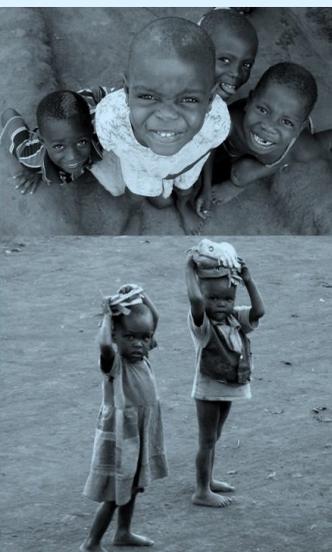


Case management of childhood fevers in the community

Exploring malaria and pneumonia care in Uganda

Karin Källander



Stockholm 2006

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CASE MANAGEMENT OF CHILDHOOD FEVERS IN THE COMMUNITY

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“The most widespread and fatal of all acute diseases, pneumonia, is now
captain of the men of death”

Sir William Osler, 1901, British (Canadian-born) physician

“It takes a village to raise a child”

African proverb

ABSTRACT

Background: Acute respiratory infections (ARI), especially pneumonia, are leading causes of death in children under-five. Symptoms often overlap with those of malaria. In Uganda, the Home Based Management of fever (HBM) strategy recommends treating all febrile children with antimalarials provided by local community health workers (CHWs) – in Uganda called drug distributors (DDs). However, HBM overlooks the pneumonia symptom overlap, with potentially adverse effects for the affected children.

Main aim: To explore aspects of home and community care for childhood fevers in Uganda and devise recommendations for integrated community based management of malaria and pneumonia.

Methodology: Five sub-studies (I-V) were performed using a triangulation of qualitative (II & V) and quantitative (I, III, IV and V) methods in households (III & IV), communities (II, IV & V), health centres (I & IV) and a hospital (IV & V). Study I was cross-sectional in 14 health centres where 3,671 child consultation records were analysed for symptom overlap. Study II used 10 focus group discussions (FGDs) with mothers, fathers and grandparents. Study III was a cross-sectional household survey where mothers of 3,249 children were interviewed using 2 week recall. Study IV used case-series in the community, interviewing caretakers of 117 referred children and tracking the child in the outpatient records of nearby health facilities. Study V used performance assessment of 96 DDs in a hospital, 4 FGDs with mothers in the community and unstructured interviews with 2 key informants.

Results: Thirty percent of children seen in health facilities (I) and 19% of sick children in the community (III) had symptoms compatible with both malaria and pneumonia. Some febrile conditions were perceived to require urgent allopathic treatment, and others were first treated with traditional remedies (II). Of children with cough and difficult/rapid breathing in the community, 35% were treated with antibiotics but when fever was present, antibiotic use dropped ($p=0.12$) and antimalarial use increased ($p<0.001$) (III). Among caretakers of children referred by DDs, 82% stated having completed referral but 52% had delayed ≥ 2 days (IV). DD assessment of rapid breathing was adequate with 75% sensitivity and 83% specificity (V). Many biomedically relevant terms for ARI existed in the local language but most were related to fever and perceived to need antimalarial treatment (V).

Discussion: Addressing only malaria in community management strategies may increase treatment delays for potential pneumonia. More comprehensive community management covering also pneumonia could potentially increase child survival. While management of pneumonia in the community involves dispensing of antibiotics by non-medically trained distributors, antibiotic drugs are already widely used in the community. With adequate training, supervision and support for DDs there is potential to rationalise antibiotic use while concurrently increasing access to treatment. To achieve high community uptake and minimise drug misuse, the local illness concepts and treatment actions need to be addressed. While DDs can operate to identify and treat children early in the disease, the high rate of referral completion demonstrates that also links to the formal health system can be maintained. With these findings, the feasibility and impact of full-scale implementation of integrated management of malaria and pneumonia in the community should be tested.

Key words: ARI, pneumonia, Malaria, Health system, Community health worker, Uganda, Home management

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- I. Kallander K, Nsungwa-Sabiiti J, Peterson S. *Symptom overlap for malaria and pneumonia - policy implications for home management strategies*. Acta Tropica 2004;90(2):211-4.
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LIST OF ABBREVIATIONS

ARI	Acute Respiratory Infection
CAH	Child and Adolescent Health and Development
CHW	Community Health Worker*
DD	Drug Distributor†
DDHS	District Director of Health Services
FGD	Focus Group Discussion
GFATM	Global Fund to fight AIDS, TB and Malaria
GOU	Government of Uganda
HBM	Home Based Management of fever
HC	Health Centre
HMM	Home Management of Malaria
HSD	Health Sub-District
IEC	Information, Education and Communication
IMCI	Integrated Management of Childhood Illness
IPT	Intermittent Presumptive Treatment
ITN	Insecticide Treated Nets
LC	Local Council
LRI	Lower respiratory Infection
MDG	Millennium Development Goal
MOH	Ministry of Health
PHC	Primary Health Care
RBM	Roll Back Malaria
RR	Respiratory Rate
SSA	Sub-Saharan Africa
UNICEF	United Nations' Children Fund
URI	Upper Respiratory Infection

* This general definition will be used for any local inhabitant with limited amount of training who provides specific basic health and nutrition services to the members of their surrounding communities to extend health care to underserved populations (Walt G. 1990).

† This more specific definition applies to the trained community members under Uganda's Home Based Management of fever (HBM) strategy who treat children with fever with pre-packaged, color-coded antimalarial treatment pack (Homapak) and counsel caretakers of sick children on dosage, treatment duration, and danger signs, and provide referral for children with persisting fever or danger signs (MOH Uganda 2002).

PREAMBLE

Child survival: Different progress in different regions

The 20th century witnessed dramatic declines in child mortality in almost all countries of the world, regardless of initial levels, socioeconomic circumstances and development strategies. In the advanced economies the declines were already apparent at the end of the 19th century. In the low-income countries, substantial declines did not take place until shortly after the end of the Second World War (Ahmad et al., 2000). But advances slowed in the 1990s. Although under-five mortality rates declined 14% globally between 1990 and 2000 (UNICEF, 2001), the largest reductions occurred in industrialized countries and the smallest in sub-Saharan Africa (SSA), where child mortality is highest (Figure 1). There is concern that continued gains will be difficult to keep up in countries affected by economic instability, deterioration of health systems and high levels of HIV transmission (Adentunji, 2000) and it is anticipated that by 2010, half of all under-five deaths will occur in SSA where child mortality rates are again increasing in some countries (UNICEF, 2001).

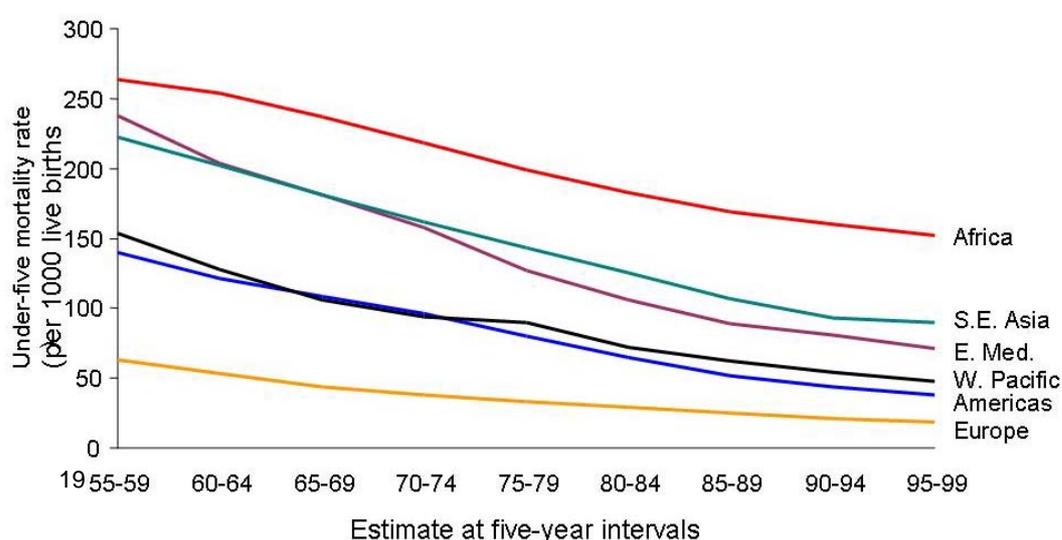


Figure 1. Regional trends in under-five mortality, 1955-1999. Source: EIP/WHO

Deaths in children under-five account for a major proportion of the global burden of disease. Every year about 10.5 million under-fives die, 99% of deaths occur in low-income countries or in poorer parts of middle-income countries (Black et al., 2003). There are determinants for childhood deaths at several levels, and interventions at social and economic levels can improve child survival. However, ultimately it is disease that kills a child, and curative care for childhood illness is a proximate determinant of survival or death (Mosley and Chen, 1984). More than half of deaths in children under the age of five in low-income countries can be attributed to only five infectious diseases, or a combination of them: acute respiratory infections (foremost pneumonia), malaria, diarrhoea, measles and HIV/AIDS (WHO, 1998, Black et al., 2003). Most deaths occur in impoverished rural communities where poor access to basic health care result in lack of timely administration of inexpensive treatment. However, an estimated 60% of these deaths could be prevented by high coverage of simple and cheap interventions such as timely treatment with antibiotics and antimalarials, oral rehydration therapy (ORT), improved breastfeeding and immunizations (Jones et al., 2003). Ultimately, however, for children who fall sick, it is the caretaker's response to the illness that can make a

difference between life and death (WHO, 1998). However, the individual responses are complex and influenced by individual, household and community level factors which are insufficiently explored in relation to the health system in which they take place and to new health policies introduced (van der Geest, 1987, Reynolds Whyte et al., 2002, Williams and Jones, 2004).

Major bottlenecks for improved child survival include the weak and inequitable nature of health systems which fail to deliver life-saving interventions – especially to the poor who need them most (Freedman et al., 2005, Gwatkin et al., 2000). Many now advocate that child survival can only be improved if strategies for intervention delivery are greatly improved, scaled-up, and tailored to the stage of health-system development (Bryce et al., 2003, Freedman et al., 2005, Travis et al., 2004). Involving the communities in the delivery of primary health care (PHC) to account for the lack of health infrastructure and skilled manpower has regained attention and many now argue that community based management is a key component in health system strengthening (Paul, 2004, Task Force on Health Systems Research, 2004).

This thesis was inspired by the striking reductions observed in maternal, neonatal, infant and child mortality through community intervention, primarily in Asia (Kallander et al., 2005, Manandhar et al., 2004, Sazawal and Black, 2003). As home management of malaria (HMM) strategies are now introduced across Africa I was particularly interested in one of the key conditions tackled in Asia, but conspicuously absent from policies in Africa – namely pneumonia!

INTRODUCTION

BURDEN OF DISEASE IN SUB-SAHARAN AFRICAN CHILDREN

The three major infections killing children in Sub-Saharan Africa (SSA) are acute respiratory infections (ARI), malaria and diarrhoea, each contributing to 20-26% of the overall child mortality (Black et al., 2003). Neonatal disorders, including congenital diseases and sepsis, constitute an almost equal share. These proportions do not vary substantially with prevalence of HIV/AIDS which is still a smaller contributor to overall child mortality, constituting about 8-10% (Walker et al., 2002, Black et al., 2003), while the proportion of under-five deaths attributable to underweight reaches above 50% (Black et al., 2003).

