

Psychosocial aspects of health seeking behaviours of patients with Buruli ulcer in southern Benin

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Summary

We investigated cultural beliefs and psychosocial factors associated with Buruli ulcer in southern Benin in order to elaborate and deliver appropriate health education messages. We conducted a qualitative study among 130 adults and 30 children in Zou province, a highly endemic region. Focus group interviews of inhabitants, patients and their assistants, health care professionals and traditional healers took place in Dasso, Ouinhi, Sagon and Zagnanado. Drawing sessions followed by individual interviews were organized among school children in Dasso and Sagon. We found that although Buruli ulcer is well known and recognized – even at a very early stage of the disease – and perceived as threatening, most people are reluctant to seek treatment at the health care centre. They are unclear about the origin of the disease (environmental factors or sorcery) and treatment is considered devastating, expensive and ineffective in some cases.

keywords Buruli ulcer, Benin, prevention, health education, beliefs, perceptions, psychosocial aspects

Introduction

Mycobacterium ulcerans infection, also known as Buruli ulcer, is the third most frequent mycobacterial disease in humans after tuberculosis and leprosy. The causative agent, *M. ulcerans*, was first described by MacCallum (1948), and over the past decade has emerged as an increasingly important cause of morbidity worldwide (Portaels *et al.* 2001). Little is known about the global burden of the disease, as nearly all available data come from passive case-finding and are therefore underestimates of true prevalence rates (Hayman & Asiedu 2000). In Côte d'Ivoire, approximately 15 000 cases have been recorded since 1978, and up to 16% of the population in some villages are affected. In Ghana, 6000 cases were recorded in a national survey in 1999, and up to 22% of the villagers are affected in some areas. In Benin, 4000 cases have been recorded since 1989 (WHO 2001).

Trauma is probably the most frequent means by which *M. ulcerans* is introduced deep into the skin or subcutaneous tissue (Meyers *et al.* 1974), where a toxin is produced, causing massive necrosis of the skin. The active clinical forms are often ulcerative, but can also be non-ulcerative: papules, nodules, plaques and oedematous forms. Buruli ulcer is therefore clinically primarily a disease of the skin. *M. ulcerans* also causes osteomyelitis: in Benin,

patients have been reported to suffer from severe forms of osteomyelitis as a consequence of an *M. ulcerans* infection, sometimes necessitating amputation (Lagarrigue *et al.* 2000).

Surgery is the only effective therapy for Buruli ulcer, but it has devastating physical, psychological and socioeconomic consequences for the patient (Asiedu & Etuaful 1998). Therefore one of the priorities of any national control programme should be to promote early detection of the disease, which would result in less traumatic and painful treatment, as well as a shorter hospital stay and lower costs. Two essential goals of such a programme are to raise the public's awareness of the disease and available treatment facilities, and to train community health workers to refer patients for treatment as early as possible (Aujoulat *et al.* 1996). Health education should therefore focus on early identification and reporting (Amofah *et al.* 2000). Since 1998, a major focus of the National Buruli Ulcer Programme in Benin has been a public health campaign to inform the population about the importance of the early detection of Buruli ulcer followed by timely treatment at a reference centre, notably the Centre Sanitaire et Nutritionnel Gbemoten de Zagnanado (hereafter referred to as Zagnanado Healthcare Centre) in Zou province, a highly endemic area of southern Benin. Patients suffering from Buruli ulcer have been treated at Zagnanado Healthcare

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Centre since 1989. Aguiar *et al.* (1997) reported 867 cases of Buruli ulcer in southern Benin for the period 1992-96. In 1999, in Zou province the rate for Buruli ulcer (22.2/100 000) was higher than that of leprosy (13.4/100 000) and tuberculosis (20.0/100 000) (Debacker *et al.*, manuscript in preparation).

From our experience with Buruli ulcer in Benin, Ivory Coast, Togo and Congo, as well as from discussions with other scientists we know that patients affected by Buruli ulcer tend to present late for treatment, at a stage when the surgical treatment as well as the disease itself have devastating consequences. In Australia, where access to health facilities is easier, people with Buruli ulcer present for treatment earlier, thus reducing the burden of disease and treatment. In African communities, where most cases occur in remote villages, people may not pay attention initially to a disease which seems to be just another sort of bump or sore. As a consequence, the first tentative public health campaigns in several African countries were based on visual information such as a poster and leaflets published by WHO and presenting various clinical features of the disease on white or black skin, entitled 'Recognizing Buruli Ulcer in your Community'.

