Treatment of neuropathic pain in Sierra Leone

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During Sierra Leone's violent decade-long war, the warring parties used amputation, especially of arms, as a means of terror. In a camp for amputees in the capital city Freetown, Médecins Sans Frontières established a clinic and a treatment programme for neuropathic pain. Insecurity and cultural and language barriers have complicated this work, but medical and humanitarian benefits have been demonstrated. Pain services are virtually non-existent in less-developed countries. There have recently been no major treatment advances for neuropathic or phantom pain; however, the general body of knowledge about amputation pain can be increased by observations from these difficult settings.

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Clinics devoted to the treatment of chronic pain syndromes are a relatively new development. The scientific knowledge behind the treatment of pain is growing through the work of organisations such as the International Association for the Study of Pain and the Pain Society in the UK. For both medical and humanitarian reasons,[1] there are acute pain services in most hospitals in the UK. There is growing evidence that improved treatment of acute pain can reduce the incidence of chronic pain. In less-developed countries, where basic medical services may be in disrepair, pain services are virtually non-existent, although interest in the subject is growing. A chronic-pain clinic in Tanzania recently reported a mixture of cases similar to that seen in UK clinics.[2] Non-governmental organisations also contribute to pain treatment services. Douleurs sans Frontières, for example, has worked in various places particularly with landmine victims.[3]

Aid organisations provide a large part of the aid to victims of humanitarian crises in less-developed countries. In recent years, these agencies have become more reflective about the quality of care provided.[4] How agencies distribute their limited resources in the face of overwhelming need is constantly being re-evaluated.[5] Their goal is not simply to increase the availability of health care, but also to focus on particular areas of need that, for reasons of marginalisation, stigmatisation, or the injustice that results from limited resources,[6] may otherwise be left unaddressed. Médecins Sans Frontières (MSF) is an emergency medical relief organisation that runs around 500 medical relief programmes in over 80 countries worldwide. It responds to humanitarian crises where there is broad abuse of freedom, and where violence and war lead to social injustice. For several years MSF provided surgical support to the main government hospital in Freetown, Sierra Leone. This article describes the work, beginning in early 2000, of an anaesthetist (PL) and a local community health officer working for MSF surgical programme in a pain clinic in the Murray Town Amputees' camp in Freetown.

Figure 1. This patient suffered a bilateral below-elbow amputation in January, 1999. Seen here in February, 2001, he reports pain in both stumps. The pain in the left stump is more intense and sometimes wakes him from sleep. He thinks it will be an everlasting pain. The goal of treatment was to allow him to use prostheses without pain.

Sierra Leone's violent past

In 1991, civil war broke out in Sierra Leone between the government and the Revolutionary United Front (RUF), which was formed by people who felt excluded from government because of corruption and nepotism. In the ensuing decade, the government of Sierra Leone became weakened and after several military coups the national army became discredited.

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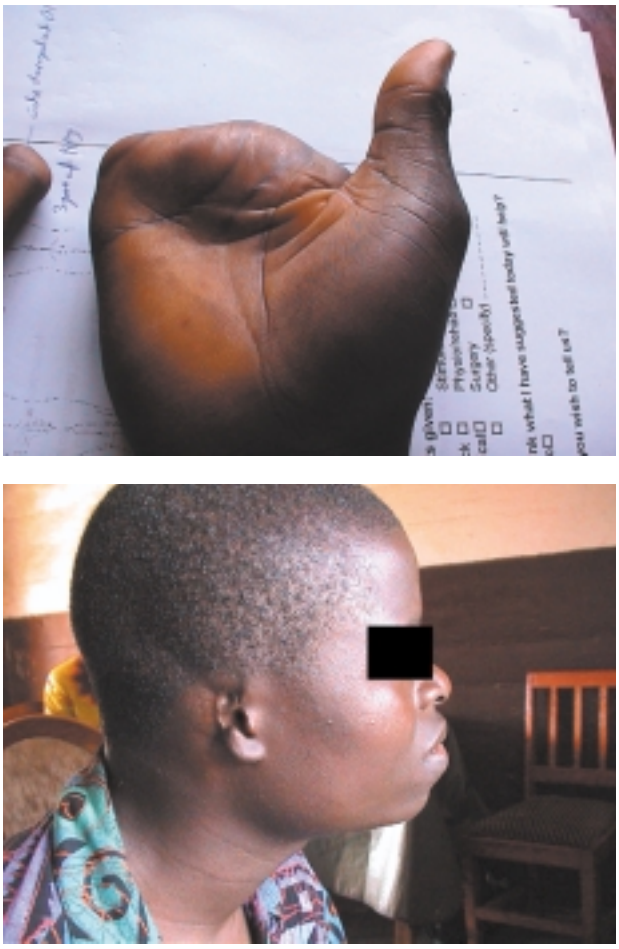


Figure 2. Seen in March, 2001, this patient had suffered a "One Love" style amputation of the hand as well as amputation of the ear. After several operations on his right hand he has stump pain and a phantom sensation (but no phantom pain). The goal of treatment was to allow him to use prostheses without pain.

