusu 2011). These three studies concentrated on coping strategies their survey participants employed when Buruli ulcer was first confirmed. This study sought to find out the coping mechanisms employed by people living with Buruli ulcer while rehabilitating. This is necessary so that health interventions can be planned around these to enable health professionals to plan for their support needs.

#### **7.4.1.1 Seeking solace in the divine and the Church**

The study revealed that all but four of the respondents were practising Christians or were believers of one faith or the other and therefore believed in the Omnipotent God. As a result the use of prayer was paramount in helping them to cope with their condition. Other studies have shown that praying (Lauver et al 2007; Manud et al, 2007) and joining support groups (Zeigler et al, 2004) are commonly used coping strategies among cancer patients. At the time of this study there were no support groups for people living with Buruli ulcer so the Church

became a source of support group for the respondents. As far as Buruli ulcer is concerned Adamba and Owusu (2011) and Adoma (2003) found a similar coping mechanism among their survey participants who had been diagnosed with Buruli ulcer. Therefore the findings from this study go to confirm or reinforce the use of prayer and the hope in the divine as a coping strategy for people who have been diagnosed with Buruli ulcer and those living with the condition.

#### **7.4.1.2 Family support**

Family support comes under the over-all notion of problem-solving as a strategy advocated by Lazarus (1993). Forms of family support which were identified in this study were the financial and social support from close family members which are the product of the close knit system known among the *Akans* which seems to challenge what Grietens et al (2008) found among their Cameroun patients where the family neglected the patients in the hospital leading to social isolation. In Ghana Adamba and Owusu (2011) and Adoma (2003) found this form as a coping strategy for the whole family when Buruli ulcer had been confirmed while this study reinforces this form of coping for people living with Buruli ulcer. Nonetheless in all these studies the respondents felt that both intra-household and communal labour arrangement in the form of *nnoboa* (refer to the Findings section) helped them to cope in life which is a new revelation as far as people living with Buruli ulcer is concerned.

#### **7.4.1.3 Coping through unacceptable means**

Folkman and Lazarus (1980) 'Behavioural escape' as well as Girden's (2001) 'Ventilation and avoidance' - in which they identified maladaptive methods of coping such as drinking, eating, smoking among others were found in the data and supports the findings in this study. This study revealed how many of the respondents engaged in other unacceptable practices to help them to cope with their condition which has not been documented for people living with Buruli ulcer. This involved illegal gold mining activities, dealing in banned substances/drugs (either selling them or using them themselves) as well as expressing their sexualities (example masturbation and indulging in same sex relationship which the respondents admit go contrary to the norms of society). This is a new insight into this form of coping mechanism among people living with Buruli ulceration and their relevance and policy implications are discussed under patient support needs and the recommendations sections respectively.

#### **7.4.1.4 Music therapy**

The use of music as a coping mechanism was expressed by all the respondents. While others depended on religious forms of music (either in the form of adoration or what they referred to praises and worship) either during church service or at home, others used it during their ‘quiet time’ with God to boost their intimacy with their creator. There were others who relied on other modern forms of music such as the traditional Ghanaian hi-life music or reggae as a coping mechanism. Others combined music with dancing to cope with their condition. Whilst others complained that they found the combination of dancing and music therapeutic they can only do this at home but not in public possibly due to self –stigma. In this study it was found to restore the respondents’ hopes with a reduced psychological distress while rehabilitating.

#### **7.4.1.5 Legitimising Buruli ulcer**

This property appears to be linked to *Loss of identity* (see preceding section). The denial, acceptance and rationalising the disease are important for health professionals because they help to address the positive aspects of the disease as perceived by the respondents themselves in order to enhance their recovery process. These are emotion focused (passive) strategies (Miller and Kaiser, 2001 and Makoae, 2008) which the respondents use as a means of providing themselves with or shaping their identities. This coping style was found to be associated with the younger respondents and those who have had the disease for most part of their lives. It was therefore difficult to determine whether the severity of the disease was the driving force for this type of coping or not.

Knowledge of this coping strategy is significant as it reflects the history of *Akan* socio-cultural beliefs and influences on chronic illness. Many of the respondents who expressed this as a form of coping were men. As an *Akan*, society expects men to be strong -willed when confronted with trouble and/or in pain else one is considered weak and a ‘woman’. Such knowledge can be used and shared with non-*Akan* health professionals as an adjunct to existing information on psychological and emotional support interventions to support people (*Akans*) living with chronic illness or suffering from other long term conditions. This is a new finding which has not been documented in the literature for people living with Buruli ulcer in *Akan* and other populations.

## ***7.4.2 My support needs***

### ***7.4.2.0 Introduction***

Buruli ulcer is a devastating skin disease so the use of the Dermatology Life Quality Index tool and discussions with the respondents in assessing the impact of the disease on their lives was the best way to identify what their support needs for health care services are. The respondents were encouraged to speak freely about their condition and their perceived needs and how best health professionals could help support them. The findings under this property provide unique insights into the support needs of people living with Buruli ulcer because there have been only two studies in the literature that have attempted to investigate the support needs of these people (Ahorlu et al 2013 and Ackummey et al, 2011). However, these studies focused on the supports needed by Buruli ulcer patients to remove the barriers to early case detection to reduce drop out and default cases. This study went beyond this – it incorporated the needs of people living with Buruli ulcer, following discharge, and as they live a life with disfigurement in their various communities so that appropriate interventions could be developed to help them self manage their condition and to uptake available skin care services. The support needs identified were either personal, community and or institutional which are discussed in the sections which follow.

### ***7.4.2.1 Personal support needs***

As elaborated in the findings section the personal support needs of the respondents were many and varied. A substantial majority of the respondents in this study reported unmet personal support needs which ranged from physical to psycho-social needs and the literature on Buruli ulcer has revealed that these needs have not been reported. These are discussed in the following sections.

### ***7.4.2.2 Lack of sensation and fear of recurrence***

These two needs are discussed together because the respondents' accounts revealed that lack of sensation to the affected parts lead to the fear of the ulcer recurring. The study found that 28 percent (n=8) of the respondents had had either new wound next to old sites or old wounds had opened up or got macerated through work or play with the same symptoms. When this happens it was difficult to ascertain whether the new wound is a relapse or new infection. The literature has categorised all these as recurrent disease. There were others whose wounds had 'ceased to heal' (n=5) for years and thus has become chronic which may need weeks or months of antibiotic therapy and proper dressing to deal with. Thus the findings in this study

seem to challenge the general belief about recurrent rate in Buruli ulcer during follow-up. This study found that the so called repeat recurrences could be new infections or re-infections or both as revealed in this study.

There are many reasons for these: the first is that for economic reasons following discharge bandages are washed and reused (both at the hospitals/clinics and at home). A recent study in Ghana by Yeboah- Manu et al (2013) found that all the bandages washed for reuse showed secondary bacterial contamination and the pathogens found in the bandages were comparable to the bacterial profile of the wound samples. So lack of proper wound care management (after discharge) among people living with Buruli ulcer such as recycled bandages could be one of the sources of wound infection among chronic Buruli ulcer wounds. The second is the indiscriminate use of antibiotic therapy which can be bought over the counter by people living with Buruli ulcer pre and post operatively. There is the propensity for the respondents to develop antibiotic resistance to secondary organisms normally found in Buruli ulcer wounds. Yeboah-Manu et al (2013) found high levels of *Staphylococcus Aureus* isolate resistance to *flucloxacillin* which is the main antibiotic in use in Ghana for treating skin infections. Similar antibiotic -*ciprofloxacin*- was found to be the antibiotic of choice patronised by the respondents and the ‘dispensers’ who treat them at home ,a finding which has not been documented in the Buruli ulcer literature. It is therefore possible for people living with Buruli ulcer in the study area to have developed resistance to *ciprofloxacin*. Following on from this is issue of ‘paradoxical reaction’ discussed under the literature review section.

These are disease-specific needs which highlight lack of organised after-care treatment regimen to enable people living with Buruli ulcer to allay this fear. In the absence of a comparable literature on Buruli ulcer related to this need, discussions with the professionals suggested that their (professionals) aim was to make sure that the respondents were safely discharged into the community without incorporating any follow-up self-management plan into the overall discharge plan. This led to the respondents being left on their own to manage their condition without any professional input.

