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Wartime children's suffering and quests for therapy in northern Uganda

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Chapter Eight

Scabies

Introduction

This chapter's main focus is on *gwinyo* (scabies), in particular children's experiences with scabies and how they managed such illness episodes. In Gulu, scabies, like ebola, was one of those less known infectious epidemics, closely linked to the phenomenon of institutionalisation in the management of problems related to armed conflict. Institutionalisation here refers to the creation of institutions for rehabilitation, counselling, and shelters, which were viewed as solutions to the insecurity caused by the displacement of people fleeing frequent LRA attacks to go to the safer areas of Gulu Municipality.

In Part II of this thesis I mentioned that children attending displaced primary schools were more likely to have *gwinyo* or scabies than children who attended mainstream municipal schools. Such children were also those who spent nights at night commuters' shelters – including Noah's Ark, Lacor Hospital night commuter's shelter, Holy Rosary, and the district water processing centre – places commonly referred to as *bagdhad* by children. Scabies was common in these shelters, and was managed in various ways, though it frequently led many children to the point of despair. Some children referred to scabies as *anyoo* (measles), but such suggestions were quickly refuted by others in the same age group. In one group discussion at Noah's Ark, six children argued how measles only affected children who were not immunised when they were still young, but scabies affected everybody at *bagdhad*. "Everybody who spent nights at *bagdhad* quickly got scabies, regardless of whether they were immunised in childhood against measles. Therefore, scabies is not *anyoo* (measles)", argued one fourteen year old girl.

The basic structure of this chapter follows the themes of prevalence, medicine use, and symptoms of scabies. An analysis of findings is made in the discussion section, and subsequently conclusions are drawn.

8. Findings

8.1. Quantitative data: Prevalence and management of scabies

Table 8.1: Prevalence of scabies within a one month recall (N=165)

Illness	Boys	Girls	Total	P-value
Scabies	83	33	116	<0.005

A relatively high proportion of children – 116 out of 165 (14%) – mentioned having had an experience with scabies within a one month recall. However, the data shows a disproportionate prevalence rate of scabies in boys – 83 (19.1%) – compared to girls – 33 (8.3%) – consequently suggesting a strong statistically significant difference between boys and girls ($P < 0.005$). This is, however, a unique outcome since by observation there were no major variations by gender in the prevalence of scabies. In addition, as evident in the presentation of quantitative data related to medicine use below, a similar number of boys and girls indicated that they used *Opele* (Benzyl Benzoate ointment) within a one month recall, which is the particular medicine used to treat scabies.

It is important to note that at the time when this survey was conducted, children who spent nights at night commuters' shelters and those who attended displaced primary schools were still recovering from the scabies epidemic, and the questionnaires were administered shortly after Medicines sans Frontiers (MSF) had implemented a curative scabies intervention to affected persons in night commuters' shelters.

Table 8.2: Medicines used in the treatment of scabies within a one month recall (N=165)

Medicines	Boys	Girls	Total	P-values
Red and yellow capsules	53	60	113	0.03
Black and red capsules	24	12	36	0.07
Amox (as called in drug shops)	10	4	14	0.23
Amoxicillin or Tetracycline	87	76	163	0.92
Opele (ointment for scabies)	64	64	128	0.11
Pen V (penicillin V)	62	64	126	0.06
Septrin	21	22	43	0.49

Results about medicine use for scabies show no statistically significant difference between boys' and girls' use of medicines, except for use of red and yellow capsules

($P=0.03$), used by girls slightly more than boys. As mentioned earlier, it was difficult to judge which particular health complaint a child was treating when she had multiple infections – which could include scabies – and used Amoxicillin within a one month recall. Results concerning the use of pharmaceuticals therefore overlap. Where children mentioned the use of Pen V, Amoxicillin, and Septrin for scabies, they indicated crushing the pharmaceuticals and applying the powder onto the affected skin. One of the most commonly used medicines for scabies, however, was *Opele*, a market drug in the form of an ointment often described by children as the best medicine for scabies, and which they commonly stated was first introduced to Gulu by MSF. The *Opele* I purchased at the time of this study had Benzyl Benzoate as its active ingredient.

