

Health-Related Quality of Life among Persons Living with Buruli Ulcer in Amasaman Community, Ga West District Accra, Ghana

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Abstract:

Objectives: This cross-sectional study compared the health-related quality of life (HRQoL) of individuals with Buruli ulcer (Focus group) and age-matched apparently healthy peers without the ulcer (Control group) living in Amasaman in the Ga West District, Ghana. Gender pattern in the Health-Related Quality of Life of the Focus group was also investigated.

Methodology: Participants comprised of consecutively recruited 84 Focus and 100 Control group subjects. Socio-demographics of all participants and the clinical profile of Focus group subjects were obtained. The Nottingham Health Profile Questionnaire was used to measure the quality of life. Data was analysed using Mann-Whitney U statistic at 0.05 alpha.

Results: Focus group had significantly higher scores than Control in all the six (6) domains of the Nottingham Health Profile ($p < 0.05$); no significant difference was observed in the total health score of females compared to males in both the Focus and Control groups ($p > 0.05$).

Conclusion: The findings suggest that, Buruli Ulcer impact negatively on the Health-Related Quality of Life of the victims. Aside medical interventions, the quality of life as well as the socio-cultural and economic impacts of Buruli ulcer should be taken in cognizance while planning community-based rehabilitation programmes for those affected.

Keywords: Buruli Ulcer; Health-Related; Quality of Life

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Introduction

Buruli ulcer, caused by *Mycobacterium ulcerans*, is regarded as the third most common mycobacterial disease in immunocompetent people, after tuberculosis and leprosy.⁽¹⁾ The definitive description of *M. ulcerans* was first published in 1948, when MacCallum and co-workers reported six cases of an unusual skin infection in Australia.⁽²⁾ The name "Buruli Ulcer" or BU is consequent upon the Buruli region in Uganda, where superficial ulcerative lesions in Ugandan children were investigated in 1962. The BU has also been observed to be a significant public health problem in West Africa.⁽³⁾ The exact mode of transmission of Buruli ulcer is a mystery, although for many decades, proximity to marshes and wetlands created as a result of human environmental disturbance, is a risk factor for infection. This suggests that people who live in swampy areas of tropical countries become infected through minor wounds or skin abrasions that come in contact with the mycobacterium-infected water.⁽⁴⁾

Available information showed that, in some West African communities, up to 16% of the people were infected with BU.⁽⁵⁾ According to a 1995 report by Marston *et al.*⁽⁶⁾ approximately 15,000 cases had been reported in Cote D'Ivoire from 1978 while another study by Debacker *et al.*⁽⁶⁾ also reported that 1700 cases of BU were managed at the Centre Sanitaire et Nutritionnel Gbemoten, Zagnanado, Benin over a 5-year period (1997-2001). A national survey was conducted in Ghana during 1999 and found 6,000 cases showed Buruli ulcer that was endemic in all the 10 regions of the country.⁽⁸⁾ The overall national prevalence rate of active Buruli ulcer lesions was 20.7/100,000 of the population, although this was as high as 150.8/100,000 in some districts.⁽⁸⁾ The most affected Ghanaian regions were the Ashanti, Brong Ahafo, Central, Eastern, Western and Greater Accra. Some of the highly affected districts are Amansie West, Atwima, Ashanti Akyem North, Upper Denkyira, Tano, Asutifi, Asunafo, East Akyem and Ga Districts.⁽⁹⁾

Bar *et al.*⁽¹⁰⁾ proposed that untreated Buruli ulcer will eventually subside with the gradual development of host immunity in most cases. However, by this time, tissue damage may be very extensive and healing by scar can lead to permanent disability or poor aesthetic.