#### **7.4.2.3 Lack of energy, tiredness and sleep disruption**

Lack of energy or getting tired affects the respondents sleep pattern so these two needs are discussed together here. Respondents described lack of energy and tiredness as feeling exhausted and lethargic after performing a small amount of work. This lack of energy interferes with their activities of daily living and does not improve instantly after rest. The literature suggests that Buruli ulcer is a systemic disease (Pszolla et al, 2003 and Wandsborough- Jones and Philips 2006) and the massive doses of poly-medication during treatment could interfere with the patient's immune system. This need may also be due to contracture and loss of bodily organs which affect 56% (n=15) of the respondents' abilities to do things they used to do.

The respondents complain that getting tired also affects their sleep patterns as well as those they sleep with (partners or siblings). Sleep disruption was also found to be an issue for other dermatological patients, including a large percentage of psoriasis patients (Golic et al, 2009), 6% and 35% of acne patients in Walker and Lewis-Jones (2008) and Poli et al's (2001) participants respectively which support the findings in this study. However while the poor sleep patterns reported by psoriasis and acne patients were related to pain, itching and effects of medication the sleep disturbances that the respondents in this study encounter are due to pain in the joints, phantom pain and feeling lethargic, suggesting some commonality related to sensory experience and impairment to people living with dermatological diseases.

#### **7.4.2.4 Transportation to clinic and back**

One of the obstacles identified in this study is the access to health services in resource poor economy such as the study area. The respondents live in rural communities and attending clinics for dressings on a daily basis was a problem. If the person living with Buruli ulcer has to travel long distances for daily dressings of his/her chronic or recurred wound the family will carefully weigh the benefits of healing or improving the persons' condition against the direct and the indirect costs of leaving home to access the service. In many families the study found that the opportunity cost of leaving the home for treatment at the clinic was a dominant factor affecting the respondents' need to access the facility. Ahorlu et al's (2013) Ghanaian study identified the importance of providing free transport and breakfast for their patients to support the uptake of treatment, which reinforces the needs expressed by the respondents in this study. However, while Ahorlu et al's (2013) study was meant to remove common



impediments or problems that limit early case detection the needs identified in this study were related to chronic and or recurred Buruli ulcer of people who have been treated and discharged and needed daily dressings at nearby clinics without walking long distances.

#### ***7.4.2.5 Sexuality and sexual feelings***

Intimacy and sexuality constitute a major health related quality of life issue among adolescents (Frisen, 2007). The adolescents in this study expressed a decreased confidence in approaching the opposite sex and their ‘normal’ peers. This could be due to two interrelated issues of: the media’s excessive portrayal of what constitutes a perfect body and the misconception of Buruli ulcer as a contagious disease. This need was expressed by both sexes and due to its sensitive nature means the need to have a trusted and empathetic person to talk to in confidence. The respondents use different linguistic or behavioural forms to express their sexuality as a coping mechanism. Some of these such as masturbation have physical, psychological and clinical implications (such as soreness to the genitals, getting addicted to the practice and getting overly tired after the practice as described by the respondents themselves). This calls for privacy, absence of which may lead to an increase in suffering. Unfortunately this need has not been documented in the Buruli ulcer literature.

#### ***7.4.2.6 Education, retraining and financial needs***

These issues are discussed simultaneously because they relate to each other. Hay and Fuller (2011) defined health illiteracy as ‘the measure of a patient’s knowledge about defined health issues which is the intended outcome of health promotion’. They went on to discuss among other things how an educated human resource is well informed of the awareness of treatment opportunities and be able to understand the signs and symptoms of a disease when compared to those without. They might have had people living with Buruli ulcer in mind as their explanation is relevant to this study. The study found that many of the respondents were robbed of their educational opportunities by Buruli ulcer (the education of 44% of the respondents in this study were curtailed) thereby leaving many of them as “health” illiterates’. However, majority of the adult respondents in this study were given opportunities for retraining in different vocations by the Catholic Church and other philanthropists but some of them either could not complete the training or had to give up these trades due to disease recurrence, re-infection, contracture or financial difficulties. The majority of the respondents expressed the desire to retrain or go back to school as a need which can reverse

their present predicament. In Golic et al's (2009) study some of their acne and psoriasis respondents were unable to follow their desired career paths due to their dermatological conditions, as found in the present study. So, therefore, severe dermatological condition such as Buruli ulcer has the potential to render sufferers unprepared for the job market due to illiteracy and loss of skills. This need again is missing in the Buruli ulcer literature.

#### ***7.4.2.7 Psychosocial needs***

The lack of support for people living with Buruli ulcer while rehabilitating may lead to the sufferer losing confidence and hope in controlling the consequences of the illness. The visible nature of the condition leads to respondents avoiding certain social situations or functions and avoiding recreational pursuits and leisure. In Jowett and Ryan's (1985) study 40% of dermatology patients felt that their social life had been affected by their skin. De Groot et al's (2011) study also revealed that the social lives of leprosy patients in the Netherlands were affected because they were found to be house-bound and frequently had to give up hobbies and other social pursuits. In this study the need for pleasure was uppermost on the minds of many of the respondents as revealed by the DLQI tool. The need to be able to socialise and enjoy leisure stems from the effects of the disease itself. Unfortunately this psychosocial need leading to social isolation of people living Buruli ulcer has not been documented in the literature.

#### ***7.4.2.8 Nutritional needs***

Good diet as a need was identified by many of the respondents as well as the professionals. The respondents admitted that they were advised by the health staff before discharge of the importance of good balanced diet in wound healing and their recovery process in general. But due to lack of education on dietary requirements and financial needs the diet of the respondents were found to be poor. The importance of dietary factors in wound healing was first established in 1746 by James Lind (Williams, 1998) as well as a considerable number of research projects which point to nutrition as one of the factors that affect wound healing (Sherman and Barley, 2011; Charney and Marlone, 2009; Levine et al 2006). Sherman and Barley (2011) for example found that fatigue is an early symptom (preceding all other symptoms) of vitamin C depletion in the body and that people of low socioeconomic status are at risk. These findings support what was found in the present study. My personal

observation of the poor dietary intake of the respondents in this study resonates what Adoma (2003) found in her Buruli ulcer study at Lower Denkyira in Ghana. The staple diet of the respondents in the study area was mainly carbohydrate with little or no protein intake amongst many of the respondents. This was not due to any form of cultural compulsion but purely due to lack of funds. Vitamin C in the form of fruits was only available to the communities when the common fruits such as orange and mango were in season. Thus an important element in the over all wound healing process was missing in this group of people which calls for intervention in the dietary intake of people living with Buruli ulcer in this rural community. Unfortunately poor dietary intake for people living with Buruli ulcer has not been discussed in the literature for any meaningful comparison to be made.

#### ***7.4.2.9 Lack of information***

There was also the need to make health information available to the respondents, their carers and healers. Many of the respondents were of the view that the paucity of information from health professionals was some of the reasons they feel neglected by the health officials. The respondents live in a close-knit community where knowledge of health needs in the form of herbs is shared. Traditional healers play important roles in the health belief systems which cannot be ignored. Some of the respondents feel that their health needs can properly be met if health professionals could incorporate their belief systems into the over all health care delivery systems because no matter what treatment they receive from hospitals they will not abandon their systems such as dispensers and other practices which they are used to if anything went wrong any time in their disease trajectory.

The literature review highlighted the issue of ‘paradoxical reaction’ resulting from the use of antibiotics. This is disease specific information which should have been communicated to health professionals but which is left in research Journals. Given that the respondents will continue to self medicate their quest for information is timely.

#### ***7.4.2.10 Need for prostheses***

The need for different kinds of prostheses was identified in the study but has not been documented in the literature for people living with Buruli ulcer. This was the second support need identified by both the respondents and the professional in the study. This ranged from expensive artificial legs/arms and wheel chairs to simple aids as crutches and grip aids. Apart from the mere mention of these aids I discovered when the respondents requested if it was

possible to have information on how to get appropriate footwear I realised that they were requesting for both physiotherapy and occupational therapy support and the right foot wear to ease their discomfort. This was evident in questions such as; '*are there no proper shoes for this deformed foot?*' This reinforces their need of lack of information. From my observations and discussions the respondents would have needed simple orthopaedic/physiotherapy assessment prior to discharge for comfortable footwear and splints as a short term measure and then possibly a follow up to determine the appropriate long term prostheses such as artificial legs and arms. The World Health Organisation determination to prevent disabilities following surgery is appropriate but was launched when some of these respondents had already had the damage done to their arms and legs. The implications of this are discussed in the recommendation section.