Table 8.3: Herbal medicines used in treatment of scabies within a one month recall (N=165)

Herbal medicines (extracts)	Boys	Girls	Total	P-values
Pawpaw leaves	82	59	141	0.003
Garlic	34	39	63	0.12
Banana sap	29	19	48	0.24
Neem leaves	24	11	35	0.042

In the context of medical pluralism, herbal remedies were used, sometimes concurrently with pharmaceuticals, in attempts to minimise suffering. Remedies which children named for scabies included washing with pawpaw leaves, as mentioned by 141 children (23.7%), garlic, as used by 63 children (10.6%), banana sap by 48 children (8.1%), and neem tree leaves by 35 children (5.9%). Apart from a strong statistically significant difference observed in the use of pawpaw leaves ($P=0.003$) – showing higher use by boys ($n=82$) than girls ($n=59$), and a slight statistically significant difference in use of neem leaves ($P=0.042$) – there was no significant difference in boys’ and girls’ use of herbal remedies for scabies. Boys’ higher reported use of neem leaves ($P=0.042$) for scabies is not a strong association, and this could signify that other factors influenced the outcome of results. Such factors could include the presence of other remedies for scabies on the market and easy access of other herbal remedies for scabies or remedies at state aided centres within Gulu Municipality. The latter analysis is consistent with the fact that fewer boys reported to have used neem leaves compared to pawpaw leaves.

8.2. Qualitative data: Prevalence, symptoms, and management of scabies

8.2.1: Exemplary narratives about an experience with scabies within a one month recall

About two hundred children wrote compositions discussing their experiences with scabies during the first phase of the study. One fourteen year old boy, Owino, described his experience as such:

I suffered from a disease called scabies. It was transmitted to me from my neighbour, i.e. the boy whom I sleep together with at the shelter. Then I was told to bathe four times per day, and I even heard this from the radio. If you have this kind of disease you should bathe four times per day, so I started bathing four times with soap. Then when I did this for four days, the scabies did not cure. I told this to my guardian, and then he told me to go to the hospital. Then I went to hospital the following day in the morning after washing my body. When I arrived at the hospital, I go to the doctor, then he writes the name of my disease, then I go to another doctor to inject me. Then after, I left the hospital for home. So I stayed home for one week and the scabies disease got cured.

Fourteen year old Akello narrated her experience as follows:

One day there was a disease called scabies which attacked my body. My sister said to me, go to the hospital. When you are going, you buy a book of 100 Shillings where they will write your name, and give it to the doctor. The doctor told me you go and wash your body and you come back in the office. So I go to one house and wash my body. The doctor treated me with white medicine [Benzyl Benzoate]. So I go home and I am now okay.

Generally speaking, as exemplified in the two narratives above and indeed in fifty percent of the children's narratives about their experiences with scabies, there were notions of blame and accusation, the most dominant of which were about a lack of personal/bodily hygiene as a major predetermining factor, and about former child soldiers as the main perceived source of the epidemic. I discuss this in more detail below.

Scabies was one of those epidemics in Gulu which received emergency intervention – mainly in the form of awareness messages. In Owino's narrative above, and other children's narratives also, there were references to hearing messages over the radio, in workshops, during counselling sessions, and in seminars in displaced primary schools, educating people at risk about scabies. In the awareness messages there was advice about bathing with medicated soap and avoiding sharing basic facilities with infected persons. In July 2004, one frequent awareness message broadcast over Radio Mega and Choice FM, sponsored by various key healthcare institutions in Gulu, advised people on how to avoid infection, how to manage scabies through bathing four times a day with medicated

soap, and if symptoms persisted, that they should consult their nearest doctor. In the main, scabies was connected to the dangers of dirt, and subsequently people at risk were advised to ensure that they lived hygienically and avoided contact with infected people. This is why, despite the fact that mainstream municipal schools hosted displaced primary schools within their compounds, it was rare that children from municipal schools interacted with displaced children, especially during the period of the scabies epidemic.

