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

Akello-Ayebare, G.

# Chapter Two

# Methodology

## Introduction

This chapter has four sections covering the theoretical approach, fieldwork methods, ethical considerations, and my personal involvement in the study. My theoretical orientation is based upon four conceptual domains: child vulnerability in healthcare, child agency, political economy of healthcare, and health seeking behaviour in the context of a market oriented and pluralistic healthcare system. The section on fieldwork methods covers the techniques used in data collection, the choice of research setting, the rationale for validity, reliability, and generalisability of this research, case selection, the rationale for employing each technique, and details on how the data was analysed. The third section in this chapter describes ethical considerations, while in the fourth section I explain my relation to the topic of this thesis and discuss possible consequences for data collection and analysis.

## 2.1. Theoretical approach

In investigating how children in child headed households were actors in their quests for therapy during their illness experiences, four theoretical orientations have constituted this study's backbone. These are child vulnerability in healthcare (Jamison 1999; MOH 1999a, 1999b, 2001a, 2001b; UNICEF 1998, 2003; WHO 2000b), child agency (Alderson 1995; Christensen 1990; Christensen & James 2000; Hardman 1973; James & Prout 1995; James, Jenks & Prout 1998; Prout & Christensen 1996; Van der Geest & Geissler 2003), the political economy of health and healthcare (Akello 2003; Doyal & Pennell 1981:46; Farmer 1999a:80; Parker 2000:419-433), and health seeking behaviour models in the context of a market oriented pluralistic healthcare system (Adome et al. 1996; Kleinman 1980; Tiping & Segull 1995). This study further draws from gender perspectives as a crosscutting issue throughout (Moore 1988; Oakley 1994; Ostergaard 1992; Richters 1994, 1998:77).

This study's objective is to provide an experience-near analysis of wartime children's suffering. Nevertheless, in the course of the thesis I will introduce analytical categories drawn from various disciplines such as biomedicine, phenomenology,

development economics, psychology, psychiatry, and medical anthropology. This is to ensure coherence and data manageability, to enable the identification of illnesses and medicines which the children named, and to assist in the logical presentation and analysis of empirical data. For example, whereas wartime children only discussed their experiences with specific illnesses, such as malaria (and malaria *madongo*), *koyo, lyeto* (coldness, high body temperature), *cado* (diarrhoea) and cholera, scabies, *aona ki avuru* (cough and flu)*, aona opiu* (tuberculosis), for analytical purposes I have drawn from biomedicine to categorise such diseases under the umbrella of 'infectious diseases'. In subsequent chapters, I address this issue in greater depth, but I turn now to outlining theoretical orientations.

**Theoretical orientations**

In this section I shed light on the underlying discourses relevant for this study, and the extent to which they can be deconstructed and confirmed by this study. First, I present these discourses, and through adapting them to this study I critique, modify, or confirm their propositions. Further, with each theory I present study results as illustration. Thus it is not only the discourses underlying the four theories in this study which are presented in this section, but also (1) illustrations of how each theory is applicable to this study – thereby confirming it; (2) where empirical evidence conflicts with contemporary theoretical assertions, this study critiques some of the major assumptions in these theories; (3) drawing from several disciplines, this study has coined various terms suitable for children, in relation to the existing theory – two quick examples are replicational and transformative agency; and (4) this study adds knowledge to existing theories, which could then form the bases for the propagation of new discourses. Below I will illustrate these assertions with each of the four major theories, starting with child vulnerability in healthcare.

### 2.1.1. Child vulnerability in healthcare

I have adapted the perspectives of the child vulnerability in healthcare discourse for this study because I found insufficiencies in child agency perspectives (see below) for analysing the health situation of the children in this thesis. In a review of primary school age children's illness experiences (Akello 2003), one of my conclusions was that whereas the children in boarding schools were social actors in their self-diagnosis and medicine

use, they were also vulnerable. Specifically, they were vulnerable because of wider factors which influenced their access to healthcare. For example, apart from the socio-economic difficulties they experienced in their quests for therapy, they were also disadvantaged because of their young age, existing healthcare policies regarding children of primary school age, and the fact that the healthcare system is adult centred and market oriented.

I therefore developed a child vulnerability in healthcare perspective in order to attempt to limit an *over emphasis* on children's agency, but also place children's daily suffering within a situation of armed conflict into perspective. Over emphasis on patients' agency has been documented to have negative effects, including with issues pertinent to compliance in healthcare (Farmer 1997b:355). For instance, such claims suggest that patients' non-compliance is the greatest problem in the control of tuberculosis. Moreover, it appears that an over emphasis on agency neglects environmental, structural, and operational factors that are beyond patients' control. These wider factors influence children's health and healthcare opportunities, and are addressed in the discussion of political economic theory below.

As mentioned above, existing healthcare policies regarding healthcare for children above five years contribute to their vulnerability. One example is that such policy documents imply that children of primary school age are a healthy group, while only children below five are vulnerable (Jamison 1999; MOH 2001a; WHO 1999b, 2000a, 2002b). Further, in emphasizing child vulnerability, adults are viewed as being in charge of, and having responsibility for, the child, therefore children are positioned as dependent and passive objects (MOH 2001a; UNICEF 2003; WHO 2002b). Placing children within this frame implies that adults are responsible providers and care givers, and that children do not yet contribute to society but receive care, protection, and training. Looking at the children whom this study focuses upon, there is substantial evidence that they are not yet mature, and are in fact in need of care and protection from the dangers of wartime. But furthermore, insufficiencies in healthcare policies addressing their needs make them even more vulnerable.

Contemporary healthcare planners and policy makers presume that it is mainly children below five who are vulnerable and in need of protection, thus different programmes including vaccination and immunization have been put in place for the prompt management of episodes of illnesses for these children (Jamison 1999; MOH

1999, 2001b, 2004; UNICEF 1998, 2003; WHO 2000a, 2000b). While children below five years receive a great deal of attention, evidence suggests that children above five years are a neglected group. In northern Uganda, which has faced the recent pandemic of HIV/AIDS and extended armed conflict, a substantial proportion of children were living on their own in child headed households at the time of this study. They were not under the care of adult healthcare givers and they took charge of their healthcare needs themselves. They were also not a 'healthy group' who required only a limited healthcare programme of oral hygiene, de-worming, and vaccination of girls of reproductive age against tetanus (c.f MOH 1999a, 2001b, 2005), but were in fact actively engaged in quests for therapy for the various – and sometimes serious – illnesses they experienced.

Another dimension of vulnerability which could apply to children in healthcare comes from psychiatry, where vulnerability is said to exist to the extent that an individual defines a situation as stressful for him/herself and is unable to recruit effective coping mechanisms to remove or reduce the disturbance (Shuval 1980:338). Wartime children were, however, able to survive despite their dire circumstances, and could deal with their daily challenges. Nonetheless, their survival strategies constituted insufficient and ineffective ways of coping and dealing with their problems, given their magnitude. To put it simply, wartime children were vulnerable because of the limited extent to which they engaged coping mechanisms in dealing with their daily challenges.

In general, the discourse on child vulnerability is adult centred. For instance, the 1989 UN Convention on the Rights of the Child views children as 'cultural minorities' whose rights to education are aimed at furthering their development, personality, talents, and mental and physical abilities to their fullest potential. Essentially children are viewed as not yet mature, and in the process of developing and acquiring culture, at risk and in need of protection. In mainstream anthropological literature, children were traditionally viewed as passive recipients of culture, being socialized by adults and not having a culture of their own. For example, such arguments place emphasis on cultural asymmetry, suggesting that vulnerable persons, including children, constitute the socially fragile, who lack agency and understanding of harmful settings and situations. Children should therefore be protected and their innocence preserved by adults until they are 'adults' themselves. Children are therefore viewed as appendages to adults and their behaviour is pitched to adult standards.