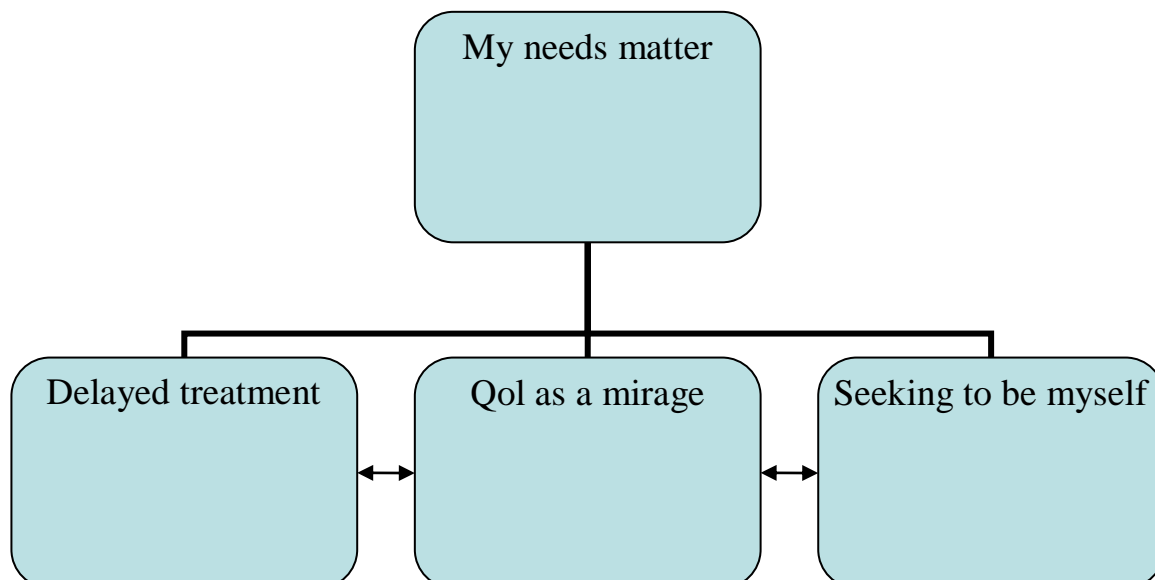
### ***7.5 Summary***

The data from the three sources have been presented in these three chapters. These chapters brought together findings from this study and those from the literature. The comparisons have revealed areas where there were agreements and disagreements. Areas which need further highlighting have been discussed. The next chapter will draw these together and recommendations to improve those areas will be discussed as well as areas which need further research.

## Chapter 8 The core category of *My needs matter*

The aim of this research was to generate a theory ‘that accounts for the patterns of behaviour which is relevant and problematic for those involved’ (Glaser, 1978 pp: 93). To achieve this aim I tried to discover the core pattern and then to delimit the investigation around it in order to arrive at the core category. The core category becomes the pivotal point for the theory which all the other principal categories relate to and which then accounts for the variation in the pattern and behaviour of the respondents in the study. The key findings from all the data sources (see Table 1) used in the study revealed the core pattern of *Reliving the trauma of my ulcer* which was arrived at from the constant comparative method of analysis. This core pattern was found to be a Basic Social Psychological Process (BSPP) that engaged the respondents in a series (pattern) of repetitive accounts of what they had gone through as people living with a chronic disease. The core category within the process of *Reliving the trauma of my ulcer* pattern was *My needs matter*. The three interrelated principal categories which were subsumed to form the core category are: *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* and the relationship between them are shown by figure 14 below.

Figure 14: Relationship between core category and principal categories



In this study the core pattern was reflected in the *Reliving the trauma of my ulcer* which is presented here as a Basic Social Psychological Problem that has engaged the respondents in a series of pattern of repeated emotional recall about their condition. The BSPP followed a three stage process whereby the category *Delayed treatment* was found to be the cause that triggered the BSPP of *Reliving the trauma of my ulcer*; so *My needs matter* was driven by the delay in receiving appropriate treatment. The second stage, *Quality of life as a mirage* was found to be the consequence of *My needs matter* and the third stage of *Seeking to be myself* was found to be the strategy employed to help manage the psychosocial condition of *My needs matter*. The three principal categories and their properties (and sub-properties) and interrelationships constitute (or explain) the core pattern (see figure 9, figure 14 and appendix 12).

Throughout my background reading I had anticipated that due to their condition issues of body image, self esteem or achieving normalcy would be the main focus of the respondents. In hindsight I can now understand and appreciate why *My needs matter* is highlighting a central concern of people living with Buruli ulcer who feel that their needs have not been adequately met or neglected. It is important therefore to understand the world as seen by the respondents themselves rather than outsiders constructing their world for them. The stories of the respondents in the study began with the onset of the disease which put into context their particular experiences of living with Buruli ulcer and how their needs matter to them.

The Basic Social Psychological Problem (Process) of *Reliving the trauma of my ulcer* was a pattern which seemed to encompass that which I had initially found to be difficult to resist as the core category. Later on I realised that it did not account for and explain the diverse range of elements of what the respondents needed to cope as people living with Buruli ulcer, therefore I ignored it. It appeared to me that the respondents merely seemed to recount, rehearse and repeat what they had gone through (which culminated in the pattern *Reliving the trauma of my ulcer*) so that their agenda of *My needs matter* will become manifest and highlight the need for further support for a campaign for statutory agencies and other similar authorities to help them meet their needs. *My needs matter* again, did not emerge from the interview transcripts alone but also from my observations and other data sources outlined in this study (see Table 1, section 3.6.9). Therefore accepting this as a core category was in line because the respondents' thoughts, feelings, attitudes and behaviours were directed to this end.

It is also important to note that the respondents accounts of *My needs matter* clearly showed a difference between what they saw as a need as opposed to what constituted a want. Whilst wanting something is a desire, a need is something that the individual hopes for their survival the absence of which means that the person cannot fulfil their normal daily activities.

Therefore the over all findings revealed that people living with Buruli ulcer feel that their needs matter to them and that they will not stop rehearsing, talking, and recounting these. The whole findings and discussions chapter explore the meaning and significance of the needs of people living with Buruli ulcer which integrates the principal categories of *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself* and its impact on nursing care of people living with Buruli ulcer. This is because much of what the respondents recounted and describe in *My needs matter* is related to achieving that goal.

In the context of extant literature the core category of *My needs matter* has semblance with Abraham Marslow's (1987) theory of human needs – hierarchy of needs - in his famous book *Motivation and personality*. This is because *My needs matter* revolves around issues proposed by Marslow and why needs are concern for people living with Buruli ulcer. Marslow's theory of hierarchy of needs hinges on human motivation (Eysenck, 1998) and it is concerned with why people think and act the way they do. Even though Marslow was a humanistic psychologist his works transcended other disciplines making it holistic. My theory of *My needs matter* appears to be in line with Marslow's holistic philosophy in that the findings in this study revealed that the needs of people living with Buruli ulcer had both physical and psychosocial elements. In the context of this study it explains why the physical and psychosocial needs of people living with Buruli ulcer matter to them and why they keep on telling and recounting these.

Marslow (1987) proposed that two motivational states affect human beings in meeting our goals, desires or needs – self actualisation and basic needs. While self actualisation links more to life experience, or what Gross (2005) has described as achieving a status where humans become all that we can be intellectually and creatively, the basic needs in the lower hierarchy of needs are concerned with what we need as humans for survival purposes (our physiological/biological needs) which include our basic needs for food, clothing, shelter, comfort, safety and security from physical and psychological danger, respect for others as well as love and belongingness. In between these Marslow proposed a need for people to hold themselves in high esteem and to respect and be respected by others. Marslow argued

extensively that human survival depends much in satisfying the lower basic needs (as explained above) first before yearning for self actualisation. Marslow organised these two distinct needs in a form of a hierarchy with self-actualising needs at the apex of the hierarchy.

