

Perceptions and Attitudes: The Challenge of Managing Buruli Ulcer Morbidity in Ghana

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Abstract: Although literature is replete on the possible causes of Buruli ulcer (BU), no one is sure where the bacterium lives in the environment. It is also a mystery how the mycobacterium enters the human body, though it is clear the bacterium is unable to do so by itself. Patients have therefore developed wrong perceptions and attitudes on the disease epidemiology and this has become a challenge to the management and intervention strategies put in place by health experts. The aim of this paper is therefore to highlight some of the wrong perceptions surrounding the disease and discuss some of the possible predisposing factors that affect its transmission and spread in the Amansie West District of Ghana. Using basically qualitative approach, the paper argues that managing the Buruli ulcer disease has been daunting because the strong local beliefs which also affects the choice of treatment by patients. The paper concludes that despite the wrong perception, the disease causing organism thrives well in arsenic rich aquatic environment. Any attempt to manage the disease therefore must first target the wrong perceptions and attitudes, in order to manage the reality.

Keywords: Buruli ulcer, morbidity, myth, reality, Mycobacterium ulcerans

Introduction

One of the neglected tropical diseases rapidly challenging health care delivery in rural Ghana is Buruli ulcer. Buruli ulcer, a disease caused by Mycobacterium ulcerans has since 1980 emerged as an important cause of human suffering (van der Werf et al., 1999). It destroys the skin's underlying tissues and causes deformities. Lesions occur mainly in the limbs (Asiedu and Portaels, 2000). Buruli ulcer is the third most common mycobacterial infection in healthy people after tuberculosis and leprosy and the most poorly understood of the three diseases (Josse' et al., 1995). The World Health Organization reports that the total Buruli Ulcer cases recorded globally in 2012 including that of Ghana was 5,076 with Africa being the worst affected region. Ghana is the second most endemic country after Cote d'Ivoire globally, (WHO, 2012). The overall National prevalence is

22.7 cases per every 100,000 inhabitants. Amofah et al., (2002), reports that cases of the disease have been reported in all the ten regions of the country with the Ashanti Region accounting for over 60% of all cases. The most affected district of the Ashanti Region is the Amansie West with a prevalence of 151 cases per 100,000 inhabitants.

Buruli ulcer is characterized by a painless nodule, plaque, oedema and ulceratives forms which at times involves the bones. It normally starts of as a painless non-ulcerative form, if left unattended, it develops into the ulcerative form with undermined skin edges which is normally painful and the affected part of the skin tissue is completely destroyed. If immediate action is not taken, it may affect the bone (MOH, 2004). Buruli ulcer involving infection of the bone leads to osteomyelitis, see plate 1B.



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(A) ULCERATIVE STAGE



(B) OSTEOMYELITIS STAGE



Plate 1 Clinical Manifestation of Buruli ulcer (Picture Credit, WHO)

Despite the fact that the most vulnerable to infection in the Amansie West District are women and children whose daily income is less than one dollar a day and the debilitating effect it can have on patients, the disease has lost profile in public health hence making it difficult to attract donor support (Asiedu and Etuaful 1998). There are uncertainties about where the mycobacterium lives in the environment and how the mycobacterium enters the human body. This makes the Management of Buruli ulcer to be frustrating and often unrewarding. The chronic and often recurrent nature of the ulcer makes it expensive to manage, both for the patient and the health service providers (Aujoutlat et al., 2003). In the absence of an effective drug treatment of the disease, the need for the development of preventive and control strategies has become even more paramount. Health education at present has been the focus. Health education over the years has focused on early identification and reporting, avoidance of contact with marshy environment, and the fact that community members should desist from using polluted water bodies, (MOH, 2001). The educational drives have not proved to achieve the desired results because of the local perceptions attached to the

disease by patients. It is therefore imperative that a research of this nature is conducted to highlight some of the local beliefs surrounding the causes and also discuss some of the real predisposing factors that affect the transmission and spread of the disease in Ghana using experiences from the Amansie West District.

Methodology

2.1 Study setting

The Amansie West District, with Manso – Nkwanta as the district capital, is located in the south western part of the Ashanti Region of Ghana. The district was carved out of the Amansie East District in 1989 as part of the government’s decentralization policy. It shares common boundaries with the Atwima District in the west, Bosomtwe District on its northern part while a regional boundary separates it from the Western Region in its southern-most part. The district falls within latitude 6.05°N and 6.35°N and 1.40° and 2.05°W covering an area of about one thousand three hundred square kilometres.