Vulnerability is also a common lexicon of development when poverty is addressed, and is mostly applied to the resource poor. This allows development planners to avoid overusing the words 'poor' and 'poverty' (Chambers 1989:4). With some precision, vulnerability is used to refer to 'vulnerable groups' such as pregnant women, children, the disabled, and disadvantaged racial categories (Chambers 1989:1; Doyal & Pennell 1981:1-47; Farmer 1999a:47). The main focus is on defencelessness, insecurity, exposure to risk, and shocks and stress. Considerable evidence suggests that vulnerability is linked with deprivation, ill-health, and malnutrition. Different authors – including Chambers (1989:1-8), Corbett (1989:59-70), and Weiss (1989) – argue that vulnerability to sickness, and high economic costs to households due to ill health, make poor people poorer through delayed treatment, high costs of treatment, and loss of earnings. These scholars further point out that poor people are more exposed to sickness, pollution, infectious and vector-borne diseases, accidents at work, and malnourishment; further, that previous sickness tends to reduce resistance to disease and slows down recovery; and that the poor have less access to timely, effective treatment (Chambers 1989:7; Corbett 1989:59). Part of the solution, as suggested, is to inquire among poor people about what they want and need, and to strive to understand their conditions and how they cope. The answers will point to interventions, which will enable them to be better off on their own terms.

Addressing the gender issue, in wartime over 90% of casualties in contemporary wars are from the poorest sectors of society, and in general, women (girls) are more likely to be victims (Richters 1994:40). Women/girls are also at a higher risk of HIV/AIDS because, among other factors, they often occupy the lowest economic echelons in most societies and in wartime are exposed to sexual violence.

Based on the assertions of the child vulnerability discourse, it is this study's contention that wartime children in child headed households are indeed a vulnerable category. This is because they are likely to be defenceless, economically impoverished, socially deprived, and psychologically affected, among other variables which contribute to vulnerability. In children's lived experiences, vulnerability forms a vicious cycle involving deprivation of their adult kin, which subsequently causes their own deprivation. Further, due to an entire community's exposure to lack and abject poverty, there is an inter-generational cycle of lack, abject poverty, and misery. These factors have a direct influence on the health and healthcare possibilities of the children who participated in this study.

In sum, vulnerability is a multifaceted concept. It refers to risk, poverty, exclusion, immaturity, sickness and illness, exposure to infectious diseases and disasters, women and children, and passiveness in decision making. Consistent with this study's focus on children above five years, vulnerability will therefore be adopted to describe their lived experiences in armed conflict as victims, as the poorest among the poor, and as an excluded group who are lower in hierarchy relative to adults, as evident in adult centred systems including healthcare. In seeking children's own perspectives, however, I critique some parts of the 1989 UN Convention and conventional anthropologists' views about children as immature yet-to-be adults, without their own culture.

### 2.1.2. Child agency

Within this thesis children will be viewed as social actors exercising various forms of agency. Theorists of child agency currently approach children as social actors in their own right. It is also argued that childhood is a social and cultural construction, and children can be social actors with their own perceptions of the social world (Alderson 1995; Christensen 1990; Christensen & James 2000; Hardman 1973; James & Prout 1995; James, Jenks & Prout 1998; Prout & Christensen 1996; Van der Geest & Geissler 2003). Summerfield (1998:8) argues that children are not just 'innocent' passive victims, but also active citizens whose values are connected to collective meanings and memories. Children are recognised in the UN Convention on the Rights of the Child (1989) as actors with values and perspectives. For instance, Article 12 of the Convention is explicit about the child's right to freely express his or her viewpoints in matters of concern to the child, and that, according to the child's age and maturity, those opinions must be taken into account in decisions made about the child[35].

Recognizing child agency is consistent with the international move towards studying children as social actors with the cognitive abilities to process their own experiences (James, Jenks & Prout 1998; Prout 2001; Prout & Christensen 1996). Scholars who view children as social actors therefore do ethnography with children to elicit their emic views, experiences, perceptions, and actions in the social and cultural world (Akello 2003; Alderson 1995; Christensen 1990; Hardman 1973:89-99; Van der Geest 1996:244).

[35] Critically looking at the Convention, it is clear that for the age group represented in this thesis (8-16 years), there is an ultimate ambivalence concerning the right to expression and participation. Children are 'given' these rights with the right hand, but the left hand takes them away by asserting that children are 'immature' (cf. section on child vulnerability above). Therefore, this study will largely rely on scholars of child agency perspectives in studying children in their own right.

Various forms of child agency – called replicational, transformative, relational, and transactional agency – have been coined for this study. They describe different ways in which children construct and shape their social relationships. Wartime children will also be viewed as active social actors exercising their power through 'weapons of the weak' strategies (Scott 1985: xvii).

Concerning replicational agency, children's dissemination and reframing of messages they receive from – among other sources – NGOs, will be analysed. For instance, the children in this study were frequently heard telling others about the importance of receiving counselling at Caritas and War Child. These messages, as will be explained, had been reframed and reinterpreted to suit their own level of communication so that, for example, what children talked about concerning the importance of counselling differed from what they practiced when confronting their suffering.

Relational agency will be used as a tool to analyse how children construct social networks, and in particular networks which are useful in dealing with daily challenges. For example, a substantial proportion of children indicated that child-to-child interactions were more useful to them than adult-to-child relations.

In transactional agency, children's quests for professional healthcare will be viewed as mediated by differential power relations. For instance, children's interactions in professional and non-professional healthcare contexts were in general shaped by their occupation of a lower social echelon than the healthcare givers.

Whereas transactional agency is used to analytically address children's disadvantaged position in social relations, transformative agency discourses assess children's perspectives in order to generate recommendations for emergency healthcare intervention, and school health re-programming for children above five years. In particular, such recommendations must be consistent with children's healthcare priorities and needs. Transformative agency should further be viewed in connection with non-responses to projects in wartime designed to promote children's emotional wellbeing. In short, children's non-response to calls for counselling will be interpreted as similar to what James Scott, in his book W*eapons of the Weak: Everyday Forms of Resistance* (1985: xvi), calls 'foot dragging, feigned ignorance and weapons of the weak strategies'; as attempts to influence the re-design and implementation of appropriate and acceptable interventions, thereby *transforming* project designs. I use transforming here with caution since, as I elucidate in subsequent chapters, the functioning of humanitarian aid agencies is, in the main, guided by preset guidelines and rarely by the beneficiaries' perspectives, needs, and priorities.

Seeking to elicit children's points of view in the arena of health and healthcare is consistent with contemporary development discourse and planning which uses micro-to-macro level perspectives as opposed to macro-to-micro ones (Chambers 1989:1-8; Katwikirize & Odong 2000; Lieten 2003:10-18; Weiss 1988:5-16, 2000; Weiss et al. 2000). Central to the process of drawing from micro-level perspectives in planning is the idea that many key project planners in the past century had only hazy ideas about beneficiaries' priorities, and were guilty of wasting resources on less successful ventures. The micro-to-macro level approach in project planning aims to avoid this pitfall through beneficiaries' participation, deriving development priorities through consultation, and using their viewpoints in project design (Chambers 1989:6; Weiss 1988:14). It has therefore been agreed that where donors' ideas override the needs of the beneficiaries, their present and future wellbeing may be jeopardized. Literature in the field of development economics further suggests that macro-economic planning has, in the past, allowed the introduction of projects which turned out to be expensive failures. Evidence shows that in some cases, projects even had a negative impact, such as an increase in women's workload, increase in wake-time, and a lack of sustainability (Chambers 1989; Oakley 1994; Weiss 1988). The need to elicit local level perspectives for project design became clear. According to Chambers (1989:1), micro-level development involves modifying projects to fit local conditions through a decentralized analysis which encourages, permits, and acts on local concepts and priorities as defined by the poor people themselves.