Marslow's lower level needs are relevant to my study in that the respondents expressed needs which were similar. For example in the principal category *Delayed treatment* the respondents pointed out the need to be motivated in getting information that will help them in reporting their condition for early treatment. Marslow again recognised the need to receive care and be cared for as well as to feel loved and belonging. My contention is that these needs matter because the absence of these led to *Delayed treatment* with its physical, psychosocial and health consequences. In this study the lack of information to proper medical treatment led to the perceived fear identified in this study. All these led to delay in seeking proper medical treatment. The lack of this need is comparable to the lower level needs identified by Marslow. My reasons are that in expressing these needs the respondents were addressing issues related to avoiding pain and its effects on their body temperature (the maintenance of body temperature is a physiological need for survival identified by Marslow)) as well as a subconscious feeling of lack of love and belonging.

I also found that for many of the respondents *My needs matter* meant a desire or a wish to have good quality of life. Therefore in the principal category of *Quality of life as a mirage* the respondents expressed needs which focused on their desire to be comfortable and to enjoy leisure and other recreational pursuits in comfortable and safe environments. In their quest to have good quality of life they sought to avoid stigma, be accepted as individuals living in a homogenous community, be protected from their immediate environment (and danger) such as avoiding activities that exposed them to recurrence of the ulcer. They again expressed the need for a predictable and safe environment to carry out their daily routines such as working in the farm. The property of *Loss* and its subcategories *of loss of education, loss of love ones, loss of skills* and *income* among others was a clear indication of the respondents desire to meet needs which are in line with Marslows lower level needs.

In the principal category *Seeking to be myself* the coping strategies and support needs of the respondents such as rest and sleep were manifestly expressed. In this category the respondents explained the strategies they employ to enable them to cope with their condition



as well as their numerous support needs which are all in line with Marslow's lower level needs.

As one moves up Marslow's hierarchy of needs they become aware that the needs gradually gets focused on life experience which appears to suggest that the person needs to satisfy the lower level needs before achieving the upper level needs. In this study the thoughts and feelings of the respondents were interrelated and centred on the three lower level needs of physiological, safety and love and belongingness; they do not in any way connect with Marslow's higher levels of needs of self esteem and self actualisation. Eysenck (1994) also challenges the idea that self actualisation is the ultimate goal for the individual. Eysenck's (1994) criticism of Marslow's hierarchy of needs resonate with the core category *My needs matter* in that no where in the views, thoughts and feelings of the respondents did self actualisation or the higher level needs become their ultimate goal.

Moreover the needs expressed by the respondents in the study did not appear in any linear form where one level of need has to be attained before moving onto the higher level as suggested by Marslow. In reality therefore the needs of people living with Buruli ulcer will move along the hierarchy as their circumstances dictate.

## **8.2 Summary**

In the discussion so far I have attempted to explain how the core category of *My needs matter* explains the diverse ways people living with Buruli ulcer aim to get their needs fulfilled and how their needs matter to them. In meeting the diverse needs of people living with Buruli ulcer means that they have to deal with a range of social, physical and psychological issues. The needs are interrelated and they do not follow any linear form but are in line with the lower hierarchy needs proposed by Abraham Marlow in his theory of human motivation. *My needs matter* was not about their care but generally about how to get the support to enable them carry out their activities of daily living. This revelation is important as it directs health professionals what to look for to support people living with Buruli ulcer.

## ***CHAPTER 9. Conclusion, Limitations and Recommendations***

### ***9.0 Introduction***

This section, the last chapter, concludes on the key findings in this study and identifies the study's contribution to knowledge. Recommendations based on the findings from the study are outlined and areas for further research as well as the limitations of the study are identified.

The aim of this study was to explore the views of people living with Buruli ulcer in an endemic area in a rural district of central Ghana in order to identify their support needs and plan for these. An exploratory Grounded theory approach was deemed appropriate to achieve the aims and objectives of the study and also to answer the four research questions.

Theoretical sampling (a feature of Grounded theory methodology) led to the incorporation of the Dermatology Life Quality Index (DLQI) questionnaire, a focus group discussion with the health professionals, participant observation technique, discussion with opinion leaders, and traditional health practitioners to achieve these aims. Through the application of the constant comparative method of data analysis, the study led to the core pattern of *Reliving the trauma of my ulcer* which was found to be a Basic Social Psychological Problem which led to the core category of *My needs matter* with three interrelated categories of *Delayed treatment*, *Quality of life as a mirage* and *Seeking to be myself*. The three principal categories were found to be the causes, consequences and strategies respectively of the core category. In a sense the perceptions of people living with Buruli ulcer in this study as a devastating, stressful and a life change experience that threatens every facet of their life reflected the contexts from which the Grounded theory of *My needs matter* emerged.

At the very beginning of the study I was aware of the literature that have made various attempts to explain the various rationale for people living with Buruli ulcer to seek medical intervention late. These studies were found to have relied on the survey research approach/technique. The weaknesses inherent in the survey research approach have been exposed in the methodology section of this thesis. As a result I thought the reasons might go beyond what have been documented in the literature all this while. I therefore decided that an exploratory approach using the Grounded theory methodology would be more appropriate to delve into the reasons for late presentation and to also ensure that the reasons emanated from the respondents themselves without any preconceived thoughts.

A critical review of the literature also revealed that despite the fact that socio-cultural studies was a priority research area identified by the World Health Organisation as well as evidence of the high morbidity rates and other health related consequences of Buruli ulcer the support needs of people living with Buruli ulcer had been neglected by researchers on this disease. Paradoxically despite the World Health Organisation's much touted quest for Prevention of Disabilities (POD) among people living with Buruli ulcer and the socio-cultural studies as a research priority, researchers have been eagerly researching into areas which seek to prevent potential disabilities associated with Buruli ulcer when the patients are in the hospital for treatment but the same patients are not followed up after discharge to ensure a disability-free life after discharge. I was of the belief that treating the individual of the illness/disease was one thing, a sustainable, holistic, and on-going follow-up care was another if The W.H.O's aims and The UN Millenium Development Goal in this perspective are to be realised. This is one of the many areas of this study's contribution to knowledge.

A search in the literature confirmed this as there were only two studies that had attempted to investigate the support needs of people living with Buruli ulcer. However these studies did not address the very issue I had anticipated all along – the care and support needs of people living with Buruli ulcer - as the authors were concerned with the supports Buruli ulcer patients needed for them to access health facilities on time, ostensibly to avoid complications associated with the disease if treatment is delayed. I saw this as purely an intervention from a biomedical perspective. A broader and a more holistic approach to understand the illness experience of people living with the consequences of Buruli ulcer is therefore necessary, so that the support needs of people living with Buruli ulcer after they have been safely discharged to live a life of disfigurement and in some cases with disability can be addressed.

The above notwithstanding I also realised that the support needs of people living with Buruli ulcer cannot be properly understood without proper assessment of their quality of life. Finlay (2000) argued that the quality of life assessment has the potential to inform health professional's understanding of individual patients needs so that we can plan towards these. I have argued that without knowledge of the needs of people living with Buruli ulcer any services planned for them will be done in a piecemeal fashion and will not be in their interest. This became evident when the needs of the respondents were compared with what the health professionals perceived as the support needs of the respondents. The fact that the professionals were able to identify only two (nutrition and prostheses) of the respondents'

numerous needs testify to this fact. People living with Buruli ulcer are rational human beings whose needs will change as society's perception changes. Therefore knowledge of their needs today will be of great importance for policy makers, clinicians, health promotion enthusiasts and epidemiologists for the future planning of services for people living with Buruli ulcer. The literature revealed paucity of information in this area also save one Ghanaian study that attempted to investigate the quality of life of Buruli ulcer patients but not those living with the condition. So all in all, it appeared to me that health professionals and researchers are only interested in the patients when they are in the hospital but not when they have been discharged. This study was timely as the objectives sought to understand the illness experience of people living with Buruli ulcer, their quality of life issues and their support needs.

By exploring the experiences of people living with Buruli ulcer the study has been able to uncover the various reasons why people living with Buruli ulcer seek medical intervention late, their health beliefs and practices, the effects of Buruli ulcer on their health and quality of life in general, their coping mechanisms and their support needs. All these were achieved by the constant comparative method of data analysis; the advantage grounded theory approach has over the other methodologies researchers have used in the study of Buruli ulcer. The findings from this study have a lot of implications for both public health and policy with regard to Buruli ulcer and these are discussed under the recommendations section below.

