

Therapeutic itineraries of patients with ulcerated forms of *Mycobacterium ulcerans* (Buruli ulcer) disease in a rural health zone in the Democratic Republic of Congo

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Summary

OBJECTIVE To describe lay perceptions of the ulcerated forms of *Mycobacterium ulcerans*, commonly called Buruli ulcer (BU), and therapeutic itineraries of BU patients in a rural area of the Democratic Republic of Congo.

METHODS Qualitative research consisting of semi-structured interviews of 19 patients with clinical signs of BU and 12 in-depth interviews of confirmed cases allowing for a detailed reconstruction of the itineraries followed.

RESULTS The first symptoms of BU are perceived as mild. The perceived seriousness of the disease increases as the ulceration persists, increases in size or results in complications. Knowledge about the biomedical aetiology of the disease is scarce; it is commonly believed to be due to witches' attacks or bad fate. Four therapeutic paths are taken: self-medication, traditional therapy, the church and the health centre. However lay perception, recourse to traditional treatments and self-medication only partially explain the long delays in diagnosis (on average 6 months); the main problem lies with health providers, particularly the lack of proper diagnostic capability.

CONCLUSIONS Diagnostic capabilities at health centre level need to be strengthened through training and supervision. Engaging with the population and the traditional healers would render health promotion messages on BU more relevant and culturally acceptable.

keywords *Mycobacterium ulcerans*, Buruli ulcer, disease perception, health seeking behaviour, therapeutic itineraries, Democratic Republic of Congo

Introduction

Buruli ulcer (BU) is a neglected tropical disease caused by *Mycobacterium ulcerans* with 16 countries reporting 27 114 cases from 2002 to 2007 (WHO 2008), although the true disease burden is not known. In the first stage, the infections are characterized by non-ulcerated skin lesions similar to a nodule, papule, plaque or oedema. These lesions evolve into ulcerations of various sizes and shape (WHO 2000) which may affect the bone (Portaels 2003). Currently, the WHO recommended treatment is a combination of streptomycin and rifampicin (S + R). This regimen gives promising results, especially for early forms and small-sized ulcers of less than 10 cm diameter (Etuaful *et al.* 2005; Chauty *et al.* 2007).

Buruli ulcer was first reported in the Democratic Republic of Congo (DRC) in 1950 (Van Oye & Ballion 1950). A national survey conducted in 2004 reported 487 cases (Kibadi *et al.* 2006). From 2002 (establishment of the National Control Programme) to April 2009, 2129 BU cases were notified to WHO (Kibadi 2009). Cases are currently being reported in 5 of 11 provinces. Though an increasing trend is often reported, no reliable incidence data exist. BU is most likely under-reported, as health personnel and the general population are not familiar with the disease. In DRC, ulcerated forms are most often notified by treatment facilities that specialize in BU (Kibadi *et al.* 2003; Phanzu *et al.* 2006). Given the severely disabling consequences of BU and the difficulties of its treatment (Kibadi 2005,

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2008), BU is an important public health issue in endemic areas.

Late presentation of BU patients is common. For instance Phanzu *et al.* (2006) state 'The fact that 94.4% of our patients had an ulcerative form sometimes associated with other clinical forms suggests that our BU patients arrived at an advanced stage of illness, usually with physical impairments or other serious complications such as sepsis, dissemination, and bone involvement. Consequently, these patients had long hospital stays (median = 102 days) and an unusually high mortality rate of 19.4%'. In the same study, the median delay observed in seeking medical care at the hospital of Kimpese was 60 days, the minimum was 7 days, the maximum 840 days. Meyers *et al.* (1974) noted that '... the reasons for many BU patients delaying to seek medical assistance were obviously complex, but cultural, economic, and transportation factors were especially important'.

Late presentation with ulcerative, extended and sometimes disseminated forms of the disease leads to more complex surgical treatment, very lengthy hospital stays and it delays the healing process (Kibadi 2004; b; Phanzu *et al.* 2006). It is correlated with uncertain prognosis and a huge financial burden for the patients' relatives (Asiedu & Etuaful 1998). Therefore it is essential to understand the patients' therapeutic choices and the reasons for late presentation at the health centre.