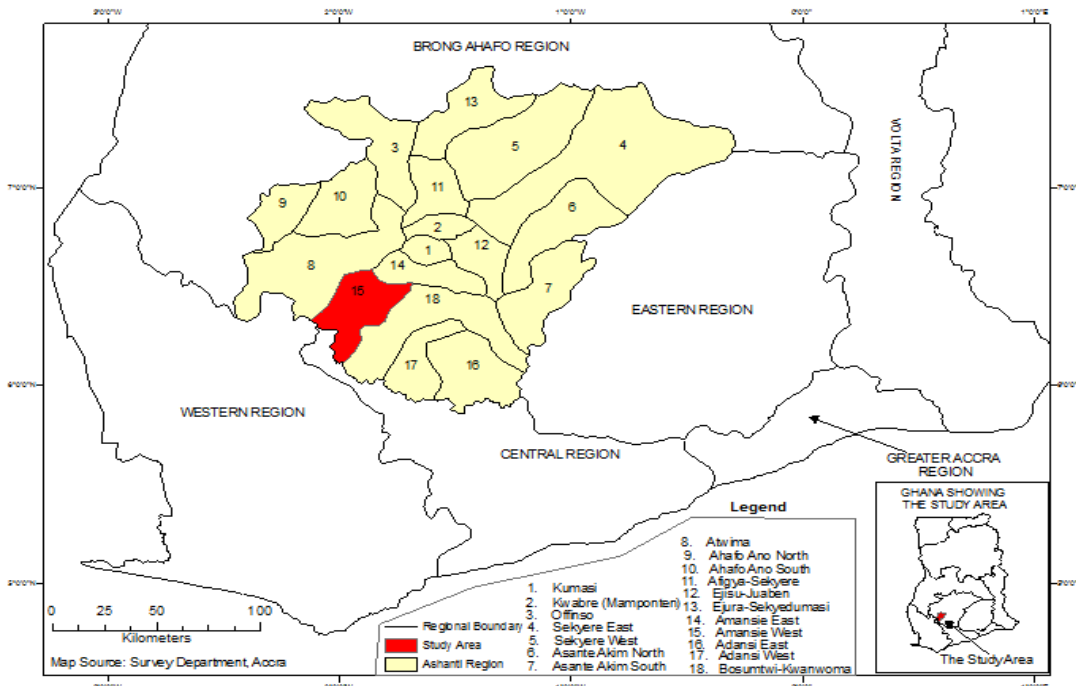


Figure 1 Map of the Amansie West District

The topography of the district is generally undulating with an elevation of about 210 metres above sea level. The most prominent feature is the range of hills which stretches across the north-western part of the district especially around Manso Nkwanta, the district capital. These ranges have an elevation of between 560-630 metres above sea level. The district is drained by the Oda and Offin rivers in the north with their tributaries such as the Pumpin, Emuuna and Jeni. These rivers have however, been polluted by numerous mining activities in the district. The climate of the district is the west semi-equatorial type, with mean monthly temperature of about 26°C. The months March and April are the hottest just before the onset of the rainy season. The District is underlain by Lower Proterozoic volcanic greenstones with intervening sedimentary rocks and granitoid intrusions (Robb et al., 1999). The main soil type of the district is ferric fluvisols.

2.1 Sampling Technique

A systematic sampling technique was used. A lottery method was first used to select the number '5' as the sampling interval from the admission and discharge book. Based on an average admission of 340 cases, a sample size of 185 comprising of both males and females of all ages were selected using the following statistical formula.

$$N = \frac{Z^2 p q}{d^2} \quad \text{where,}$$

N = The desired sample size (when population is greater than 10,000)

Z = The reliability co-efficient for 95% confidence level set at 1.96

2.2 Study Population

The study was done in the Amansie West District. Specifically, data for the study was obtained from the Buruli ulcer control unit (BUCU) of the St Martins' Hospital at Agroyesum, one of the specialized hospitals for BU treatment in the Ashanti Region. The study population consisted of medically diagnosed Buruli ulcer patients whose disease had reached the ulcerative stage. Data was collected using in-depth interviews with the help of a guide (questionnaires) consisting of both closed and open-ended questions. The questions covered all study variables in a form of a check-list and this was administered by the researchers and research assistants. The study focused on the perception of the cause of the disease and the preferred choice of treatment.