All parties involved in the war have been implicated in the perpetration of war crimes,[7] and civilians have been the victims of various human rights abuses, including rape, abduction, and violent amputation.[8,9] Furthermore, armed forces present as part of regional peacekeeping organisations have not been innocent. The West African peacekeeping force known as ECOMOG were present in Sierra Leone at the invitation of the government. In January 1999, they were nearly thrown out of the country by the RUF during the campaign "Operation no living thing". During their fight back for control of Freetown, ECOMOG were widely involved in killings and beatings.

This decade of conflict has claimed thousands of lives and produced more than 400 000 refugees. Over 1 million people are estimated to have been displaced.[10] Criteria for human development and life expectancy—access to improved water sources, immunisation rates, and access to essential drugs—place Sierra Leone bottom in the world tables.[11] One of the most distressing legacies of this war is the large number of amputees.

The origins of amputation in Sierra Leone

The number of people in Sierra Leone who had amputations is not known, and some exaggerated figures have been produced. However, more conservative estimates put the numbers at fewer than 1000 people who have lost an arm or a hand in the country, many of whom may not have been seen by medical or rehabilitation services. However, an unknown number have died from infection or associated injuries, isolated from any assistance by distance and insecurity. In January 1999 alone, Freetown's main hospital treated 97 victims of amputation by axes and machetes (figure 1). MSF, working in one hospital, treated over 40 cases of serious lacerations to the arms and legs that were caused by attempted amputations.[7]

Various accounts are given for how the amputations started.[12] Some accounts suggest that, in their early days, the RUF needed to influence the civilian population; for example, to discourage them from taking in the harvest in a particular area. Amputation of the hands of people who defied their orders would intimidate all the people in an area. Forms of political intimidation have also been cited. In his election campaign, Ahmad Tejan Kabbah (President of Sierra Leone since 1996) is alleged to have said, "use your hand to vote for me". Many people said that after amputation their hands were put into a bag and the perpetrators said they would send the bag to the president. The practice of amputation across the palm, leaving just the thumb, may derive from a closed-fist thumbs-up sign of another political group, called "One Love" (figure 2).

Initial pain assessment

Murray Town Amputees' Camp in Freetown has been home to 2000 people, about 140 of whom have lost an arm or hand, and a further 80 have had leg amputations. Together with their families, they have been displaced

Table 1. Initial assessment of 40 arm amputees in May, 2000

Characteristic	Number of amputees (n=40)
Sex	
Male	32 (80%)
Female	8 (20%)
Mean (range) age, years	39·4 (16–68)
Amputation	
Total	51
Machete	35 (71%)
Axe	12 (19%)
Gunshot	4 (10%)
Unilateral amputation	29
Bilateral amputation	11
Site	
Below elbow	49 (98%)
Above elbow	2 (2%)
Other injuries in addition to the amputation	21/40 (53%)
Mean (range) time since injury, months	22·5 (10–49)
Pain characteristics	
Stump pain	40 (100%)
Phantom sensation	37 (93%)
Phantom pain	13 (33%)

Panel 1. Descriptions of stump and phantom pain and explanations given by the patient for the phenomena

Descriptions of stump pain
Pricking, shocks, nervous, trembles, one point tender
Heavy, draws*, can radiate up arm
Bite bite, shocks, runs down arm, easier when he hangs the arm down
Swell up, cry, thunder, bites, made worse by the sun
Scratches, stiff, warm, worse in heat, worse after drinking water
Current, feels like it has been freshly cut
Explanations for stump pain
"Because some of my nerves and veins have been cut off and as a result I am not getting complete blood circulation."
"Sometimes [I] think that because I walk under the sun, which is hot that is why I feel the burning pain. When I get the desire to work with my hands and there is no way for me I then feel the pain"
"I believe it is because the blood is not circulating properly due to the amputation done to my hand"
Descriptions of phantom pain
Numb, vibrates, stiff, like being hit by a stick, hot water, massage and bandage helped
Scratching, warm, a painful scratch
Like something growing bit by bit—the hand and so it hurts, at the same time the stump shakes
Hot pepper
Warm, pepper, needles
Explanations for phantom pain
"Because I still have the memories of my normal hand in my mind, since I was not born like this"
"Because I still have the memories of this missing part in my brain"

*The word "draws" in Krio translates as stretching.

from their homes by the war. Visited by foreign journalists and VIPs, they have become a symbol of Sierra Leone's troubles; they are famous.