The consequences of Buruli ulcer under the principal category *Quality of life as a mirage* (and its properties and sub-properties) and the ability to cope and adjust to the condition plus the identified support needs can all be explained by *My needs matter*. What became obvious in this study is that the Grounded theory of *My needs matter* and its three interrelated categories does not only highlight the difficulties and problems associated with Buruli ulcer it also seeks to uncover what influences their coping and adjustments as well as their support needs. If these needs are met it is hoped that people living with Buruli ulcer will enjoy good quality of life and also enhance their eudemonistic and their hedonistic well-being.

The fact that the findings from this exploratory study are consistent with some studies in other parts of Ghana and other Africa countries which used the survey approach is not only a significant revelation but has implications for both intra and inter-governmental decision-making approach in dealing with some of the problems of people living with Buruli ulcer.

The implications are that the rigour built into this study makes the findings a benchmark against which future studies on Buruli ulcer in the endemic areas will be measured.

The theory of *My needs matter* encompasses the respondents physical discomfort such as contracture and other health related issues that concern their social, environmental, psychological and cultural needs. Issues concerning the self, identity, body image disturbance as well as self presentation all lead to health concerns that serve as constant reminder of what the respondents have gone through in the past. For example if adolescents living with Buruli ulcer feel that the only way they can conform to societal norms of appearing and looking good is by dressing to hide their disfigurement then health professionals dealing with them should be concerned with issues of health promotion and education activities which are non-existent at the moment. I do believe this is one of my contributions to knowledge on people living with Buruli ulcer, the topic which is discussed next.

### ***9.1 Contribution to knowledge***

As I indicated in the introduction chapter (Chapter 1) this study sought to answer the following four research questions:

- i, what prevents people living with Buruli ulcer from seeking early medical treatment?
- ii, what are the experiences of people living with Buruli ulcer?
- iii, what health-related concerns do those living with Buruli ulcer have about managing their condition and
- iv, what are the support needs of people living with Buruli ulcer that may enhance their quality of life and well being?

I have used the grounded theory method to research into the social world of people living with Buruli ulcer by answering the above four research questions and have been able to get closer to reality. As a result this study's contribution to knowledge includes the following:

1. The findings in this study have supported what is already found in the literature with regard to the reasons why people living with Buruli ulcer take long to seek medical intervention. Indeed this study has not only confirmed but extended the knowledge on these reasons by using a different approach.

2. This study has also found out the contribution of the medical profession in the delay in diagnosing Buruli ulcer which confirms Illich's (1996) concept of *clinical iatrogenesis*. This finding therefore acts as a pointer to clinicians and policy makers about how Buruli ulcer could appear in various forms making it a unique dermatological condition. This revelation calls for the need to strengthen the knowledge base of front line health professionals and dermatologists dealing with skin diseases in the developing world

3. My grounded theory of *My needs matter* is unique in that it has emerged from constant interrogation of the data until saturation was reached. This is the first qualitative study using the grounded theory approach to understand the support needs of this vulnerable group of people from their own perspective. These findings are useful in that they emerged from the respondents' own accounts through in-depth exploratory interviews.

4. The health related quality of life of this group is very important in identifying their needs, something that has never been investigated. That this is the first study to have used the Dermatology Life Quality Index (DLQI) as a tool to find out the impact of Buruli ulcer on the respondents' quality of life makes this study unique. I have nevertheless accepted the fact that due to the small sample size it will be difficult to transfer the generalisability of this finding to other Buruli ulcer endemic areas. However, the use of theoretical sampling and the fact that the three principal categories reached data saturation does help to contribute to the rigour of the data. The findings have nonetheless opened the gate for this tool to be replicated in other Buruli ulcer endemic communities. The DLQI tool has found that Buruli ulcer leads to low quality of life and the respondents well-being is affected too.

5. There are only two studies that have attempted to explore the needs of Buruli ulcer patients while at the hospital. The contribution of this study is that it has extended this further by exploring the needs of these people while in the communities where they are going to stay for the rest of their lives. By exploring their needs this study has also identified the coping mechanisms employed by this vulnerable group which will help health professionals to plan intervention around them. The identification of the various needs found in this study is in line with one of the W. H. O's research priority areas (socio-cultural studies) and therefore hopefully enable policy makers plan well to reduce the problems identified by the respondents and the health professionals.

6. The literature on Buruli ulcer identified stigma as one of the causes of delay in seeking medical intervention. By exploring the views and concerns of the respondents this study has not only confirmed that by using a different approach, it has indeed identified the consequences that enacted and felt stigma affect people living with Buruli ulcer. This revelation is important for health care professionals dealing with this group of people to know and plan the interventions needed to deal with these forms of stigma affecting the lives of these people.

7. The study again reinforces the findings on ulcer recurrence. What has been added is that by exploring the concerns and views of the respondents, recurrence of Buruli ulcer could be re-infections or new infections and that the indiscriminate use of antibiotics by the respondents and ‘dispensers’ has the potential to lead to antibiotic resistance in the study area as well as other endemic areas in Ghana.

### ***9.2 Limitations of the study, recommendations and future research***

The findings of this study should be acknowledged and considered in the context of the following limitations. The identified limitations are the products of the study approach and deficiencies in the data collection. These may affect the truth value and credibility (the validity) of the study as well as its application to the general population.

1. By adopting the grounded theory approach the four research questions did not seek to test any specific hypothesis, but they rather generated concepts and working hypothesis through my interactions with the studied world. Therefore their impact portrays an interpretive and descriptive world but not an exact picture of it.

2. The study used purposive sampling technique which might have led to unknown selection bias. Therefore caution needs to be exercised when examining the transferability of the results to other people living with Buruli ulcer or other Buruli ulcer endemic areas. However grounded theory offers the potential for theoretical generalisability to wider but similar contexts rather than statistical generalisability informing further study and practice.

We must also not lose sight of the fact that during the one-to-one interviews the respondents may have given reconstructed accounts (particularly when sensitive issues are raised). Others

might have forgotten certain important events due to time factor and therefore their 'stories' might have lost very important and crucial points which would have enhanced the quality of the study. To surmount this problem sometimes parents were invited to shed lights on certain issues. Again time factor might have also affected their accounts.

3. The study focused on the reconstructed experiences of the respondents and six health care professionals only. I was unable to observe and evaluate the care given to Buruli ulcer patients at the hospital during the period of the study even though this had been anticipated and included in the research plan. A thorough first hand experience of the nursing care given to the respondents would have helped at least to understand their conditions better to have enabled me to compare their accounts with my observations. This would have enhanced the quality of the study and would have provided me the opportunity to reflect on this. As it is I have relied on reconstructed accounts from the respondents and only six professionals which have the potential to affect the credibility of the findings.

4. Apart from Ghana, Nigeria and Sierra Leone the other endemic regions in West Africa are French –speaking countries. My literature review was limited to articles published in English language. Articles published in French were assessed but if they had abstracts in English. This hampered the literature that was needed for comparing the data and findings in this study.

### ***9.3 Recommendations***

The findings from this study revealed a combination of a disease that has a severely debilitating effect on peoples' bodies. The psychological and physical effects of Buruli ulcer as highlighted in this study requires a holistic and inter-professional approach to deal with the needs of the people who live with it. This section has a list of recommendations which if implemented could promote the health needs of people living with Buruli ulcer. While some of these could be achieved at the local level others have policy, health promotion and public health and clinical implications. I have indicated that some of the under mentioned recommendations could enable people living with Buruli ulcer better manage their conditions.



1. There is the need to include knowledge of *Mycobacterium ulcerans* as an emerging dermatological condition in the medical training of doctors and nurses in the developing world. Given that there are few dermatological services in the rural areas in Africa there is the need to develop and cascade medical /dermatological skills down to the community level to benefit community nurses who are generally closer to the rural communities than doctors. This calls for a closer inter- professional collaboration between doctors and community nurses to raise awareness of Buruli ulcer and skin health in general as a public health concern in the developing world.