P = Proportion of babies who die

q = 1 - P = 86.0% or 0.86

d = Degree of freedom

$$N = \frac{Z^2 p q}{d^2}$$

$$= \frac{1.96^2 \times (0.14) \times (0.86)}{0.05^2}$$

$$= \frac{3.842 \times 0.116}{0.0025}$$

$$= \frac{0.4625}{0.0025} = 185$$

Therefore sample size = 185

Regular verification and validation of data were done with all inconsistencies being checked and resolved with the researchers, research assistants and the data entry clerk.

The study used both primary and secondary data sources. As a starting point, there was a review of the available literature on the disease. This was followed by in-depth interviews with health officials who are responsible for the treatment and management of Buruli ulcer. They included Doctors, nurses, laboratory assistance and ward assistance. The interviews covered themes on their general roles in managing the disease as well as their detailed knowledge about the disease. Additionally, the study used focus group discussions (FGDs) as its primary data collection technique to solicit information from the Buruli ulcer patients and their relatives. This approach is deemed appropriate when the object of the research is to explore attitudes or reactions of a group or community in response to some commonly experienced aspects of their environment (Ulin et al., 2005). Through such interactive discourse, participants are able to offer insights on the perspective of the community, revealing clues to the social contexts that shape their opinions (Scammell et al., 2009). Each focus group had six participants composed of men and women. Issues discussed during the FGDs included the question of perception of the cause of the disease, the preferred choice of treatment and management, their perception about negative and possible impacts of the disease, and recommendations for improvements. All the

proceedings, which were mainly in the local language, were recorded and later transcribed, analyzed and organized around the key themes.

Results and Discussions

3.1 Perceptions and Attitudes

The success of any initiative to deal with health problems very much depends on recognition and health seeking behavior of the people affected as it is often said that perceptions mould people's reactions to the world around them. Individual health actions need to be considered within the specific socio-cultural belief models which orient local definitions of health and illness (van de Graaf, 1997). The importance of understanding the determinants of environmental risk perceptions has been emphasized by a number of authors (Asiedu et al 2000). This concern, according to WHO (2012), is partly the outcome of a shift away from top-down approaches to development toward more community based interventions. The community's understanding and perceptions on the cause of a phenomenon is influenced by their level of education. Education is a means of social change and helps in changing ones perception about the occurrence of a phenomenon. For this reason, it is always important to find out the level of education, if ones intention is to explore the attitudes and perception of society on issues related to health and development. On the score of this, respondents were asked the last level of education they attained before the infection, see figure (3.1).

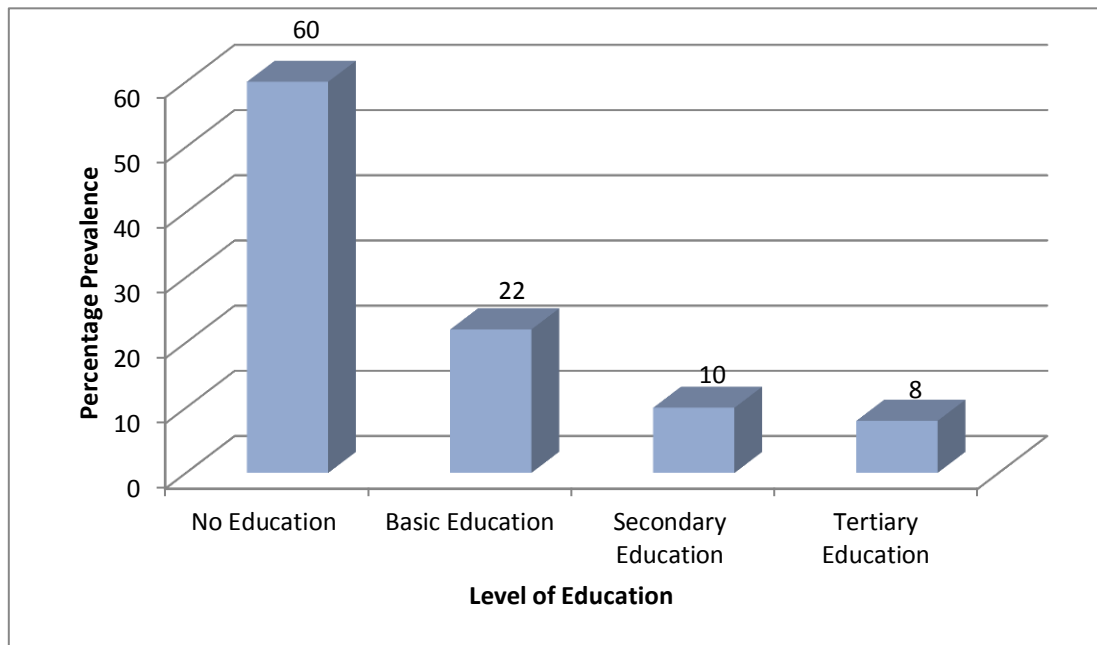


Figure 3.1 Patients level of Education (%)