MSF decided to assess chronic pain among the large cohort of arm amputees after the community health officer (a trained primary healthcare provider) confirmed a pain problem.

Interviews were conducted via interpreters who had worked as physiotherapy and prosthetics assistants for Handicap International who witnessed daily the problem of amputees being unable to use prostheses owing to chronic pain. The interpreters were trained in the general characteristics of pain and use of the questionnaire that was used to assess pain. A local nurse explained the patients' information sheet to the study participants, making clear that, at this stage, we were offering nothing in the way of treatment. We wanted amputees' own descriptions of the pain they felt.

During our week of assessment (May 2000) the political and security situations deteriorated. The peace agreement signed in 1999 failed as fighting between all parties was resumed. Conflict was especially intense where United Nations (UN) forces were moving into RUF-controlled areas. In some rural areas, UN peacekeepers and some non-governmental organisation personnel were kidnapped. Quite quickly over 500 UN troops were captured, their vehicles, weapons, and uniforms were stolen. There was a feeling of anxiety and suppressed panic. Following this, many non-governmental organisations including MSF took the decision to partially evacuate. Therefore, the pain assessment was hurriedly completed. Nevertheless, 40 questionnaires were gathered (table 1) and examined back in the UK.

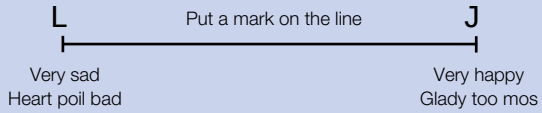
These early results showed that many of the amputees were still living with pain. Their amputations had happened between 10 and 48 months previously. The "chop" was with a machete in most cases, or with an axe in some; a few were the result of a bullet wound. We hoped very much that with the deterioration in security a new cohort was not in the making.

All of the 40 people we assessed had stump pain.[13] 13 had phantom pain (table 1). Both stump and phantom pain were described in ways similar to those in which they are described in other parts of the world (panel 1). The explanations for the pains were both practical and consistent, the latter probably reflecting the discussion between amputees living closely together inside the camp.

Pain scoring was a central part of the research. In our initial assessment, we had found that a number scale (0 for no pain; 10 for worst pain imaginable) seemed comprehensible, whereas a word scale (none, mild, moderate, severe and extreme) was not understood. Translations into Krio (a language based on English that is the first or second language of most Sierra Leonians) and other languages were not exact or not available. We subsequently developed word scales for both mood and pain in Krio (panel 2).

When we asked people what they now wanted in life, pain relief was not on their list. They replied in terms such as finding their family members (some of whom are alive, some of whom are not alive), returning to their homes, finding their lost possessions, finding employment, obtaining a modicum of personal success or progress, stability in the country, and regaining self-respect. Revenge was rarely mentioned and is still rarely an issue. These are important answers, but they did not mean that we should not attempt to intervene with the pain problems.

Panel 2. Krio visual analogue and word scales for mood and pain



In the past month how sad or happy have you been?

Very happy	o	A glady too mos
Happy	o	Glady
Normal	o	E nor bad, or half half
Sad	o	Me heart poil
Very Sad	o	Me heart poil bad

Word scale for pain

None	None
Minor	Small
Medium	Half and half
Severe	Serious

Table 2. Site of the pain in first 181 new patients seen in the clinic

Pain site	Number of patients
Generalised body pain	23 (13%)
Head, face, mouth	14 (8%)
Neck	8 (4%)
Thorax	16 (9%)
Abdomen	7 (4%)
Back	42 (23%)
Upper limb stump	
Unilateral	83 (46%)
Bilateral	19 (11%)
Total	102 (57%)
Lower limb stump	
Unilateral	42 (23%)
Bilateral	1 (1%)
Total	43 (24%)

A single patient may have several sites of pain.