The therapeutic itineraries followed by patients presenting ulcerative forms of BU at first consultation have rarely been studied (Janssens *et al.* 2005; Mulder *et al.* 2008). One study conducted in Benin by Johnson *et al.* (2004) focused on traditional therapy. Our objective was to better understand the reasons for late consultations and diagnosis for BU in DRC in order to reduce delays in treatment. Specific objectives were

- documenting the therapeutic recourse available and itineraries followed by patients with ulcerated forms of BU including determining how early BU patients arrive at formal care units;
- describing lay perceptions of the disease in as far as these are related to health seeking behaviour.

Methods

Study site

This facility-based study was conducted in the Rural Health Zone (RHZ) of Nsona-Mpangu (Lower Congo Province) in RDC, which is the most endemic area for BU in the DRC (Smith 1970; Meyers *et al.* 1974; Kibadi *et al.* 2006). We covered the first-line health centres of eight villages [Vémadiya, Lufu-Gare, Manzonzi, Minkelo

(Mawete), Mpelo, Nkamuna, Nsona-Mpangu and Songo-lolo]. Each first-line health centre has a dedicated BU treatment facility, so any patient potentially has access to specialized BU care within 10 km from home. Medical care to BU patients is free.

Patients

We conducted a qualitative survey in March 2007, consisting of semi-structured interviews of 19 patients with a clinical diagnosis of *M. ulcerans* infection. The health centres were surveyed to find patients responding to the inclusion criteria. The sample was exhaustive and the 19 patients are those who presented and were diagnosed with BU at the health centres at the time of the survey. Inclusion criteria were BU clinical diagnosis (WHO 2000, 2001), an ulcer 10 cm or more in diameter at the time of consultation at the health centre, and placement under special *M. ulcerans* infection treatment, namely streptomycin and rifampicin plus surgery (WHO 2004). The patients came from all endemic villages from the RHZ of Nsona-Mpangu were a representative sample of the population living in the RHZ.

In addition, 12 complementary in-depth interviews were conducted in September 2007 of those patients whose skin ulcer biopsy was PCR positive for *M. ulcerans* at the Institute of Tropical Medicine (ITM) of Antwerp, Belgium (WHO 2001). Unfortunately one of the 13 confirmed patients was not available for in-depth interview.

Data collection

A semi-structured question guide was developed and pre-tested between October 2006 and December 2006 on six patients, which covered perception of the disease (severity, causality, transmission) and the patient's personal disease history, focusing on his health-seeking behaviour and itineraries. The guide for the in-depth interview of confirmed BU patients included the same topics but focused on gaining more detailed information about the therapeutic itineraries followed in order to reconstruct them in detail. The interviews took place in private, in a dedicated room in the health centres. They were led by one of the authors (KK) in local languages (Kikongo or Lingala) and lasted an average of 1 h for the semi-structured and 2 h for the in-depth interviews. All interviews were tape-recorded. For paediatric patients, the parents or guardians were interviewed in the presence of the child.

Data analysis

The interviews were exhaustively transcribed verbatim in local languages and translated into French. Data were

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encoded on the basis of research topics and themes emerging from the interviews were analysed with the support of the QSR N6 software (QSR International Pty Ltd, Melbourne, Australia, 2002).

Ethical aspects

The study protocol was approved by the Ethical Committee of the School of Public Health, University of Kinshasa, DRC (N° ESP/CE/043) and by the Ethical Committee of the Universitair Ziekenhuis Antwerpen, (N° 6/42/197) in Belgium. Participation in the survey was voluntary and written informed consent was obtained from all participants or their guardian.

Results

The socio-demographic characteristics of the 19 patients with clinical suspicion of BU are listed in Table 1. Both sexes were equally represented. 14 worked as farmers and 5 were still in school. Age range was 9–72 years. Data available from the 19 patients was used to analyse the lay perception of the disease. The analysis of the therapeutic itineraries is based on the in-depth interviews of the 12 confirmed cases.