Our preliminary hypothesis when we undertook the study was that lack of information or awareness of the disease was not the only reason for delayed treatment seeking, and we wanted to clarify the other factors involved. Behavioural trends in disease prevention and health care are influenced not only by one's level of health literacy but also by overall cultural beliefs and complex psychosocial factors, such as the extent to which the individual feels in control of his/her health (Wallston *et al.* 1976), the perceived seriousness of a disease and one's vulnerability to it (Hochbaum 1958), the perceived costs and benefits of a proposed treatment (Rosenstock 1960), and a sense of one's ability to cope with the disease (Bandura 1977). All these aspects are part of complex social cognition models which aim at explaining and/or predicting the occurrence of health behaviours. As stressed by Conner and Norman (1995), there is 'a substantial overlap between many of the constructs contained within the main social cognition models'. Hence our analysis did not stick to one particular model, but tried to identify various psychosocial factors likely to influence the health seeking behaviours of patients with Buruli ulcer which go beyond the simple knowledge about disease and treatment facilities. In west African countries sorcery plays a central role in the structuring of society (Valade & Paulme 1985) and has major implications for health and illness representations, and for therapeutic choices (Fishel Sargent 1982a; Fassin 1992).

Objectives

Prior to planning the public health campaign about Buruli ulcer, in order to elaborate relevant health education messages and strategies, we conducted a qualitative study in July 1999 in Zou province, to better understand what people know, think and feel about Buruli ulcer and treatment facilities; to see which cognitive and emotional obstacles prevent patients from presenting to the health care centre; to identify terms used locally to describe Buruli ulcer in order to incorporate them into health information campaign messages; and to determine the most appropriate people for delivering such health education messages.

Participants and methods

Study sites

The study took place in four villages (Dasso, Ouinhi, Sagon, and Zagnanado) of Zou province in Southern Benin. Ouinhi is Zou's capital, whereas Dasso and Sagon are two highly endemic foci for Buruli ulcer, located 40 and 14 km, respectively from Zagnanado and its health care centre. The predominant ethnic group in Zou are the Mahi-Fon, an animistic group who worship ancestors and believe that traditional healers are mediators between the living and the dead, and that by means of divinations they can interpret the nature and origin of disease and natural disasters.

Study design and population

Our approach was based on focus group interviews with 130 adults and two children, and on drawing sessions plus interviews with 28 children. According to standards in qualitative methodology (Pope & Mays 1995; Malterud 2001), the sample was theoretical, which meant that participants were chosen for their relevance to the investigated issues rather than for their statistical representativeness of the population living in the investigated area.

The at-risk populations of Dasso and Sagon were subdivided into seven focus groups with a total of 78 adults, and two drawing sessions with 28 children. The focus groups were segregated by gender and age: the elderly, who traditionally enjoy higher social status were interviewed separately. We visited each village school and assigned two pupils from each class (aged 6-14 years) to a workshop where they were asked to draw a picture that represented what they knew or felt about Buruli ulcer. They were then asked to comment individually on their drawings.

None of the participants were told beforehand what the topic of discussion would be. In each village the aim of the

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enquiry was first explained to the chief of the village and schoolmaster only. They were responsible for spreading the information around, so that people could volunteer to join the focus group discussions at a specific place and time. According to the number, age and gender of participants who presented, several groups were defined, and several focus group interviews (up to four in Sagon) were held the same day. How the waiting might have influenced the participation of those who were interviewed later during the day is not clear, although we noticed that the late groups focussed on Buruli ulcer earlier in the discussion than the early groups.

In addition to the at-risk populations, in order to triangulate data sources, five focus groups were formed: (i) Buruli ulcer patients at Zagnanado health care Centre: one group of six adults and two children; (ii) patients' assistants at Zagnanado health care Centre: one group of 10 (in most African countries, it is customary for a hospitalized patient to have an assistant, usually a family member, who takes care of food and laundry); (iii) health workers in Zagnanado: one group of 15; and (iv) traditional healers in Ouinhi: two groups of eight and 13, segregated by age. Altogether, 12 focus groups consisting of 130 adults and two children (patients), and two drawing workshops with 28 children were organized during a 2-week period in July 1999. The geographic origin and distribution of adults and children into the focus groups and drawing workshops are indicated in Table 1.