Acute respiratory infections (ARI)

ARI is the most common cause of death in under-five children, with an estimated 2.7 million annual deaths globally (Mulholland, 1999). In SSA, the estimated proportion of deaths attributed to pneumonia is 17-26% (Black et al., 2003). Most ARI deaths are caused by pneumonia, while bronchiolitis account for the majority of the remaining deaths. ARI is a collective name for both upper respiratory infections (URI) and lower respiratory infections (LRI). URIs are extremely common and as they are typically mild and caused by viruses, they are best treated at home without antibiotics. LRIs are usually more severe and can be caused by both viruses and bacteria. While the incidence of URI is similar worldwide, the occurrence of LRI, particularly pneumonia, is 10-50 times greater in low-income countries (Mohs, 1985). In high-income countries most LRIs are viral but in poorer countries an estimated 2/3 are bacterial (WHO, 1999). *Streptococcus pneumoniae* (often referred to as pneumococcus) (37.9%), *Haemophilus influenzae* (33.2%), and *Staphylococcus aureus* (7.9%) are the most common bacteria (WHO, 1991c). In young children, respiratory syncytial virus (RSV) is the leading viral agent although its frequency fluctuates with epidemics (Weber et al., 1998). Whereas pneumococci and *H. influenzae* predominate among infants and toddlers, atypical bacteria (*Mycoplasma pneumoniae*, *Chlamydia pneumoniae*) and viruses appear more often in older children. ARIs are transmitted mostly by infected persons' sneezing, coughing or talking, although many young children can be healthy carriers of pneumococci in the nasopharynx. The term *pneumonia* is usually used in the broader sense to refer to severe acute infections of the lungs by viral, bacterial, and other pathogens (Schuchat and Dowell, 2004). Bacterial pneumonia often follows a viral infection or occurs in association with an underlying predisposing condition, such as immunodeficiency (Chin, 2000).

Symptoms of pneumonia include a sudden onset of cough, fever, fast and difficult breathing, vomiting, convulsions and chest indrawings (Chin, 2000). If left untreated the case fatality rate in children in the community is high – sometimes exceeding 20% (Dio et al., 1983) and death can occur within 3 days of illness onset (Reyes et al., 1997). Preventive measures include improving nutrition and breastfeeding among infants, which strengthens the immune defence and reduce the chances of the child becoming ill and dying from pneumonia. Other measures include reducing the incidence of low birth weight deliveries, reducing indoor air pollution (tobacco smoke, cooking and heating smoke), and keeping infants warm (Mulholland, 2003). Some ARIs can be prevented with vaccinations, including measles, diphtheria, whooping cough and, more recently, *H. influenzae* b (Hib), which almost completely eliminated Hib disease in the Gambia (Adegbola et al., 2005). Clinical trials for pneumococcal conjugate vaccines are also ongoing in several African countries. Although efficacious for included serotypes, they do not reduce pneumococcal colonisation of the

nasopharynx, and although vaccine serotypes become less common, they are instead replaced by other serotypes (Schuchat and Dowell, 2004). Meanwhile, and for the foreseeable future, curative case management of childhood pneumonia will remain important. For children with pneumonia appropriate case management with antibiotics can avert most deaths, but only if families recognise signs of illness and seek care promptly. However, due to lack of recognition of symptoms of severe illness and socio-economic, geographic and cultural factors many moderate and severe ARIs are treated in the home or seek care too late, sometimes resulting in death.

Malaria

Despite control attempts around 1.1 million people die every year from malaria, 90% of which are under-fives in SSA. The proportion of childhood deaths attributable to malaria in SSA is 20-26% (Black et al., 2003). Four types of malaria parasites infect humans, i.e. *Plasmodium falciparum*, *P. malariae*, *P. vivax* and *P. ovale*, with transmission occurring through bites of infected female Anopheline mosquitoes. *P. falciparum* is the most widespread type and the only one capable of producing severe and potentially fatal cerebral malaria.

Most malaria episodes start with children developing fever, vomiting, headache and flu-like symptoms. If left untreated, the disease may progress rapidly to convulsions, coma and death - often within 24 hours of symptom onset (Greenwood et al., 1987). In high-transmission areas most malaria deaths in children are due to anaemia resulting from repeated untreated malaria infections. The mortality rate is highest during the first two years of life, with the exception of the first two months when children are protected by the maternal antibodies. By school age, a considerable degree of immunity has normally developed and asymptomatic parasitemia can be as high as 75% (Greenwood et al., 1987). Current strategies for preventing malaria include vector control, use of insecticide treated nets (ITNs) and intermittent presumptive treatment (IPT) to prevent anaemia. No effective vaccine exists in the market at present, although promising vaccine candidates are in clinical trial stages (Alonso et al., 2004). Due to insufficient coverage of preventive measures, prompt treatment with effective antimalarial drugs for early symptoms is considered the most important method to prevent death. However, owing to health systems constraints, 75-80% of fever cases are managed at home or in the community (Foster, 1995, Filmer, 2005) and more than 40% of children who die from a febrile illness die at home without prior contact with the formal health care system (Author's calculations based on (MOH Tanzania, 2004)).

Diarrhoea

An estimated 2.2 million children die of diarrhoeal disease every year and is responsible for 17-26% of under-five deaths in SSA (Black et al., 2003). Diarrhoea is a symptom of a gastrointestinal infection caused by bacterial, viral and parasitic organisms, most which can be spread by contaminated water. Rotaviruses are by far the most common pathogen in childhood diarrhoea but coliform bacteria, Shigella and Giardia are also common (Nakano et al., 1990). The introduction of ORT in 1979 reduced the deaths from diarrhoeal disease by almost 60% in only one decade (Victora et al., 2000). Further reductions are expected to result from scale-up of hygiene promotion (such as hand washing) (Luby et al., 2005) and the promising rotavirus vaccine (Glass et al., 2005). The experiences with ORT can provide useful guidance for other child survival programmes, as it demonstrates successful delivery by national programmes at coverage levels sufficient to reduce mortality. With scientific communication to the medical community, revision of medical curricula, training of health

workers, support to local ORT production and social marketing to stimulate demand, adequate coverage could be achieved and sustained. With strong advocacy and adequate political will and financial support, it is believed that also interventions designed to combat other major causes of child mortality in under served populations can be successfully implemented.

CHILDHOOD FEVERS IN SUB-SAHARAN AFRICA

However, patients present with symptoms, not *diseases* and a common characteristic for ARI, malaria and diarrhoea is that they all present with fever. This is also the most common symptom reported by mothers with sick under-fives. Although fever can be caused by a large number of infections in tropical Africa, the malaria attributable fraction of fever (MAFF) is often high, ranging from 30-60% (Bremner, 2001), dropping to 0-20% in urban areas (Wang et al., 2005). Apart from malaria, ARI and diarrhoea, other acute febrile illnesses in SSA include measles, meningitis and urinary tract infections. Fever in the first two months of life is a sign of possible bacterial infection, often caused by pneumococci (WHO, 1993b). In SSA, most episodes of fever in under-fives should be seen as potentially dangerous infections requiring careful monitoring or treatment. As laboratory technology is needed for determination of underlying disease, the aetiology of fever is often difficult to establish. Although diarrhoea is also a cross-cutting symptom in sick children, often overlapping with fever, the focus of the thesis was on respiratory symptoms and fever and the malaria – pneumonia overlap.

Malaria and pneumonia symptom overlap

Not only do malaria and pneumonia both present with fever, but they also share several important characteristics. Both present with cough and increased respiratory rate at mild stages, and convulsions, respiratory distress and chest indrawings at more severe stages. Although fast breathing (tachypnoea) in a child with cough is a key sign of pneumonia, it is often also seen among malaria patients, partly explained by the effect of fever. Studies demonstrate that the respiratory rate increase with 3.7 breaths per minute per degree centigrade, with no significant difference between children with pneumonia or malaria (O'Dempsey et al., 1993a). However, the increased respiratory rate in malaria patients may also result from increased cytokine levels, anaemia, lactic acidosis, or septal interstitial oedema due to cytoadherence of parasitized red blood cells to the pulmonary endothelium. Also acute pulmonary insufficiency, pulmonary oedema, and left ventricular failure have been discussed as factors affecting breathing rate, but such manifestations are only seen in a few patients with severe disease (O'Dempsey et al., 1993b). Data on malaria and pneumonia resemblance was first published in 1933 when Williams discovered that cases classified as acute bronchitis could be effectively treated with quinine (Williams, 1933). Given the frequent lack of x-rays and microscopes in health centres in SSA to differentiate the two diseases, children with overlapping symptoms should receive dual disease classification and treatment with both antimalarials and antibiotics (WHO, 1991a). Whereas the extent of this overlap has been studied in hospital out patient departments (OPD), where 50% of children had symptoms compatible with both malaria and pneumonia (Kolstad et al., 1997, Perkins et al., 1997), it has not been documented in routine health centre practice or in sick children in the community.

HOME CARE AND CARE SEEKING BEHAVIOUR

Recognition, interpretation and labelling of illness symptoms

Although children with overlapping symptoms in health facilities receive dual disease classification and treatment, the initial diagnosis is made by the primary caretaker who in most cases is the mother. The actions taken for a sick child typically starts with caretakers recognising illness signs and, following interpretation and labelling of the condition, proceed to address it through culturally recommended therapies (Lubanga et al., 1997). The health care actions which follow often depend on the meaning of local illness concepts (Wallman et al., 1996) and who or what is to blame for illness is based on shared cultural ideas within a particular society (Freudenthal, 2000). Although signs of acute illness do not always trigger care seeking behaviour, such as fast breathing and chest indrawings for ARI (Mull et al., 1994), caretakers may still be aware of the symptoms by considering them in a context of local illness classifications (Nichter and Vuckovic, 1994). In Tanzania, convulsing children are classified as suffering from *degedege* and treated with strong smells by traditional healers (Comoro et al., 2003). The recommended treatments for different illnesses often diverge between local communities and biomedical investigators, described in the anthropology literature as a result of *emic* (local) and *etic* (outside, e.g. biomedical) perceptions of efficacy (Etkin, 1991). Whereas the local *emic* illness terms and treatments used for malaria have been explored previously (Kengeya-Kayondo et al., 1994, Lubanga et al., 1997), little is known about *emic* ARI illness classifications in SSA. Also the understanding of which fever and ARI illness classifications trigger prompt antimalarial or antibiotic treatment is very limited.