Furthermore, for MSF the development of a protocol to treat neuropathic pain that could be adaptable to the various difficult situations in which the organisation works would also be useful.

Pain treatment

Chronic-pain treatment was established when we were able to resume the MSF programme in the Murray Town Amputees' Camp in early 2001. The pain clinic was not limited to particular problems, and anyone with pain was able to attend; however, most of those who attended were amputees (table 2). The aim was to establish the clinic, train a local community health officer, and let the clinic function for a period, and then reassess. One useful outcome measure was whether such an activity could run with minimum expert input.

One of the local staff we employed was at first sceptical of there being a problem with pain, but became convinced otherwise during an early meeting with one of the camp's committees to discuss the planned intervention. One man described in detail the burning, "drawing" (stretching), and pricking in his elbow stump; he spoke in a loud voice with emphatic gestures and with vocal support from several others in the group. After this experience, the local staff member impressed upon us that there was a real problem here that we must do something about.

Consultations were by appointment and patients were given reminders to attend. The information we collected included demographics, pain descriptors, pain scoring, mood, use of prostheses, activities of daily living, and clinical examination. We also asked about other injuries—beatings were common and there were other amputations, including ears (figure 2) and toes. Assessment of a new patient took approximately one hour; follow-up visits took 15 mins. If treatment had been started, the follow-up consultations were weekly, with the aim of checking for side-effects and repeating key messages as the opportunity arose (panel 3). Doses were increased as tolerated on a simple dosage regimen; patients could reach any dose on this regimen.

Treatment goals were set in an attempt to avoid unrealistic expectations (eg, to be able to sleep at night without being woken by the pain, or to be able to wear a shoe). We were aware that rumours spread quickly with people living closely together and maintenance of realistic expectations was essential both for therapeutic reasons and because this group had already been exposed to various broken promises.

We took advice from the community health officer who was in charge of the general clinic and talked to the religious leaders, the camp committees, and to Handicap International. The latter played an important part in advising appropriate people—such as those having difficulty in rehabilitating owing to pain, or for whom pain was limiting the use of prostheses—to come to the clinic. They also gave feedback about problems or misconceptions that occurred and provided some of the elements common in pain clinics in more developed countries, such as physiotherapy and some psychological support. We could not hope to run along genuinely multidisciplinary lines, but we did try.

Although the clinic was positioned within the MSF health clinic and beside the Handicap International working area, the working conditions were not ideal. The room was noisy, positioned as it was between an orthotic workshop and a hut containing the generator. About 3·5 m square, the room was also hot. A maximum of three interviews could be undertaken at the same time.

Clinic tools were simple, mostly paperwork such as the record sheets and appointment cards (figure 3); examination was with cottonwool and a blunt pin. All of the criteria for starting medication (panel 3) had to be met by patients before treatment was started (unless examination results were equivocal and the other four criteria were met). Most cases showed both hyperalgesia with a blunt pin (thought to be indicative of a wind-up phenomenon in the spinal cord) and allodynia (pain with a stimulus not normally resulting in pain, which may reflect rewiring as Aβ fibres sprout into C fibre regions) with cottonwool.

We chose the antidepressant amitriptyline and the anticonvulsant carbamazepine for treatment because there is wide experience with their use and demonstrated efficacy

Figure 3. Tools of the clinic: cottonwool, amitriptyline, carbamazepine, blunt pin, and appointment card.

Panel 3. Aims, dosage, and criteria for treatment of amputees

Key messages

We believe that you have pain

Pain does not mean continuing damage, the damage has already happened

Medication may or may not help the pain

Medication may take weeks or months to help

Medication must be taken regularly

Side effects become less as you continue to take the medication

Only rarely are further operations useful

Exercise and physiotherapy are good at reducing pain

Dosage schedule

Week 1	Amitriptyline 25 mg at night Carbamazepine 200 mg at night
Week 2	Amitriptyline 50 mg at night Carbamazepine 200 mg morning and night
Week 3	Amitriptyline 75 mg at night Carbemazepine 200 mg morning, midday and night

Patients remain on the dose they can tolerate

Drugs were used in combination, except in women of childbearing age

Criteria for starting medication

Pain description included words such as shooting, shocking, burning, or cramping. The local term "drawing" was also commonly present, which translates as stretching

History consistent with the physical damage of nerves

Examination with cottonwool and blunt pin showed evidence of a difference from normal skin such as allodynia and hyperalgesia or numbness

Pain scores and how it affects the patient's life were suggestive of a significant problem. For example pain waking them from sleep

Patient wished to try it and could follow instructions

in the treatment of neuropathic pain.[14–16] Side-effect profiles were acceptable and the drugs were already on the MSF list of essential drugs. The drugs were used in combination, except in women of childbearing age for whom only amitriptyline was used owing to the association between carbamazepine and neural tube defects.