Specialized surgery, post-operative nursing care, and physiotherapy intervention are often required to shorten the course of the disease, minimize deformity and thus achieve good outcomes. The patient would nonetheless spend a significant time in a hospital or rehabilitation setting. For instance a review of 102 patients in Ghana indicated that the average length of hospital stay was more than 100 days; and the Buruli infection led to 10 amputations, 12 joints contractures and 2 deaths arising from complications such as tetanus and sepsis of the ulcer.⁽¹¹⁾ Such circumstances have economic implication which may be beyond the means of local health services in Ghana. Even in better economies like Australia with better access to health care, the cost and complexity of treating *M. ulcerans* infections was observed to be considerable.⁽¹²⁾ In Ghana, the average total cost of treatment per patient was 966.85; 706.08 and 658.74 American dollars in 1994, 1995 and 1996 respectively,⁽¹¹⁾ while Amofah *et al.*⁽⁸⁾ gave an estimated cost of US \$780 per patient. This is very crippling for the health budget of a low-income country with a per capita income of US\$434 according to a 2005 estimate by the European Union.⁽¹³⁾

The Global Buruli Ulcer Initiative (GBUI) established by the World Health Organisation has, since the emergence of the disease, carried out studies on Buruli ulcer in endemic areas in Africa, Asia, South America and the Western Pacific countries even though the precise existing distribution of the disease is not known.⁽¹⁾ However, a considerable proportion of the GBUI researches have focused entirely on the medical implications of this disease. This is in spite of the fact that, Buruli ulcer can have deleterious medical, psychological and socio-economic sequel for the patients and their families, thus affecting their overall quality of life.

Quality of life measures can generally be used as supplementary objective clinical or biological measures of disease to assess the quality of service, the need for health care, the effectiveness of interventions, and in cost utility analyses.⁽¹⁴⁾ Their use reflects a growing appreciation in the importance of how patients feel and how they are satisfied with treatment, in addition to the traditional focus on the disease outcomes. In this respect, the quality of life measures capture patient's perspectives

of their disease and treatment, their perceived need for health care, and their preferences for treatment and outcomes.

Management of BU, like many other such clinical conditions, can be made more comprehensive by taking into account the Health-Related Quality of Life (HRQoL) component of the disease so that appropriate interventions can be guided towards the total rehabilitation of the individuals afflicted by the disease. There is however a dearth of information on the health-related quality of life (HRQoL) of Buruli ulcer patients in Ghana. The following questions were answered in this cross-sectional survey: How does the HRQoL of patients who have Buruli ulcer compare with their counterparts without the disease living in the same community? Does the HRQoL of individuals who have Buruli ulcer follow a gender pattern?

Materials and Methods

Study Site:

The study site Amasaman community is the capital of Ga West District of the Greater Accra region, located about 20 Kilometer west of Accra, the capital city of Ghana. The District span is a land area of 692 Km² and has a population of 548,000 people.⁽¹⁵⁾ Majority of residents in this community are subsistence farmers. A Community Health Centre is situated in Amasaman and caters for all Buruli Ulcer patients in the Ga District and its surrounding communities.

Participants

One hundred and eighty four people comprising 84 individuals who have Buruli ulcer (Focus group) and 100 apparently healthy individuals without the disease (Control group) were included in this study. Their ages ranged between 3 and 60 years. To be eligible for participation, individuals in the Focus group were clinically diagnosed by a qualified medical practitioner to have Buruli Ulcer, and had been or were receiving treatment for the disease. Eligibility criteria for the Control group subjects include no history of Buruli ulceration with absence of any form of physical deformity.

In addition to the respective group's eligibility criteria, all participants had been resident in the Amasaman community for at least one year immediately prior to the time of

this survey and; did not have any past or present incidence of mental ailment or any other chronic or disabling conditions such as stroke and Parkinson's disease. Also excluded for recruitment into the Control group were apparently healthy family members of the Focus group participants because of the possibility of being psychologically affected by the condition of their relative and to avoid data contamination. The participants were all those who agreed to take part in this study over a period of five months that the recruitment lasted.