Decision-making processes and gender

Decisions about care seeking for a sick child are generally negotiated in social networks, involving relatives and friends who draw upon general values, knowledge and rules shared by the society (Molyneux et al., 2002). Intra-household relations and factors like age, sex and relationship to the head of household determine household members' power in decision-making. Low female control over cash is often a limiting factor in the management of sick children; underutilisation of health services is more often due to their affordability, availability and acceptability by women rather than the influence of local beliefs or aversion of western medicines (Sen, 1990, Wallman et al., 1996, Tanner and Vlassoff, 1998). Whereas research in the field of gender and health care is expanding in high-income countries, the focus in low and middle income countries has mainly been on women's reproductive health (Thorson, 2003). However, there is a troublesome amount of evidence from various countries that household spending for health care is biased against the younger age groups (Sauerborn et al., 1996) and girls (Kurz and Johnson-Welch, 1997). This result in shorter duration of antibiotic treatments (Larsson et al., 2000), poorer health and nutritional status, and higher mortality among under-five girls (Ravindran, 1986). Although health care seeking and treatment bias are critical in relation to child survival, this has not been much explored in relation to ARI and fever in SSA (Nichter and Vuckovic, 1994).

Provider choice and the role of the private sector

The caretakers' responses to an illness episode, such as timeliness of health care seeking, type of provider consulted and type of treatment obtained, may greatly affect the illness outcome (Mosley and Chen, 1984). Provider and treatment choice involves a myriad of cognitive and non-cognitive factors related to illness type and severity, pre-existing lay beliefs about illness causation, the range and accessibility of therapeutic options available; and their perceived

efficacy (Mackian et al., 2004, Rathgeber and Vlassoff, 1993). Given the many shortcomings in the public health services and client dissatisfaction due to uncomfortable physical environment, inadequate provider interaction and unpleasant staff attitudes, many patients prefer to seek health care from private ‘informal’ providers (Olenja, 2003).

The informal sector is largely unenumerated and consists of both biomedical and traditional providers. The informal biomedical sources are often illicit as drugs retailers often illegally acquire their supplies from the formal health system, demonstrated by the direct correlation between drugs missing in public dispensaries and those available in drug shops or private clinics (Whyte and Kariuki, 1991). With private drug retailers patients can negotiate the treatment needed and often choose the type and quantity of the medicine they want, enabling people to have more control over their health care expenditure (Brieger et al., 2004a). According to biomedical principles, the treatment provided by ‘informal providers’ is often suboptimal and prescribed “inappropriately” for the wrong indications. However, users often have their own form of rationality which is often very different from what national committees have written into policy (Reynolds Whyte et al., 2002). Although essential drugs policies and restrictive legislations for drug retailers have been tried to regulate the uncontrolled private sector (Waters et al., 2002), the potential to instead involve private allopathic providers as partners in child health programmes has recently gained attention (van der Geest, 1997, Marsh et al., 2004, Axelsson et al., 2003). Yet, most efforts aiming to improve supply and use of drugs for children’s illnesses are still focussed on the public primary-level health facilities (Reynolds Whyte et al., 2002, Claeson and Waldman, 2000). Although self-treatment has become undeniably central in everyday life, it is very poorly explored (Ogden and Bantebya-Kyomuhendo, 1996) and community drug utilisation studies for childhood infections – especially for ARI - are rare in SSA (Nichter et al., 1994).

The traditional private practitioners, often referred to as traditional healers, have shown to have particularly important roles in the health care for children (Hausmann Muela, 2000, van der Geest, 1997). The use of traditional medicine is deeply rooted in many African cultures with a base in medical theories with social and religious characters emphasising prevention and holistic features (van der Geest, 1997). Although some traditional responses to health problems may be harmful to the patient (Whyte, 1982, Iyun and Tomson, 1996, Comoro et al., 2003), traditional healers’ are often emotionally committed in the therapeutic process, explaining why they are often preferred over the impersonal treatment experienced in health facilities (van der Geest, 1997). Thee two systems – the ‘allopathic’ and the ‘traditional’ – are often used simultaneously or sequentially, and ‘traditional healers often mix traditional remedies with allopathic drugs (Sachs and Tomson, 1992, Wallman et al., 1996). Whereas this “medical pluralism” has been demonstrated for treatment of severe malaria (Comoro et al., 2003, Hausmann Muela, 2000), its role in treatment of milder fevers and ARI in unclear.

HEALTH SYSTEMS: GOALS AND FUNCTIONS

WHO defines health systems as systems which “include all actors, organizations, institutions and resources whose primary purpose is to promote, restore or maintain health” (WHO, 2000c). In most countries a health system has public, private, traditional and informal sectors. Although the goal of a health system is to improve health, other intrinsic goals are to be responsive to the population it serves. This responsiveness is determined by the way, and the environment in, people are treated, and should ensure that the financial burden of paying for

health is fairly distributed. Four key functions determine the way inputs are transformed into outcomes that people value: resource generation, financing, service provision and stewardship (WHO, 2000c). The effectiveness, efficiency and equity of national health systems are critical determinants of population health status (Task Force on Health Systems Research, 2004, Travis et al., 2004).

Health systems in developing countries are being identified as a key constraint to the implementation of child health programmes (Freedman et al., 2005). A core component of a functional health system which has received insufficient attention is the referral process (Font et al., 2002). The health system is based on two fundamental assumptions that patients who need health care not available at primary level can access this from secondary or tertiary levels, and that tertiary hospitals are sufficiently equipped with technology and manpower to provide this more advanced care. However, studies show that referral to tertiary care is unrealistic for many caretakers (Peterson et al., 2004) and that the quality of care provided in tertiary hospitals for referred paediatric patients is far below expectations (English et al., 2004). While these constraints relate to impoverished people and health systems, another important health system constraint is the “priority problems” focus which may distort the existing systems with unintended negative consequences to “non-” or “low-priority” health problems. As an example, the 3 by 5 initiative to accelerate access to antiretroviral therapy to three million people infected with HIV by 2005 has steered focus away from common childhood illnesses, and large financial and human resources are now spent on paediatric HIV/AIDS treatment which contributes much less to the overall child mortality (Jones et al., 2003).

CONTROL STRATEGIES FOR CHILDHOOD ILLNESSES

Historically child health programmes dealt with individual conditions within national or international disease-specific programmes, so-called ‘vertical’ programmes (Nicoll, 2000). Following closely behind the highly successful Programme for Control of Diarrhoeal Disease (CDD Programme), a global Programme for Control of Acute Respiratory Infections (ARI Programme) was launched by WHO in 1984. During the early 1980s, effective diagnosis and treatment of childhood pneumonia was not widely available in most low-income countries and was thought to require sophisticated medical diagnostic methods such as stethoscope examination and x-rays. However, the ARI Programme relied on early detection and treatment of pneumonia by first level health workers using simple treatment guidelines based on increased respiratory rate according to age, chest in drawings and decreased level of alertness in the child (WHO, 1991b). The programme also used a limited set of inexpensive standard antibiotics, with the potential both to limit costs of treating pneumonia and reduce the growing problem of antibiotic resistance. Eighty-five countries adopted the ARI control programme based on the WHO model, 19 of them with nationwide coverage (Mulholland, 2003).

However, both the CDD programme and the ARI programme have had particular difficulties in handling illnesses among children under-five, as these frequently present with symptoms that could be due to conditions spanning more than one programme (for example ARI and/or diarrhoea and/or malaria) or with multiple conditions (measles and malnutrition) (Nicoll, 2000). Awareness of this limitation called for a more integrated approach to managing sick

children, as well as the need for child health programmes to go beyond single diseases and address the overall health of a child.

Integrated Management of Childhood Illness (IMCI)

Building on the strength of experience from ‘vertical’ programmes over the past two decades, the WHO and United Nations Children’s Fund (UNICEF), developed the Integrated Management of Childhood Illness (IMCI) strategy (Gove, 1997). The ARI programme was (perhaps prematurely (Mulholland, 2003)) absorbed into the broader IMCI strategy in which standard treatment algorithms and health worker management of ARI was combined with similar approaches for the other main childhood illness problems. Under IMCI “pneumonia” is defined as cough or difficult breathing with fast breathing or chest indrawing and “malaria” as presence or history of fever in countries where malaria is endemic. Children with overlapping symptoms in health centres should receive dual IMCI classification and treatment with both antimalarials and antibiotics.

When the symptom based IMCI strategy was first introduced in Tanzania in 1995, the focus was on improving the quality of care in first-level health facilities (Lambrechts et al., 1999). Gradually, the programme became more integrated, addressing child health, growth and development. Hence IMCI evolved into a broader strategy consisting of the three components (1) improving case management skills of health workers; (2) improving health system support; and (3) improving household and community practices related to child health, nutrition and development (Community IMCI, or C-IMCI) (Gove, 1997). Interventions in all three components encompass both curative and preventative care. Context specific treatment guidelines developed by previous disease-specific programmes were incorporated into an 11-day training course for health workers and adaptation guides were produced to identify clinical policies, guidelines, and local terminology for context specific charts and modules (WHO, 2002b).

Implementation of IMCI is now completed or ongoing in more than 80 countries and a recent multi-country evaluation showed reduced child mortality by 13% (Armstrong Schellenberg et al., 2004), improved drug prescription (Gouws et al., 2004), health care seeking (Arifeen et al., 2004) and quality of care (Chopra et al., 2005). However, shortcomings have been observed, such as inadequate counselling of caregivers by health workers (Karamagi et al., 2004) and unreasonable referral criteria for impoverished caretakers (Peterson et al., 2004). Another setback involves the commitment of countries to scale-up rapidly (within 2-3 years), resulting in suboptimal training and faltering health system support, such as supervision and district-level management (Nsungwa-Sabiiti et al., 2004). A major drawback is the rare up-scaling of C-IMCI, as interventions in health facilities only will have limited impact unless households and communities are involved in the planning and implementation process (Winch et al., 2002, Bessenecker and Walker, 2004).

The delay to introduce C-IMCI owes to the fact that the strategy has been difficult to define and the equivalent of ‘standard treatment guidelines’ does not exist for home or community management of illnesses (WHO, 2004a). Health planners often have no clear idea of the technical content of C-IMCI, and are therefore reluctant to commit resources towards its implementation (Winch et al., 2002). As an aid to planning of C-IMCI, WHO and UNICEF identified 12 family and community practices (FCPs) that, if properly promoted and adopted by communities, potentially would contribute to improving child survival (Bessenecker and

Walker, 2004). Whereas the progress to integrate C-IMCI strategies into the health system has been slow in the majority of low-income countries (Task Force on Health Systems Research, 2004), Bangladesh, Nigeria and Nepal have reported successful C-IMCI implementation (IMCI National Working Group, 2004, Brieger et al., 2004b, Dawson, 2001). A common characteristic is that they all have concretised the FCP message “improved home treatment for infections” to involve therapeutic management of infections like malaria and/or pneumonia in the community.

Home and community management strategies

Owing to the postponement of C-IMCI in combination with health care access barriers at household, community, health service delivery, health sector policy and strategic levels (Hanson et al., 2003), complementary health care delivery strategies have been employed to reach sick children in the communities. The most prominent are the home and community based management strategies, which have shown that safe, timely and appropriate treatment can be provided in the communities through the use of community health workers (CHWs). In Asia, community based management of pneumonia resulted in impressive reduction in overall child mortality (26-28%) and pneumonia specific mortality (37-48%) (Sazawal and Black, 2003, Kallander et al., 2005). Whereas CHWs ability to correctly assess, treat and refer children with pneumonia has been demonstrated in Asia (Hadi, 2003) and South America (Zeitz et al., 1993), the capacity of African CHWs to manage ARI has rarely been tested. Given the lack of experiences from SSA, health policy makers remain doubtful towards the approach (WHO, 2002a). Consequently, very few countries in SSA have replicated the successful Asian experiences or introduced the strategy in their national child health programmes (Kallander et al., 2005).

