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

Akello-Ayebare, G.

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

Grace Akello-Ayebare

ISBN: 9970 05 033-8
Cover page by Grace Bithum and Yusuf Nsanja

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

Proefschrift

ter verkrijging van de graad van
Doctor aan de Universiteit Leiden
op gezag van Rector Magnificus, prof. mr. P.F. van der Heijden,
volgens besluit van het College voor Promoties
te verdedigen op woensdag 20 Mei 2009
klokke 16:15 uur

door

Grace Akello-Ayebare

Geboren te Tororo, Uganda in 1973

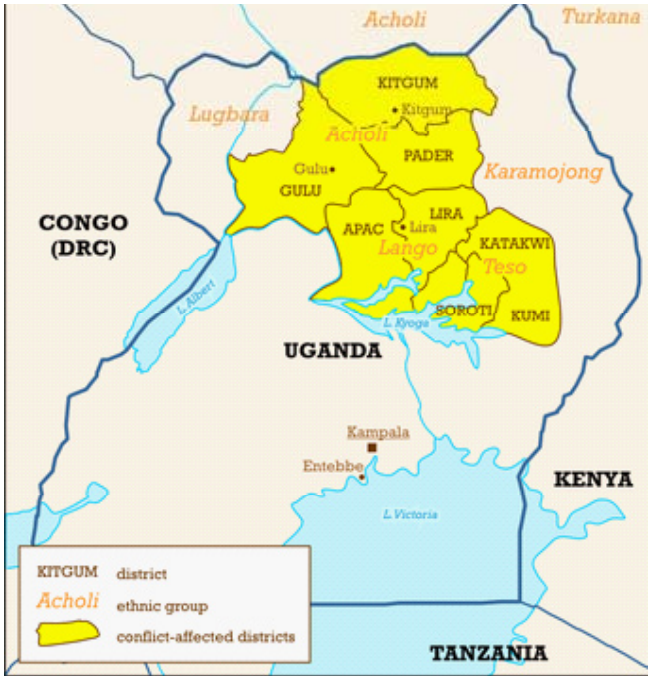
PROMOTIE COMMISSIE

Promotor:	Prof. dr. J.M. Richters
Copromotores:	Dr. R. Reis, University of Amsterdam Dr. C.B. Rwabukwali, Makerere University
Overige leden:	Prof. dr. H.M. Oudesluys-Murphy Dr. A.M. Polderman Prof. dr. J.M. van der Geest, University of Amsterdam Prof. dr. S. Reynolds Whyte, Copenhagen

This research was funded by the Netherlands Organisation for Scientific Research (NWO/WOTRO, grant WB 53-1023). Thesis writing was done at Amsterdam School for Social Science Research at the University of Amsterdam.

Map of Africa

Map of Uganda showing districts of Gulu, Kitgum and Pader



(Source, IOM-Gulu office)

Abstract

Wartime children's suffering and quests for therapy

This ethnographic study set out to examine children's suffering and quests for therapy in the context of an ongoing civil war in northern Uganda, with an aim of generating recommendations so that their 'right to health' can be met. Suffering was defined as experiencing illnesses, whether due to infectious diseases or emotional distress, and quests for therapy as activities children implemented to restore normality. In effect, I investigated what wartime children identified as common illnesses which affected them and how they restored normality, whether through the use of medicines or through other coping strategies. The research findings were aimed at providing baseline information for policies and healthcare interventions consistent with children's own needs and priorities. Central to this study was the idea that existing discourses about the healthcare needs of children of primary school age had too narrow a focus.

During fieldwork I asked children what illnesses had affected them in the recent past (for example within a one month recall), how children knew they were ill, what medicines they used for their illnesses, and if illnesses were persistent what other coping mechanisms they engaged in. This study examined both boys' and girls' illness narratives in an attempt to generate gender disaggregated data. Data was collected over a one year period in 2004-2005 and through regular visits to Gulu in 2006 and 2007. A survey was conducted with 165 children (N=165) aged nine to sixteen years, of whom eighty-eight (n=88) were boys and seventy-seven (n=77) were girls in addition to an extensive ethnographic follow-up of 24 children.