8.2.2. Prevalence, symptoms, and severity of scabies from children's perspectives

By observation, between July and September 2004 all children of primary school age who spent nights at Noah's Ark night commuters' shelter had scabies. This prompted the Noah's Ark, counsellors, to conduct what they called counselling sessions for their infected clients. In these counselling sessions, which I regularly attended, health awareness messages focused on notions of cleanliness, hygiene, the use of medicated soaps, and how to avoid catching scabies. Occasionally Protex medicated soap would be distributed to what counsellors called "the dirtiest children, perhaps because they did not want to bathe at home". Such children would then be forced to bathe before going to sleep.

During twelve focus group discussions and over forty individual interviews in August 2004, all children at Noah's Ark named scabies as the most severe skin disease they had ever experienced. One fourteen year old girl described her experience of scabies, and her disgust with the epidemic, as follows:

When you are attacked by scabies, the skin keeps on itching as you scratch it. Pimple-like swellings appear on the skin, which are quickly filled with pus. These are quite unpleasant to look at. Worst still, children from other primary schools laugh and call you dirty, someone who does not bathe and a rebel from the bush.

One boy whose entire body was affected by scabies could hardly sleep due to the persistent itching of his skin. He bought two Pen Vs to apply on his skin, but he could not afford enough for his entire body. In another example, drawing again from the case in the prologue of Ojok and his siblings, I observed that they were all infected with scabies. Ojok's hand had both severe fresh pimples and those which showed signs of healing, but his youngest sibling was even more affected. Ojok indicated that since his younger sibling's scabies was more severe, he had bought Amoxicillin capsules and applied it on the affected areas. Fortunately for them, in late August to early September 2004 MSF implemented an emergency intervention effectively treating all affected persons with *Opele* ointment.

In an exercise in 2004 at five displaced primary schools, listing and ranking common illnesses experienced at home or at Noah's Ark, some children ranked scabies as the most severe. In one focus group discussion with twelve to fifteen year old girls, an argument ensued about which was the most severe, scabies or malaria. After a lengthy argument, the children agreed that malaria was more severe than scabies since they had not seen anyone yet die of scabies; what is more, malaria affected almost everybody, but scabies attacked only children who slept at *bagdhad* or those children who escaped from the bush. In diagrammatic representations of common illnesses done by children in one displaced primary school, all of the 120 children portrayed an individual with scabies. The pictures featured a person scratching his/herself, and showing dark spots and patches on his/her skin. In one exercise at a displaced primary school, as five boys discussed the drawing exercise they wondered if the child had been sleeping in Noah's Ark shelter, or had recently escaped from the bush, indicating that he was a former LRA fighter.

In various interviews with former child soldiers we discussed the commonly held belief – expressed by the children above – that they were the likely source of scabies infection; something they strongly denied. One fourteen year old former child soldier instead attributed such assertions to the common practice of blaming them for every bad thing which happened in Gulu. While it could be true that because of the living conditions in the *ilum* (bush or rebel captivity) such persons were exposed to various infective agents and could therefore be sources of infectious epidemics, it is also true that former child soldiers faced severe hostilities and exclusion in the very communities in which they were reintegrated.

In July 2005, when I conducted similar information gathering exercises, fewer children mentioned scabies as a common illness, perhaps because the epidemic was by then under control, and affected the children less severely. However, there were still exceptions. Children who were affected used both pharmaceuticals and herbal remedies to treat scabies. The pharmaceuticals used were largely antibiotics; the same used for other purposes such as treating cough and diarrhoea. In one focus group discussion an eleven year old girl shared how she had tried – with limited success – using “a mixture of goat's milk, delident toothpaste, and garlic as a remedy for scabies. However after so many times of trying, there was no improvement. I stopped trying”. In this discussion, some children laughed at her description, but by the end, after each individual's narrative, no child laughed anymore. Other children also shared their use of delident toothpaste as

a treatment for scabies, but it was very expensive so they had to give up. A substantial number of children disclosed that they had tried washing in the River Nyao, since one healer had once told them about its curative powers, but the river could not cure scabies. One boy even indicated having used chloroquine tablets – knowing full well that that they are used in the treatment of malaria – by crushing them and applying the powder to his scabies infected skin. In his conclusion he mentioned how, “with scabies, the way it pains, the way the skin keeps on itching, you can do anything to get better”.