On the contrary, based on the rather weaker evidence that presumptive home treatment with antimalarials in under-fives in malaria endemic areas resulted in more timely treatment (Dunyo et al., 2000, Deming et al., 1989), reduced severe morbidity (Sirima et al. 2003) and reduced mortality (Kidane & Morrow 2000), many African countries have adopted the home management of malaria (HMM) strategy (WHO, 2004b). This vertical malaria strategy is a concrete attempt to reach the target set at the roll back malaria (RBM) summit in Abuja in 2000, where heads of states made a commitment to ensure that by 2005 at least 60% of malaria episodes would have access to correct, affordable, and appropriate treatment within 24 hours of symptoms onset (WHO, 2000a). However, HMM are now scaled up in many countries based on meagre evidence of impact, and despite the global recommendation of integrated child care, HMM is introduced vertically for malaria with unknown consequences for other infections with similar symptoms, such as pneumonia.

As a response to these concerns, a technical meeting was organised in Stockholm in 2002 where bilateral and multilateral organizations, researchers and policy makers reviewed the evidence of community management of pneumonia (WHO, 2002a). The meeting resulted in a WHO/UNICEF joint statement which encourages countries to scale-up pneumonia case management in the community and integrate pneumonia care in HMM strategies (WHO/UNICEF, 2004). However, the recommendation has sparked little activity and most programmes are still implemented vertically, treating all fevers as malaria (Winch et al., 2005, Kallander et al., 2005).

THE CONTEXT: UGANDA

Country profile

Uganda is a landlocked country located in Eastern Africa covering an area of 241,038 sq km. It straddles the Equator and is bordered by Kenya in the East, Sudan in the North, Tanzania in the South and the Democratic Republic of Congo (DRC) in the West. The population of about 24.8 million people (2002 census) is increasing at a rate of 3.4% - one of the fastest growing populations in the world (World Bank, 2004). Fifty-one percent of the population is between 0–14 years and a vast majority (87%) resides in the rural areas. For the last 17 years, persistent insurgency in the north has resulted in the displacement of over 1.4 million Ugandans. With a GDP per capita estimated at US\$320, Uganda is ranked number 144 among the 177 countries in the world (UNDP, 2005), which is yet far ahead of neighbouring DRC. The country has recovered from the economic decline following years of civil strife of the 1970s and 1980s and after a series of Structural Adjustment Programs, it has achieved a sound macroeconomic basis for restoring growth and reducing poverty (World Bank, 2004). Still the proportion of Ugandans living below the poverty line remains unacceptably high (Okuonzi, 2004). Although agriculture is the mainstay of the economy, the country is dependent on significant external donor support; in 2002, 52% of the total government budget was from external donors (World Bank, 2004).

Health indicators

According to WHO classification, Uganda belongs to the “high child, very high adult” mortality stratum (WHO, 2000c). Uganda’s health status is characterized by a high level of disease burden with prenatal and maternal conditions, malaria, ARI, AIDS, and diarrhoea together accounting for over 60% of the total deaths. Apart from infectious diseases, Uganda is also simultaneously experiencing an increase in non-communicable diseases such as diabetes, cancer, mental illness, and chronic heart disease. Among children most deaths are due to ARI, malaria, diarrhoea and neonatal disorders, HIV/AIDS and measles (Black et al., 2003).

Although Uganda is known for economic growth over the last decade, these achievements were not followed by corresponding overall reduction of morbidity or mortality (Okuonzi, 2004). Life expectancy at birth (43 years) has fallen over 22% since the advent of the AIDS epidemic (US Census Bureau, 2005). Even though the country reversed the HIV/AIDS epidemic, reducing HIV prevalence from 18% in the early 1990s to 6% in 2001, data suggests worsening indicators of health status and health service delivery compared to five years earlier. Maternal mortality fell only modestly during the last 10 years and there has been virtually no improvement in infant and child mortality. Similarly, there has been little improvement in children’s nutritional status since 1995 and total fertility rate remains high at 6.9 children per woman. Table 1 contains data for some of the most important health indicators in Uganda.

Table 1. Trends in health status indicators, Uganda 1989-2000

	1989	1995	2000
Infant Mortality (per 10000 live births)	119	97	101
Under five mortality (per 10000 live births)	180	147	151.5
Maternal Mortality	523	506	496
Deliveries supervised by skilled health providers	38%	38%	38%
Total Fertility Rate (children born/woman)	7.3	6.9	6.9
Contraceptive Prevalence	5%	15%	23%
Stunted children (<2 SD from norm)	43%	38.8%	38%
Life Expectancy at Birth (years)	46.4	-	43
HIV prevalence	15%+	-	6%

Source: MOH Uganda, 2003

Millennium Development Goals and trends

In an attempt to improve the state of global health, initiatives have been launched to better diagnose, treat, control or even eradicate diseases and other health problems. Principal among these are the Millennium Development Goals (MDGs) adopted under the Millennium Declaration in 2000 by all 189 member states of the UN General Assembly (United Nations Development Group, 2005). The MDGs are a set of time-bound targets, which include reducing poverty, achieving universal primary education and reducing under-five mortality (Box 1). These targets are to be achieved by 2015, from their level in 1990 (United Nations Development Group, 2005).

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria, and other disease
7. Ensure environmental sustainability
8. Develop a global partnership for development

Box 1. Millennium development goals (MDGs)

Uganda has a mixed prospective to achieve the MDGs. It is expected to reach the MDGs for AIDS and TB, but not for hunger, child mortality and maternal mortality (Table 2). The Ugandan situation is by no means unique for SSA, where many countries are experiencing slow trends in child mortality reduction. If the global trend of the 1990s were to continue at the same rate until 2015, the reduction in under-five mortality rate would only be about one-quarter and the appointed target not achieved until 2165 (Vandemoortele, 2002). Meeting the global target will require that the rate of reduction increases more than five-fold between 2000 and 2015—an extremely unlikely scenario (Task Force on Health Systems Research, 2004). Primarily it is the weak health systems that contributes to the bottleneck for achieving the MDGs, as there are no functional and effective systems to deliver cost-effective interventions (Nicoll, 2000).

Table 2. Summary of some Ugandan health MDGs

Goal and indicators of progress		1995 level	Current level	Goal (2015)
Goal 1	Halve between 1990 and 2015, the proportion of people who suffer from hunger			
Indicator	Prevalence of underweight children under five years of age	25.5%	23%	12.75%
Goal 4	Reduce by two-thirds, between 1990 and 2015, the under-five mortality rate			
Indicator	Under-five mortality rate (per 1000 live births)	147	141	49
Goal 5	Reduce by three-quarters, between 1990 and 2015, the maternal mortality ratio			
Indicator	Maternal mortality ratio	1100	880	275
Goal 6	Have halted, by 2015 and begun to reverse the incidence of HIV/AIDS, malaria and other major diseases			
Indicator	HIV prevalence among 15-24 year old pregnant women	30%	5%	Reduce prevalence
Indicator	Malaria prevalence	Unavailable	46%	Reverse prevalence
Indicator	Proportion of TB cases detected and cured under directly observed treatment short course (DOTs)	33%	63%	>33%

Source: World Bank (2004)

The health system

Administrative structure

The health system in Uganda is characterised by the decentralisation process which date back to 1986 (Jeppsson, 2004). Decentralisation has transferred all political and administrative authority from the central government to the local government and the responsibility for health service delivery now lies within the districts (Rwabwoogo, 2002). Most bilateral and multilateral donor agencies have favoured decentralisation as keeping in line with “democratic principles” (Jeppsson, 2004). To increase coordination, control and sustainability in development cooperation, the Sector Wide Approach (SWAp) was introduced in Uganda, addressing whole sectors rather than specific activities or projects. However, due to undefined expectations, SWAp countries and donor agencies, such as the Global Fund to fight AIDS, TB and Malaria (GFATM), often resist these initiatives with continued support of vertical programmes (Donoghue et al., 2005, Sundewall and Sahlin-Andersson, 2005).

Decentralization of the health sector in Uganda is linked to the political-administrative structure of local governments. District health services are at the level of the district council, an elected body of representatives. The health sub-districts established in connection with the Health Sector Strategic Plan are at the county level and is the responsibility of the District Director of Health Services. As a step to improve service delivery, 21 new districts were recently added to the prior 56 districts in Uganda. The districts consist of counties which in most cases are also electoral constituencies. A county is divided into sub-counties, a sub-county into parishes, and a parish divided into villages (Figure 2).

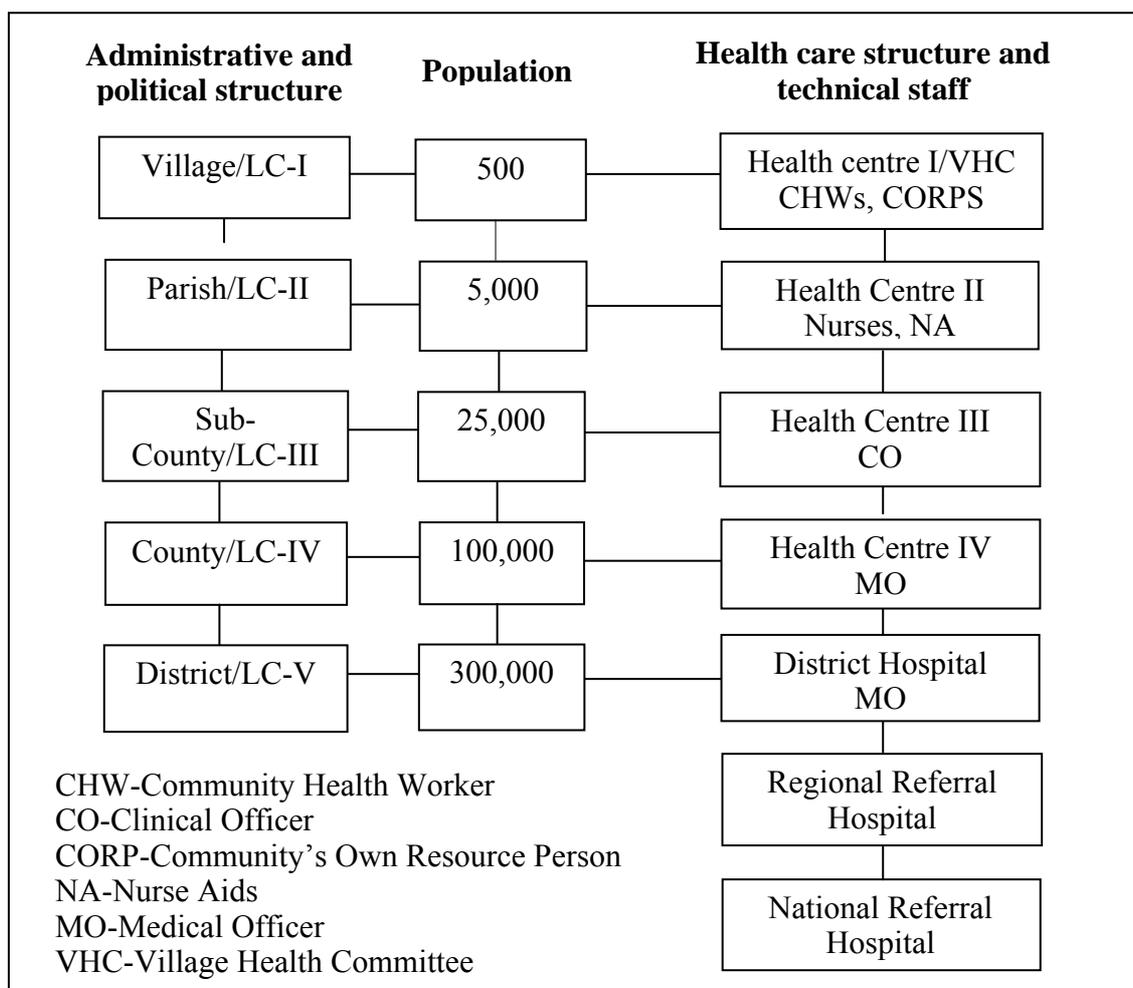


Figure 2. Administrative and political (Local Councils) structures, their approximate population and the corresponding health structures in Uganda