Social interaction is an essential part of medical work, but is inhibited when one is working with another culture, especially when working through interpreters. We sometimes found it hard to tell when people were upset: facial changes were small or the patient became silent. Working with interpreters could be frustrating because they may lead the patient to avoid upsetting issues or not relate information they find distressing.

Mirrors have been reported to be useful in the treatment of the phantom pain of amputees (see page 187 of this issue),[17] the theory being that putting back the visual input can complete a neural circuit. We know what a profound experience seeing the missing limb can be. We constructed a mirror box to be used in treatment. Despite explanation of the aims and what they might feel, for most of the seven patients who tried it, the mirror box brought back the terrible events of the amputation. When we talked with each of them the next day, they did not seem to be angry but they also had no intention of trying the mirror box again. As a method of potential help the use of the mirror box was justified as it is noninvasive, simple, and patient directed, but the preparation, explanation, and discussion of expectations was inadequate in this difficult setting.

Reassessment

In late 2001, the clinic was reassessed (the locally trained community health officer had been in charge for the previous seven months). We reassessed the patients on medication, those who had stopped medication, and those never on medication; each group made up about a third of the total number of patients (now about 220, although not all amputees). We repeated some of the assessments used earlier in the year.

The side-effects of amitriptyline and carbamazepine frequently limit their use. Not surprisingly, therefore, side-effects were the most common reason given for stopping medication. Some people had moved away. Most who had stopped said they were interested in starting medication again, and these people were reviewed.

The majority of those on medication had complied with it for 7 months. The reasons for long intervals without medication were generally understandable (eg, illness or travelling away for a funeral). Short intervals occurred mostly because the patient forgot to take their medication or there were competing commitments such as training or a meeting. There was some confusion over dose and when to take medication. Most said they took the tablets for pain relief, although some said they took them to aid sleep, for a generally well body, or for an increased appetite.

After medication, improvements were found in measures of mood, in day-to-day life (eg, employment, prostheses use, reaching physical goals, and in activities of daily living) and in pain (measured by word scale and number scale). Patients on medication thought it had reduced their pain, and on examination there were fewer physical signs. These improvements cannot be attributed to medication alone; the passing of time and the increasing stability in the country may account for some. Patients did not simply receive tablets or no tablets, they also all received an assessment and some explanation of what they felt and had a chance to talk. These features may be equally important.

The future

The general situation in Sierra Leone in early 2002 seems to be improving. There is free access for the UN forces throughout the country, disarmament of combatants is taking place, and displaced people are gradually returning to their home areas. The atmosphere during the mid-May parliamentary and presidential election was very calm. Rebuilding Sierra Leone is an enormous task and how conditions develop in the wider context of West Africa remains to be seen. Fighting has recently increased in neighbouring Liberia.

MSF's treatment of pain has both humanitarian and medical features. The chance for people to tell their story and to have acknowledgment of the pain seemed to be

useful for them and, we hope, reduced fear. The main problems faced in undertaking this work were related to security, and the language and cultural barriers that had to be overcome.

Published research into neuropathic and phantom pain is exciting, but no major treatment advances are appearing. The striking CNS changes and plasticity of the system have been demonstrated in various studies, largely with positron emission tomography.[17] The body of knowledge about amputation pain can be added to by observations from frequently neglected and difficult settings like Sierra Leone.[13,18]

This work indicates that a combination of explanation, interest, and medication can help to improve the well-being of a vulnerable group in a setting of some social turmoil after nerve damaging injuries have led to neuropathic pain. Part of the benefit that results from such work is through showing people that we believe them about their pain, and can explain it a little, which in turn makes them less frightened by it.

Acknowledgments

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Authors' contributions

PL wrote this paper as an account of his experiences in Sierra Leone. NF contributed to the writing of the paper.

Web sites

About the RUF
www.fas.org/irp/world/para/ruf.htm
About the IASP International Association for the Study of Pain
www.iasp-pain.org
About UNAMSIL
www.un.org/Depts/dpko/unamsil/body_unamsil/htm
About Human Rights Watch
www.hrw.org
Médecins Sans Frontières
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