In a one month observation exercise in two drug shops in Cereleno suburb in September 2004, sixty-seven children aged between six and sixteen bought *Opele* for scabies. Each package of this ointment cost 1500 Shillings (0.65 Euro), and this relatively high amount of money for a one time expenditure was unique since, unlike malaria tablets which children frequently bought two or three of at a time, the packaging of *Opele* did not allow children the flexibility of buying smaller quantities. One child indicated using his entire day’s earnings from *leja leja* to purchase *Opele* to treat his scabies. However, as compensation, it was also possible for an entire family to share one package of ointment. In unstructured interviews with one drug shop owner in Pece, where three children had reported for an application of *Opele* on their scabies, he disclosed that he had made a special arrangement in order to help parents who could not afford to buy the entire tube. Each child paid 200 Shillings (0.085 Euro) each time he applied the *Opele* to the severely affected areas.

In August and September 2004, approximately 150 children were observed in five drugs shops in Cereleno and Pece purchasing Amoxicillin capsules for the treatment of scabies. Although Amoxicillin was also used for cough, sprinkling on wounds, and for diarrhoea, a substantial proportion of children observed at the drug shops indicated that the capsules were also good for sprinkling on scabies-infected skin. One nurse running a drug shop also advised five children who asked for Amoxicillin for their scabies to ensure that they first cleaned the infected areas with Protect before applying the Amoxicillin capsules. In her drug shop she sold various medicated soaps, including Protect, however no child bought what they described as “that expensive soap”.

8.3. Key informants’ perspectives on and interventions to control scabies

In order to tackle the scabies epidemic, the general approach taken was the dissemination of numerous awareness messages about the spread, control, and management of scabies,

funded by the African Medical Research and Educational Foundation (AMREF), MSF, and other healthcare institutions, including the District Directorate of Health Services (DDHS). Gradually the messages evolved from washing four times a day, to emphasising the importance of washing several times a day with medicated soap. In short, focus was on individual hygiene as the main preventive measure to the control of scabies. The DDHS was overwhelmed by various placards, awareness messages, and announcements about scabies from various NGOs attempting to ensure the wellbeing of vulnerable people in conflict zones. Their message, in short, was that scabies was a highly infective skin disease which people should deal with as follows: they should bathe regularly with medicated soap; they should avoid coming into contact with people who are infected; and if affected, they should seek medical attention at a state aided health centre.

The most phenomenal response to the scabies epidemic came in the intervention by MSF. Announcements were made over local radio stations, including Radio Mega, calling for all affected persons to gather in one of the various night commuters' shelters at specified times. At Noah's Ark, MSF staff arrived one evening in early September 2004 with a white liquid. Nobody was able to tell me its name, not even Noah's Ark's head nurse. Affected persons were instructed to bathe with the Protect soap provided, and then come for administration of medicines all over their body. Some children described the activity as 'dipping', where the whole body was smeared with the white liquid. Subsequently, most of the children's and adults' scabies dried up and was cured within two to three days. That marked the phenomenal control of the scabies epidemic. A few children missed their chance for 'dipping', but the shelter nurses were left with some of the medicine which they could administer themselves.

MSF responded at a time when most wartime children were virtually exhausted from trying various remedies, including toothpaste, to no avail. Children who went to health centres for medications for their scabies were often told about the importance of individual hygiene, and it was these individuals' experiences with the recommended hygiene rituals that led to the messages being redefined several times over; from bathing many times, to bathing many times with soap, to then needing to bathe often with medicated soap. Needless to say, the fact that a substantial proportion of wartime children had difficulties in accessing basic food requirements, let alone medicated soap, and lived in a situation of great insecurity, was not taken into consideration in these

awareness messages. For example, at Noah's Ark during the months of July through September 2004, there were sensitisation efforts and seminars for the people sheltering there who needed a safer place to spend their nights. In each of the sessions, children and adults were told about the importance of hygiene, using medicated soap, and avoiding close contact with scabies infected persons at the shelter. In Chapter Thirteen I will show how some counsellors frequently singled out children who appeared very dirty for more intensive counselling about the importance of personal hygiene. Only on rare occasions, however, were the very dirty children given Protect medicated soap and instructed to bathe.