The district level health sector in Uganda is composed of a hierarchy of health centres (HC-II, HC-III and HC-IV) and district hospitals. At the village level there should be outreach activities organised by the parish level health centres. Health facilities can be government owned, private for-profit (PFP), or private not-for-profit (PNFP). Dispensaries are the most common health facility, especially in the rural areas (World Bank, 2004). Geographic access is limited with an average 49% of the population within 5 km of a health unit, ranging from 9% in Kitgum to almost 100% in Kampala (Uganda Bureau of Statistics, 2001, Hutchinson, 1996).

The public sector

The public sector referral level of a health sub-district is an upgraded health centre-IV (HC-IV) with surgical services for obstetric care and inpatient care for patients referred from the HC-II level. The present general district hospital is expected to cater for referrals from its own health sub-district and for referral cases that cannot be treated at the upgraded HC-IV level. At sub-county level, the HC-III provides maternity and some laboratory services for the whole sub-county. The parish level health centre, HC-II, is the first fixed health facility where responsibilities include curative, preventive and promotive activities. However, only about 43% of the parishes have a health facility within their boundaries. Also the infrastructure in most peripheral health units is in a deplorable state with equipment in non-working condition and poorly managed essential drug supplies (World Bank, 2004). Under the health sector

strategic plan (HSSP) a Village Health Committee (VHC) or similar structure will be set up as HC-I in every village to be responsible for a series of tasks, including selection and oversight of community health worker activities. Implementation of the strategy is being piloted in some districts.

The private sector

The private sector – with private-for-profit (PFP) and private not-for-profit (PNFP) facilities - has a long history of providing health services in Uganda. The PNFP health sector consists of religious and nonreligious providers whereof 70% are owned by autonomous dioceses and parishes. The rest are owned by NGOs (Jeppsson, 2004). Generally, PNFP facilities provide a mix of public and private goods and the service mix is similar to that of government facilities. Detailed information of the size, types of services and quality of health services offered in the PFP sector in Uganda is limited. Overall, the PFP sector is quite diverse, consisting of hospitals, clinics, nursing and maternity homes, drug shops, traditional healers and midwives. Community drug vendors are an important and unregulated component of the PFP sector and in rural areas; these provide about 75% of allopathic drugs at the community level (Corkery, 2000).

Human resources

Uganda faces a severe problem of skilled manpower and the numbers of nurses and physicians are below the SSA average (Uganda Bureau of Statistics, 2001). The work force in rural health facilities mainly consists of clinical officers with 3 years' basic training, nurses with 18 months training and nurse aides with 3 months training. Nurse-aides constitute 56% of the workforce and these operate independently 40% of health units, whereas medical officers often are found first at district level (World Bank, 2004). There are also considerable discrepancies in human resources across districts with the national average being 80 health staff per 100,000 population. The more affluent regions are found in and around the capital of Kampala, whereas the north-east is least developed with less than 10-30 health staff per 100,000 population (Jeppsson, 2004). The lack of nurses and nurse aides is particularly severe at HC-II level, but are also insufficient at HC-III level, where shortages in clinical and laboratory staff also is acute (World Bank, 2004).

Home Based Management of fever (HBM)

In an effort to bridge the gap in service delivery for rural and poor populations and account for the lack of health staff, the Uganda Ministry of Health (MOH) in collaboration with WHO and UNICEF, adopted the HMM strategy in 2002 and introduced it on a national scale – locally referred to as Home Based Management of fever (HBM) (MOH Uganda, 2002). The HBM strategy is implemented largely at community level involving community sensitisation, selection of community based volunteers and mobilisers, community capacity building, “information, education and communication” (IEC) materials, provision of antimalarial drugs to volunteers, and monitoring and supervision (Batega et al., 2004). HBM is implemented as a complementary effort to the MOH's overall National Malaria Control Strategic Plan and is in line with the GOU's decentralisation policy, as the implementation at district and community level is the responsibility of local governments.

The core component of HBM is the distribution of first-line antimalarial drugs free of charge to all children under five with fever using community based volunteering drug distributors (DDs) (Bolaji et al., 2004) (Box 2). The strategy was used as a vector to disseminate the new

first-line malaria treatment policy as it changed from Chloroquine alone to Chloroquine combined with Sulfadoxine-Pyrimethamine (SP). This combination treatment is produced locally and distributed in age-specific, colour-coded packages called "Homapak".

Box 2. Uganda Ministry of Health Implementation Guidelines for the Home Based Management of fever strategy (MoH Uganda, 2002)

Drug Distributor (DD) tasks

Two DDs per village are trained for 3 days and supervised by the local health centre In-Charge in fever management using Homapaks. DDs record children by name, age, location, name of caretaker, date, time of fever onset and whether child needed referral. For history or presence of danger signs, the DD should immediately refer to the nearest health centre. For cough or diarrhoea, the DD should recommend seeking formal care. After 3 days the DD should follow-up the child in the household and if no recovery is observed, advise on referral.

Criteria for referral

1. A child with any of the "danger signs"
 - Convulsion
 - Loss of consciousness/coma
 - Vomiting everything/severe vomiting
 - Child not able to drink or breast feed
 - Very sick child (unable to sit or stand)
 - Difficulty in breathing
2. A child who has not improved or who is getting worse after treatment with Homapak for 2 or more days and is brought back to the distributor
3. A sick child brought who is less than 2 months or above 5 years of age
4. A child is brought without fever but other conditions like cuts, fractures or poisoning

The success of HBM will depend both on caretakers' early recognition and care seeking for fever symptoms, as well as DDs' ability to recognise and treat fever, advice caretakers on dosing, and recognise referral symptoms. However, with the rapid scale-up of HBM, it is questionable whether it was designed to address the local fever illness perceptions and culturally appropriate measures taken by caretakers. Failure to address the cultural practices may result in poor uptake by the communities and low compliance with treatment and referral advice (Winch et al., 1996, Hausmann Muela, 2000). Given the documented symptom overlap of malaria and pneumonia (O'Dempsey et al., 1993b) and the observation that overlapping 'emic' disease concepts sometimes are used for 'etic' malaria and pneumonia symptoms (Gittelsohn et al., 1991), vertical malaria programmes may increase antimalarial use for fever illness concepts which also include rapid breathing or chest-indrawings (Nichter et al., 1994). Although HBM uses referral criteria to ensure that children with pneumonia symptoms are advised to seek formal health care, referral health facilities are sometimes too distant or too costly, as demonstrated by their low use for sick children (Filmer, 2005). Whereas referral from health centre to hospital has been proved problematic (Peterson et al., 2004), this new type of community referral to health centres has rarely been studied.

RATIONALE FOR THE STUDIES

Although Uganda is on track for several of the MDGs, considerable effort is needed to turn the reverse trend observed for child mortality. The two top causes of death are malaria and pneumonia. By capitalising the Asian community management of pneumonia model in a context where most focus is on malaria, potential gains could be achieved in child survival. However, before the feasibility and impact of an integrated approach for malaria and pneumonia can be evaluated, a number of critical knowledge gaps need to be closed with regards to health care actions taken for the febrile child:

Whereas hospital based studies have demonstrated that symptoms frequently overlap for malaria and pneumonia, the extent of symptom overlap in health centres and communities is unknown.

Home care and care seeking practices for sick children are heavily influenced by caretaker recognition and labelling of illness symptoms. While HBM aims to treat biomedically defined fever early with antimalarial drugs, it is unknown how this recommendation matches with local understanding of fever and how Homapakas will be used for local fever illness concepts.

While Asian studies have shown wide availability of antibiotics outside the formal health sector and high antibiotic use for mild ARIs, drug utilisation for ARI is largely unexplored in SSA. Whereas care seeking practices and treatments used for potential malaria are well known, the different providers and drugs used in the community to treat children with ARI, fever or both needs further exploration.

A key assumption for HBM is that children with ARI or persisting fever are successfully identified and referred to a formal health facility for further assessment and treatment. There is a gap in knowledge on how this new type of “community referral” functions and whether children referred under HBM access referral care at the health facility.

WHO and UNICEF now recommend integrated management of both malaria and pneumonia in the community. This requires CHWs to make correct assessment of children with potential pneumonia. Whereas CHWs’ ability to count and classify the key pneumonia symptom rapid breathing has been shown in other continents, their performance in SSA has rarely been tested. Furthermore, methods to elicit relevant local terminology and illness concepts for communication material are also needed.

AIM AND OBJECTIVES

GENERAL AIM

To explore caretaker and health system behaviour in relation to care and treatment of children with symptoms of ARI and fever, to devise recommendations for improved case management of pneumonia and malaria.

SPECIFIC OBJECTIVES

- I. To assess the extent of malaria-pneumonia symptom overlap in children under five at health facility level and its policy implications for home management strategies.
- II. To explore the local understanding and treatment practices for childhood fever illnesses and discuss implications for the Home Based Fever Management (HBM) strategy.
- III. To determine the extent of malaria/ARI symptom overlap at community level, the timeliness in care seeking, and the treatments and sources of care sought for ARI.
- IV. To determine the rate of, the reasons for, and the compliance with referral from community to health centre, as well as the reasons for non-compliance, sources of care sought and diagnosis received at referral health facilities.
- V. To assess drug distributors (DDs) ability to count and classify rapid breathing in children under-five and to explore caretaker understanding of pneumonia symptoms in Western Uganda.

METHODS

STUDY AREAS AND POPULATION

When the studies in this thesis were conducted Uganda had 56 districts. Although 21 new districts were added in late 2005, administrative information, maps and district populations mentioned in this thesis apply to the situation prior to the introduction of the new districts.