Investigation methods

The investigation method used for the focus group interviews was a discussion guide which included four topics: (i) general knowledge and beliefs about disease, (ii) general knowledge and beliefs about treatment options and therapeutic itineraries, (iii) specific knowledge and beliefs about

Buruli ulcer, and (iv) sources of information on health issues and Buruli ulcer.

The focus groups were conducted by three investigators: a health education specialist (IA) from Belgium and two national medical doctors (CJ, CZ), acting as a moderator, a translator and a note-taker. The interview was conducted in French and translated into Fon. The participants spoke both French and Fon. CZ was born in the area and is known locally as a 'Buruli doctor' working at the Zagnanado Healthcare Centre. To which extent his participation, mainly as note-taker and observer, might have influenced the expression of the people is unclear. He mostly acted as a facilitator for preliminary contacts and interpretation of data (in the presence of cultural particularities or beliefs).

All three investigators had a thorough knowledge of Buruli ulcer. They had together designed the discussion guide, which consisted of a list of questions relating to each topic. This guide was used rather as a check-list than a formal and sequential interview guide, so as to allow the discussion to evolve naturally, reflecting the group's dynamics and interaction. All discussions were videotaped and later transcribed verbatim. The children were individually asked to comment on their drawings, and one of the investigators took notes.

Analysis

The first stage of the analysis was performed for each focus group, on the same day, by the three investigators involved in the study. In these meetings the investigators shared what appeared as most relevant or striking, and systematically reviewed the discussion guide to assess the information germane to their different areas of investigation they gained that day. This was also the time when the researcher who had acted as the secretary and observer could provide

Table 1 Sample

	Elderly men			Young men				Women			Children			Total	
	D	S	O	D	S	Z	O	D	S	Z	D	S	O		
Population at risk: seven focus groups; two drawing workshops	7	7	-	20	12	-	-	9	23*	-					78
Patients (one group)	-	-	-	-	-	3	-	-	-	3	12	16	-	2	28
Assistants (one group)	-	-	-	-	-	-	-	-	-	10	-	-	-	-	10
Health workers (one group)	-	-	-	-	-	6	-	-	-	9	-	-	-	-	15
Traditional healers (two groups)	-	-	8	-	-	-	13	-	-	-	-	-	-	-	21
Total		22			54				54			30			160

D, Dasso; S, Sagon; Z, Zagnanado; O, Ouinhi.

* Two groups of women in Sagon, with 11 and 12 participants, respectively.

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explanations and translations of discussions in the local language between subgroups of participants.

At stage 2, the thematic contents of transcribed data were analysed. Data were indexed according to thematic categories and subcategories. A draft categorization had been initially created with the main categories reflecting the areas covered by the discussion guide, i.e. general information regarding disease, general information regarding treatment options and therapeutic itineraries, specific information regarding Buruli ulcer (disease and treatment), sources of information on health issues and Buruli ulcer.

As there were overlaps regarding treatment options and therapeutic itineraries for non-specific diseases and for Buruli ulcer, the main categories were changed into information regarding disease and treatment options (general information and information specific to Buruli ulcer), obstacles likely to prevent patients from presenting to the health care centre, and communication issues: local terms used to describe Buruli ulcer and sources of information considered as reliable. The main categories thus reflect the objectives of the study. The various subcategories of these main categories had not been decided upon beforehand, but emerged from the discussions that followed every focus group and drawing session and from the data itself (transcribed verbatim and field notes). The evolution of the categorization is explained in Table 2. The comments of the children on their drawings were analysed using the same categories.

This part of the detailed analysis was performed by one researcher who produced a draft report (Aujoulat 1999a) that was discussed with the two other investigators (CJ & CZ) in the presence of the promoter of the project (FP) and an independent scientist (M. Debacker), familiar both with Buruli ulcer and the geographical area of investigation, during a meeting at the Institute of Tropical Medicine in Antwerp (Belgium), before the final validated report was issued (Aujoulat 1999b).

Results

The results hereafter are presented according to the final categorization described above. The subtitles correspond to the subcategories that emerged during the analysis. The findings below are a synthesis of the opinions expressed by the participants and are illustrated with quotations from the transcription of both the adults' focus group interviews and the children's comments on their drawings.