Although the perspectives by Chambers (1994), Lieten (2003) and Weiss (2000) are donor community based and adult centred, their arguments are consistent with issues pertinent to this study: investigating wartime children's perspectives and emic views in order to generate recommendations for policy and planning for inclusive healthcare for children. It is proposed in this study that children can identify the 'common' illnesses that they experience, and I discuss how they deal with them themselves, according to their priorities. Premised on this participatory approach, recommendations will be made to child healthcare institutions, and a project will be designed which is empowering, and in which children have ownership (see Akello 2003; Chambers 1989:8; Kalnins et al. 2002:223; Lieten 2003).

It is one of this study's goals to introduce micro-level perspectives in planning for the healthcare needs of wartime children in child headed households. It is likely that such a healthcare project will be more effective in directing income and budget allocation or expenditure towards priorities as identified by the children, and therefore it could be a successful and sustainable project. In a nutshell, by employing child agency within the theoretical framework, this study facilitates the identification of children's own perspectives and actions in health and healthcare, and the results can be utilized for the development of better healthcare for these children.

### 2.1.3. Political economy of health and healthcare

The theoretical orientation of political economy in healthcare has many overlaps with the child agency perspectives above. Essentially, scholars of the political economy of health and healthcare (Doyal & Pennell 1981:1-47; Farmer 1999a:80; Parker 2000:419) argue that health, or lack of it, and the quality of healthcare accessed, is largely determined by social competition between groups of people in different economic classes and by the unequal distribution of resources. It is pointed out that problems in the field of healthcare in developing countries are often linked to social and economic inequality and poverty (Farmer 1999a; Parker 2000). These are interpreted as consequences of the penetration of a capitalist economy. Desjarlais et al. (1995:19) point out that poverty takes a considerable toll on the wellbeing of its victims, as it creates the conditions for malnutrition, illness, social strife, political instability, and despair. Moreover, because poor people lack productive assets, they suffer from physical weakness, illnesses, and population pressures, and therefore poor people will always remain poor.

Poverty has also been documented as a contributing factor to people's high infection rates with HIV/AIDS, since people will engage in high risk behaviour such as prostitution as a source of livelihood (Farmer 1999a). Globally, poverty is the major risk factor for the transmission of AIDS and tuberculosis, as it is for most other forms of social suffering. An unjust distribution of disease and healthcare services characterises both the old and new world order, and the gap between the rich and poor is growing. Health gradients of premature mortality and excess morbidity separate rich from poor, both between and within societies (Farmer 1997a:279; 2003). One of the unfortunate sequelae of identity politics has been the obscuring of structural violence, which metes

out injuries of vastly different severity. It is possible to speak of extreme human suffering, and an inordinate share of this sort of pain is currently endured by those living in poverty (Farmer 1997a:259).

The general trend revealed in the first phase of this study demonstrated that although Gulu district has two of the country's best healthcare centres, namely Gulu Independent hospital and Lacor Catholic hospital, no children above five years from child headed households were observed, or had mentioned, seeking professional help there. This finding can be attributed to what Parker (2000) named structures of oppression, and Farmer (1999a, 2003) calls structural violence, whereby social inequality, injustice, and poverty (Farmer 1999a:80) make wartime children in child headed households a risk group in health and healthcare.

Since the adoption of structural adjustment policies and the malfunctioning of the national formal healthcare system in Uganda, a substantial proportion of healthcare givers have resorted to private practice. Further, it has been documented that there is a growing rate of private investment and trade in pharmaceuticals as commodities, and not as substances for healthcare (Bush & Hardon 1990; Hardon 1990, 1994; MOH 2001a; Van der Geest et al. 2002; Whyte 1998:191; Whyte & Birungi 2000). The market-orientedness of the healthcare system, coupled with social inequality and poverty, are important contextual factors for this study's question of how wartime children in child headed households are actors in the quest for therapy for the various illnesses from which they suffer.

### 2.1.4. Health seeking behaviour in a pluralistic healthcare system

Proponents of healthcare utilization models, including Kleinman (1980) and Good (1994), argue that variation in illness management is influenced by age, gender, and differences in positions in the household, among other factors. The various pathway models available describe illness behaviour as a logical sequence of steps, starting with the definition and perception of symptoms to the use of different healthcare providers. Cultural and social factors are integrated into these models (Fiereman & Janzen 1992). Determinant models focus on a set of variables which explain health seeking behaviour and the choice of different forms of healthcare (Suchman 1965; Fabrega 1976; Fiereman & Janzen 1992; Igun 1979; Tiping & Segull 1995). These variables include: the recognition of and significance attached to the symptoms, the perceived seriousness of the illness,

the persistence of the illness, the perceived cause, knowledge of illness remedies, and faith in the efficacy of medical care available; as well as economic factors such as the price of medicines, distance from healthcare services, costs in terms of time, and gaps in communication with healthcare providers. It is further acknowledged that therapeutic choice is the outcome of a hierarchical sequence of transactions, or of transactions that have taken place simultaneously (Fabrega 1976; Fiereman & Janzen 1992; Igun 1979; Tiping & Segull 1995; Unschuld 1986).

Tipping & Segull (1995:31) provide a useful summary of the literature of healthcare seeking behaviour. They identify seven determinants, including socioeconomic variables such as education levels, maternal occupation, marital status, and economic status; age and sex; healthcare costs; social status of women (Sergent 1989); type and severity of illness; patient and doctor relationships (Mechanic 1992); distance and physical access; and perceived quality of service provision. Importantly, all healthcare utilisation models so far developed are adult centred.

My own viewpoint follows Desjarlais et al. (1995:255), who state that patients are pragmatists seeking results, and not purists seeking theory. The implicit reference to rationality in the health seeking model is far removed from the reality of lived experience, and the inherent desire or need to alleviate suffering in the case of an illness episode (see Good 1994:56). While it is true that children's quests for therapy are influenced by the market economy, and other macro factors, I will show later the various complex dynamics in alleviating suffering. Ogden (1995:1901) has also extensively critiqued the dominant healthcare seeking models by asserting that:

> for instance, Tipping & Segull's conclusion that, therefore health seeking behavior relates to the adequacy of household resources seems of an oversimplification given the evidence they themselves provide. It seems more likely that there is a wide range of variables affecting therapeutic decision-making. Being poor is probably an important factor, but inadequacy of resources is only one feature of poverty.

Turning to the issue of pluralism in healthcare, Kleinman (1980:49-50) identifies that each society has a healthcare system consisting of three often overlapping sectors: the popular, professional, and folk sector. In their quest for therapy people may, depending on the illness, use all sectors in a sequence or simultaneously. In what follows, some general characteristics of a pluralistic healthcare system are described, as well as some specificities of the Acholi pluralistic medical system. The description is based on the

literature as well on the findings of the first phase of this ethnographic study.

*The popular sector of healthcare*

In most countries, the popular sector is the largest healthcare sector, constituting a complex matrix over several levels: individual, family, social network, community beliefs, and activities. It is also in the lay, non-professional, non-specialist, popular culture arena where illness is first defined and healthcare activities initiated (Kleinman 1980). In Uganda, including Gulu district, over 80% of illnesses are managed in this sector (Adome et al. 1996, 2000:1-12; Birungi 1998:1455-1460; Whyte 1998:191-334), and over 90% of the therapies administered are pharmaceuticals.

Kleinman (1980:53) regards the steps taken in dealing with disease and illness as being hierarchically ordered. These steps include perceiving and experiencing symptoms, labelling and evaluating the disease, the sanctioning of a particular kind of sick role (acute/infectious, chronic, impaired, medical, or psychiatric), deciding what to do and engaging in specific healthcare seeking behaviour, applying treatment, and evaluating the effect of self-treatment and therapy. In Gulu district, for common illnesses all the foregoing processes, including obtaining a remedy, occur within the popular sector, while the implicit hierarchy in steps taken is questionable. In reality, it is possible even to seek therapies before first determining disease aetiology, the options available, and all 'rationalities' involved. Noticeably, at the time of this study in Gulu, children in child headed households independently sought therapies for common illnesses in the popular sector. For other illnesses, however, particularly chronic cases, patients including children are more likely to participate in all three over-lapping sectors in their search for a remedy and alleviation of their suffering.