8.4. Discussion

Scabies is an ectoparasite infestation, caused by the mite *Sarcoptes scabiei*, variety *hominis*, and transmitted by person to person contact. The typical and atypical clinical presentation of pruritus (skin itching) is the hallmark of scabies, which occurs in young, pregnant, immuno-compromised, and elderly persons (Hengge et al. 2006:769). Hengge et al. further argue that despite commonly held beliefs, scabies is only infrequently acquired from contaminated fomites (e.g. clothing, towels, and bedding). Although Hengge et al. (2006) suggest that scabies is endemic in impoverished communities, in Gulu District scabies was a new disease, closely linked with displacement and the phenomenon of people spending nights in night commuters' shelters characterised by overcrowding facilitating person to person contact and poor hygienic conditions. For example, it is alleged that after scabies was first identified in Noah's Ark night commuters' shelter, it was only a few weeks later that it presented in epidemic proportions.

Topical Benzyl Benzoate therapy (of a 10-25% concentration) has been widely used for adults and in a diluted form for children, babies, and breastfeeding mothers. The most common adverse event is an initial burning sensation caused by local irritation, which is common with the more concentrated lotion (25%). When severe, the Benzyl Benzoate must be washed off; however, with analgesia and antihistamines before treatment the stinging often diminishes after 10-15 minutes, allowing the lotion to remain applied (Hengge et al. 2006:774).

In analyses of this study's data pertinent to children's and key informants' perspectives about scabies, I will only address the issues of prevalence and the management of scabies. Other findings related to scabies are directly aligned with the

institutionalisation of complex socio-economic and political factors, which have been elaborated upon in preceding chapters. The advantages and disadvantages of employing short term curative approaches in the management of this infectious epidemic are also addressed in the preceding chapters focussing on malaria, diarrhoea and respiratory tract infections. Where I again evoke the limitations of focusing on the disease itself in its management, it is for the purposes of emphasis, but also to show that infectious diseases have unifying factors in their occurrence and management.

8.4.1. Prevalence of scabies

As mentioned earlier, Gulu District experienced an epidemic of scabies during the first phase of this study. By observation, the people affected were, in the main, children who attended displaced primary schools, spent nights at night commuters' shelters, and people residing in displaced persons' camps. The major unifying factor was that they were resource poor persons, residing in overcrowded areas and they were severely affected by armed conflict.

In the previous chapter on the social lives of wartime children, I mentioned how at break times children from Gulu Prisons P.7 School avoided interacting with children from displaced primary schools. One of the reasons for this in 2004 was that they were considered dirty and often had scabies, and this is in part because at *baghdad* and displaced primary schools there was limited space and few facilities to cater for the numerous children and even adults who nightly commuted to these shelters for safety. In a large part congestion, poor living conditions, and a lack of basic sanitation measures – especially in contexts where all basic facilities were shared – provided opportunistic factors facilitating the easy spread of such infectious epidemics. That the scabies epidemic reached alarming proportions within only a few months of the first case being identified – that of a former child soldier who spent nights at one of the shelters – is therefore no surprise.

Although the statistical evidence suggests a higher prevalence of scabies in boys than girls, by observation there was no statistically significant difference in infection rates according to gender. It is possible that the quantitative results indicate that scabies affected more boys than girls, since more boys spent nights in night commuters' shelters in 2004. However, the fact that only a small proportion of girls reported having had scabies is important since it reveals something about attitudes towards the disease. The displaced school and all the night commuters' shelters where I carried out my research

had experienced an epidemic of scabies, meaning that virtually all the children had been affected. However, through sensitisation of displaced persons through varied media, including radios and health seminars, the children interviewed had come to shun this disease and associate it with dirt, poor hygiene, and lack of soap. Such attributes are rarely associated with the female gender in patriarchal societies, and it is therefore likely that while a higher number of girls were probably affected, quite a few were unwilling to discuss it. It is also likely that girls were reluctant to share their experiences with scabies since general notions of *baghdad*, dirt, carelessness, and poor individual hygiene were used to explain the epidemic. The specific notions in awareness messages about scabies, promoted by key emergency healthcare interventions, contributed to such negative connotations.

