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Experiences of Pain and Expectations for Its Treatment among Former Buruli Ulcer Patients

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Abstract. Buruli ulcer (BU) is one of the 17 neglected tropical diseases for which the World Health Organization has adopted resolutions to improve treatment. BU was previously described as a relatively painless condition; however, recent research has indicated that some patients experience substantial pain. The objective of this study was to explore patients' experiences of pain and their expectations for its treatment. Semistructured interviews were conducted in a BU-endemic region of Ghana. Interviews were held with former BU patients ($N = 20$) and community controls ($N = 19$). Former patients were asked about BU-related pain and their expectations for its treatment. The interviews were conducted in October 2014, and were audiotaped, translated and transcribed into English, and then qualitatively analyzed. Of the 20 former BU patients interviewed, 19 (95%) reported experiencing pain, with patients reporting pain as a consequence of the ulcer and wound management. Some participants expressed pain through crying, whereas others did not openly express pain, sometimes because they feared the repercussions of doing so. Patients wanted to receive pain relief; however, many were unable to name a medication. Nonpharmaceutical options were cited as being an alternative. Many BU patients experience pain; however, former patients and community members alike appear to have a limited knowledge about available pain relief. A low-cost alternative to medication may be the use of nonpharmaceutical means for pain relief. Routine pain assessment may reduce patients' fear and unwillingness to express pain. Awareness of such issues will be valuable when implementing a BU pain relief guideline.

INTRODUCTION

Buruli ulcer (BU) is an infectious disease caused by *Mycobacterium ulcerans*, and is the third most common mycobacterial disease after tuberculosis and leprosy in immunocompetent individuals.[1,2] Although BU has been reported in over 30 countries worldwide, the highest prevalence and incidence is in west Africa.[3] BU affects the skin, subcutaneous tissue, and occasionally the bone. Nonulcerative forms of the disease may present as nodules, papules, plaques, and edema; however, if left untreated, ulceration may occur. Treatment of BU consists of an 8-week antibiotic regimen of streptomycin and rifampicin with surgery added as adjuvant therapy when required. Nienhuis and others reported that the majority of small ulcers (< 10 cm) were healed 1 year after treatment.[4] Wound care is necessary in this period as it can assist in speeding up the healing process and the frequency can vary from once daily to three times per week.[4] Wound care entails removal of necrotic tissue and cleaning and dressing of the wound. Physiotherapy in BU patients involves teaching patients how to position a limb to prevent deformities, how to exercise affected joints, and the use of devices such as splints.

Literature on pain in BU has predominantly stressed the typical lack of pain of the condition at presentation. This lack of pain is suggested to occur as a result of the nerve damage caused by mycolactone produced by *M. ulcerans*.[5,6] However, recent data suggest that almost 30% of BU patients experience severe pain during wound care dressings, with few receiving pain relief.[7] The pain may evolve from the manipulation of the wound combined with a decrease in mycolactone production 6–12 weeks after the start of antibiotic treatment.[8]

Apart from the human suffering, pain during the treatment may be a factor contributing to the development of functional limitations common in BU. It is reported that almost half BU patients have functional limitations after treatment, with no differences found between patients receiving antibiotics alone or antibiotics and surgery.[9] Health-care professionals (HCPs) report difficulties in the assessment of pain and are hesitant to prescribe pain medication due to cost and side effects for the patient.[10]

A guide was recently developed for the assessment of pain and (non)pharmaceutical interventions for BU. This guideline advocates assessment of pain using a combination of the Wong–Baker Faces Pain Rating Scale and clinical judgment in BU patients. This guide also includes three levels of pain relief dependent on the outcome of the aforementioned assessment, with stronger pain relief medications being provided along with increasing pain (J. de Zeeuw, unpublished data). This guideline, however, was created using the input provided by HCPs, whereas the experiences and expectations of BU patients themselves are also relevant in tailoring the guideline to patients' needs.

The aim of this study was to gain insights into patients' experiences of pain due to BU and expectations concerning treatment of BU of community members and former patients.

METHODS

Study design and participants. This study used a qualitative design, consisting of semistructured face-to-face interviews, in the catchment area of Agogo Presbyterian Hospital, one of the specialized BU treatment centers. The participants, both former BU patients ($N = 20$) and community controls ($N = 19$) resided in a village, Ananekrom, close to Agogo, known to have a high incidence of BU cases. Community controls were included to gain an idea of the

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expectations that healthy persons would have, as this may influence the expectations of BU patients when they first seek medical attention. A convenience sample was used and participants were required to be ≥ 18 years. Community members and former BU patients were matched for sex and age. A community volunteer aided in finding former BU patients who were willing to participate in the study. Community controls were approached in the town market place and asked to participate.