*The professional sector of healthcare*

In Gulu district the biomedical sector is comprised of the organised healing profession. This sector consists of, for instance, the private profit making system such as Gulu Independent hospital, the missionary private non-profit healthcare system such as St. Mary's hospital in Lacor, and the state-funded hospital such as GRRH. The state also put in place sub-health units in each sub county, including Laliya, Laroo, and Layibi health centres. However, the general trend during the study was for the state-aided health centres at all levels to be dilapidated, poorly staffed, and lacking most healthcare facilities, including pharmaceuticals. It was therefore common for individuals countrywide to

seek healthcare in these centres only to be referred to the popular sector to purchase pharmaceuticals.

The situation in Gulu was also compounded by armed conflict. Apart from GRRH, which was partially functioning and highly dilapidated, other sub health units were virtually deserted in 2004, but re-opened in 2005. The regional referral hospital structures also functioned as areas of refuge and safety when the insurgency was at its peak. The units which were still partially functioning at this hospital were the maternity units for child deliveries and the paediatrics units where severe cases were admitted for treatment and close monitoring; severely malnourished children were admitted for feeding, and immunisation of under fives was carried out. The general wards where other patients were treated were virtually un-inhabitable buildings where admitted patients provided their own beds, food, and medicines. Occasionally, at the time of this study, GRRH received batches of pharmaceuticals and medical facilities such as syringes, cotton, and disinfectants, donation by charity organisations.

In general, it was the poor, including children from child headed households, who constituted the highest proportion of patients visiting this district state-funded dilapidated government hospital. The middle class and the elite in Gulu largely resorted to the well facilitated Gulu independent hospital, St. Mary's hospital in Lacor, and other private providers for quality healthcare.

*The folk sector*

The folk sector is a small specialised sector in the healthcare system. Indigenous healers are the main healthcare providers in the folk sector, and in Gulu there were different categories of folk/indigenous healers. There were indigenous healers who have more knowledge about herbal remedies than the average individual, and as such were frequently consulted for specialist help. There were diviners, who in addition to administering herbal medicines also used the spirit media to diagnose, prescribe herbal remedies, and where necessary perform rituals in attempts to restore normality to their sick clients. Further, there are religious healers. I will come back to these three categories of indigenous healers at a later stage.

In general, during the study individuals consulted with indigenous healers for a variety of persistent and chronic ill health conditions, for all sorts of misfortune, and to mediate in reconciliation when inter-clan crimes had been committed. In one ceremony I observed in Pabbo displaced persons camp a wide range of rituals were conducted to ensure the wellbeing of an ex-combatant. It is to this sector that individuals who needed to alleviate suffering, and who had not been able to find effective care in the popular and biomedical sector, resorted. They may not find a cure, but it is believed that other aspects of healing for emotional suffering may be found in this sector.

Issues which were examined in this domain of inquiry other than this study's main objectives were, 1) whether children had other explanatory models for emotional distress and other forms of chronic illnesses and therapy quests; 2) how children situated themselves in the largely adult centred ceremonies; and 3) whether children did 'find healing' in this sector.

Apart from local indigenous healers, religious healing churches were on the increase in Gulu district. Next to the traditional religious churches of Protestants, Catholics, and a few Moslems, there were Pentecostals, Jehovah's Witnesses, and Charismatics. The Pentecostal churches and Charismatics from the Catholic Church were famous for their healing services, and for deliverance sessions for the spiritually oppressed and those seeking freedom from their suffering. My viewpoint is that the metaphors used in these churches, such as 'deliverance' and 'healing services', represent the role of religious healers in social, mental, or emotional healing. After extensive ethnographic study, I propose that religious healers can be considered folk healers because they use spirit media, supernatural powers, and invoke notions of divine powerful beings in their healing discourses. Perhaps their role borders the popular sector because regular attendants of healing services were taught that they are 'joint heirs' with Jesus Christ. Being a 'joint heir' is a characteristic intertwined with access to divine power, thereby enabling sick people to lay hands over themselves in case of any form of suffering and also to pray for other sick people to chase away *cen* (evil spirits), manifested as spirit possession in the popular sector. In subsequent chapters, I will show how religious healers' attempted to ensure mental and social healing among people who lived in the context of civil war.

Another group of healers were of Indian and Chinese origin, who came to Uganda as multinational traders in pharmaceuticals and other remedies. The Chinese and Indian

traders also lived in Gulu municipality at the time of this study. In the first phase of this study I did not focus on them since no child explicitly mentioned seeking a remedy from them but they did mention that they used a variety of market drugs. In the second phase, I linked the services provided by the Chinese and Indian healers to the fact that children revealed using various market drugs including Action, Painex, Hedex, Malaralex, Vickskingo, and unspecified ointments, to mention a few examples. Indian and Chinese healers were major distributors of such pharmaceuticals and therapeutic herbal remedies.

In short, the complexity of the healthcare system has a role to play in influencing wartime children's quests for therapy. While the pharmaceuticals accessed in the popular sector for infectious diseases and easy-to-manage illness experiences were generally sufficient, for chronic illness experiences and complex emotional distress, sufferers also engaged in quests for therapy in the folk sector. In subsequent chapters, I will use empirical evidence as the basis for the suggestion that there are insufficiencies in the underlying assumptions focussing on rational choices in quests for well-being which are only influenced by factors such as disease aetiology, gender, social status in healthcare seeking behaviour model. There were also differences in individual wartime children's quests for therapy, which may be gender related.

### 2.1.5. Gender as a cross-cutting issue

Gender differences in children's illness experiences, and in how they were actors in their quests for therapy, will be addressed with the help of gender theories (Denzin 1997; Moore 1988; Ostergaard 1992; Richters 1994). Underlying these theories are explanations for differences in terms of power relations and symbolic constructions of femininity and masculinity. Women's (girls') experiences are different from those of men (boys), and therefore these differences should be the starting point for a more accurate representation of reality (Clough 1994:74; Denzin 1997:56; Richters 1994, 1998:77-112). It is this study's contention that dominant gender differences in society are replicated in the power relations in child headed households. This is because children live within these social relations, interact with them and even modify some of them according to the contexts in which they live.

Within households, there is gender inequity in terms of decision making and access to resources (Denzin 1997). The latter could affect treatment seeking by boys or

girls, and the type and quality of healthcare received. Moreover, most gender theories were developed in household settings other than child headed households (Moore 1988; Ostergaard 1992), and considered mainly adult behaviour. The question here is how gender discourses apply to wartime children, especially in regard to their illness experiences, quests for therapy, and differential access to healthcare.

Scholars who subscribe to gender theories spell out the unique experiences of women in wartime. It is demonstrated that women (girls) bear the greatest brunt of armed conflict due to their gender. They are often exposed to gender-based violence and rape (Richters 1994). Available reports show that although there is a significant reduction in HIV/AIDS prevalence rates in Uganda, in the war-torn areas of northern Uganda HIV/AIDS infection rates have increased (MOH 2001; UDHS 2003; UNICEF 2005). Recent statistics suggest that the prevalence of HIV in Uganda in general has declined significantly since 1995 from 18.5% to 6.2% in 2002, but in northern Uganda infections have increased. For example, HIV prevalence was lowest in Matany hospital in Moroto district at 0.7%, but was highest in Gulu district with an overall prevalence of 6.2% (MOH & STD/ACP 2003). This disparity has been attributed to the presence of the state military, which constituted the highest reserve of the HIV/AIDS virus, and also to the general breakdown of the social structure in the north, with a subsequent high prevalence of gender-based violence such as rape (MOH 2004; UDHS 2003; UNICEF 2005)[36].