8.4.2. Management of scabies

Noah's Ark's approach of counselling the wartime people at greatest risk of scabies infection is telling. As mentioned earlier, the Gulu-DDHS was mainly involved in the dissemination of awareness messages about the prevention and management of scabies, while MSF adopted an emergency therapeutic approach of applying Benzyl Benzoate to infected children. It is doubtful that the awareness messages from the DDHS were in any way effective in controlling the scabies epidemic, much as the health personnel often boasted about how they had intervened, and curative interventions such as that of MSF, though immediate and quite effective, also reveal a narrow approach which focuses on the pathogen and medicalises socio-economic problems. Certainly it is commendable to employ any technique available or within contextual factors such as limited funds in order to minimise suffering, but there are questions which remain to be answered. Are there not better ways to completely put an end to such intermittent infectious epidemics? Although Hengge et al. (2006:777), Lawrence et al. (2005:34-42), Reid et al. (1990:595) and Taplin et al. (1990: 67-73), suggest that there is evidence that health education combined with improved diagnosis skills and improved drug supply will result in a significant reduction of scabies, in Gulu only MSF's intervention – of applying scabies medicines on infected people – led to control of the scabies epidemic. All information disseminated about how to avoid contracting scabies and how to individually manage it were fruitless. This study does, however, critique the idea of simple mass treatment in the case of scabies since this will produce little long term effect as people at risk are not empowered to manage

the epidemics themselves. And as mentioned earlier, the most effective interventions for infectious epidemics lie not in curative approaches but in preventive measures.

When children were confronted with scabies, their approaches were to systematically (or non-systematically) search for a cure. By non-systematic I imply desperate *bricolage*-like efforts undertaken to minimise suffering, such as the use of crushed Amoxicillin, Pen V, and other antibiotics applied onto the infected skin. Other narratives suggest the use of goat's milk and different types of toothpastes. Needless to say, rarely were such frantic attempts useful as effective treatment for scabies. Nevertheless, there is some inherent satisfaction which individuals achieved through having at least tried their best to intervene, to challenge, and to minimise their suffering. It is this satisfaction which, for lack of a better way to put it, I refer to as the 'unintended effect' in the quest for therapy, because the idea that individuals have tried everything possible within their means – even with limited or no success – means that they do not feel the need to blame themselves about having done nothing. I will pursue this insight in subsequent chapters, particularly in the discussion concerning dilemmas in short term curative approaches in the management of emotional suffering.

Furthermore, information gathered from the children about how they managed their scabies infections implies that they did attempt to adhere to the awareness messages broadcast throughout the region. And although it was expected that people at risk would be able to manage their scabies based on information provided, one of the examples above shows how despite the fact that one child strictly adhered to the information disseminated, he had only minimal success. This leads me to suggest that perhaps even curative approaches are better than information dissemination in the control of infectious disease epidemics. What is more, such messages advocated using medicated soap, which at a cost of 1500 Shillings (0.62 Euro) was far higher than normal soap at a price of 200 Shillings (0.13 Euro), and beyond the financial means of most wartime children. It then becomes clear how such simplified messages could send conflicting messages to people who are suffering and are in need of a solution, yet are constrained by poverty, low purchasing power, and an inability to meet their basic needs for such things as shelter, clean water, and food. That there were no efforts to address such complex socio-economic factors in the control of scabies is not surprising given the typical ways in which healthcare interventions attempted to alleviate the suffering of people in conflict zones through promoting awareness messages, emphases on curative approaches, counselling

people who were infected and those at risk, and sensitisation seminars. I will come back to the foregoing analysis in subsequent chapters.

Conclusion

Scabies was a severe epidemic due to its acuteness, severity, and highly contagious nature. The scabies epidemic was also distinctly connected to resource poor living and overcrowded sleeping conditions. Although children indicated various ways of dealing with scabies, they were generally of limited success. Even approaches recommended by key healthcare intervention agencies, which relied on the persistent dissemination of health awareness and preventive messages, were not effective in minimising the epidemic. MSF's focused curative approach – where they instructed affected people to bathe with the medicated soap provided, and then smeared each client with Benzyl Benzoate ointment – did drastically minimise the epidemic, and such a one time intervention is certainly welcome. Nevertheless, it leaves questions pertinent to the social determinants in disease production unanswered. This study, in the main, attributes the phenomenon of scabies – and other infectious diseases discussed in previous chapters – to wider socio-economic factors in wartime.