Findings regarding disease and treatment options

Two assumed causes of disease were identified: a disease may be natural, '*sent directly by God,*' or induced by

another person through sorcery. Natural diseases are brought on by environmental or behavioural factors. While diseases assumed to be induced maliciously by another person are not different in nature from other diseases, sorcery is indicated if a patient is not healed and his or her family loses all their belongings as a result. A common disease with uncommon symptoms is assumed to be another indication of sorcery. '*The disease may be induced if you get a terrible headache, with the feeling that your head is divided into four. When it is just a normal pain in the forehead, you do not even think of sorcery*' (Group of Assistants, Zangnando). Any disease can be natural, induced or both.

The assumed cause of disease dictates the kind of treatment sought and, conversely, the success of a particular treatment reveals the underlying cause of the disease. A patient with a natural disease will recover on his own or at hospital. A patient with an induced disease will have to employ a traditional healer to counteract the sorcery.

Self-treatment is usually the first step, and if it is not successful, patients separately, alternatively, or simultaneously turn to traditional healers, religious representatives, or health care centres and hospitals. Patients who opt for a traditional healer may choose between two general types: phytotherapists (healers who use medicinal plants to treat illness), or those who rely on divination and behavioural proscriptions (dietary rules, sexual taboos) to free patients from disease. The power of such a traditional healer is believed to be similar to that of a sorcerer, except that it is used to heal instead of to harm.

Patients choose to go to a hospital or a health care centre for treatment if two or more of the following conditions apply: (i) they believe there is a natural cause for their disease, (ii) the disease appears to be serious and has not healed spontaneously or with traditional treatments and (iii) treatment at the health care centre is known to be effective, if not necessarily pleasant (for example blood transfusion, access to modern drugs). In general, patients tend to present to the traditional healer first, so as to counteract a possible spell as the origin of disease. Only after the traditional healer has failed to heal them, do they conclude that the disease may have a natural cause and could therefore be managed by modern medicine.

Findings regarding Buruli ulcer

Buruli ulcer appeared to be well known in Zou province of Benin. The different stages and forms of the disease were clearly described by the adults during the focus groups and were well illustrated in the children's drawings.

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Main categories (A) Disease	(B) Therapeutic itinerary	(C) Buruli ulcer (BU)	(D) Sources of information
Interview categorization			
Subcategories	(1) Indicators of disease (2) Seriousness of disease (3) Origin of disease (4) Personal susceptibility to disease (5) Sources of information on disease	(1) Patients' possible reactions to counteract a disease (2) Expectations towards the person consulted (3) Expected outcome (4) Access to healing place	(1) Knowledge about BU (2) Symptoms of BU (3) Origin of disease (4) Seriousness of BU (5) Outcome of BU (6) Personal experience of BU (7) Treatment facilities (8) Prevention possibilities
Intermediate categorization (draft report, September 1999)			
Main categories	(A') Representations of disease	(B') Choice of therapeutic itinerary	(C') Knowledge, perceptions and experience about BU (D') Communication issues (E') Obstacles to presenting at health care centre
Subcategories	(1) Indicators of disease (2) Seriousness of disease (3) Origin of disease - Natural cause - Sorcery - Mixed cause	(1) Auto-medication (2) Traditional treatment (3) Health care centre	(1) Local expressions used to describe BU (2) Valid sources of information on BU (3) Geographical accessibility (4) Financial accessibility (5) Living at the health care centre - Cost of living - Role of the patients' assistants (6) Description of treatment at the health care centre (7) Efficacy of treatment
Final categorization (present paper)			
Main categories	(A'') Disease and treatment options (including A', B' and C'2, C'3, C'6)	(B'') Obstacles to presenting at health care centre (including C'4, C'5, and E')	(C'') Communication issues (= D')
Sub-categories	(1) General (2) Buruli ulcer	(1) Relapse (2) Scarring (3) Surgery (4) Geographical and financial obstacles	(1) Local expressions used to describe BU (2) Valid sources of information on BU

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There was no consensus as to the cause of Buruli ulcer. Buruli ulcer is often thought to be induced, because it is normally not easy to heal and is expensive to treat. Many people seem to believe that Buruli ulcer arises from natural causes and is made worse by sorcery. The health workers interviewed at Zagnanado Healthcare Centre also believed that there are two distinct diseases with the same clinical features: one is a naturally caused disease called Buruli ulcer, which can be cured at the health care centre; the other is an induced disease called *sasa*, which requires the intervention of a traditional healer. They say there is no way to distinguish one disease from the other; one can only wait and see which treatment proves to be effective. Only the women strongly advocated a natural cause of Buruli ulcer, arguing that the frequency of the disease ruled out sorcery. If it were induced, they explain, it would not afflict so many people of different ages and social backgrounds. 'Would a sorcerer really want to kill all these people? Even the children, the very little ones, who have not had a chance yet to do someone any harm? The disease must have a natural cause' (Group of Women, Dasso).