Instrument for Data Gathering

The Nottingham Health Profile (NHP) Questionnaire was the instrument used for measuring the health status of the subjects. This instrument was designed to give a brief indication of perceived physical, social and emotional health problems.⁽¹⁶⁾ It has 2 parts comprising part I which has thirty-eight (38) questions divided into six domains: Pain, (P), Emotional Reaction (ER), Sleep (S), Social Isolation (SI), Physical Abilities (PA) and Energy Level (EL) which are indications of a person's perceived Emotional, Social and Physical Health status, and part II which contains 7 items recording the effects of health problems on occupation, jobs around the house, personal relationships, social life, sex life, hobbies and holidays. Each section of the NHP is scaled from 0 (the worst HRQoL) to 100 (the best HRQoL). It is easy to administer and takes about ten minutes to complete.

The NHP was translated into the 2 commonly spoken Ghanaian languages in the study district, namely Twi and Ga, by language experts from the University of Ghana, Accra for ease of administration. Back translation into the original English version was carried out by a different language expert in order to ensure accuracy. The concurrent validity of the Twi and Ga versions with the original NHP was established before administering them on the 34 pants.

Procedure

This study design was approved by the Amasaman Hospital Ethics Committee and the Ga District Health Service Directorate.

Individuals who met the inclusion criteria were consecutively recruited from the Amasaman Health Centre and communities in

the District. Additional subjects were recruited from visits undertaken with the Amasaman Buruli ulcer management team in villages surrounding Amasaman. Control subjects were however consecutively recruited villages visited in the Ga District and also in the Amasaman Township itself. The procedure of the study was explained to each participant and their informed consent was obtained prior to participating. In the case of children, consent was obtained from their parents or guardians. Every individual approached for recruitment into the study agreed to participate in the survey.

The appropriate language version of the Nottingham Health Profile (NHP) was administered by an assessor who speaks, writes and reads fluently in English, Twi and Ga languages. Administration of the instrument was done on a one-on-one basis so as to prevent the participant's responses from being influenced by other people in the community and to also ensure the questionnaire is properly completed and returned. The assessor was blinded to the study outcome.

Data Analysis

Statistical analyses were carried out using the SPSS version 11. Results from qualitative variables were expressed in frequency percentages. Mann-Whitney U test was used to compare the NHP scores between the Focus and Control groups as well as between the male and female participants in each study group. Significance level was set at $p \leq 0.05$.

Results

Distribution of the 184 participants by gender showed a 1:1.02 male to female ratio for all participants. Socio-demographic profile of the participants is shown in Table 1. Both the Focus and Control group members had comparable socio-demographics.

The clinical profile of the Buruli ulcer disease as presented in Table 2 showed that, more than half of the Focus group participants have had an ulcerated lesion and 6 (7.1%) had developed contractures of soft tissue around the area of the lesion.

Comparison of health status between the Focus and Control groups (Table 3) revealed significantly higher sum of ranks for each of the six (6) domains of health status on the Nottingham Health Profile (NHP) in the Focus

group compared to the Control ($p \leq 0.05$). Tables 4 and 5 show the comparison of health status between male and female participants in the Focus and Control groups respectively. While only the sum of ranks for Sleep was significantly different with the females and record significantly higher values ($p = 0.03$) in the Focus group, a significantly higher score on the Social Isolation ($Z = 2.50$, $p = 0.01$) domain of the health status was obtained by the males in the Control group.

Discussion

In research studies involving human subjects, a problem frequently encountered is the unwillingness of eligible individuals to participate in the study. However in this survey, all individuals who were approached to participate and who met the inclusion criteria agreed to partake in the study. This could be a result of the involvement of the Amasaman Buruli ulcer management team in the recruitment of the participants.

The male to female ratio in the Focus group was 1:1, suggesting no gender pattern in the prevalence of the disease. This trend may be because women in the Amasaman community engage in occupation similar to their male counterparts and being at par with men in terms of economic activities makes them to be equally vulnerable to contracting the disease. An assertion based on the fact that, farming which is the main occupation of the inhabitants of the community exposes them to the disease.