Perception

In most cases, BU is identified as *mbasu* (wound caused by an attack of witches or wound due to bad fate). A 47-year-old father whose 11-year-old daughter was suffering from BU explains: ‘At first we thought of a *mbasu* case, the *bubon* that gets black or red with no cause. People told us that it was a case of *taza*, i.e. a headless *bubon*. The latter can disappear in a “vacuum” [by itself, with no treatment]. On the opposite, *mbasu* is a *bubon* with a head that turns red. We call it *phuta rouge* [red wound]. This type of *bubon* always becomes a wound. The swelling became a wound after one and a half month’.

Table 1 General characteristics of 19 participants with a clinical diagnosis of BU recruited from the Nsona-Mpangu Rural Health Zone, DRC, 2007

Sex	Male	9 (47%)
	Female	10 (52%)
Occupation	Student	5 (26%)
	Farmers	14 (73%)
Age group	9–24 years	8 (42%)
	25–40 years	3 (15%)
	41–56 years	5 (26%)
	57–72 years	3 (15%)

At the beginning of the disease, symptoms are banalized. A boy aged 19 explains: ‘Before becoming a wound the *bubon* turns red first. So we call it *phuta rouge*. The skin above the *bubon* changes colour first. In the neighbouring Angolan villages where I was, it is called *phuta bwangi*’ [red wound]. When it appears on the body, we do nothing. We only observe it, as it does not hurt. We await developments, as it can disappear.’

Patients say that BU is serious, but all claimed not to be scared. Sadness seems to be the prevailing feeling. They are however concerned about the evolution of the symptoms. The perceived seriousness of the disease increases as the ulceration persists, its size increases or as complications (pain, fever, and disability) appear. A boy, 14 years old, says: ‘When the wound appeared, I was not scared, I was just sad. My brother, who came from Kinshasa, told me that it was *mbasu* due to the fact I walked over some bad luck thing. Thereafter the wound became big, Mother and Father were worried. They asked me to go to the health centre.’

The vast majority of the patients interviewed had no biomedical knowledge about the cause of the disease, except for three who evoked a microbial agent in stagnant water. They had that information from a documentary movie on BU, which they watched during a prevention campaign. For the majority of patients, however, the aetiology is of supernatural origin. A 40-year-old woman typically explains: ‘My child was attacked by a curse, namely witchcraft. Otherwise, how can you explain the fact that only my child is suffering from this disease? All the village children play together, all play in stagnant water and go to the bush and to school together, they all share the same conditions. Why? We were attacked.’

Therapeutic itineraries

Four kinds of therapeutic recourse were identified in the RHZ of Nsona-Mpangu. For self-medication, patients or relatives use allopathic drugs (non-specific antibiotics, anti-inflammatory, topical antiseptics, etc.) without prescription or prior medical consultation. They purchase the drugs over the counter on the street markets or from patent medicine dealers, cut the ulcer, and dress or bandage the wounds at home. Or the patient or his relatives obtain traditional treatment from a healer or a ‘gifted person’. The latter generally puts poultices of herbs and leaves on the sick wound. The wounds are treated with solutions such as salted water or palm oil. This treatment is sometimes associated with food taboos (i.e. pork meat). Option 3 is that the patient or his relatives go to the church where the cause of the disease is revealed, for example, to be of a devil origin. Treatment consists of prayers meant to make

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the lesions disappear. Option 4 is the health centre: The patient consults a health facility of the Nsona-Mpangu RHZ. Two possibilities of treatment exist at this level. First, the nurse diagnoses (wrongly) an ulceration and prescribes a non-specific treatment consisting of multi-drug therapy and the usual antiseptics. Or, the BU is properly diagnosed and the patient receives specific treatment for BU (S+R combination plus surgery) as recommended by WHO (2004).