Study I was performed in 4 Ugandan districts (Mukono, Nakasongola, Masaka and Kumi) and study III in 8 Ugandan districts (Apac, Bugiri, Kasese, Kibaale, Masaka, Mubende, Tororo, and Yumbe). The three studies II, IV and V were all carried out in Kasese district in Western Uganda (Figure 3).



Figure 3. Map of Uganda with research districts in bold

Whereas the quantitative cross-sectional studies (I & III) strived for geographical representation, one district – Kasese - was chosen for the more in-depth studies of fever and ARI treatment in relation to HBM (II, IV and V). This district was chosen in consultation with local study partners and MOH in Kampala because of the holoendemic malaria transmission, high pneumonia incidence, typical coverage of public health services (i.e. half the population within 5 km of a health centre) and because of its early implementation of HBM. Kasese district is located in the Western Region of Uganda along the Equator. It borders Bushenyi in the South, Kabarole in the East and North-East and Bundibugyo in the North and is along the national border of the Democratic Republic of Congo (DRC) (DISH Uganda, 2002) (Figure 4). The total land areas of Kasese District is 3184 square km (approximately the size of Luxembourg) but as 461 square km are covered by water, 885 square km taken up by the

Queen Elizabeth National Park and 652 square km by the Rwenzori National Park only 1647 square km is left for human settlement. The 1991 census estimated a district population of 409500 people. This gives an average population density of about 249 people per square km for settlement areas.

The population is made up mostly by Bukonjo who are the most numerous of the Rwenzori peoples. The Bukonjo are agriculturalists residing on the mountain slopes where they grow mainly cooking banana, yams, potatoes, cassava and beans. During the last decades they took up coffee and cotton growing. In addition, they rear goats, sheep and fowls. Production was initially for subsistence and they supplemented their produce by hunting and fishing on the Lakes Edward and George (Nzita and Niwampa, 1997). The ADF armies (Allied Democratic Front), with origins in DRC, caused insurgency in the region in the late 1990's but since the rebels were controlled by the Ugandan army in 1999-2000 the area has regained its peaceful climate. Health infrastructure is poor, especially for people living in the mountains. In 2002, Kasese district had 3 hospitals, 3 HC-IV, 22 HC-III, 35 HC-II and no HC-I (Village health team, Community health workers) (Table 3).



Figure 4. Map of the main study district, Kasese, in Western Uganda

Table 3. Facility types in Kasese district, 2002

Facility Type	Public	Registered NGO	Registered For Profit	Number of Health Units	Number of Ambulances	Number of Health Units under construction
Hospitals	1	2	0	1		
HC-IV with operating theatre	1	2	0	0		1
HC-III with maternity unit	19	3	0	0		1
HC-II	34	1	0	0		-
HC-I	0	0	0	0		-
Registered Drug Shops	-	-	63	0		-
Registered clinics	-	-	23	0		-
Pharmacies	-	-	2	0		-
Total	55	8	88	1		2

Source: DDHS office in Kasese.

MAIN RESEARCH METHODS

In this thesis, one household survey (III) and one health facility survey (I) were conducted. In addition, focus group discussions (FGDs) were conducted at community level in studies II and V. In study IV a case-series study was performed with household interviews and secondary data collected from case notes in the community, health centre and hospital. In study V direct observation of DD performance was carried out at hospital level.

Four methods in particular have been recommended for understanding how socio-cultural, economic and geographical factors affect home care and care seeking behaviour (INRUD, 2002): (1) structured interviews; (2) focus group discussions; and (3) unstructured interviews, and (4) observations. In addition to using these four methods, existing secondary data in form of clinical records, case notes and local health statistics were reviewed. In order to comprehensively answer the research questions and overcome errors and limitations implicit in each type of method, triangulation was applied (Patton, 2002). Triangulation commonly refers to the combined use of several kinds of methods to study a single problem or program, including using both qualitative and quantitative approaches. Three other types of triangulation have also been identified, i.e. (1) *data triangulation* (the use of a variety of data sources in a study), (2) *investigator triangulation* (the use of several different researchers or evaluators), and (3) *theory triangulation* (the use of multiple perspectives to interpret a single set of data) (Patton, 2002). In this thesis we mainly used methodological and data triangulation.

Structured interviews

Interviews with questionnaires are commonly used research techniques in health-systems research (Varkevisser et al., 1991). The instrument is structured with fixed questions not allowing freedom to adjust any of its elements, such as contents, wording or order of the questions. To determine fever and ARI prevalence in under-fives and care seeking practices related to the illness episode, structured interviews were conducted with mothers or primary caretakers in study III and IV. The information obtained for study III concerned symptoms during last fever or ARI illness episode, treatment practices and sources and types of drugs used. For study IV, the information collected concerned timing, types of and reasons for the actions taken in relation to children referred from community to health facility, as well as reasons for non-compliance with referral advice (Appendix 1). In both studies, a 2 week recall was used, which has been recommended for studies on morbidity, care seeking and drug use for an illness episode (Kroegeer, 1985).

In study III, a total of 192 interviewers (24 in each district) were used for collection of data. Most interviewers were teachers, health workers or students with secondary education and were selected in consultation with the local study supervisors. The selection was based on reading and writing skills, ability to communicate in both English and local language and availability during the study period. The interviewers were trained in data collection for 3 days using general instructions, role-plays and practical exercises. Each of the questions was discussed, translated into the local language for clarification and standard local terms were agreed on for the illness terms. In study IV, three local interviewers were recruited based on literacy skills, availability during the study period and familiarity with the neighbourhood. All three of the interviews had completed teachers' college but only one was employed. The interviewers were trained for one day in interview technique and the meaning of the

questions, as well as the appropriateness of the local translation. The questionnaire was pilot tested and questions revised where necessary. The author (Karin Källander) was frequently doing audit in the field to supervise and give feedback.

Focus Group Discussions (FGDs)

Focussed interviews with groups, i.e. focus group discussions, has a wide application in qualitative and behavioural research (Patton, 2002). The advantage of this method is that the group interaction can be utilised to explore people's own experiences and knowledge, the way they think regarding a problem, and how their views are constructed or expressed in a certain context (Dahlgren et al., 2004). FGDs are also suitable for uncovering factors related to complex behaviour, for studies on decision making or when studying how people negotiate about their norms and belief systems (Maxwell, 1996). Disadvantages with FGDs include that minority opinions may not always be expressed and that the researcher's preconceptions can drive the group's interactions (Hardon et al., 2001). In study II (Appendix 2), FGDs were used to explore household fever recognition, interpretation and classification of febrile conditions, care seeking behaviour, source of treatment, home management and household members involvement in the decision making process. In study V (Appendix 3) FGDs were used to elucidate local terminologies for ARI, labelling of illness, perceived severity and associated actions. Here, a WHO/IMCI video footage of children with ARI was shown on a portable computer to probe the discussions and confirm the illness concepts. This method has previously been successfully used for visualising the illness in focus (Freudenthal, 2000) and for elicitation of ARI illness terminology (Ryan et al., 1996).

Unstructured interviews

Informal conversational interviews are often referred to as "unstructured" interviews" or "qualitative research interviews" (Dahlgren et al., 2004). Questions asked are open-ended, in contrast to the closed questions of quantitative surveys, and participants are encouraged to speak with their own words (Maxwell, 1996). The main disadvantage with unstructured interviews is that it takes both time and experience to construct good open-ended questions (Dahlgren et al., 2004). In study V, two key-informants from the Faculty of Social Sciences, Makerere University, were recruited for unstructured interviews based on their origin (from Kasese district) and ability to communicate both in the local language Lukonjo and English. The main purpose of the interviews was to cross-check whether the information abstracted from the FGDs and direct translations of the illness terms elicited were consistent.

Observations

Participant observation is a complementary tool to interviewing, especially to understand the context of what people say in the interviews (Hegelund, 2005). By definition, observation is a technique that involves systematically watching and recording behaviour and other characteristics. The degree of involvement, both with people and in the activities researchers observe, can vary. In *passive* participation, the researcher is present but does not interact with the people involved. In contrast, the *active* participant seeks to *do* what other people are doing to more fully learn the cultural rules for behaviour (Hardon et al., 2001). For evaluation of performance of health workers the method *direct observation* is often the best to use (McCusker, 1982). A challenge of participant observation is for the researcher to remain objective, despite subjective preconceptions or pre-understanding of the phenomena studied (Hegelund, 2005). During the period June 2004 to October 2004, when study IV and V were carried out, the author was present in the field most of the time. She observed daily life in the

villages to understand the factors that influence behaviour and practices in households and communities. An observation diary was kept which was later used to add context to the analyses. For study V, performance evaluation was conducted by directly observing DDs' ability to assess respiratory rate in children in the paediatric ward of Kagando hospital, Kasese district. These observations were different from the more ethnographic observations in study IV, as they were structured and followed a check-list for evaluation of DD's performance.

Using available information

Usually large bodies of data are already collected, although they may not be analysed or published. Locating sources and retrieving information is a good starting point in any data collection effort (Hardon et al., 2001). Disadvantages with this method includes data not always being easily accessible, ethical issues concerning confidentiality and information may be imprecise or incomplete. In study IV, patient registries with classification and treatments given were reviewed in public and private health facilities and in the community through DD records. In the same study, the health statistics and demographic information for the parishes covered was collected from the sub-county office and utilised to give background information to the study area.

DESIGN, SAMPLING, SAMPLE SIZE AND DATA COLLECTION (I-V)

In this thesis, a triangulation of methods was used to study health care of the “febrile child” at various levels in the health system in light of the new Home Based Management of fever strategy (HBM) (Figure 5). When studies I-II were carried out (1999-2002), the HBM strategy had not yet been introduced. In 2003, when study III was performed, only Kasese district had started implementation of HBM in a few sub-counties. In study IV & V the HBM strategy had been fully implemented in Kasese district and in 11 other districts.

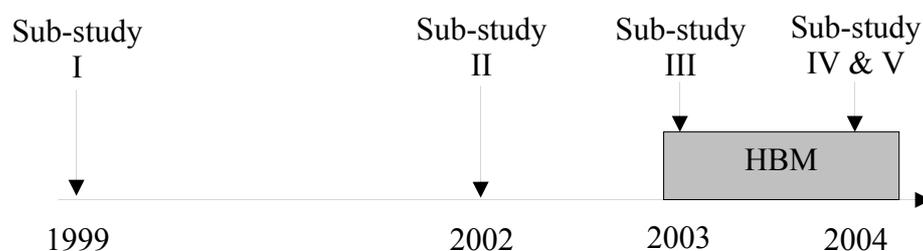


Figure 5. Timing of studies in relation to HBM implementation in Kasese district.

For the quantitative studies, the appropriate sample size was determined by required precision. In qualitative studies the aim is to identify information-rich cases in a purposeful manner. Information-rich cases are those from which one can learn about issues of central importance to the purpose of the research, thus the term purposeful sampling (Patton, 2002). The sampling for study I included 14 purposively selected peripheral health centres included based on their absence of inpatient beds and non-proximity to a hospital, in 4 Ugandan districts. In study II three rural villages in three purposively selected sub-counties in Kasese district were included. The sub-counties were selected because of the pending introduction of HBM in the area. In study III, 15 households from each of 212 rural villages in 4 purposively selected and 4 randomly selected Ugandan districts were sampled. The 4 districts selected on purpose represented geographically distributed areas with ongoing UNICEF activities. Study

IV was a case-series study in one purposively selected sub-county in Kasese district. In study V, all 72 antimalarial DDs in one sub-county and 24 DDs from a neighbouring sub-county were recruited and included in the study. Fifteen young and 15 old mothers from the same sub-counties were invited to participate in FGDs.