2. Cost of treating Buruli ulcer is high which is affecting the health budgets of affecting countries. Efforts should be made to avoid recurrence to enable the individual to live an independent life. This calls for health professionals to design interventions which will help the patient to self-manage his/her condition. This will include a thorough investigation into the individual's support needs and a care plan based on these. But care must be taken to note that whilst individuals are unique so interventions should be seen to be tailored to meet individual needs.

3. This study for example revealed that Buruli ulcer scars are susceptible to breaks in the skin barrier due to the hot and dry tropical weather conditions. In attempt to avoid this that people living with the condition apply either Vaseline or Shea Butter on the affected scars to maintain the skin tissue and integrity. Up to date no effort has been made to investigate the efficacy of this intervention (Vaseline and Shea Butter). It is recommended that dermatologists find the best topical emollient which will be the ideal in the tropics and to teach patients simple moisturising techniques not only to protect Buruli ulcer scars but to reduce the rate of recurrence caused by the harsh tropical weather conditions.

4. The study also revealed that due to economic reason people living with Buruli ulcer recycle old bandages for dressing wounds. These bandages have been found to harbour wound pathogens some of which have become resistant to the commonly used antibiotics in Ghana. It is therefore recommended that nurses at the local clinics, 'dispensers' and the general public be made aware of this while clinicians find out the appropriate disinfectants since for economic reasons people living in the rural areas will continue to reuse bandages.

5. Majority of people living with Buruli ulcer live in remote areas in the developing world. It is recommended that in order to avoid recurrence and improve early case detection dermatological health services should be ‘carried to the people’. This could be in the form of mobile clinics to enable those living with Buruli ulcer as well as new cases to have easy access to such facilities. Short courses geared specifically to the identification and management of small wounds should be organised at the community level for ‘community nurses’. These ‘community nurses’ should involve people who have had Buruli ulcer in the past. They must be involved in any local educational programmes such as early detection of Buruli ulcer and simple dressing techniques as they could be the best people to help in the fight against recurrence and delay in seeking early medical intervention.

6. There is also the need to include physiotherapists and occupational therapists prior to discharge to deal with how patients will manage their conditions including how to deal with contracture and prostheses needed to protect areas of the skin lacking sensation. A joint physiotherapy and occupational therapy approach to determine short term needs of these people is what is needed. This should include the following: simple low cost wooden crutches for those who have difficulty walking on their own following discharge; simple grip aids for those with mutilated and severely deformed arms; simple splints and advice on suitable footwear designed to meet individuals’ needs. These should be seen as short term measures prepared or designed with simple low cost local materials before thinking of such expensive prostheses and wheel chairs for long term use.

7. The study revealed the consequences of negative body image for adolescents and its effects on their health related quality of life. Of particular salient importance are sex, sexuality and intimacy during this period in the individual’s life. For adolescents living with Buruli ulcer to regain their confidence in managing their conditions and be able to form relationships with their peers and the opposite sex health professionals should be conversant with social skills training as advocated by Rumsey et al (1986) and Patridge (1998). By increasing the repertoire of nurses’ methods of dealing with negative body image they (nurses) should be able to boost the confidence of people living with Buruli ulcer. People living with Buruli ulcer can be empowered if they have trained health professionals in sexuality issues who they can speak to in confidence. This should include a confidential free-of-charge telephone helpline or leaflets which should be made available to them at all times.

8. The study revealed that the respondents cope and adjust to their condition through prayers and the church as well as the extended family system. There are others who will still manage their condition through their belief systems and their loyalties to traditional health practitioners (herbalists, *Mallams*, faith groups and Dispensers) are not in doubt. Many children would also rely on their teachers when they return to school following treatment. The people have gone a long way to deal with their physical challenges. Their emotional and spiritual challenges are not yet over. Buruli ulcer took the hope of many of the respondents so emotional healing is very important in the recovery process. It is recommended that any initiative regarding their emotional healing, empowerment and compliance to treatment will be successful if the church, the family, traditional health practitioners and teachers are involved in the over all healthcare delivery system from inception through evaluation. This would make the affected person feel that the interventions are emanating from sources they can trust.

9. Good diet has been shown to promote wound healing. In the developing world the goal of fighting skin infection and infestation and promoting wound healing can only be achieved if there is an inter-professional approach in dealing with skin care prevention and protection. This should include dieticians and nutritionists who should take the dietary needs of these people into consideration. It was revealed by the health professionals in this study that many surgeries were postponed because the patients were too anaemic. The inter-professional team needed to deal with this issue should include community nurses and ex-patients. They should educate people living with Buruli ulcer about the importance of having diets rich in the essentials nutrients by taking the dietary habits and cultural practices of the people into consideration. The team should then encourage families to identify local dishes rich in the essential vitamins and the most cost effective ways in preparing these. This should be part of an on-going educational programme aimed at improving the nutritional needs of these people which might reduce the constant fatigue and recurrence reported by the respondents in this study.

10. Education and retraining such as that which were offered to the few respondents by the Catholic Church should be seen to be tailored to the beneficiaries' condition and abilities. This involves a thorough assessment of the beneficiaries' abilities to cope by involving a multidisciplinary team including occupational therapists and physiotherapists. Such an assessment should be seen to be ongoing throughout the training period. The scheme should

be seen to take the needs of children into consideration. Efforts should be made to connect the scheme to local businesses for work placement and integration purposes. The world is changing and training needs should reflect the needs of the current job market. So training in computing, radio and television repairs and small business management (including basic book keeping and accounting) should be emphasised. Local entrepreneurs who will be willing to offer jobs to such people after their training should be given tax rebates as an incentive for others to emulate. Loans in the form of micro-finance should be considered for such people to enable them self manage their small local businesses.

11. The DLQI tool has been shown to have universal applicability to almost all skin diseases as the literature review has shown. However judging from the respondents' differing conditions in this study I will critique that there is a need for a modified form of the tool in which the questions will refer specifically to the effects on amputations, oedematous limbs, contractures and disfigurements rather than the over all skin problems per. Alternatively the tool will be more applicable with people with the condition at onset rather than after treatment and living with the aftermath of the condition. Nonetheless it has enabled me to identify the needs of the people living with the effects of Buruli ulcer.

#### ***9.4 Areas for future research***

This study has applied the grounded theory method to examine the lives of people living with Buruli ulcer in a community setting. The application of the grounded theory method revealed a lot of new findings which have been discussed. In addition to this the study has provided insights into how best health professionals can help support the needs of people living with Buruli ulcer as well as recommendations which could enhance their care and support needs during rehabilitation in order for these people to self manage their conditions. Nonetheless the study has also identified the following areas for further research in the areas which were either beyond the scope of this study or which were later on found to be relevant to the people living with Buruli ulcer. These are discussed next.

1. The study used the Dermatology Life Quality Index (DLQI) as a tool to identify the health related quality of life of people living with Buruli ulcer. Future research using a larger sample or a longitudinal study is needed (using this tool) to ensure the transferability of such findings to other Buruli ulcer endemic communities. However, the congruence of the qualitative data

to the quantitative data does provide a basis for further exploration to build up a more accurate survey based portrayal of the scale of quality of life impact.

2. The support needs of people living with Buruli ulcer are necessary to enable proper interventions to be instituted to enable them better manage their conditions. Future research is needed to replicate this study with Buruli ulcer patients in both institutional and communities settings to help health professionals better understand the over all support needs of people living with Buruli ulcer.

3. Clinicians are called to research into the optimal readily accessible topical emollients to maintain the integrity of the skin after the ulcer has healed in the tropics instead of the trial and error of Vaseline and Shea butter.

4. The respondents in this study complained of feeling weak and tired which interferes with their sleep and daily activities. Whilst this could be attributed to a weak immune system following surgery, anaemia due to poor diet or the effects of multi-drug use, research is needed to find out the cause of this so that interventions could be put in place to enable health care professionals, with a greater degree of certainty, assist these vulnerable people.

5. Traditional health practitioners have been found to play important roles in the health of the people in the study area. There is the need for a concerted effort to research into the best way to incorporate them into the overall health delivery system of people living with Buruli ulcer.