Women (girls) in Uganda are at a higher risk of HIV infection than men due to biological, socio-cultural, and economic factors. Since unprotected sex is the main cause of HIV infection (MOH & STD/ACP 2003; MOH 2001b:3; MOH 2004:10), sexually related factors put women at higher risk of HIV infection. Studies show that there is increased pressure for young girls to engage in sex with older men as a survival strategy (MOH & STD/ACP 2003), and that poor women and girls are likely to engage in risky behaviour such as prostitution as a source of livelihood (Farmer 1999b; Schoepf 2003).

Refugee and internally displaced women are a high-risk group for HIV/AIDS due to the socio-economic and psychological breakdown of traditional family structures and support systems (MOH 2004:14). What is not made explicit in the MOH reports is that with armed conflict there is an increase in sexual violence such as rape (See UNICEF 2005). Infection rates are more likely to increase among women and girls due to such

[36] The terms prevalence and incidence, respectively, refer to the total number of cases of disease in a given population and the number of new cases over a specified period. Incidence implies the rate at which healthy people are being infected, while prevalence denotes the total cumulative disease burden on the population (MOH 2004:7).

crimes. With displacement also comes dire misery and abject poverty, and women as household providers have to forage for the food requirements. Evidence suggests that children who were commuting at night engaged in child prostitution (HURIFO 2002; UNICEF 2005). Results in this study also show girls' vulnerability to attacks, being waylaid, and experiencing various forms of gender-based violence, including rape and defilement.Although available literature above concerning women's asymmetrical exposure to HIV infection points to general problems such as lack of water, food, sanitation and poor housing, and with displacement as major issues, there had also been a breakdown of social networks, and the social structure including familial, legal, and kin relations in Gulu at the time of this study. Taking these factors into consideration, this study investigated the gender differences in children's experiences in wartime.

### 2.2. Research methods

Studies with children require the adoption of techniques particularly suitable for them. This study employed ethnographic methods suitable for investigating children's agency, perspectives, and daily experiences. Largely qualitative data collection techniques were employed in this study, the results of which were triangulated using a survey to assess children's perspectives on the common illnesses they experienced and their quests for therapy. What is more, a relatively different approach for the assessment of emotional distress, mainly based on children's emic views of stressors and extreme events in their daily life, were used. Concerning qualitative techniques, children were, in the main, asked indirect questions to elicit their emic views (Bernard 1988; Denzin 1997; Spradley 1979; Weiss 2000; Weiss et al. 2000). Details of the qualitative techniques used are given below.

#### 2.2.1. Study population and case selection

The wartime children who participated in the study were:

1. Children aged 8-16[37] years in child headed households, who had lost their parents to armed conflict and HIV/AIDS, lived in resource poor suburbs of Gulu Municipality, spending nights in night commuters' shelters, and studying at displaced primary schools within Gulu municipality.

[37] No child had a birth certificate. The ages mentioned throughout this thesis are those which children told the author. Cross verification was done with records at the displaced primary schools where children attended and the records at the World Vision projects for people with HIV/AIDS where registered parents also gave names and ages of their children.

2. Children identified through World Vision's HIV/AIDS programme for child headed households, who were taking care of bed-ridden parent(s) living in villages and camps within a 5-7 km radius from Gulu municipality.
3. Children (frequently boys) in child headed households, whose parents had rented cheap housing for them in Gulu Town to prevent their abduction.
4. Children whose parents were unable to care for them because they were either maimed by landmines, disabled, or had drinking problems.
5. Children and former child soldiers living in abject poverty. Abject poverty was included in addition to the four criteria above because there was a need to select a manageable (small number of study participants) or ethnographic sample and yet many children in Gulu municipality met the four criteria above. In addition, some children indicated having close kin who assisted them in various ways, including with material support, while others lived on their own with no support.

Twenty-four children, who met the above criteria, were requested to be study participants. Children were told about the length of the study, what was required of them, that they would be visited regularly to discuss their health complaints and quests for therapy, and that sometimes they would be called upon to be co-researchers. There was a deliberate attempt to include both boys and girls. All the children who participated in this study gave verbal consent and expressed willingness to participate in an extensive study involving frequent consultations, sometimes in their homes. These children showed their individual commitment through suggesting different activities, including workshops during weekends and end of semester activities. Although other children were invited for discussions, and participated in surveys and other qualitative techniques, twenty-four children participated actively throughout the entire phase of ethnographic fieldwork.

To ascertain whether the selected children were from child headed households and met the four additional criteria in the study population selection, children were asked specific questions about their origin, whether they knew where their parents lived, whether their guardians took care of them, if they lived within the municipality or in camps, whether they spent nights in night commuters' shelters, how they came to live there, and for how long they had lived in a child headed household. Children taking care of adult kin who were sickly due to HIV/AIDS were recruited into the study via World Vision food distribution points, which registered clients in its antiretroviral therapy

(ART) programme. The World Vision district ART programme coordinator introduced six willing child participants to the researcher who also explained to them what the study was about and sought for their consent to participate in the ethnographic research.
Two more children from St Kizito Alero-Cuku disclosed during interviews that their parents were registered at Lacor Hospital for regular medicine collection. From children's description of their parent's health status and types of medicines they accessed from Lacor hospital, and through interviews with the parents, I recruited them in the study. The parents of the two children were registered clients for ART at Lacor Hospital as part of the President's Emergency Plan for AIDS Relief (PEPFAR). The remaining eighteen children who extensively participated in this study were children who lived in child headed households within Gulu town, orphans who spent nights in shelters and attended displaced primary schools.

Recruitment of children for extensive follow-up seemed a considerable and tedious exercise for the following reasons: 1) A substantial number of children, especially those who attended displaced primary schools and lived in night commuters' shelters, met all the four original criteria for participation in the study; 2) Owing to the profound need to include only a limited number of children for extensive follow-up, a substantial proportion was excluded, much as they met the study recruitment criteria. Hence, an additional criterion was added to the proposed four – indicated in the eight month paper submitted to the Amsterdam School for Social Science Research (See Akello 2005); 3) Only children who lived in abject poverty and barely accessed their daily basic needs, in addition to meeting the four criteria in sample selection stated in (Akello 2005) were recruited into the study. That is how twenty-four children were selected for intensive and extensive participation in the ethnographic research; 4) From the children selected, those excluded were siblings, and a number of children who 'knew' the common criteria NGOs employed when recruiting children for their projects. In order to investigate gender perspectives, both girls' and boys' illness experiences and quest for therapy were examined. As in any ethnographic study, willingness to participate was paramount. The children selected were of a minimum age of eight, a decision premised on child development psychology assertions that it is from age eight that children are able to interpret bodily changes, such as in the case of illnesses, and act upon them (APA 1990; Garmezy & Rutter 1985). As mentioned earlier, the upper age limit of sixteen years is consistent with both the national and international age brackets for children.

### 2.2.2. Data collection

Katwikirize & Odong (2000), Weiss (2000) and Weiss et al. (2000) suggest techniques for rapid appraisal which could be used to assess issues pertinent for communities, through their participation. Weiss (2000) recommends the use of rapid assessment procedures (RAP) to identify what the population perceives as their major problems or needs. Based on these priorities and available resources, NGOs and humanitarian agencies can select the issue(s) to address. Rapid assessment procedures essentially involve a participatory problem-solving process, where beneficiaries identify and rank problems, analyze priority problems and their root causes, rank potential solutions to address root causes, and subsequently develop a plan to address top ranking solutions (Katwikirize & Odong 2000; Weiss 2000; Weiss et al. 2000). For example, results from a RAP among displaced persons in Gulu district showed that *lweny* (insecurity) and congestion are the two problems of greatest concern for the camp population. The other priority problems were *kec* (hunger) – where the most vulnerable were disabled persons, widows or widowers, and orphans or child headed families – and *two* (sickness), lack of land for cultivation, lack of drugs, and poverty (Weiss 2000).