The therapeutic itineraries followed by the 12 PCR positive patients, reconstructed on the basis of the in-depth interviews, are presented in Figure 1. Table 2 specifies the duration of the different steps. All 12 patients first experienced a 'wait and see' period (as did the seven patients for whom BU was not confirmed). This period lasted on average 2 months, during which patients expected spontaneous disappearance of the lesion or waited to see if it worsened. This time was also used to

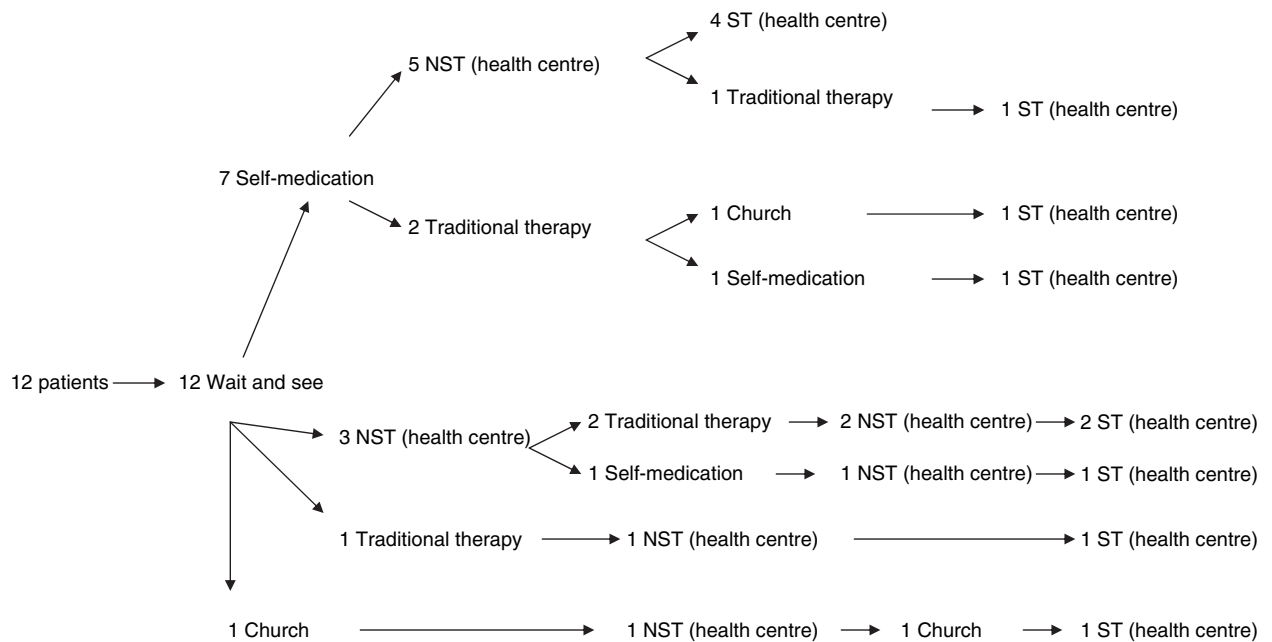


Figure 1 Therapeutic itineraries followed by 12 BU patients, Nsona-Mpangu, Rural Health Zone, RDC, 2007. NST, nonspecific treatment; ST, specific treatment.

Table 2 Duration of 12 therapeutic itineraries of confirmed BU patients, Nsona-Mpangu Rural Health Zone, DRC, 2007

Step	'Wait and see'	First recourse	Second recourse	Third recourse	Fourth recourse	Fifth recourse
Patient 1	3 months	Church 2 weeks	NST 2 weeks	ST after 4 months		
Patient 2	2 months	NST 1 month	SM 2 months	NST 1 month	ST after 6 months	
Patient 3	1 month	SM 1 month	NST 4 months	ST after 6 months		
Patient 4	2 months	NST 1 month	TT 2 weeks	NST 2 months	ST after 5½ months	
Patient 5	1 month	SM 1 month	NST 15 months	ST after 17 months		
Patient 6	2 months	SM 2 weeks	TT 2 weeks	Church 1 week	NST 2 months	ST after 5¼ months
Patient 7	2 months	SM 1 month	NST 2 months	ST after 5 months		
Patient 8	1 month	SM 5 months	NST 2 weeks	ST after 6 ½ months		
Patient 9	3 months	NST 2 months	TT 2 weeks	NST 2 months	ST after 7½ months	
Patient 10	2 months	TT 2 weeks	NST 4 months	ST after 6½ months		
Patient 11	2 months	SM 2 weeks	NST 1 month	TT 2 weeks	ST after 4 months	
Patient 12	3 months	SM 3 weeks	TT 3 months	SM 3 weeks	ST after 7½ months	

NST, nonspecific treatment (Health Centre); SM, self-medication; ST, specific treatment (Health Centre); TT, traditional therapy.