Interviews. An interview topic guide was developed using literature on pain and its assessment as well as previous experience and perceptions on the subject. Specific topics included the patients' experience of pain, beliefs surrounding pain in BU, perceptions on expression of pain; and methods that could reduce pain. In healthy community controls, many of the same topics were covered; however, "experiences" of pain in BU were replaced by the community members' "perception" of pain in general and in BU.

Participants were also asked questions on anticipated levels of pain and expectation of its treatment under different scenarios. The first was a light headache experienced by someone who had contracted malaria. The second, intermediate pain, was pain experienced as a result of abdominal surgery. The final scenario was that of a person involved in a car accident, who was remarked to be in the worst pain imaginable.

Data collection. Two health workers from Agogo Presbyterian Hospital conducted the interviews and each was given instruction and practice on how the interviews should be conducted. The interviews were conducted away from the market place, in a quiet, private setting. The interviews were conducted in the local language of Twi, and a voice recording of each interview was obtained. During the interview, the interviewers also wrote down, in short, the answers of the participants, in case there was an issue with the recording. The interviews for this study were conducted in October 2014 and lasted between 20 and 50 minutes.

Data analysis. The recorded interviews were independently translated and transcribed from Twi into English by a translator, who had a good command of both Twi and English and was instructed to translate the interviews as closely as possible to the original answers provided by the participants. Qualitative content analysis of the data was accomplished through the use of open and axial coding. Interviews were analyzed by two researchers (Rebecca J. Woolley and Anita Velink) simultaneously to ensure reliability of the analysis performed. Both researchers independently analyzed one of the interviews, and from this, the initial codebook was assembled. The researchers then analyzed all of the interviews separately and added them to their own codebook. Regular meetings were held to discuss the themes and to merge the codes into one codebook. In cases of disagreement, a third and fourth researcher (Janine de Zeeuw and Ymkje Stienstra) were consulted. This process was repeated until all the interviews were analyzed. Axial coding was then used to develop related codes and concepts from within the data. This was then assessed by both researchers (Rebecca J. Woolley and Anita Velink) together, and the third and fourth researchers were also involved in providing feedback to ensure that the coding of the data, ordering of the codes, and selection of the themes were adequate.

Ethics. Medical ethical approval was obtained from the Medical Ethical Review Committee of the Kwame Nkrumah University of Science and Technology; School of Medical Sciences, Komfo Anokye Teaching Hospital in Ghana (ref: CHRPE/AP/230/12). Written consent was obtained from all the participants.

RESULTS

Participant characteristics. Of the 20 community members approached, one declined as they felt they were too busy to participate in the study. All participants were found in the same district within the catchment area of the BU specialist treatment center, Agogo Presbyterian Hospital. From the former 20 BU patients, 60% of those interviewed were females, compared with approximately 58% among the community members. The age of the former BU patients ranged from 18 to 55 years compared with 18 to 66 years among the community members. The median ages of the former BU patients and community members were 27 and 30 years, respectively.

Former patients' experiences of pain. Of the 20 former BU patients, only one reported not experiencing pain as a result of BU. However, this patient did express experiencing pain as a result of the daily streptomycin injection, but appeared to not perceive it as a problem.

> *I had a small lesion and did not encounter any pain but I only express pain during daily injection.*

The remaining 19 participants expressed experiencing pain as a result of the wound itself, for example, when the nonulcerating form became an ulcer.

> *I felt the pain most when it ulcerated and initially there was fluid draining from the wound and that gave me more pain.*

Many participants voiced that they had also experienced pain as a result of the management of BU. Half of the former BU patients reported experiencing pain as a result of wound care, with six (30%) reporting to have experienced pain as a result of physiotherapy and three (15%) reporting pain as a consequence of surgery.

> *I had pain during dressing. Most especially when I went to the hospital and the slough was cut off. That was when I had serious pain.*

> *I had the pain at the time of dressing. That was when it was most painful.*

> *Pain was also experienced by patients as a consequence of daily activities.*

> *Mine was at my back so whenever I had to carry my baby on my back I felt the pain.*

> *I was always in pain especially during the night and when I was walking*

A patient who originally stated that pain was caused by physiotherapy also recounted how he experienced a worsening of pain as a result of "the dressing solutions they use." Another patient reported that "the removal of the soaked gauze from the ulcer was very very painful." Other participants attributed increases in pain to activity and "striking of the wound."