In addition to first hand data collection techniques used to elicit wartime boys' and girls' emic views, this study benefited from existing studies by various researchers in Gulu which have extensively assessed psychosocial distress in children. Key informants were also interviewed to explore their viewpoints about what children identified as healthcare issues and to assess their perspectives in provision of healthcare services to children living in context of war. Nevertheless, children's perspectives were central to this study. Listed below are the specifically adapted techniques which I used for eliciting children's perspectives during data collection.

*Qualitative Techniques*

**1. Typical day:** Children were requested to list their daily activities, the challenges they face in performing them, and the ways they deal with these challenges. As well as being an entry point and facilitating rapport, this technique was vital in gaining insight into the different activities that the children were engaged in, what their priorities were, extraordinary events linked directly to the civil war, and also in finding out how they themselves were actors in illness experiences, how they dealt with difficult circumstances, and how they situated themselves and their agency in different contexts.

**2. Drawing:** Children, regardless of age, were interested in diagrammatically illustrating their illness experiences and the medicines they used in both the first and second phase of this study. One hundred and fifty (N=150) children illustrated common illness experiences and medicines used within a one month recall. Drawing was a useful technique, much as it presented difficulties such as the children's constant consulting with the author about how to illustrate 'persistent headaches' and 'stomach aches'. Nevertheless, this technique was used not only as an entry point but also as an avenue for illness experience categorizations, and for formulating questions for in-depth interviews and vignettes.

**3. Time lines:** This technique assessed children's life histories. Here, children were explicitly asked to name pleasant and unpleasant experiences in their lives, from early childhood in a 'time line' representation. Through this procedure I identified what the children considered as important life experiences. The time line was also used to facilitate a two week or one month recall of illnesses experienced and medicines used. Children were also requested to show other coping[38] strategies in the illustrations of time lines.

**4. Venn diagrams:** In the Venn diagrams exercise, a child represented him/herself as a central person surrounded by close kin, siblings, and any other social networks they perceived as important. This technique was used to investigate how children used their agency, and also to discover other strategies they employed in order to confront different problems in extreme living conditions, and within an adult centred healthcare system. The activity facilitated insight into children's social networks, community perspectives, and the various challenges that the community confronted together with the children. Other insights obtained were pertinent to the children's perceived enemies, how they negotiated difficult relationships, and also how child-to-child interactions were useful compared to child-to-adult interactions in dealing with daily life challenges.

**5. Free listing and pile sorts**: This approach was vital in eliciting and ranking the common illnesses and emotional problems that the children experienced. For example, children were individually and in groups asked to name 'common' illnesses they experienced within a one month recall, and to rank them by severity. Concerning emotional suffering, children identified the core problem, likely causes, and possible solutions. A similar

[38] Coping is used in this study to imply all forms of activities which children in wartime do to minimize their suffering.

exercise was administered to assess commonly used medicines and other coping strategies. After the lists were compiled, the children 'prioritized' them by sorting them into a hierarchy of importance. Free listing and pile sorts were vital in assessing the severity of infectious diseases, psychosocial suffering in wartime, and children's immediate needs and priorities.

**6. Narratives of illness experiences and quests for therapy within a two week or one month recall:** This technique was used to investigate the commonness of different illnesses, and how children dealt with them themselves. Narratives are systematic stories, sometimes written, through which children talk about their illness experiences. In such stories, the thematic areas explored in-depth included: how children knew they were ill, when they determined its severity, what steps they took in seeking therapies, where they got the medicines, and how they met the healthcare expenses and user charges. In the first phase of this study, the children wrote narrative compositions; in the second phase of ethnography, over 400 children wrote compositions or told me stories about recent illness experiences and procedures taken to ensure wellbeing.

**7. Specific questions:** In assessing some issues – including the particular emphases in healthcare policies and planning for children above five years, children's experiences in the context of armed conflict, and activities in daily life to ensure their wellbeing (such as income generating activities) – children were asked specific questions. For instance, I wanted to know how they perceived the de-worming project, oral hygiene, and tetanus immunizations for girls of reproductive age. Further, I investigated what health or ill health is, according to the children, and asked what they would like to see in emergency aid interventions geared towards ensuring their wellbeing.

**8. Life histories:** This technique was adapted to triangulate the 'time lines' method. Children's past experiences were extensively investigated through selecting specific timeframes; for instance, when the conflict was at its peak, what were individual children's experiences? Underlying the collection of life experiences or life histories, my objective was to establish typical and major experiences in a person's life and to show how large scale processes of socio-cultural change act out in local contexts (Schoepf 1992:261). Since this study's main focus was to assess how, for all illnesses the children experienced, they were engaged in quests for therapy, the life histories allowed me to discover issues pertinent to different types of illness experiences, especially in the

emotional category. I was able to understand how the children determined the severity of their illness experiences, where medication was sought – and if costs were involved, how they got these fees – and for chronic and emotional suffering, what were children's coping mechanisms in alleviating suffering.

**9. Vignettes:** Vignettes were a vital entry point for investigating children's illness experiences and emotional suffering. Using children's own narratives, diagrammatic illustrations, and other findings obtained through interacting with the children, vignettes were written and orally presented to different groups of between seven and twelve children, sometimes including both boys and girls for the discussion. Since Acholi was the most commonly used language, the vignettes were translated into Acholi. Questions were then asked in line with the 'experience of the person in the vignette', particularly whether the children had had similar experiences, and if so, how they dealt with them. Further, in order to elicit emic views concerning sensitive life experiences, such as gender-based violence, the researcher used 'typical stories' in the third person in order to facilitate discussions on these topics. In the process, the author requested the children to give examples about issues of gender-based violence and rape. They were specifically asked whether they personally had witnessed, heard about, or were perpetrators, and whether they or their friends were victims. Where the children had heard about such events, they were requested to discuss such scenes, giving examples. Such discussions shed light into differential gender experiences, and the problems which boys and girls of primary school age confronted. Subsequently, I was able to gain insight concerning gendered life experiences in armed conflict.

Other issues were also raised by the vignettes, such as the 'life stories' of a child who had different illnesses such as malaria and diarrhoea, and the medicines used for these illnesses. Children were then asked questions, for instance, how would they advise the child in the vignette? They were asked if they had had similar experiences to the child in the vignette, what medicines they used for different illness episodes, and if they did not use any medicines, what factors constrained them from accessing these medications. What recommendations do they have for healthcare providers, and what advice would they give to the person in the vignettes?

Further, vignettes were used when the author investigated the experiences and daily lives of a group of children aged eight to sixteen years, and how they dealt with their daily life problems in the context of displacement, abject poverty, and misery.

**10. Structured and unstructured in-depth interviews:** Structured in-depth interviews involved an extensive discussion about particular thematic issues. For instance, after an examination of medical records, children were requested for an in-depth interview in which their illness experiences were discussed in detail. Frequently, there were also study themes specific to individual children. For example, former child soldiers needed numerous and in-depth interactions in order to investigate their life world, their challenges, and how they dealt with them.

I used unstructured interviews when following the children during their day to day activities, for example during tea breaks, meals, and weekend meetings. Other ideal places for unstructured interviews were at the children's homes and on our numerous journeys to visit NGO premises to find out about their activities geared towards alleviating children's suffering. Authors, including Hammel (1990) and Price & Hawkins (2002:1334) underscore the importance of gossip in finding out about social dynamics, which this method is particularly good at eliciting.