Majority (77.4%) of the participants were within the age range 11 to 35 years, with more than one-third (35%) of the Focus group members aged below 15 years. This age distribution underscores the vulnerability of children living in this community to Buruli ulceration. Children in the rural Ghanaian communities more often than not go about their daily routines without appropriate clothing and footwear. This in addition to their less developed immunity places them at a greater risk of being afflicted with this kind of infectious disease. The gender and age pattern of the Focus group in this study is similar to earlier reports^(17, 18, 19) that found no difference in the prevalence of BU in males and females but reported higher prevalence of the disease among children below 15 years of age. This result however differed from other published

literatures that indicated a gender difference in the prevalence.^(7, 20) The disparity in trends of our result and the previous reports may be accounted by the differences in the socio-cultural environment where this and the previous studies were carried out. In addition, the study by Debacker *et al.*⁽⁷⁾ reported that, males were more at risk only in people over 59 years.

Three-quarters of the Focus group participants were unmarried; this could be because a significant proportion of them (36.95%) were below 15 years old, which makes them too young to get married. However, it is also probable that, the presence of Buruli ulcer especially the deforming type could have made them less desirable as marriage partners. It is of significant importance that, a considerable proportion of the participants especially the Focus group members had only up to the primary (elementary) level of education. Apart from the generally fewer education opportunities in the rural communities in many developing countries including Ghana, education for people with Buruli ulcer is truncated by the considerable amount of time spent on hospital admission which can be for surgery and other forms of treatment. Low academic qualifications of the victims, the physical constraints of the disease, and inadequate employment opportunities from governmental agencies and private companies may be the cause of low level of employment (about 60.7%) among the Focus group, compared to 49.0% among the Control group. Incidentally most of the jobs available in this rural community are labour intensive and few employers would be willing to employ "physically disabled" workers who may not be able to cope with the physical demands of such jobs. Moreover, majority of the Focus group members lost their jobs because of the physically disabling effect of the disease, as well as the usually long period of hospitalization. Factors such as a lesion on a joint, older age, female gender, a lesion on a distal part of an extremity and a persistent wound have been reported as independent risk factors for stopping work or education by Buruli ulcer patients.⁽²¹⁾

Frequency distribution by ulcerated body parts affected showed that, the upper limbs were most frequently affected (56%), followed

by the lower limbs (43%). This contrasts with a report by Debacker *et al.*⁽⁷⁾ which noted that, lower limbs were 3.2 times more frequently involved than the upper limbs in older patients. Hospers *et al.*⁽²²⁾ had also observed that, Buruli lesions on arms and legs showed a bilateral symmetrical distribution and if correction is made for differences in body surface area both upper and lower limbs are affected equally. However, another study by Asiedu *et al.*⁽¹⁹⁾ indicated that, right arms (upper limbs) lesions are common in children while left leg lesions (lower limbs) are common in adults. They also submitted that the left leg is most often exposed to weeds and grasses when farmers use cutlasses and children often grasp vegetation with their right hands. Thus high prevalence of Buruli ulcer infection on the upper limbs in this study can be explained by the fact that, a greater proportion of our participants were children below 15 years.

It was observed in this study that 85% of the participants have had surgical intervention within two years preceding this survey. This is an indication of the victims seeking medical attention at some stages of the disease. Recent increased attention to epidemiology of Buruli ulcer in Ghana has ensured that, health workers in the various districts conduct regular screening programmes in order to detect the disease before it ulcerates and causes more complications. This development would invariably reduce the menace of this disease in Ghana. Efficacy of such prompt intervention had been adduced to by Kanga *et al.*⁽²³⁾ who observed that surgical team missions carried out in health centers, early detection and treatment of cases together with the implementation of a specific poly-chemotherapy led to an effective control of the disease in Cote D'Ivoire. However, a significant proportion of the population may still fail to access prompt surgical intervention perhaps due to the dogmatic and societal beliefs about the disease. For instance it had been reported that the main factors Ghanaians believe to be the causes of Buruli ulcer are witchcraft and curses from ancestral spirits.⁽²⁴⁾ These researchers also noted that the delays in obtaining treatment were occasioned by financial difficulties, fear of the mutilating effect of the disease and social stigma.