Much concern was expressed about the possible contagiousness of the disease. Traditional healers insisted on the need to completely isolate a patient during treatment. Some men stressed that contagion was associated with the odour of the wound. 'If the smell of the sore enters your body, you too get the disease' (Group of Elderly Men, Sagon). Interviews with patients and health workers at Zagnanado Healthcare Centre revealed some fears of contagion. Children in particular told how they had been kept at home, completely isolated from others for months before they were taken to the health care centre. Staff at the health care centre expressed a concern that Buruli ulcer might be contagious, although they knew of no fellow workers who had ever been infected by a patient. But women appeared to be very confident and forceful in expressing their opinion that Buruli ulcer was not contagious. Some had assisted a child or relative during hospitalization, eating and sleeping at the patients' side and laundering their bandages and dressings. They argued that as they did not catch the disease from this close contact, it must not be contagious; and even if the disease were found to be contagious, they said they would not be deterred from caring for loved ones who had Buruli ulcer.

Participants in one focus group said that 'Buruli ulcer is worse than malaria because its cure is associated with a certain number of rules and regulations. Even if the wound has healed, the patient is not allowed to go to funerals or to have sexual intercourse for 3 months following the treatment' (Group of Assistants, Zagnanado). Traditional healers impose these taboos as part of the rites associated with the healing process. As one healer explained, 'Once a

disease has healed, a certain number of proscriptions are to be respected. If one does not respect such proscriptions, the disease recurs. The type of proscription varies with the disease and the patient' (Group of Elderly Traditional Healers, Ouinhi).

Obstacles to presenting to the health care centre

There was serious concern among the investigated population about the risk that the disease may appear again after treatment, regardless of the type or efficacy of treatment. 'One can never say that it has healed completely. It always comes back, sometimes after 4 years' (Group of Women, Dasso).

After healing, Buruli ulcer usually leaves a visible scar. People who have had the disease are ashamed of their scars and try to hide them. 'The disease is very hard to cope with. You may be a well-dressed and good-looking person, but the disease has left your foot distorted. And when people look at you, they first think you are handsome, but when they look at your feet, they can see that you are mutilated and your flesh has been cut out here and there. Really, it is embarrassing' (Group of Women, Sagon).

Even those convinced that the treatment offered at Zagnanado is the only effective remedy are hesitant to go to the health care centre because of their anxiety over the outcome of skin grafting. 'Skin grafting always leaves scars. If, for instance, samples of skin are taken from 3 different sites, there will be 3 more scars. Of course, you can try to hide the scars with your clothes, but your clothes will never cover your feet, and those are not nice to look at' (Group of women, Sagon). 'Really, if one could imagine a way of curing without cutting out a healthy part to cover the damaged part and leaving another scar, if the disease could be cured without creating more scars, we would appreciate that' (Group of Men, Sagon).

Much concern was expressed about the social consequences of scarring and disabilities associated with Buruli ulcer which can reduce a person's opportunities of marriage or employment. Non-verbal cues such as gestures and facial expressions clearly confirmed the interviewees' claims, reinforcing the notion that this aspect of Buruli ulcer was a major problem. Children expressed their fears about scarring and disability in their drawings. The risk of amputation was of particular concern. A 6-year-old girl commented on her drawing in the following terms: 'One child has an ulcer on the belly. The other child looks at her and is shocked. It looks awful' (Jacqueline, 6 years).

In every focus group there was at least one person who had firsthand knowledge and experience of the treatments and living conditions at Zagnanado Healthcare Centre,

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and could describe in detail all the stages of treatment, from diagnosis to medication, anaesthetics, surgery, skin grafting and physiotherapy. Yet, most of the people interviewed said they would prefer to avoid surgery and skin grafting if possible. The treatment was well described by the children in their drawings.