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socially negotiate the symptoms with relatives and to progressively label them as a disease. An old woman explains: 'When a *bubon* or a small wound erupts on the body, why go to the hospital? One must stay at home. Nobody knows the evolution. The thing can disappear. One must wait until the disease reveals itself completely in order to know where it comes from, and then you will know how to tackle it.'

The decision to seek help and treatment is motivated by the desire to recover from the disease and to heal the ulcer. Seven of the 12 patients resorted to self-medication, three went to the health centre, one first consulted a traditional practitioner and one appealed to the church. The three patients who first went to a health centre (Figure 1) were motivated by the fact that they lived nearby with a relative working there. A woman aged 58 explains: 'I lived and grew up close to clinics in Matadi. I know that when something in the body is wrong, I have to go to the hospital. My daughter who lives with me works for this health centre.'

Seven of the nine patients who did not go to a health facility first, used it as second recourse. They justified this by the lack of wound healing at the previous step. The two remaining patients had recourse to a traditional healer. At this stage of their itineraries, 10 of 12 patients had therefore consulted at a health centre. Of these 10 patients, three decided later to go to the traditional healers, one returned to self-medication and one went to church. The other five were treated at the HC with non-specific medication and remained undiagnosed for a period of 2–4 months (one remained undiagnosed for 2 weeks and another for 15 months) (Table 2).

For those who did not pursue their treatment at the health centre, the lack of wound healing was again the reason evoked. A young woman says: 'I was at the health centre..., the evolution of my wound was slow and not good. So I stopped the modern treatment and went to see a traditional healer. And there, my wound got healed.' A 60-year-old woman who experienced a recurrence of her ulcer explains: 'At the start of the second wound, I left and went to consult traditional healers, because the modern treatment brought no change. In fact swelling appeared again and became a wound on the same place at the foot that had healed previously; I went to see a traditional healer. He offered « prayers » so that the wound heals. He took salt and put it in the wound. He gave me some salt to put in water and said I should bath my feet in it.'

It is worth noting that half of the 12 patients used traditional therapy at some point: one after the common waiting phase, two after self-medication and three after consultation at the health centre. These three also explained their use of traditional therapy by a search for

healing. An 18-year-old patient who had recourse to traditional therapy after the common 'wait and see' step tells us: 'I stayed at home with my wound for more than a month. I watched developments. I told Mother. She said that we had to consult traditional healers first. She said that treatment for this disease is traditional only. We stayed at the traditional healer for about 2 weeks. He applied plants on the wound. I decided to go to the healer because there was no change in my wound at home. Mom and the village people thought it was better to go see the traditional practitioner. At the traditional healer, there was no change either. An old man who resides in this village and who had returned from Angola, told us that this disease was not a traditional matter. He said that it was well cured through modern medicine, because his own child who had suffered from the same disease was healed by modern medicine. He recommended us to go to the health centre.'

It is important to notice that the time devoted to a traditional treatment is relatively short (2 weeks). This is also the case for the recourses to churches (Table 2). All 12 patients finally ended up with receiving the recommended specific treatment for BU. The median time between onset of symptoms and starting specific BU treatment was 6 months.

Discussion

After patients notice the early symptoms of BU, a 'wait and see' period of, on average, 2 months is the first step in all the therapeutic itineraries. Patients explain this attitude by the fact that they do not know the possible evolution and consequences of the lesions. This is probably related to the fact that in a rural environment, small nodules and plaques are very common, usually self-heal and are not specific for any disease. This is in line with the results of a survey conducted in Benin (Johnson *et al.* 2004) which also shows that a significant number of patients wait a long time before considering seeking help; be it traditional or modern.