Data show that there was a high burden of illnesses among the children. Children narrated their experiences due to malaria, *koyo* (coldness), *lyeto* (fever), and *abaa wic* (headache) which sooner or later were diagnosed as malaria and malaria *madongo* (severe malaria); diarrhoea (including cholera); cough and flu (influenza); scabies; eye infections; wounds and injuries; and other health complaints. Infectious diseases constituted the highest proportion of the illness burden among wartime children. Health complaints which suggested emotional distress included misery, abject poverty, suffering from chronic complaints, fear of abductions, loss of close kin, living with the experience of sexual violence, and other wartime abuses. The symptoms of emotional distress were

persistent headaches, sleeplessness, stomach aches, *cwinya cwer* (sadness), *can dwong ataa* (deep emotional/social pain) and *cen* (evil spirits). Children's coping mechanisms for emotional distress included discouraging open expression of suffering, using medicines for sleep, using a special plant *atika* (Labiate species among other species), and engaging in income generating activities.

Children readily accessed herbal medicines and pharmaceuticals, including prescription only medicines such as antibiotics and antimalarials. At state aided health centres, clients could access pharmaceuticals free of charge if the pharmacy had them, but more commonly clients were instructed to purchase their own medicines from commercial outlets. The quality and quantity of the medicines which sick children accessed from commercial outlets was determined by their purchasing abilities. Although the availability of medicines as commodities provided curative solutions for the symptomatic management of illnesses, children were exposed to various dangers including misuse, over-use, and even dependencies on pharmaceuticals.

The main conclusions in this thesis are that children readily discussed their illness experiences of an infectious nature because of their acute onset, primacy, and the rapid deterioration of the bodily condition. Infectious diseases disorganize a relatively stable condition of emotional distress in children's life worlds, and infectious diseases are a priority and an immediate need. Children managed the acute conditions through short term curative approaches. Although I link the prevalence rate of infectious diseases to wider socio-economic factors, I propose that it is fitting for children to engage in short term curative approaches in their management, in the context of medical pluralism. This is because the context in which children lived made it impossible for them to practice preventive approaches in the control of infectious diseases. Further, the context of civil war and uncertainty reinforces individuals in opting for short term solutions, even for complex, multilayered problems. Although the use of pharmaceuticals and herbal remedies could bring about wellbeing in children, and alleviate their complaints symptomatic of emotional distress, this thesis mainly critiques curative approaches since they lead to *pharmaceuticalization* of emotional distress. In effect, dependency on medicines in the symptomatic management of emotional distress blurs its core causes, and yet actual healing would only be achieved through a deliberate attempt to deal with these core causes. Concerning emotional suffering, the main conclusion is that some of the illnesses

are severe and require immediate redress, though there are no simple ways of dealing with them. For example, I propose the concepts of 'unintended cure' to suggest that it is not entirely fruitless for sufferers to engage in curative procedures to minimize emotional distress. I further analyze the 'silencing of sufferers', 'individuation' of social suffering, and 'social processional' suffering, to show that there are health consequences in not dealing with core causes of distress and that both time and the addressing of social issues are important factors enabling individuals, families, and communities to come to terms with their suffering.

Findings further highlight epistemological, methodological, theoretical, and policy issues regarding wartime children's illness experiences and quests for wellbeing. Epistemological issues suggest factors underpinning the production of knowledge: which knowledge was privileged, the limitations therein, and the level of researcher's involvement in the study. For instance, I show that my personal involvement as an insider consciously or unconsciously influenced the research process and knowledge production. The methodological issues focus on the relevance of employing research approaches suitable for children, and introspection when examining their suffering. The latter was important for examining emotional distress and posing a critical reflection on somatization. The theoretical framework highlights child vulnerability in healthcare, child agency, political economic and gender issues, and health seeking behaviour in the context of medical pluralism. Although children were approached as social actors and their perspectives are privileged in this study, their young age, perceived inexperience, the general neglect of their viewpoints, and the market economy which facilitated the access of medicines as commodities fundamentally affected the provision and utilisation of pharmaceuticals and other healthcare services. The preceding argument leads me to reject an over emphasis on children's agency and instead reinforce a focus on child vulnerability in healthcare, given the context in which the children lived. This study has also critiqued the narrow policy regarding healthcare interventions for children above five years, which focuses on mainly curative approaches such as de-worming, vaccination of girls against tetanus, and oral hygiene, while also promoting awareness about pathogens or the effects of exposure to extreme events. Thereby I underscore the importance of addressing wider socio-economic factors in effective preventive approaches dealing with infectious diseases and emotional suffering.

Table of contents