Financial obstacles which prevent seeking treatment at Zagnanado are twofold: the cost of transportation and the cost of the treatment itself. Most villagers have no means of transport other than walking or sometimes cycling. A patient who is too sick or weak to walk to the health care centre has to hire a *zemidjan*, a sort of taxi moped. The cost of such transportation is unaffordable to most villagers.

The cost of treatment at the health care centre was described as high. For many, even greater than the cost of treatment is the cost of living at the health care centre. Being hospitalized means that the patient and one of his or her relatives must be away from home for an extended period of time. Often, families have to sell some of their belongings to pay for the treatment and its associated costs. Buying food for the patient and his or her assistant can be a real problem. A typical meal at home often consists of a simple gruel of cornmeal and water. Some people admitted that they were embarrassed to eat the same kind of food in the hospital as they were used to at home, because others might notice how poor they are. Furthermore, Buruli ulcer patients are normally told that, to promote their recovery, they must eat foods richer in animal or vegetable protein than they would ordinarily have. Enriched gruel requires ingredients such as soy flour, fish, and peanuts, which are more expensive to buy, thus adding to the overall cost of treatment.

Communication issues

The Mahi-Fon have a word for Buruli ulcer, *ouévikpa*, meaning 'wound caused by worms'. The word is rather abstract, referring vaguely to something that lives, moves and crawls, and may therefore also be translated as 'wound caused by germs'. However, in the advanced stages of the disease, if inadequate treatment has led to secondary infection of the ulcer, worms may indeed appear in the form of maggots. Worms were represented in almost all the children's drawings, and were identified as the main cause of the disease. The worms are said to enter the body through an unknown pathway and to cause disease in synergy with some aggravating catalyst such as ageing, fatigue, environmental factors, or sorcery. Another word often used for Buruli ulcer is *djomakou*, 'wound that does not heal'. As the wound does not heal, treatment is expensive. Both reasons lead many to believe that the disease is the result of a curse, rather than an environmental factor.

Former patients to deliver health education messages

The answer to the question 'How did you find information about Buruli ulcer or its treatment?' or 'Who would you consult to obtain this information?' was invariably, 'From someone who has had the disease' (Groups of Assistants in Zagnanado, Women in Sagon, Women in Dasso). All felt that the most reliable source of information regarding any disease was the patient him/herself. 'You know what you are talking about when you have had the disease' (Group of Men in Dasso). In the same way, when asked how a particular patient was usually referred to them, the traditional healers answered that the patients knew about them from former patients they had successfully cured before. Therefore someone who has previously contracted the disease is considered a reliable source of information on such disease.

Discussion and conclusion

We adopted a qualitative approach for this study, and preferred focus groups to individual interviews or questionnaires, as this method allows for the collection of a great deal of information about people's thoughts and feelings, without limiting discussion to a predetermined set of subjects or questions. As Folch-Lyon and Trost (1981) put it, 'Members of the same cultural group have similar cognitive structures, similar perceptions of their social environment, and adhere to similar normative beliefs. In group discussions, the internalized influence of cultural factors and value structures of the social group to which participants belong and on which they have modeled their perceptions are reinforced and manifest themselves readily (...) Focus group sessions are helpful in answering questions of how and, in particular, why, people behave as they do'. Focus groups were a cost-effective way of finding out what people know, think, and feel about Buruli ulcer and how those perceptions affect their behaviour. Interactions that occurred during the group discussions were particularly important, and led to the expression of feelings and attitudes that would probably not have been expressed had the participants been interviewed separately. For instance, the discussion about the feeling of shame linked to the visible scars first emerged after some hesitation (which was perceptible from the way people were looking at each other) and oratory precautions. There was also reluctance to talk about the scars. Perhaps there is a social stigma linked to the presence of scars indicative of Buruli ulcer, as with the sequelae of people who had leprosy, and who are still considered 'lepers' although they were cured and are not contagious anymore.

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As Johnson (1997) found in another endemic region of Benin (Mono), the population we investigated was familiar with Buruli ulcer and could describe its various stages and the treatment at the health care centre in detail. Our conclusions are: the most reliable source of information regarding any treatment option is someone who has had the disease and was successfully cured. The disease is well known and is considered serious and mutilating. Surgery is a well known but poorly accepted treatment. The scars resulting from treatment are considered unsightly and a social handicap in some circumstances. Fear of amputation is widespread. There is serious doubt about the effectiveness of treatment; the disease is said to recur in most cases. The cost of treatment and conditions of living at the health care centre can be an obstacle to a patient's decision to refer to the health care centre during the early stages of the disease. There is no consensus as to whether the disease is natural or induced by sorcery. Many people think the cause is mixed, except for the women, who believe it is naturally caused. Many people believe Buruli ulcer is contagious. Those who do not are almost exclusively women, who feel a strong responsibility for their children and community. The results of group discussions differed only for the two latter points, depending on the presence of women.