Out of the 185 respondents covered in the study 60% had never had any form of education, 22% had basic education, 10% had only reached Secondary Education Level and 8% tertiary level when the disease occurred. According to those without any form of education, they were infected at an early age of their lives and therefore lost the opportunity to enter school for the first time. Again, the magnitude of the deformity could not allow them to go to school as they feared being stigmatized. But the possibility of attaining any level of education was still in doubt as the level and severity of infection was too high. Some patients for example had either both or one hand amputated as well as their faces disfigured. It is also important to note that a greater part of those without any level of education (33.4%) belong to the

male sex. Perhaps their closeness to their fathers whose activities were directly related to the environment might be a point to consider. If one considers the fact 60% had no education and the highest level of education for 22% was at the basic level then, it is no exaggeration concluding that the disease could have a profound effect on education in the district. There was a relationship between the level education and perceived causes of the disease, see table 3.1. Furthermore, the research showed that there was an inverse relationship between perceived cause of the disease and level of education as evidenced in table 3.1. Patients with secondary and tertiary level of education could link the disease to the environment than their uneducated counterparts.

Level of Education	Causes of Buruli ulcer				Total
	witch craft	curse from gods	no idea	from the environment	
No education	45	40	10	5	100
Basic education	15	45	8	32	100
Sec education	12	40	6	42	100
Tertiary education	1	20	0	69	100

Table 3.1 Cause of Buruli ulcer by Patients level of Education (%)

The question on the perception of causes of BU was posed to patients and members in their household. The study found out that 85% attributed the causes to witch craft and curse from the gods of the land. These respondents had no formal education as indicated in table 3.1. They believe that the patients might have incurred the displeasure of the gods or they are paying for the wrong committed by their fore fathers. 10% had no idea of the epidemiology of the disease. Only 5% of respondents with no education could link the disease to aquatic environment. This revealing trend obviously shows that the numerous public educations to explain the causes of the disease have not achieved their target. This wrong public perception is one of the reasons why many patients do not seek early treatment and only report for medical treatment at the ulcerative stage where it becomes expensive and difficult to treat. It is therefore important that this bad public perception is corrected in order to reduce the rate of spread of the disease in the community.

Risk to health, as an area of study, have begun to receive attention in developing countries (WHO, 2004), and social science theories and empirical data on perceptions of environmental risk focused almost exclusively on factors related to frequently occurring disagreements between the lay population and technical experts. In other words, when assessing the risks, experts place emphasis on quantitative data, whereas citizens are much more likely to base their opinions on qualitative aspects, such as the nature and origin of the threat to which they are exposed, usually involuntarily. To this end, a focus group discussion was organized to qualitatively engage the views of the respondents on the causes of the disease. One infected woman had this to say:

“I do not understand how I got the disease because

none of my family members have it even though we live in the same house, drink water from the same source and virtually share everything in common. Because am the only person infected, the family believe that it is the work of the evil spirit”.

This assertion was generally agreed by all respondents. In a related development a 34 year old male infected person also had this to say:

“I certainly believed that it is the work of the supernatural forces, my late grandfather told me that there was once a popular fetish priest in this village who wanted to marry my mother but our family members objected. The fetish priest cursed our family; it is believed that my sickness is the result”.

The responses from the focus group discussions (FGD) are indications of the poorer understanding of the epidemiology of the disease. This dearth of understanding is a problem as it leads to stigmatization, social exclusion and lack of social integration. In some cases, its impact disproportionately affects girls and women, whose marriage prospects may diminish or who may be left vulnerable.

Again, the lack of proper understanding of the cause of BU also influenced the treatment option sought by patients. The choice of treatment also varied across respondents’ level of education. Respondents with higher level of education preferred seeking treatment from health facilities whereas respondents with lower level of education sought solace in indigenous sources such as faith healers, herbal concoction and self-medication, see table 3.2. This is due to their lack of appreciation and believes in scientific principles. The level of education eventually had adverse consequences on control and prevention programs that were being run.