Relatives are the first to be informed. In line with the theoretical literature on health seeking behaviour (Kleinman 1980, 1986; Good 1996; Jaffré & Olivier de Sardan 1999), the latter and the neighbourhood play an important role in labelling the observed symptoms as a disease and in defining it. Eventually, consensus is reached on its origin and therapeutic recourse.

Once the symptoms have been defined as a disease, the majority thinks of a supernatural aetiology. In the majority of cases, the disease is termed as *mbasu* (Kibadi 2004; Kibadi *et al.* 2007). Once it is decided that something ought to be done, the majority of infected persons first practice

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self-medication and the others choose traditional therapy, church or to go to the health centre. During this period, self-medication continues to play an important role.

The perceived aetiology partially explains the therapeutic itineraries followed and the important role played by traditional healers. This is in line with results obtained by Aujoulat *et al.* (2003) and Mulder *et al.* (2008) in Benin and Stienstra *et al.* (2002) in Ghana, which also show that traditional beliefs influence the choice of treatment. As could be expected (Benoist 1996), the itineraries present themselves as various intricate routes involving multiple providers. Some trends can be identified however. In our study, the perceived aetiology, the perceived severity and the quest for finding a solution and healing the wound appear central reflecting a pragmatic approach of the disease from the patients viewpoint. Mulder *et al.* (2008) also found that increasing severity, extent and duration of BU were influencing factors on health seeking behaviour. Education or at least a certain social proximity with health centres and modern medicine also played an important role in the choices of some patients.

The presence of a BU treatment centre, the distance and costs do not seem to heavily affect the patient's therapeutic itineraries although they might play a secondary role. In fact, the three patients who consulted traditional healers after first going to the health centre lived near a centre. However, they went to consult traditional healers at distances of at least 20 km. On the other hand, traditional therapy has some advantages. One woman says: 'We prefer tradi-therapy because patients are quickly treated; the treatment is free with the traditional practitioner, and "witches' attacks" are also taken into account. The child can stay there and, in the meantime, we can deal with our agricultural work.'

However lay perception, to traditional healers and self-treatment only very partially explain the long delays in presentation and diagnosis. The main problem lies with health providers, particularly their lack of proper diagnosis capabilities. Indeed many patients remain undiagnosed for a long period at the health centre, eventually leading them to resume their quest for help outside the health system.

The average qualifications of the nurses, lack of knowledge about BU and of practical experience with its clinical diagnosis, in a context of an overall poor functioning of the health services, explain these problems. However, there is room for manoeuvre to reduce the long period before proper specific treatment is started. For instance, in Benin neither availability of health staff nor cost of treatment (affordability) had a significant impact on the choice of the recourse (Johnson *et al.* 2004). But the introduction in 1998 of the 'Ulcère de Buruli Program' funded by the Belgium bilateral cooperation (DGDC) was an important

factor in the marked reductions in patient delay in Benin. In 2000, promotional sessions on BU were organized by the Program in the Zou, Oueme, and Atlantique regions. After these efforts, patients reported earlier to the centre than in 1999 (Debacker *et al.* 2004).

In 2002, DRC established a national program for the control of BU that undertakes a limited set of control activities. Since 2002, in the RHZ of Nsona-Mpangu, IEC campaigns have been organised. These seemingly do have some effect in terms of consultation and behaviour change, although major efforts are still needed.

Conclusion

The World Health Organization currently recommends BU (S+R) medical treatment associated/or not with surgery (WHO 2004). The impact of this new medical and surgical treatment remains an open question in Africa, where the definition of the disease in local languages in the endemic areas is related to supernatural origins and even to notions that the disease cannot be healed (Kibadi *et al.* 2007). Our results indicate that the way forward is: first, to reinforce diagnosis capabilities at health centre level through training and supervision in order to allow earlier diagnosis and rapid initiation of treatment; and second, to intensify and adjust information of the public, healers included, in order to make it more relevant and culturally acceptable.

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