The significantly higher scores for each of the six (6) domains of Health Status on the

Nottingham Health profile (NHP) recorded by the Focus group indicates that this group had lower health-related quality of life compared with the Control. Drummond and Butler⁽¹²⁾ had noted that severe skin ulceration from mycobacterium ulcerans can be associated with considerable illness. Specifically, the poor performance by the Focus group in the domain of Energy Level can be explained by the fact that Buruli ulcer forces the patients to rest. Physical activity of the Focus group participants was also low, attesting to the high morbidity they experienced. Inactivity that results from Buruli ulceration, associated pain and unavoidable rest after surgical interventions would cause disuse atrophy and muscle weakness. Combination of these factors would result in low functional activity and thus reduced Energy Level.

The higher Emotional Reaction and Social Isolation scores recorded in the Focus group could be explained by the pain they experience and the socio-cultural milieu in which the patients live. Pain as a clinical entity also has a psychological component and the presence of Buruli ulceration negatively impacts the psychological health of the afflicted and their emotional reaction. In addition, it is a common socio-cultural belief to attribute diseases of this kind to evil machinations and wrong doing on the part of the sufferer or his/her family.⁽²⁴⁾ These factors could precipitate low self-esteem in the BU victim and thus explain the reason for the higher Emotional Reaction and Social Isolation scores recorded in the Focus group.

There are a number of characteristics of current highly invasive surgical therapies for Buruli ulcer that can potentially cause dissatisfaction and reduce HRQoL. Among these are the necessity for a prolonged stay in the hospital for treatment, lifestyle limitations including restrictions on diets and physical activities and possible worry over an unhealed ulcer or limb deformities and outright mutilation of body parts. Thus, the physical and psychological demand of such therapy produces negative effects on patients' perceptions of their health-related quality of life irrespective of gender. It is therefore not odd that significant difference was observed in only one domain of the health status measure

(Sleep) between the males and females in the Focus group. High scores for sleep among the females could result from combined effect of their higher, albeit non-statistically significant, scores for pain and emotional reaction in the females. Distress associated with Buruli ulcer combined with the burden of the traditional role of women in home making including taking care of the children, cooking for the family and other household chores may negatively affect sleep function among females such that they get fewer hours of sleep. Social isolation recorded by the females in the Control group could be a reflection of the fact that generally in this, like most rural communities, men do a lot more social interacting than women. Higher scores in this NHP instrument indicate poor functions.

Conclusion

The outcome of this study suggests that, Buruli Ulcer exert negative influence on the Health-Related Quality of Life of the victims compared with their age-matched peers living in the same community. This was significantly more profound among the female individuals with buruli ulcer.

Recommendation

Based on the findings of this research work, it is recommended that apart from medical interventions, the quality of life as well as the socio-cultural and economic consequences of Buruli ulcer should be taken into cognizance while planning community-based rehabilitation programmes for those affected.

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Table 1: Socio-Demographic Profile of the Participants (N=184)

Variables	Focus Group		Control Group	
	n	%	n	%
Gender				
Male	42	50.0	49	49.0
Female	42	50.0	51	51.0
Marital Status				
Single	64	76.2	66	66.0
Married	12	14.3	26	26.0
Divorced	7	8.3	7	7.0
Widowed	1	1.2	1	1.0
Level of Education				
No Formal	18	21.4	13	13.0
Kindergarten	25	29.8	40	40.0
Elementary	38	45.2	35	35.0
Secondary	3	3.6	0	0.0
Tertiary	0	0.0	12	12.0
Type of Employment				
Self-employed	31	36.9	31	31.0
Unemployed	51	60.7	49	49.0
Government employed	1	1.2	14	14.0
Private sector	1	1.2	6	6.0
Age (years)				
0-5	5	5.9	2	2.0
6-10	11	13.1	12	12.0
11-15	15	17.9	19	19.0
16-20	22	26.2	15	15.0
21-25	11	13.1	18	18.0
26-30	6	7.1	11	11.0
31-35	3	3.6	8	8.0
36-40	3	3.6	2	2.0
41-45	0	0.0	3	3.0
46-50	2	2.4	5	5.0
51-55	3	3.6	3	3.0
56-60	3	3.6	2	2.0