Level of Education	Choice of Treatment				
	Faith healers	Herbal concoctions	Self medication	Health facility	Total
No education	43	42	9	6	100
Basic education	12	47	10	31	100
Sec education	10	42	7	44	100
Tertiary education	2	22	0	66	100

Table 3.2 Choice Of Treatment By Patients Level Of Education (%)

The research revealed that about 43% of respondents depended on faith healers who were mostly pastors of faith based churches, 42% said they use herbal concoction and 9% could not be specific as they were on self-medication. This means that over 90% of respondents do not seek treatment from health facilities. This figure correspond to the over 85% who blamed the cause of the disease to magico-spiritual factors. The implication here is that the perception of cause influences the treatment sought by the infected. For this reason, it is important that any attempt to encourage early report and treatment should first focus on working on their perception. These findings corroborates earlier studies in the Ga South District of the Greater Accra Region which found lower incidence of Buruli ulcer among educated respondents than respondents with no formal education (MOH, 2005). This is because educated people are more likely to practice good hygiene and adhere to the principles and tenets of the educational campaigns.

The wrong perception surrounding the cause also led to serious stigmatization as patients were regarded as unclean. Stigma is the reaction of society towards people with certain characteristics (for example, a deformity or an ulcer) which are perceived as abnormal and undesirable; the result is that such people are deprived of the same social inclusion and human right as are enjoyed by others. Fear, devaluation, and social inequality were a response to the physical deformities and scars that remain after medical and surgical treatment of the disease. These physical signs visually mark and depart the individual from societal standards of beauty. The patients were ashamed of their scars and tried to hide them because they really felt embarrassed about it. The social consequence of scarring and disability associated with Buruli ulcer also reduced patientsd opportunities of marriage and employment, the research revealed. They also contended that a non-verbal cue such as facial expression and gestures from non-patients also led to the lowering of patients' social status. The deformities also led many to believe that the patients were unable to participate in economic activities, normal family, educational, and community life. These people were viewed as a burden to themselves, their families, and their community. In a focus group discussion, one woman had this to say:

“My husband has divorced me because his family believes that there is witchcraft in my family that is why I am suffering from the diseases”.

Another focus group discussion was carried out to investigate the extent of stigmatization in the communities under study. A middle aged woman at Tontokrom had this to say:

“I have been ejected from my room in the family house that I use to occupy because they think my ulcer is as a result of the activities of the witchcraft”.

All sorts of bad names are given and in the event, one may voluntarily vacate the community for fear of being stigmatized. This therefore leads to psychological stress in the patients, as they most often feel embarrassed.

Another woman at Edubea recounted how she is frowned upon by members in the family. This is what she said:

“Anytime I visit the riverside to fetch water, am not allowed closer because they believe my ulcer is as result of punishment by the gods. My family members say that the infected portion is where the witches pound their fufu in the night”.

This perhaps explains why more public education needs to be carried out. A class six (6) pupil intimated that ever since she contracted the disease, she has always be the subject of discussion among her friends:

“Some will not even play with me. They refuse every offer I give to them because they believe they will be infected by coming into close contact with me. I therefore remain in the class room during break time”.

This in part is one of the reasons why most children stop going to school when they are infected.

The psychological trauma associated with the disease leads much to be desired. This was manifested at Agroyesum, one of the endemic communities in the district. An elderly infected man was so psychologically traumatized that he felt reluctant to speak to the researcher at the first approach. He however changed his position upon persistent counseling by the researcher and his assistant. This is what he said:

“I am so embarrassed that I wish the world came to the end today”. My family

members believe I am a wizard and therefore the disease is the consequences of the activities of witch practice. I am sometimes denied food as a punishment”.

For this reason he felt no need to come out and go through this psychological trauma again. This stigma creates social and economic difficulties. Overcoming stigma is an essential step to the integration of people affected by BU within the general health services and to restoring normal relationships

3.2 The Reality

Analysis of the content of the various educational programs suggests that the occurrence of the disease is largely a consequence of environmental changes. Among other things, the basic mantra in the campaign as curled from the Ministry of Health document, 2001 is “early identification and reporting, avoidance of contact with marshy environment, and desist from using polluted water bodies” (MOH, 2001). In an interview with the director of the disease control unit of the Amansie West District, he had this to say:

“We selected this mantra because various studies, whether in Ghana or elsewhere, by reputed international scientific medical research centers and respected academics have confirmed that the mycobacterium lives in aquatic environment that has been disturbed through Mining, Dam construction or Agricultural activity”.