In general, the most informal emic views and data were obtained through unstructured interviews. For instance, the topics which the individual children and NGO staff talked about at length provided insights into their social contexts, their values, relationships of power, and the vested interests that operate 'under the surface'. It was during unstructured interviews that some children even acknowledged that they did not use medicines for such illnesses as cough and flu – much as they had frequently mentioned various medicines for them – unless the symptoms were persistent and severe. Frequent disturbances by *cen* (evil spirits), and the use of *atika* (Labiate species) plants and medicines for sleep, were overt components of unstructured and in-depth interviews. This ethnographic research therefore embraced and analyzed in-depth or unstructured interviews as an essential component of ethnographic data collection.

**11. Examining medical records**: Persons visiting any government aided healthcare centre in Gulu were required to present an exercise book to the health professionals for record purposes, and writing a diagnosis. This was a vital source of information regarding the children's health problems. Regular examination of these medical records was done at GRRH, Layibi, Laliya, and Laroo outpatients' health units. During frequent visits to the children's homes, discussions of recent illnesses were validated by examining their medical records. In general, it was largely infectious diseases which were recorded in these books, usually malaria.

As indicated above, in-depth interviews would frequently be conducted following an examination of such medical diagnoses, in order to analyze wartime children's experiences. Further, through participant observation in various state-aided and private healthcare units, insights were obtained concerning contemporary medical practice, child-doctor interactions, and the medications the children used most frequently for these illnesses.

**12. Participant observation and 'following the children around':** This study adopted the phrase 'following the children around' in order to show the extensiveness and intensiveness of the interactions with the children in child headed households. In essence, for the twenty-four children who were willing to participate in the study, there were numerous meetings and interviews aimed at gathering their life experiences in armed conflict, finding out what they did when they were sick, what medicines they used, where and how they got these medicines, and if they were buying them, where and how they got the money. The researcher engaged with the children in their daily life activities to assess how they were actors in managing illnesses and their quest for therapies. Through regular visits to a psychotherapist and psychiatrist, I also participated in the available interventions addressing the effects of experiencing traumatic events.

**13. Focus group discussions:** Bernard (2002:228) and Morgan (1997) recommend having six to twelve members per focus group discussion, plus a moderator. Between seven and eight people is a popular size. Bernard further asserts that if a group is too small, it can be dominated by one or two loudmouths. In a substantial number of discussions, groups of between seven and twelve children were involved in analysing various themes in this study's problematic. Central to these discussions were children's participation, both as co-researchers and facilitators of focus group discussions.

The children had to be willing to take on these special roles, which included interviewing other children recruited in the study. Willingness to participate was one criteria, but I was also interested in their skills in asking questions, being articulate and group-oriented, and whether they had some basic knowledge of the study's problematic. If the child fulfilled these criteria, they were invited to join to facilitate peer group studies (see Price and Hawkins 2002:1334). Price and Hawkins (2002) also demonstrate the importance of using peer researchers as key informants, who are strategically placed by virtue of their membership and understanding of the communities in which the research is undertaken.

**14. Workshops:** Regular group discussion sessions – also called workshops – were

organised for twenty to fifty children, especially during the weekends and at the end of the semester. Five of these workshops assessed severe experiences in wartime, and medicine use. Three sessions addressed the commonness of infectious diseases, and how individual children dealt with such episodes. In one workshop children represented diagrammatically what they regarded as extreme, horrific, and unbearable events in wartime.

**15. Participant observation in Non Governmental Organisations' (NGO) functioning, and making written requests to NGOs**: I investigated NGO dynamics through participant observation in workshops, sensitization seminars, and counselling activities organized by NGOs for 'beneficiaries'. One other key technique to assess NGO functioning was making written requests for major NGOs to intervene to ensure the wellbeing of a select number of children in child headed households. Other data given are from secondary sources including NGO publications and reports.

**16. Collecting and presenting children's pharmaceuticals to paediatricians and pharmacists:** Children were observed in the activities related to their quests for therapy, including at various pharmaceutical distribution centres such as drug shops, groceries, and pharmacies. Children also named and represented diagrammatically their pharmaceuticals, and brought the pharmaceuticals they commonly used for presentation to workshops on medicine use. Each of these samples were collected and presented to specialists in the disciplines of pharmacy and biomedicine to identify their active ingredients. A list of the various pharmaceuticals and active ingredients are given in Appendix Seven.

**17. Collection and presenting of children's herbal medicines to Makerere University's Botany herbarium for identification:** Each of the different plant species presented by children in workshops on medicine use, during home visits, and when discussing particular illness episodes were collected and presented to specialists for identification, and the scientific names of plants were obtained. Some indigenous species were, however, not identified, and therefore when reference is made to their medicinal properties, the *Acholi* name is used. Some scientific names of identified species are presented in the Appendix Eight to facilitate the reader's grasp of the plant types.

**18. Participation in NGO and healthcare institution activities:** Another approach by which emotional issues were assessed was through collaboration with the psychiatric unit at Gulu Regional Referral Hospital (GRRH), and with NGOs, including the World Vision Centre for Formerly Abducted Children (WVCFAC), Caritas, Gulu Support the Children Organization (GUSCO), Noah's Ark, and Save the Children in Uganda (SCiU). These

were key organizations which had projects addressing trauma and psychosocial issues in wartime children and former child soldiers.

*Quantitative techniques*

**19. A survey on common illnesses and medicine use:** One hundred and sixty-five (N=165) children of whom eighty eight were boys and seventy seven were girls responded to questions about the illness experiences or health complaints which affected them within a two weeks to a one month recall, and about the medicines they used. The sample of 165 children was purposively selected basing on criteria for sample selection above and children's willingness to participate. In addition, the context of insecurity due to war meant that the study population was highly mobile, there were no records for reference and some children (especially former child soldiers) were not willing to share their experiences with researchers. Nevertheless, representativeness of this sample calculated at 95 percent confidence interval (i.e. CI at 95% = 1.39-1.54) suggests a normal distribution by gender (see table 4.1. for more details). Questionnaires were self administered, but in the main a substantial proportion of children in night commuters' shelters and displaced primary schools needed help in answering the questions, for instance in writing the name of illnesses and medicines used.

While different techniques were used where appropriate, the core of this ethnography lies in in-depth interaction with wartime children. This facilitated the author in gaining insights through experience-near discussions, sampling by time (see below), and documenting realities in their lives, and not merely offering information which they imagined the author would be interested in. Gender disaggregated data was collected by involving both boys and girls throughout the entire study, in all the activities above.

Clearly there are techniques which are more suitable for assessing variables in common illness experiences, such as experiences with infectious diseases and quests for therapy, than for studying emotional distress. However, a considerable number of the above techniques were crosscutting both areas. What is more, a lot has been done in assessing post traumatic stress disorders in children in Gulu, and this study drew from such top-down assessments of psychosocial distress in war affected children.

### 2.2.3. Validity, reliability, and generalization

The study population constituted children aged eight to sixteen years living in child headed households, and those taking care of close kin sickly due to HIV/AIDS. Child headed households are a growing phenomenon in Uganda, and in Africa in general. Data yielded from this study is therefore potentially generalisable for a substantial proportion of the child population in Sub-Saharan Africa. Reliability, essentially, is the idea that the method used to assess a concept measures it accurately and gives the same answer each time it is used (Fielding & Gilbert 2002:11). Reliability therefore concerns consistency. Validity's concern, on the other hand, is the extent to which a method used to measure a concept does it *accurately*.

The findings generated by this study of wartime children's illness experiences as lived experience, using ethnographic methods, are not only valid but also reliable. Different methods of data collection were used, including surveys triangulated with narratives, participant observation, focus group discussions, and vignettes, while gathering the perspectives of key informants and available records facilitated validity. Sampling by time was another technique employed in order to increase the validity and reliability of data collected. Here, respondents were observed in different situations – both in terms of setting and timing – in order to holistically assess their daily life activities. The meanings of these activities, and why they engaged in them, were subsequently established through in-depth interviews. Becker (1998:119-121) gives advice on how to increase the validity of findings by looking for 'excluded' or 'atypical' cases in data collection. Such excluded cases in this study included children living in normal households, children living with chronic illnesses, and former child soldiers. Their particular perspectives regarding the different meanings of healthcare issues were assessed, including common illnesses and medicine use, trauma, and the medicalisation of psychosocial ill health conditions. Moreover, excluded cases or atypical cases frequently provided insights which the general respondent population did not provide.