Study I - Symptom overlap for malaria and pneumonia—policy implications for home management strategies

Design, sampling and sample size: A cross-sectional study was carried out in 14 IMCI health centres in 1999. Before sampling, the districts were stratified into four groups: Central, Eastern, Western and Northern. For each of the four regions, one IMCI implementing district was chosen through random sampling (Mukono, Nakasongola, Masaka and Kumi) (Figure 3). Altogether, 16 health workers who were trained on IMCI 1–3 years prior to the study were involved in the study. These included facilities serving catchment populations between 5,000–10,000, were located in the least served halves of the districts with a median distance to their primary referral hospitals of 34 km (range 7–80). Given that the primary focus of the study was to estimate referral patterns in children seen in IMCI health centres, an estimated total sample of 3600 children was found sufficient to generate the 200 referrals needed for a referral estimate with 95% confidence and $\pm 7\%$ absolute precision. For sub-study I, which was a secondary data analysis of this larger referral data set, the sample size of 3600 was deemed sufficient to also estimate symptom overlap, confirmed in post-analysis calculations demonstrating 95% confidence and $\pm 2\%$ absolute precision of the estimate.

Data collection: All sick children 2 months to 5 years who were seen in the 14 study health centres were managed according to IMCI guidelines and their history and symptoms recorded on IMCI recording forms (Appendix 4). These forms recorded the results of the health worker's integrated assessment of the child's symptoms and the resulting illness classification. The forms were collected and formed the basis of analysis of the frequency and predictors of malaria and pneumonia symptoms overlap in sick under-fives.

Data analysis: The IMCI case definition for malaria was presence or history of fever, either by health worker assessment or mother's reporting. The pneumonia case definition was cough or difficult breathing along with fast breathing according to health worker's counting of respiratory rates above IMCI cut-offs (≥ 50 breaths/min for 2-11 months and ≥ 40 breaths/min for 12-59 months). Recording forms were coded and double entered into EpiInfo. The data was analysed in JMP (SAS institute) for malaria and pneumonia symptom overlap. The effects and interaction of age and duration of fever for symptom overlap were determined and tested for significance using multivariate logistic regression.

Study II – Local fever illness classifications: implications for home management of malaria strategies

Design, sampling and sample size: In this qualitative FGD study carried out in 2002, three rural villages were purposively selected from three different sub-counties in Kasese district. Focus group participants were identified and recruited with the help of the local village chiefs through “typical case sampling” (Hardon et al., 2001). In this study, *typical cases* were mothers, fathers and grandparents with relatively low education background (no more than secondary schooling) residing in the study area. The cut-off age for young parents was 15-24 years and for old parents 25-49 years. Grandparents included were above 50 years of age and had been actively involved in raising both their own children as well as their grandchildren.

Data collection: Ten FGDs consisting of eight to 14 participants were held separately with homogenous groups of young mothers, old mothers, young fathers, old fathers and grandparents. An FGD interview guide (Appendix 2) directed the conversation. It covered household fever recognition, interpretation and classification of febrile conditions, care seeking behaviour, source of treatment, home care and household members involvement in the decision making process. A trained moderator fluent in the local language Lukonjo led the discussions while another researcher took near-verbatim notes. Tape-recorded data were transcribed and translated into English and complemented with field notes.

Data analysis: The style of analysis of qualitative data varies according to the degree of predetermined or theoretically founded categories for interpretation (Malterud, 2001). In this study a theory-based analysis template was used to organise the data according to pre-existing theoretical categories, such as illness recognition, labelling, treatment actions and decision making. This was done by applying codes within the structure of the thematic interview guide, using the software N6 (NUD*IST v.6 2002). Relevant quotations were extracted and presented verbatim. The unit of analysis was the whole group rather than the individuals (Hardon et al., 2001). Quotes concerning illness classifications and their associated symptoms were extracted and summarised in a table.

Study III – Home and community management of acute respiratory infections in children in 8 Ugandan districts

Design, sampling and sample size: A cross-sectional survey was carried out during August and September 2003 in 8 Ugandan districts sampled with geographical representation; four purposively and four randomly selected. The four purposively selected districts were chosen for their involvement in UNICEF activities as the survey was a baseline for the programme aiming to improve family care practices (FCP). The randomly sampled districts were selected with regional representation using secret ballot system. The sample size calculation was based on an assumption that the least prevalent FCP (such as exclusive breast feeding or ORS use for diarrhoea) was 10%. To be able to demonstrate an intervention effect of at least 5% increase with a confidence level of 95%, a power of 80% and a design effect of 2 for each separate district, a district-specific sample size was calculated, ranging from 341 households in Yumbe to 460 in Masaka). The total sample size for all 8 districts was 3,223 households. For the secondary data analysis of community prevalence of fever and ARI symptoms, this sample size was considered sufficient, confirmed in post-analysis calculations demonstrating 95% confidence and $\pm 2\%$ absolute precision of the estimate.

The 3,223 households were selected using multi-stage cluster sampling where 15 households were selected from each of 212 rural villages or Census Enumeration Areas (EAs). The number of EAs sampled from each district was proportional to the district population size, ranging from 22 in Yumbe to 30 in Masaka. Based on census listings from the Uganda Bureau of Statistics, each of the 8 districts' EAs were listed in alphabetical order and the 212 included EAs were systematically sampled. Peri-urban (EAs with trading centres) and urban EAs were excluded from the lists. From each EA, 15 households were systematically selected; starting from the most central home identified by the village chief, and continuing to the nearest door until 15 households had been included. If the selected household did not have children under-two, or refused to be interviewed, it was replaced by going to the next household. If the

respondent was not at home replacement sampling was done by continuing to the next household.

Data collection: The questionnaire was based on a generic UNICEF/WHO questionnaire with 14 different modules, such as breastfeeding, immunisation, HIV/AIDS and care of the sick child. Since the primary focus of the FCP study was to reflect practices important for care of small children, such as breastfeeding, nutrition and growth monitoring, information was collected for children under-two. For the purpose of the study in this thesis, only the “care of the sick child” module was analysed. The entry question was whether any child under-two had been sick using two week recall. Questions on illness symptoms were first spontaneously reported by the caregiver, then probed for by the interviewer. The local translation of ‘hot body’ was used to ask about fever and, as biomedical breathing terms rarely have exact equivalents in the local languages, locally appropriate illness concepts such as ‘difficult and/or rapid breathing’ (‘DRB’) were used for acute respiratory infection. This symptom combination and acronym will be in quotes to highlight that these are mothers’ reported symptoms which may not equal clinical symptoms. For questions regarding drug use, the interviewer asked to see the drugs or the packages. The questionnaire was in English and the questions translated by the interviewer during the interview, using the local terms agreed in the training session. Data collected was caretakers’ stated practices and only dealt with information regarding the most recent illness episode.

Data analysis: Data was single entered in EpiInfo 2000 by a data entrant trained and supervised by a statistician, checked for consistency and errors. In the analysis ARI was defined as reported symptoms of cough with ‘DRB’. Analyses on ARI and fever symptoms, associated treatments, and actions taken were performed in STATA8 for proportions using chi-squares with p-values adjusted for the cluster effect. District, age <1 year versus ≥ 1 year and sex were used as primary stratifying variables.

Study IV - Community referral in Home Management of Malaria in Western Uganda: A case series study

Design, sampling and sample size: Between June and October 2004, a case-series study was conducted in one purposively selected sub-county (Kyondo) in Kasese District (Figure 4) where the HBM programme had been running since late 2002. Under-five population in the sub-county was approximately 3,600. In the late dry and early rainy season all 40 community drug distributors (DDs) and all children referred were included and followed for a total of 528 DD weeks of observation. According to sample size calculations, 96 referred children were needed to give 95% confidence to an estimate of referral completion rate with absolute precision of $\pm 10\%$.

Data collection: Three local data collectors visited all included DDs fortnightly for collection of completed recording forms with patient and referral information. Referred children were located in consultation with the DD and visited in the household after 4-14 days. After giving informed verbal consent, the primary caretaker was interviewed using a semi-structured questionnaire using two week recall. Questions were asked regarding symptoms prompting contact with the DD, actions taken by the DD, referral timing and completion, as well as reasons for non-compliance with referral advice and alternative coping behaviour. Six weeks into the study two new local terms for ‘fast’ and ‘difficult’ breathing were identified and added to the questionnaire. Referred children whose caretakers stated having completed

referral were traced in the outpatient registry of any of the 7 nearby health facilities mentioned by the caretaker, to confirm attendance, timeliness in attendance, health worker classification and treatment.

Data analysis: Data was entered in EpiData (www.epidata.dk) and analysed in STATA8 for overall referral rate, cause of referral, referral completion rate, timeliness in referral and reasons for referral non-compliance. Frequencies and proportions were measured in percentages and cross tabulations were analysed using chi-square. During the study there was an outbreak of chickenpox causing many referrals. Such, and other, non-febrile episodes were excluded from the analysis.

Study V - Can community health workers and caretakers recognise pneumonia in children? Experiences from Western Uganda

Sampling: Study V used a combination of methods applied in two sub-counties (Kisinga and Kyarumba, Figure 4) in Kasese district, selected for their active participation in the HBM programme and lack of involvement in the previous studies. The first quantitative part was an end-of-training assessment of DDs ability to count and classify breathing rate in children under-five. According to sample size calculations, a total number of 96 DDs were needed for determination of sensitivity and specificity of their assessment of breathing rate with 95% confidence and an absolute precision of $\pm 10\%$. All 72 DDs in one sub-county and 24 from another sub-county were invited in writing and all agreed to participate, generating a total of 96 DDs. For the qualitative part, 15 young (15-25 years) and 15 old mothers (25-49 years) from the same two sub-counties were invited to participate in FGDs. The mothers were recruited based on “typical case sampling” (Hardon et al., 2001) given their roles as mothers, age, interest in participating in the study and not having been involved in the HBM intervention (none was a DD). The two key informants were identified based on recommendations from the Faculty of Social Sciences at Makerere University for unstructured interviews.