It is imperative at this point to present some of the existing literature that confirms the above assertion. Veitch *et al* (1997) reporting a large outbreak of the disease on Philips Island, Australia associated the source of infection to an irrigation dam which lay in the midst of the cluster of cases. The number of cases reported from the community reduced after the irrigation site was modified and limited from the public. Scot *et al*, (2004) noted that cases of Buruli ulcer are associated with tropical wetlands of West and Central Africa, and cases have increased rapidly in these areas since the 1980's, particularly after irrigation and dam construction. Travis (1999) also noted that people living near slow-running waters were more likely to contract the disfiguring disease. Merit *et al*, (2004) also reported the re-emergence of the disease among people who live/or work close to wetlands, especially slow-flowing (riverine) or stagnant water bodies (marshes, swamps), often created as a result of some form of human environmental disturbances. Bayley (1971) reported

cases of the disease along the tributaries of Densu River in the Ga North District of Ghana. James *et al* (2003) in Benin also identified three risk areas according to origin of patients reporting at hospitals with Buruli ulcer and noted that most of them were coming from Laguna areas of coastal Benin, marshy inland areas where market crops and rice are cultivated, and river valley areas.

Apart from associating aquatic environment with BU infection, it has also been observed by (Smedley *et al.*, 1996) that high levels of Arsenic (As) concentrations prevail in such environment and this could cause BU occurrence to increase. The Amansie West District, which accounts for most of the BU cases in Ghana, happens to have the highest levels of (As), possibly released into rivers, lakes and ground water by intensive gold mining and agricultural activities (MOH 2001). This is supported by the studies of Duker which revealed that the arsenic levels of gold bearing soils could have influence on the growth of Mycobacterium and this may contribute to the spread of (BU Duker *et al.*, 2006). Again, Duker concluded arsenic may play a vital role in the spatial distribution of BU. This region has large patches of arsenic risk and may be related to BU disease (Duker *et al*, 2006). The arsenic levels are very high at the basin of the two main rivers, the Oda and Offin. This is where artisanal mining activities are on ascendency.

Human activities in the Amansie West District have elevated arsenic contamination in the environment (Bell, 1998). High levels of arsenic in drinking water have been detected in most parts of the district, with concentrations frequently exceeding the World Health Organization guideline contaminant level (MCL) of 10 µg/L (Smedley *et al.*, 2002). Some of the human activities that have adversely affected the environment are mining, waste disposal, indiscriminate use of fertilizers, pesticides, herbicides, manufacturing and chemical spillage. A similar report was made by Jahan *et al.* (2002) that in the state of Victoria (Australia), mining of gold had caused an estimated 30,000 tones of arsenic to be redistributed to the surface across the landscape through erosion into streams and rivers. Hence, arsenic accumulates in soil contaminates both surface water and groundwater which is taken up by plants and is then entrenched in mammalian/insectivore food chain (Green *et al.*, 2001).

Conclusion

The research has revealed that despite the progress registered in recent years in research and public education on the possible cause of the disease, major gaps still remain unabridged. The reservoirs of *Mycobacterium ulcerans*, its mode of transmission to humans and immune-pathogenesis are still poorly understood. Currently, there is still a wide perception among patients that the disease is cursed by supernatural powers. This wrong perception has therefore rendered many intervention policies ineffective. Patients therefore do not seek the right treatment from medical experts and where they do, they still supplement that effort with local concoctions. The paper concludes that any effort towards the effective management of the disease must first target working on the perceive “myths” if

that management option is to enjoy massive public acceptance. Such education as role play, sketches using the local language should be encouraged. It is also important that the local and most common means of communication which represents the culture and aspirations of the people is used. Finally, the consistencies of such educational programmes are important. This is because the frequency with which information is carried across helps in shaping and changing peoples’ attitude on an event. It is only when this is done that the reality can be achieved. Again there is the need for health authorities to intensify control activities and accelerate research. Basic research is needed to understand the biology and epidemiology of the causative agent of this emerging disease so that the missing epidemiological links necessary to unravel the mysteries of this emerging disease can be achieved.

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