Studying with children generated questions of reliability regarding their perspectives, since their *emic* views were frequently different from dominant or existing viewpoints. In such cases, children's perspectives were documented as belonging to a cultural group distinct from that of adults. Throughout the text, and in the discussion of results, children's

perspectives are presented and some of their ideas compared to dominant discourses, particularly those of adults and documented literature.

### 2.2.4. Key informants

Two psychiatrists, five nurses, two paediatricians, seven NGO coordinators, fifteen counsellors, twenty-eight primary school teachers, five primary school head teachers of wartime primary schools, four camp leaders, and thirteen drug shop and clinic owners were regularly interviewed to assess their perspectives on children's healthcare needs and priorities. Parents and legal guardians were also interviewed to assess their perspectives about children's healthcare priorities.

### 2.2.5. Data analysis

Qualitative data collected was analyzed by first transcribing the interviews, and then categorising them; categories consistent with this study's problematic were selected either for quotes or for frequent use within this thesis. In attempting to maximize the voices of the children, direct translations and the proximal meanings of phrases are given, where possible, and every attempt was made to present the children's perspectives as they themselves would like them represented. In particular, some children's narratives and written illness experiences were adapted and presented verbatim.

*Case analysis*

Children's illness narratives and quest for therapy were categorized into 'typical cases' and 'atypical cases'. 'Typical case' narratives were used as 'synecdoche' (see Becker 1998:67-68) or as representative illness narratives for wartime children in child headed households. In this thesis, the prologue and selected compositions and excerpts from children's discussions provide such synecdoche cases. In contrast, 'atypical cases or narratives' represent experiences which could be less representative for the study population. These atypical narratives were used in analyses for the triangulation of results. Adapting typical and atypical narratives facilitated a holistic representation of wartime children's experiences and quests for therapy.

*Survey data analysis*

Statistical Package and Service Solutions (SPSS) is a well known computer software programme for the analysis of social science data. SPSS version 9.0 was used for this study. In the survey with one hundred and sixty five children (N=165), the questions in

the semi-structured questionnaire which I issued were open ended, requiring multiple responses. Therefore, in data analysis I took a multiple response analysis approach. The 165 self-administered questionnaires were coded and fed into an SPSS spread sheet, prior to the computation of results. Some of the statistical summaries and P-values are presented as quantitative data and analytical categories of quantitative data in subsequent chapters.

### 2.3. Ethical considerations

The study was approved by the Uganda National Council for Science and Technology. The Resident District Commissioner of Gulu district, the Chief Administrative Officer, the District Director of Health Services ( or District H ealth Officer as the position holder was renamed in late 2007), school head teachers, and NGOs that provided services to war affected children in Gulu district, provided additional permission to conduct this research.

Wartime children were approached as social actors for this study. Permission was sought from each of them to participate in the ethnographic research. Children who accepted to participate in the study were given the option to commit themselves to regular interviews and home visits. The twenty-four children who were extensively involved in the study were told of the purpose of the study, the length of the study, and what was required of them, and they gave verbal consent to participate in the study. Children who were not willing to participate in the study either due to their demands for money before they share their experiences or individual attributes such as shyness were excluded. Some child soldiers were particularly reluctant to share any of their experiences either with researchers or counsellors. When all efforts to discuss with them failed, I focussed on ex-combatants who were willing to participate in the study.

It is also important to note that the legal framework in which this study was conducted regards individuals below sixteen years as cultural minorities and that the adult caretaker would be approached on behalf of children or for the adult to provide permission to participate in the study. Where possible, the adult caretakers or adults children regularly interacted with, were approached to seek their permission for children's participation in the study. What I need to emphasise however, is that children who lived in child headed

households were independent actors and this study generally approached children as social actors. Institutional managers such as school teachers and NGO coordinators of night commuters' shelters mentioned above were consulted about children's participation in this study and they provided additional legal consent.

Children who shared with me their severe experiences in wartime were referred to the regional psychiatrist and psychologists for review and counselling. Although I organised this myself, I am ambivalent about the existing approaches to help children relieve their distress at the time of the study. On one hand children identified and prioritised differently how their distresses could be minimised. On the other hand it was an *ethical requirement* in assessment of psychosocial distress that any child who named having suicidal thoughts or having recently been exposed to extreme events should be immediately referred to professional counsellors. Moreover, I did not believe that medical anthropology, like other social science disciplines, had a firm enough foundation or knowledge base to refute the preset procedures of science especially in assessment of mental distress. Perhaps results from medical anthropological data could complement assessment and management approaches of wartime mental distress.

All the one hundred and sixty five children (N=165) who participated in the general survey and the additional 24 children who were followed about during ethnographic research process were requested to participate in a study about their common illness experiences. All the children gave verbal consent.

Examining life histories and narratives in the context of armed conflict was quite a delicate issue. Children were assured of anonymity and confidentiality, and interviews were only tape recorded if respondents granted permission to the author. Nevertheless, throughout the thesis I have used the children's real second names, first to place them in the northern Uganda locality, and secondly, these second names are not specific to the children, but rather they are names commonly used by Acholi people. Occasionally, however, I refer to individuals also by their first name, since a specific request was made and they consented to my using their two names.

A summary of some general information and life experiences of the twenty-four children who extensively participated in the study are provided as an Appendix One in this thesis. I have chosen to use pseudo first names and their correct second names when giving such biographical information, to ensure anonymity. Use of only first or second

names for this particular group would not suffice since there are children who participated in this study with similar second names.

### 2.4. My personal involvement in the study

My personal involvement in this study should not be left unmentioned. Consciously or unconsciously, it has influenced the way I approached the field of study, the way I interacted with informants, and the analysis of my data [see Akello (2007) for further analyses of the intersubjectivity issue]. Throughout this thesis I acknowledge the importance of intersubjectivity and detachment in my research. In this section I will provide some biographical information to suggest how I view myself as an insider with proximal interpersonal subjectivitivies with wartime children.

I have historical and symbolic attachments to Gulu district in northern Uganda where this study was conducted. I speak Acholi, and also conducted research in the same district in 1999 in Pabbo camp, 27km west of Gulu Municipality. More importantly, however, part of my childhood experiences as an orphan[39] living in abject poverty, and at the time of this study, my experience of taking care of a close kin member sickly with HIV/AIDS, take centre stage in my intersubjectivity and shared subjectivities with wartime children. With my childhood experiences, I can fully relate to living in a poor, fetid environment, I know how these are core predisposing factors to preventable and curable infectious diseases, and I have experienced hunger due to lack of food and lack of basic necessities. I am aware of the emotional suffering which comes from losing my father at an early age. These are often expressed in somatic symptoms such as persistent headaches and the feeling of something invisible moving around my body causing a lot of pain and suffering. In essence, by recognising my shared experiences with wartime children, and employing intersubjectivity as an analytical tool, I show how wartime children and I drew from shared subjectivities to compose the stories told in this thesis. Ultimately, I make it explicit that the research process has also been relevant for my own therapy.

Another essential objective of this section is to demonstrate the importance of the researcher being his/her own research instrument in introspective research, to facilitate

[39] In Uganda, an individual is an orphan after loss of one or both parents. This is slightly different from the Western context where being an orphan entails losing both parents.

the collection of concrete and valid data. In short, whereas studying a culture close to the researcher's means that one understands most of the issues, I am conscious that the closeness might mean that one neglects some aspects of the culture. This study's strength lies in the researcher's ability to understand the issues at stake.