Patients' expression of pain. When asked about how former BU patients expressed their pain, the majority of patients described that they would often cry out loud.

> *I used to cry anytime I was in pain especially during physiotherapy and wound dressing.*

Other patients reported using subtle ways of expressing pain via their facial expression.

> *I was only able to express the pain by being quiet and change my facial expression like I wanted to cry.*

Some patients reported that they did not openly express their pain, but rather kept quiet. However, they did not give a clear reason as to why they chose to stay quiet.

> *I was always quiet and mute but I sometimes told them I was in pain.*
>
> *I managed to endure the pain without telling anyone.*

Patients were asked why they or another patient may not want to indicate to the HCPs that they were experiencing pain. Factors raised were fear of the nurses and fear of treatment. Some patients may not report or express their pain as they "feel they will be shouted at" by the nurses. Another patient reported that he did not indicate that he was in pain as he feared that this may lead to a change in his treatment.

> *My fear was that if they realize that my pain was getting worse that they would call for operation.*

Reported differences in the expression of pain in general. The majority of participants, both community controls and BU patients, expressed that children display more pain than adults do. It was reported that while children were more likely to "cry out loud" when in pain, an "adult will murmur when there is pain." Many factors were attributed to the increase in pain expression for children when compared with adults, including adults having a "better pain threshold than the children," and that as an adult, "you cannot complain as much."

When asked about the differences between male and female expression of pain, while some reported that there was no difference, the majority reported that women were more expressive of pain than men.

According to some participants, men are "naturally born to endure pain," whereas women are not, and therefore, will "complain about very little pain." Some patients commented on the social expectation for men to endure pain more than their female counterparts.

> *Women cry because they get a lot of care and sympathy as compared to men. And if a man should cry he will be laughed at because men are known to be courageous so they don't have to cry.*

Health workers role in treating pain in BU. When asked about what the participants expected the health workers could do to reduce pain, the majority, both community controls and former BU patients, said that it was important to provide medication.

> *I think they should give that person a pain killer/analgesic to reduce the pain.*
>
> *The only thing that could reduce my pain was to come to the doctor who gave me some medicine to take which eventually will reduce my pain.*
>
> *I was given medication but I don't know the name.*

When asked to specify, some replied that they had received "capsules and injections" to relieve the pain. Therefore, despite asking for clarification, it was unclear whether these patients had actually received pain medication.

Of the 39 participants, four reported that there are other ways of reducing the pain experienced by BU patients. One patient commented that the nurses should "take care and dress the wound very gently." Another patient suggested engaging the patient in an activity could help to reduce the pain.

Scenarios of pain. The participants were told of three hypothetical scenarios, each with a different level of pain, and then asked to report what care and pain relief treatment they would like to receive. The majority of participants answered that the patients should receive "tablets and injections" to help reduce the pain, making no distinction between the levels of pain experienced by each patient in the scenarios. However, the majority of the patients reported that giving medication and taking care of the wound were important for the relief of pain for the hypothetical patients.

Knowledge of pain medication in general. For those who named a drug, acetaminophen (paracetamol) was the most commonly mentioned, with only a couple mentioning nonsteroidal antiinflammatory drugs and stronger analgesics such as morphine. Of the 39 participants, 14 reported that they did not know the name of a medication that could help reduce their pain. Of these 14 participants, nine were former BU patients, and therefore, almost half of the former BU patients questioned could not name a drug used to reduce pain. A reason given for not being able to mention a pain relief medication was as a result of having a lack of medical knowledge.

> *Because I don't work at the hospital, I don't know the medicine.*
>
> *All I know is the injection; I don't know the specific drug.*

Ten participants mentioned other drugs as a means of reducing pain. The most commonly mentioned medication were antibiotics such as amoxicillin and cloxacillin. However, other agents were also mentioned as painkillers, including hydrogen peroxide and multivitamins.

Expectations of pain treatment in BU. When asked about how they would expect to feel after receiving pain relief medication, there was a disparity between the answers given, with approximately half expressing that the patient would have no pain, and half reported that the patient would experience a reduction in pain.

> *They will be very happy. They will confess of not having pain anymore or use their affected part in activity. They might even share tears of joy because there is no more pain.*

It was also reported that pain could be reduced by nonpharmaceutical means such as through watching television, listening to music, and reading as a means of distraction from pain.