### ***9.5 Conclusion***

All in all this study has revealed that Buruli ulcer is a devastating condition with its unique problems. If the disease is reported early treatment is available. The reasons for late presentation discussed in the literature appear to place the responsibilities squarely on the respondents and their families. Some of these reasons have been over-simplified in the literature. I am convinced (through my observations and discussions ) that policy makers and other stakeholder organisations on Buruli ulcer need to critically look at other fundamental structural bottlenecks in the over all health care delivery systems in rural Ghana to address the issue of late presentation as it is the key to avoid the complications associated with Buruli ulcer.

I was mistaken to have thought that issues of body image and disfigurement would have been the primary concern of people living with Buruli ulcer. The grounded theory of *My needs matter* has proved otherwise. People living with Buruli ulcer are not a homogenous group. Their needs varied but these needs were found to be basic and for survival purposes but not for self esteem or self-actualising. The implication is that it will be easier to adopt similar strategies to deal with their needs. We cannot provide proper health services to people living with Buruli ulcer without adequate assessment and analysis of the needs as reported by them. Epidemiologists can help with Buruli ulcer prevalence whilst physicians can provide treatment. But with the upsurge of recurrence with Buruli ulcer and its consequences proper allocation of resources should be directed to understanding the impact of the disease from the view point of those living with the condition. The needs of the disease arise from its impact. Therefore the needs of people living with Buruli ulcer should not be allowed to be determined by politicians but by professionals in close collaboration with the people themselves. Otherwise it will lead to a mismatch between what these people need and what policy makers will actually provide for them. As new findings keep on emerging with regard to this devastating condition a complete decentralised health care delivery system whereby findings from research could be readily cascade to frontline health workers coupled with the recommendations outlined in this thesis will help tackle the numerous needs identified in this thesis.

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## APPENDICES

## **APPENDIX ONE: W. H. O. RECOMMENDED STUDIES UNDER ITS CULTURAL AND SOCIO-ECONOMIC STUDIES.**

1. To determine local explanatory models of skin disorders and Buruli ulcer in particular; local terminology associated with Buruli ulcer, patterns of health-seeking behaviour and factors influencing these patterns of health-seeking behaviour.
2. To determine community opinions of any proposed interventions such as health-education, treatment, and community-based rehabilitation.
3. To determine the potential role of traditional healers in the early recognition and treatment of Buruli ulcer and the possible use of home and traditional remedies.
4. To determine the socio-economic dislocation of social and cultural norms caused by Buruli ulcer and the coping strategies employed by affected people and their family members.
5. To determine the impact of Buruli ulcer (including disability) on the lives of the patients and family members.
6. To determine the cost of both static (or facility-based) and outreach management of Buruli ulcer. This will include both direct and indirect costs of such management strategies. Such costs studies should also include the assessment of the cost of treatment of various forms of the disease.
7. To determine the economic impact of the disease treatment on the health system, the community and the country at large.

Source: World Health Organisation (W.H.O) Fact Sheet 199 updated June 2013.

**APPENDIX TWO: THE FOUR PRAGMATIC TARGETS AGREED UPON IN GENEVA , MARCH 2013.**

1. By the end of 2014, at least 70 % of cases reported from any district or country to be confirmed by PCR.
2. By the end of 2014, proportion of category III lesions reported from any district or country to reduce from 2012 average of 33% to below 25%.
3. By the end of 2014, proportions of patients presenting with limitation of movement at diagnosis from any district or country to reduce from the 2012 average of 25% to 15%.
4. By the end of 2014, proportion of ulcerative lesions at diagnosis reported from any district or country to reduce from 2012 average of 84% to 60%.

Source: World Health Organisation (W. H. O) Buruli ulcer Fact Sheet No. 199 updated June 2013.

## **APPENDIX 3 : DERMATOLOGY LIFE QUALITY INDEX**

**APPENDIX 4**

**CHILDREN'S DERMATOLOGY LIFE QUALITY INDEX QUESTIONNAIRE**

## **APPENDIX FIVE: CONSENT FORM AND PARTICIPANT INFORMATION SHEETS.**

### **PARTICIPANT INFORMATION SHEET**

Bournemouth University

#### **Title of research project:**

The voice of people living with *Mycobacterium Ulcerans* (Buruli Ulcer) disease: A grounded theory to understand the illness experience and support needs of people living with Buruli Ulcer in a rural district of central Ghana.

#### **What is the purpose of the study?**

Buruli Ulcer (BU) is a skin disease and it is the third most common disease of its kind after Tuberculosis and Leprosy. If treatment is not sought at the early stages of the disease it may lead to destruction of major organs leading to functional limitations.

Notwithstanding the physical and psychological traumas that sufferers endure with associated loss of productivity due to long hospital stays most of the major researches so far on BU have focused understanding of the disease from the professional point of view. The views of the people living with the condition regarding the illness, treatment modalities, support needs, health-related quality of life impact etc have not been addressed within the existing literature. This may affect the holistic care people living with BU need. Therefore researching into the lives of people living with BU is an important area of enquiry because the ways of finding out that knowledge lie with them and not the professionals. This study therefore seeks to explore the illness experience of people who are living with the consequences of BU using a methodology which has not been applied before. The experiences of people living with Buruli ulcer are needed to inform future development and to provide a holistic care for them.

#### **Why have I been chosen?**

You have been invited to participate in this research project as you are a person who has suffered from Buruli Ulcer disease.

**What will happen to me if I take part?**

If you agree to participate, you will be invited to attend an interview at a place of your choice for up to one hour. The interviewer will ask you to explore your views, reflections and opinions about your experience of BU. This interview will be tape –recorded and then transcribed. The transcripts will be returned to you for you to ensure that the comments are the accurate reflection of what you said at the interview.

**Are there any possible risks or disadvantages of taking part?**

There should be no risk involved in this study. The contact details of the professionals dealing with your illness are provided at the bottom of this sheet should you wish to discuss anything that may disturb or upset you in relation to the study.

**What are the possible benefits of taking part?**

You may see no direct benefit(s) in taking part of the study. However, the outcome of the study could inform the management that they understand the experience of BU victims and may be able to influence how the programme is delivered. The study also has the potential to open up new areas for future research into BU.

**Will I receive any remuneration or expenses for taking part?**

The interview is voluntary and will be conducted at a venue that is convenient to you to reduce travelling expenses.

**Do I have to take part?**

Your participation in this study is entirely voluntary. You may refuse to be involved in it, or may withdraw from it at any time regardless of reason. There will be no repercussions if you do this. Your participation or otherwise will not impact on the treatment you are currently receiving at the rehabilitation centre.

**Will my taking part in this study be kept confidential?**

Yes, your confidentiality and anonymity will be assured and all details of the study will be stored on the researcher's personal computer and will not be made available to any third



party. Your personal details will not appear anywhere in the research as you will only be identified with a code which will be known only by the researcher.

### **What will happen to the results/outcome of the research study?**

This is purely an academic research and the results will be kept at Bournemouth University in England. A copy will be made available to the Buruli Ulcer Control Programme at Korle-Bu Teaching Hospital if they request.

### **Who has reviewed the study?**

The study has been reviewed and approved by the Research Ethics Committees of Bournemouth University (England) and the Ghana Health Service Ethics Committee, Ministry of Health, Ghana.

### **Contacts details for further information:**

1.The Director,  
Research and Development Division,  
Ghana Health Service,  
Accra.

Tel 0302681109/ 0302679323

2.Mr Joseph Adomako,  
District Director of Health  
Manso Nkwanta.

Tel. 032097732

3.Dr Edwin Ampadu,  
Director, National Buruli Ulcer Control Programme,  
Accra.

Te. 021686337

Contact details of two Bournemouth University supervisors:

Dr Ann He mingway

School of Health and Social Care,  
Bournemouth University,  
Royal London House,  
BH1 3LT England.  
Tel 0044 1202962796

Prof Steve Ersser,  
SHSC,  
Bournemouth University,  
BH1 3LT.  
Tel 0044 1202524111

## **BOURNEMOUTH UNIVERSITY**

### **PARTICIPANT CONSENT FORM**

#### **Title of research:**

The voice of people living with *Mycobacterium Ulcerans* (Buruli Ulcer) disease: A grounded theory to understand the illness experience and behaviour of people living with Buruli Ulcer in a rural district of central Ghana.