As the main purpose of a public awareness campaign on Buruli ulcer would be to promote early presentation at the health care centre, one of the questions raised by this study was 'Why do patients usually present to the health care centre at an advanced stage of their illness?'

Some psychosocial aspects of behaviour patterns that influence personal health were listed in the introduction of this paper. In the case of Buruli ulcer, it was found that surgical excision and skin grafting are poorly accepted in the Zou province of Benin. The financial and personal costs involved are major obstacles which prevent people from going to the health care centre, as the expenditure involved is perceived to be greater than the expected benefits (especially as the disease is thought to recur in most cases). Moreover, the sense of self-competence and adequacy at coping with the disease is often low as the disease may be linked to sorcery, and people fear that the disease may recur, sometimes many years after treatment. Indeed, the results of a recent study carried out by C. Zinsou & F. Portaels (unpublished data) in the villages surrounding Zagnanado, demonstrated that up to 6.5% of all treated patients may experience a new episode of the disease. However, a new episode does not necessarily mean a relapse as the patient may also be directly re-infected by another isolate of *M. ulcerans* from the environment.

Health education messages for a public health campaign should not focus on raising awareness of the disease (as the

disease and treatment facilities are already well known and well described), but rather on the efficacy of treatment at an early stage of the disease, so as to make it more acceptable. Regarding sorcery, rather than to deny it by trying to demonstrate that the disease always has a natural cause, this issue should be integrated to the health education messages by emphasizing that in most cases the disease is natural. People should be encouraged to present at the health care centre in the first place so as to eliminate a *possible natural cause* of the disease. Only in a second stage, if the disease could not be healed by modern medicine, should they turn to the traditional healers. At present, most patients turn to the traditional healers first, so as to counteract a *possible spell from the sorcerer!* C. Johnson, R. Hougnihin, A. Guédénon, D. Ifebe & F. Portaels (manuscript in preparation) found that the same attitude prevailed in other regions of Benin. As underlined by Fishel Sargent (1982b), '*research on patient-practitioner relationships has demonstrated that decisions to select particular therapeutic options, and compliance with therapeutic regimes, are influenced by the extent to which patients and practitioners share fundamental assumptions regarding clinical reality*'. The implication of this for practice is that in order to reach their goal, health educators should work with the people's representations, not against them!

The potentially most appropriate people to convey health education messages about Buruli ulcer are the patients themselves after successful treatment at the health care centre, as they were unanimously considered a reliable source of information. A study performed by Debacker *et al.* (manuscript in preparation) in 2000 indicated that a patient previously treated at the Zagnanado health care centre recommended treatment at this centre for 68.3% of the patients.

Schoolteachers, who often notice Buruli ulcer on children at an early stage, might also be relevant mediators of health education messages, provided they are given appropriate training, in particular to fight the idea that Buruli ulcer is contagious. Schoolteachers showed much interest in learning more about the disease, its origin and treatment. Some women, especially those who have had a sick child cured at the health care centre, might also be trained so as to be able to convey health education messages regarding Buruli ulcer. Women were very assertive on the fact that Buruli ulcer was not contagious and unlikely to be due to sorcery, and their stay at the health care centre to assist a member of their family might open options for training them.

Health care professionals were hesitant to a certain extent about the possible cause and origin of the disease (whether natural or induced). They are therefore likely to convey ambivalent messages if not adequately trained

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previously. In all cases, but especially here, adequate training on health education issues should include a thorough investigation of the people's representations and beliefs regarding the disease and treatment facilities.

As for most qualitative studies, the results of this one are valid only for the investigated area and should not be projected onto other areas without prior verification of their reproducibility. For instance, it could be that in other areas, people do not have the same level of awareness and knowledge regarding disease and treatment facilities. Moreover, as the study was exploratory, the results produced still deserve to be better documented and more systematically verified, for instance through in-depth interviews with patients at the health centre or in their villages.

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