DISCUSSION

This study was conducted to ascertain patients' experiences of pain in BU and also learn what the community and former patients' expectations are with regard to treatment. The majority of former BU patients reported experiencing pain as a result of BU and half as a result of wound care. Other causes of pain included the nonulcerating lesion becoming an ulcer, physiotherapy, surgery, and daily activities. The majority of former patients stated they would have liked to receive pain medication. Participants also reported nonpharmaceuticals could reduce pain, such as the distraction technique.

Though some of the patients reported that they cried as a result of their pain, others kept quiet and endured the pain. This quietness while in pain is in line with previous research on pain expression among some African ethnic groups in west Africa, whereby stoicism was considered to be a desired response in reaction to pain.[11] The varied responses reported in this study highlights how individual factors and social and cultural norms can have a profound effect on perception and expression of pain.[12–14] The findings in this study corroborated previous research on HCPs perspectives on pain expression among BU patients, that some patients suppressed their pain, whereas others would exaggerate it.[10] It is possible that the patients who overtly expressed their pain by crying were perceived as exaggerating their pain. In addition, the notion that BU is a painless disease may also contribute to the idea that patients exaggerate their pain.

Patients often did not express their pain for fear of repercussion. Fear of being shouted at by nurses was a reason given for not expressing pain. The possible consequence of surgery being considered as an option seemed to be a deterrent in admitting pain.

Patients and community controls alike expected that pain could be treated with medication or be reduced by nonpharmaceutical means. Nonpharmaceutical options to reduce pain that were not mentioned by patients or HCP but that could be feasible in an African setting include relaxation through respiration, or exercise.[15] In the previous research, HCPs reported one factor which influenced their decision whether to prescribe pain medication was related to the affordability of the pain medication for the patient, as the patient had to cover the cost.[10] Nonpharmaceutical options could be one way in which pain in BU could be reduced without causing a financial burden on the patient.

Previous research has indicated that the availability of step 1 analgesics (World Health Organization pain ladder) such as acetaminophen in sub-Saharan Africa fluctuates with the accessibility to mild and strong opioids (steps 2 and 3) being lower. Fear of addiction to opioids has also been suggested as a reason for low prescription rates of opioids in sub-Saharan Africa.[16] As a result of the previously stated factors, HCPs may not inform patients of other pain relief as it is either not widely available, or is not commonly used by staff or a combination of the two. When implementing a pain treatment guide, it will be important that HCPs recognize that many patients are not aware what medication would reduce their pain, and even if acetaminophen is asked for, the patient may be in more pain than the request would suggest. Based on the information obtained from this study, an e-learning program for HCPs on the importance of the identification and treatment of pain is currently being developed.

This study had several limitations, one of which was that HCPs performed the interviews. If the former BU patients were familiar with these HCPs, it could have influenced their answers as they may have been less willing to give a strong opinion about what they expected from nurses and doctors and about the management by the HCPs. However, some patients did talk about their fear of nurses. Interviewing non-BU patients did remove this bias by and large; but interestingly, this non-BU cohort did not add information much different to that obtained from the former BU patient cohort.

Another limitation was the language barrier. All of those interviewed spoke only Twi. Twi is a spoken language, rather than a written language. Although all interviews were recorded and transcribed into English, this may have produced some translational errors. The possibility for these errors to arise, however, was reduced as much as possible as the interviewers and translators were skilled in both English and Twi.

All the interviews were conducted in a village near Agogo Presbyterian Hospital. Therefore, it is possible that the beliefs and experiences of the participants in this village may differ from that of inhabitants of other villages in Ghana. Subsequently, the results of this study may not accurately reflect the experiences and ideas of people across the whole of Ghana.

In conclusion, patients' reporting of pain is individual and varied for many reasons. Fear of being shouted at or fear of surgical intervention were reasons given to be stoic and quiet about pain. Cultural norms and lack of knowledge of pain management were uncovered. The assessment of pain remains complex and current strategies of the detection of pain and its assessment are reliant upon the initiative of the patient. However, routine assessment of pain in BU may provide more useful information on pain. Including pain as a topic of discussion from the first contact moment with the patient may encourage patients to report pain and is likely to reduce the fear of repercussions that may result by reporting pain. The knowledge from this study can be helpful in the introduction of a guide on the management of pain in BU, a condition long considered to be painless, by allowing for routine pain management early on.

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