- I agree to take part in this research which is to understand the illness experience and behaviour of people living with Buruli Ulcer (BU).
- The researcher has explained to my satisfaction the purpose of the study and the possible risk involved.
- I have had the principles and procedures explained to me in Akan as well as the information sheet. I understand the principles and procedures fully.
- I am aware that I will be required to take part in an interview which will be tape-recorded.
- I understand that any confidential information will be seen only by the researcher and will not be revealed to any one else.
- I understand that I am free to withdraw from the investigation at any time.
- The researcher has provided me the full address and telephone numbers of the following personalities who I can contact at any time:

Dr. Edwin Ampadu

(Local supervisor of the research),

Director, Ghana Buruli Ulcer Control Programme,

Accra.

Tel 0302686336/7

Mr Joseph Adomako,

Director of Health Services,

P. O. Box 1,

Manso Nkwanta.

Tel 0322097732.

Signed/ Thumbprint .....

Date .....

Signature of researcher .....

Date and time .....

## **APPENDIX SIX: INTERVIEW GUIDE (PILOT INTERVIEW)**

Brief introduction as a way of breaking the ice.

Introduce the topic by giving the rationale for the research.

Set ground rules for the discussion.

Let respondents give brief introduction of themselves before the diagnosis of BU –

Family, job(s), relations, social lives etc.

Explore how BU was first diagnosed and their immediate reaction - how, when, where, etc.

Discuss with respondents if they had heard of the condition prior to the diagnosis. If so explore why they did not seek early medical intervention? Explore if they had sought treatment from other sources other than Western orthodox medicine and their reasons for these. Do they still rely on these?

Explore how they decided to seek medical intervention; how long did it take them to do this? Explore their experience as patients at the hospital: encourage them to remember as much as they can; how they felt when diagnosis was confirmed, how the information was relayed to them, when they were told of the possibility of amputation/ surgery and the possible consequences of disfigurement. How were they prepared for these. Any help from the hospital such as counselling prior to the surgery?

Any emotional/psychological support from family, the hospital etc. the daily dressings of the wound, their lives as patients in general etc. EXPLORE!

Explore quality of life issues: the effect of their skin condition on their social life, relations, jobs, and the effect of being unemployed, education (explore), activities of daily living (explore) and how these affect them emotionally, mentally and psychologically, the effects of the use of prostheses, etc. Administer the DLQI tool.

Discuss issues of body image and disfigurement and how these have affected their self esteem. Their coping strategies (explore personal and any assistance from the hospital etc)

Effect of BU on their health in general. Any special moments of feeling lonely and how they overcame that etc. Explore if the condition has brought about any other illness and how they dealt with these. Explore any health-related concerns.

Discuss what they say their social, psychological, spiritual, educational support needs are. Explore which of these (in their view) have been met: how, when, who, etc. Explore which have not been met and how they think these can be met.

## APPENDIX SEVEN: REVISED INTERVIEW GUIDE

Themes emerging

A, Reasons for seeking treatment late include

1, Cost of going to hospital, 2 parents had to make the decision, 3 spiritual intervention first via deities, *Mallams*, spiritualists etc. 4 Local herbs were thought to be reliable for all skin diseases, 5 Local clinic will give you same medicines a dispenser will give you.

Explore the following:

1 What costs are involved in going to hospital? If in monetary terms find out sources of income of the main bread winner at the time of the disease. Explore other direct and indirect costs – cost of the anticipated operation/surgery, other costs such as the carer, feeding at the hospital, accommodation and other indirect costs.

2 Explore if the parents were the decision makers how were they involved in the final decision. What about their beliefs and the use of herbs/traditional medicine. Weigh cost and beliefs and find out which was the motivating factor.

3 Explore why so much reliance on dispensers at the expense of trained health care professionals at the clinic, and who are these dispensers, what training have they have and how do the respondents see them?. Find out where they are and seek the views of dispensers, *Mallams*, traditional healers and spiritualists. Let the parents clarify these if possible if they are available.

B Preparing to the hospital

1, What made them decide to seek medical intervention? Explore how long the decision-making took and who eventually took the decision. How did they go to the hospital? How were they received at the hospital – the staff reaction seeing such extensive wounds.

Explore how they would describe their over all health prior to going to the hospital. Explore any anxieties expectations and life at the hospital in general with their carers. Explore how their carers felt if they were to stay for more than anticipated. Explore direct and indirect

costs incurred as much as possible and how treatment was financed. Any personal difficulties they will share with me with their lives at the hospital. EXPLORE everything about their lives as in-patients.

#### C, Preparing to leave the hospital/ Home coming

Explore how prepared they were prior to discharge. Any difficulties and/or concerns regarding home-coming. Any problems integrating into their communities following the surgery. Explore how they dealt with dressing their wounds if they were not completely healed. Explore if they have had any recurrence and how often. Explore if following discharge they continued with their health seeking behaviours i.e traditional healers, dispensers or any other forms or relied on the clinic/ hospital and explore any reasons.

#### D, Consequences of the surgery/ treatment

Explore any consequences from close relations, school, the general public eg. stigma and what form it took. Explore how they dealt with any form of stigma. EXPLORE in detail the effects of BU on their health and life generally.

E, The DLQI questionnaire: compare the consequences described in D above. Explore QOL and HRQOL issues as much as possible.

F How did they cope bearing in mind Akan culture? Explore their coping strategies and how they adjust to life with disfigurement.

G Any support/help they think they need? Where they think these support will come from and explore if any of these have been met – who, how were these met?

H Go back to pilot interview guide and check if there are issues which need revisiting and explore.



## **APPENDIX EIGHT: DISCUSSION GUIDE – FOCUS GROUP INTERVIEW**

Focus group discussion with the professionals will cover issues such as:

i, their experiences with BU in general: knowledge of the disease from their own experience and that from the literature.

ii, Explore issues of myth and whether in their view the disease is contagious or not.

iii, Explore their relationships with traditional healers, the use of herbs as well as over the counter medication and treatment by 'dispensers'.

iv, Discuss and explore any training they have had post- registration following the outbreak of BU.

v, Discuss and explore their role as professionals in education and health promotion and prevention activities with regard to the disease.

vi, Discuss their relationship with BU patients when they are in hospital – the care given, their reaction when BU has been confirmed and explore how discharge and follow-up are planned for BU patients.

vii, Explore any concerns they have about people living with the condition in the communities.

viii, Allow the group to discuss what they feel the needs of BU patients are, and the needs of people living with the condition (explain the difference).

ix, Explore their knowledge on government policies of Buruli ulcer at the time and now.

x, Allow them to discuss any other issues they feel relevant.

**APPENDIX 9**

**CORRESPONDENCE RELATING TO ETHICAL APPROVAL.**

## APPENDIX TEN: THEORETICAL CODES AND HYPOTHESIS- THE BASIS OF THE GROUNDED THEORY

### The Principal categories and corresponding hypotheses which formed the basis of the Grounded

- **Core category: *My needs matter*** provides the **context** for dealing with the respondents experiences.
- ***Delayed treatment***: *Delayed treatment* is the **cause** of the psychosocial condition of *Reliving the trauma of my ulcer*.

#### **Hypothesis**

*Reliving the trauma of my ulcer* which led to the core category of *My needs matter* was driven by the delay in receiving appropriate treatment as a result of *Nondisclosure* and *Delayed Diagnosis* by the respondents' and the health professionals respectively.

- ***Quality of life as a Mirage***: Quality of life as a Mirage is the **consequence** of the psychosocial condition of *Reliving the trauma of my ulcer*.

#### **Hypothesis**

*Reliving the trauma of my ulcer* may lead to quality of life being seen as a mirage (an illusion or something they cannot reach in life) to the respondents. These **consequences** are both physical/ biological (example shown by the loss of *physical bodily organs*) and psychosocial (such as loss of recreation, loss of loved ones, loss of income).

- ***Seeking to be myself***: *Seeking to be myself* is the **strategy** to manage or contain the psychosocial condition of *Reliving the trauma of my ulcer*.

#### **Hypothesis**

The psychosocial problem of *Reliving the trauma of my ulcer* requires strategies by people living with Buruli ulcer to deal with it.

**APPENDIX 11**

**TREATMENT DATA**

**APPENDIX TWELVE: CORE CATEGORY, PRINCIPAL CATEGORIES AND THEIR PROPERTIES AND SUB-PROPERTIES.**