Table 2: Clinical Profile on Participants with Buruli Ulcer (N=84)

Variables	n	%
Body Parts Affected		
Head and Neck	0	0.0
Trunk	1	1.2
Upper Limb (s)	47	55.9
Lower Limb (s)	36	42.9
Stage of the Disease		
Nodule	4	4.8
Pre-Ulcerative Lesion	14	16.7
Ulcerated Lesion	45	53.6
Healing and Healed	15	17.9
Contracture	6	7.1
Duration of Buruli Ulcer (Years)		
0-2	67	79.8
3-5	15	17.9
6-8	2	2.3
Family Members Afflicted		
No relative affected	73	86.9
Sister	4	4.8
Brother	3	3.6
Niece	1	1.2
Mother	1	1.2
Aunt	1	1.2
Granddaughter	1	1.2

Table 3: Comparison of Health Status between Focus and Control Participants Using Z Statistic (N=184)

Variables	Sum of Ranks	Z	p
Energy Level (EL)			
Focus (n=84)	10440	7.73	0.00*
Control (n=100)	6580		
Emotional Reaction (ER)			
Focus (n=84)	11152.5	9.41	0.00*
Control (n=100)	5867.5		
Pain (P)			
Focus (n=84)	10439	7.71	0.00*
Control (n=100)	6581		
Physical Activity (PA)			
Focus (n=84)	10977.5	9.23	0.00*
Control (n=100)	6042.5		
Sleep (S)			
Focus (n=84)	10094	6.99	0.00*
Control (n=100)	6742		
Social Isolation (SI)			
Focus (n=84)	10548.5	7.98	0.00*
Control (n=100)	6471.5		

Key: * = significantly z value at $p < 0.05$

Table 4: Comparison of Health Status between Male and Female Participants of the Focus Group Using Z Statistic (N=84)

Variables	Sum of Ranks	z	p
Energy Level (EL)			
Male (n=42)	1644	-1.28	0.20
Female (n=42)	1926		
Emotional Reaction (ER)			
Male (n=42)	1700	-0.76	0.45
Female (n=42)	1870		
Pain (P)			
Male (n=42)	1710	-0.67	0.49
Female (n=42)	1860		
Physical Activity (PA)			
Male (n=42)	1686	-0.90	0.37
Female (n=42)	1884		
Sleep (S)			
Male (n=42)	1533.5	-2.11	0.03*
Female (n=42)	1952.5		
Social Isolation (SI)			
Male (n=42)	1852	0.60	0.55
Female (n=42)	1718		
Total Health Status			
Male (n=42)	1653	-1.18	0.24
Female (n=42)	1917		

Key: * = significantly z value at $p < 0.05$

Table 5: Comparison of Health Status between Male and Female Participants of the Control Group Using Z Statistic (N=100)

Variables	Sum of Ranks	z	p
Energy Level (EL)			
Male (n=49)	2759	2.35	0.19
Female (n=51)	2291		
Emotional Reaction (ER)			
Male (n=49)	2491.5	0.12	0.91
Female (n=51)	2558.5		
Pain (P)			
Male (n=49)	2361.5	-0.94	0.35
Female (n=51)	2688.5		
Physical Activity (PA)			
Male (n=49)	2360.5	-0.96	0.34
Female (n=51)	2689.5		
Sleep (S)			
Male (n=49)	2292	-1.33	0.18
Female (n=51)	2758		
Social Isolation (SI)			
Male (n=49)	2786	2.50	0.01*
Female (n=51)	2264		
Total Health Status			
Male (n=49)	2599	0.86	0.39
Female (n=51)	2451		

Key: * = significantly z value at $p < 0.05$

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