Data collection: The DDs underwent 2-day training by one nurse and one clinical officer using Integrated Management of Childhood Illness (IMCI) methodology. The training included classroom discussions and practices. Themes included basic physiology of respiratory organs, classification of ARIs, analysis of causes and factors contributing to ARI, signs and symptoms of pneumonia, and counting of respiratory rates on children shown on video and in real life. At the end of the second day of training, DDs were evaluated for their ability to count and classify breathing rate by observing three children with clinically verified pneumonia with rapid breathing and three children with normal respiratory rate (RR); generating a total of 576 evaluations. Fast breathing was defined according to the IMCI criteria; ≥ 50 breaths/min for 2-11 months, and ≥ 40 breaths/min for 12-59 months. DDs were asked to 1) judge whether the child’s RR appeared fast or normal by impression, 2) count the RR for 1 min, and 3) classify the child as fast or normal according to age specific cut-offs. The study coordinator (Karin Källander) and one clinical officer instructed them when to start and stop counting and simultaneously observed the respiratory rate with 6 DDs at a time. Paired t-test and Wilcoxon signed-rank test was used to determine inter-rater agreement between the two researchers, and was found to be high (mean difference=0.23 breaths/min, SD=1.60; Wilcoxon p=0.24). Hence mean rate could be used as gold standard. K values (Taube, 1995) were calculated as a chance-adjusted measure of agreement between DD impression of rapid breathing and classification of rapid breathing based on counting. Socio-

demographic profiles for the DDs, including age, education, and number of children, were collected to determine predictors for successful assessment.

For ARI terminology and associated actions, a focused ethnographic study (FES) modified after WHO recommendations (WHO, 1993a) was used including triangulation with four FGDs, a video elicitation task (Gove and Pelto, 1994), and unstructured interviews with key informants (Maxwell, 1996). The FGDs were conducted by a trained moderator fluent in the local language, who directed the conversation with the help of an interview guide (Appendix 3). A video footage of children with severe symptoms of respiratory illness was shown on a laptop in the FGDs to probe discussions and verify illness terminology. The FGDs were digitally recorded, transcribed and translated into English. The local terminologies and concepts elucidated from the FGDs and video task were summarised and cross-checked in unstructured interviews with the two Lukonjo speaking key-informants.

Data analysis: The quantitative data was entered in EpiData (www.epidata.dk) and analysed in STATA8. Descriptive characteristics of DDs and study children were summarised. Sensitivity and specificity were calculated from 2x2 tables. The influence of DD sex, education and number of children on performance was assessed using multivariate logistic regression. All standard deviations and confidence intervals were adjusted for cluster effects induced by repeated DD measurements. Median-test was used to test equality of DD median difference rating with gold standard.

The composite sensitivity of DD assessment to predict pneumonia was calculated by multiplying DD sensitivity to assess rapid breathing (true positive DD assessment) with the 76-81% sensitivity of rapid breathing to predict pneumonia (true positive IMCI assessment) (Weber et al., 1997, Kolstad et al., 1997) and adding the erroneous rapid breathing classifications (false positive DD assessment) multiplied by the false negative IMCI assessment (pneumonias without rapid breathing). Similarly, the composite specificity of DD assessment for pneumonia was true negative DD assessment x true negative IMCI assessment (60-89% specificity) (Weber et al., 1997, Kolstad et al., 1997) + false negative DD assessment x false positive IMCI assessment. The projected over-treatment and failure-to-treat was further calculated (Chandramohan et al., 2002).

The qualitative data analysis was based on the major thematic areas of local terminologies for ARI, labelling of illness, perceived severity and associated actions. Data was organised into meaningful categories using the software N6 (NUD*IST v.6 2002). Relevant quotations were extracted and presented verbatim to give credibility to the data. Findings concerning the relation between *emic* and *etic* illness terminology, ARI illness classifications and preferred treatment were summarised in a table. The unit of analysis was the whole group of mothers, rather than the individuals (Maxwell, 1996).

STATISTICAL METHODS

The statistical methods used for analyses were:

- i) *Chi-squared test* was used to compare two groups of categorical data such as the proportion of children with symptom overlap by sex and age group. Fishers' exact test was used when cell counts were less than five in at least one cell.
- ii) *Logistic regression* was used in situations where the effect of several independent variables was estimated while controlling for a number of confounding factors and allowing for assessment of interaction between variables. In study I, multivariate logistic regression was used to determine independent predictors (i.e. age and duration of fever) for symptom overlap and the interaction between these variables.
- iii) *Paired t-test* was used to test whether the difference between a pair of variables measured on each individual on average was zero. In study V, the paired t-test was used to determine inter-rater agreement between two researchers who simultaneously assessed respiratory rate in a child.
- iv) *Wilcoxon matched-pairs signed rank test* is the non-parametric equivalent of the paired t-test and tests the equality of matched pairs of observations. The null hypothesis is that both distributions are the same. This test was used for the significance testing of the inter-rater agreement obtained from the paired t-test in study IV, since normality of data not could be assumed.
- v) *Wilcoxon's ranked sum test* is also a non-parametric test, alternative to the two-sample t-test when data is not normally distributed, and used to test the hypothesis that two independent samples (i.e., unmatched data) are from populations with the same distribution (also known as the Mann-Whitney two-sample statistic). In study III, the Wilcoxon's ranked sum test was used to compare median costs spend for different sources of care and in study IV the median age among those referred versus non-referred.
- vi) *Median test* is performs a non-parametric test on the equality of medians. It tests the null hypothesis that the samples were drawn from populations with the same median and where measures are repeated. This test was used for test the equality of the drug distributor (DD) median difference rating compared with gold standard rating (V).

ETHICAL CLEARANCE

All studies were approved by the Makerere University Higher Degrees research and Ethics committee (30/5/2002). Studies I, II and III were approved by the Karolinska Institutet Regional Ethics Committee (Dnr 03-543, 02-373 and 03-259, respectively). Study IV and V were approved by the Karolinska Institutet Northern Ethics Committee (Dnr 03-697 and 03-697, respectively). Study I was also approved by the AFRO-IMCI Research Committee and both study I and study III by the Uganda Ministry of Health. Permission to carry out the studies was obtained from the district administrative authorities and village chiefs. Informed consent was obtained from community members who volunteered to participate in FGDs. Drug distributors agreed in writing to participate in training and evaluation. Parental consent was sought before assessing children on the ward.

SUMMARY OF METHODS

Table 4. Summary of the methods used in the five studies

Title of study	Methods	Study population and sample size	Year
I. Symptom overlap for malaria and pneumonia - policy implications for home management strategies.	<ul style="list-style-type: none"> • Cross-sectional study in IMCI health facilities 	<ul style="list-style-type: none"> • All children under five seeking care from 14 IMCI health facilities during 3,5 months • Total number of children=3,671 	1999
II. Local fever illness classifications: implications for home management of malaria strategies.	<ul style="list-style-type: none"> • Focus Group Discussions (FGDs) 	<ul style="list-style-type: none"> • Mothers, fathers and grandparents (10 groups with 8-14 participants in each) 	2002
III. Home and community management of acute paediatric respiratory infections in 8 Ugandan districts	<ul style="list-style-type: none"> • Cross-sectional household survey with interviews using 2 week recall 	<ul style="list-style-type: none"> • Mothers/caretakers of children ≤ 2 years • Total number of households=3,223 	2003
IV. Community referral in Home Management of Malaria in Western Uganda: A case series study	<ul style="list-style-type: none"> • Case-series study of referrals using household interviews with caretakers, drug distributor records, health facility records, and unstructured observations 	<ul style="list-style-type: none"> • All 117 children referred from 40 drug distributors during 20 study weeks 	2004
V. Can community health workers and caretakers recognise pneumonia in children? Experiences from Western Uganda.	<ul style="list-style-type: none"> • Direct observation of drug distributor end-of-training performance • FGDs • Unstructured interviews 	<ul style="list-style-type: none"> • Drug distributors (n=96) • FGDs (n=4) with young and old mothers (n=30) • Key informants (n=2) 	2004

RESULTS

SYMPTOM OVERLAP FOR MALARIA AND PNEUMONIA IN IMCI HEALTH CENTRES (I)

The frequency and predictors of malaria and pneumonia symptom overlap was explored in 14 IMCI practicing health centres. Of 3671 children visiting the health centres during the study period, 30% fulfilled criteria for both malaria and pneumonia (Figure 6). Eighty percent satisfied the malaria case definition (fever) and 32% the pneumonia case definition (cough and fast breathing). Among children with “pneumonia”, 93% also had “malaria”. More importantly, among children with “malaria”, 37% also had “pneumonia”. Age <1 year and fever duration ≥ 2 days were independent predictors of symptom overlap with odds ratio of 1.3 (95% CI 1.1-1.5) and 1.6 (95% CI 1.3-1.8), respectively. There was no significant statistical interaction between these two variables.

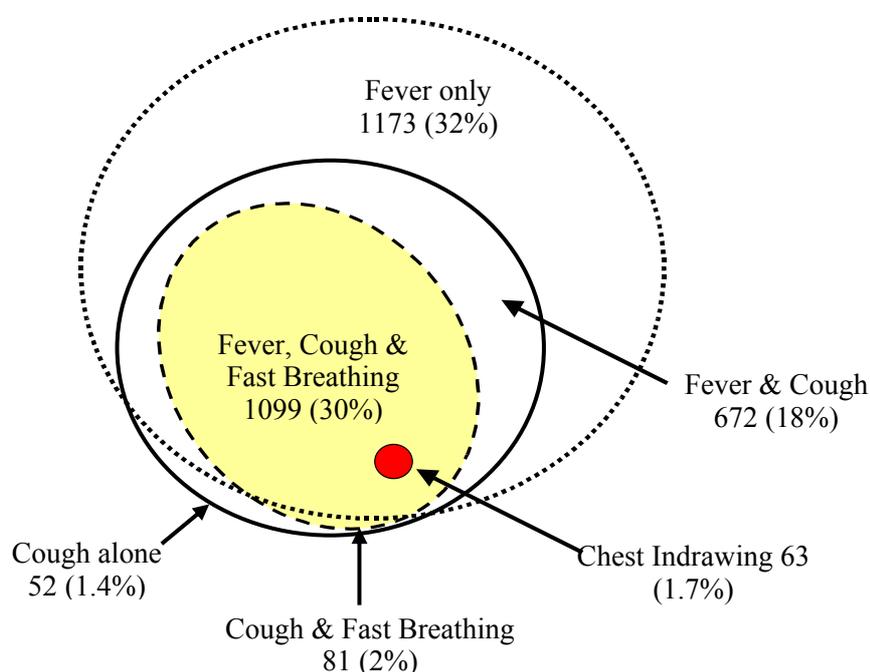


Figure 6. Symptoms and signs among 3671 consecutive Ugandan children 2 months to 5 years seeking care at 14 IMCI practicing health centres. n (% of children)

In summary, one third of all children seen in IMCI practising health facilities are classified as both malaria and pneumonia and should receive treatment with both antimalarials and antibiotics.

LOCAL FEVER ILLNESS CLASSIFICATIONS (II)

The classification and treatment of childhood fevers was studied among caretakers in the community. ‘Fever’ was a common illness term referred to as ‘omutsutsa’. A number of parameters were used to label the type of “fever”, including season, type and combination of symptoms, progression of symptoms, success of initial treatment, and degree of hot body (Figure 7). Most caretakers took some kind of action immediately after realising that the child was sick. Informing and consulting neighbours, in-laws and grandparents was considered an important first step. Other immediate actions were first aid remedies, and once the type of febrile illness was clearer, the preferred “first line” treatment would apply (Figure 7). Early

treatment in the home often involved allopathic medicine left over from previous episodes or obtained from neighbours or drug shops. If the child improved, treatment would normally stop but if symptoms persisted, care was sought from health facilities or traditional healers.

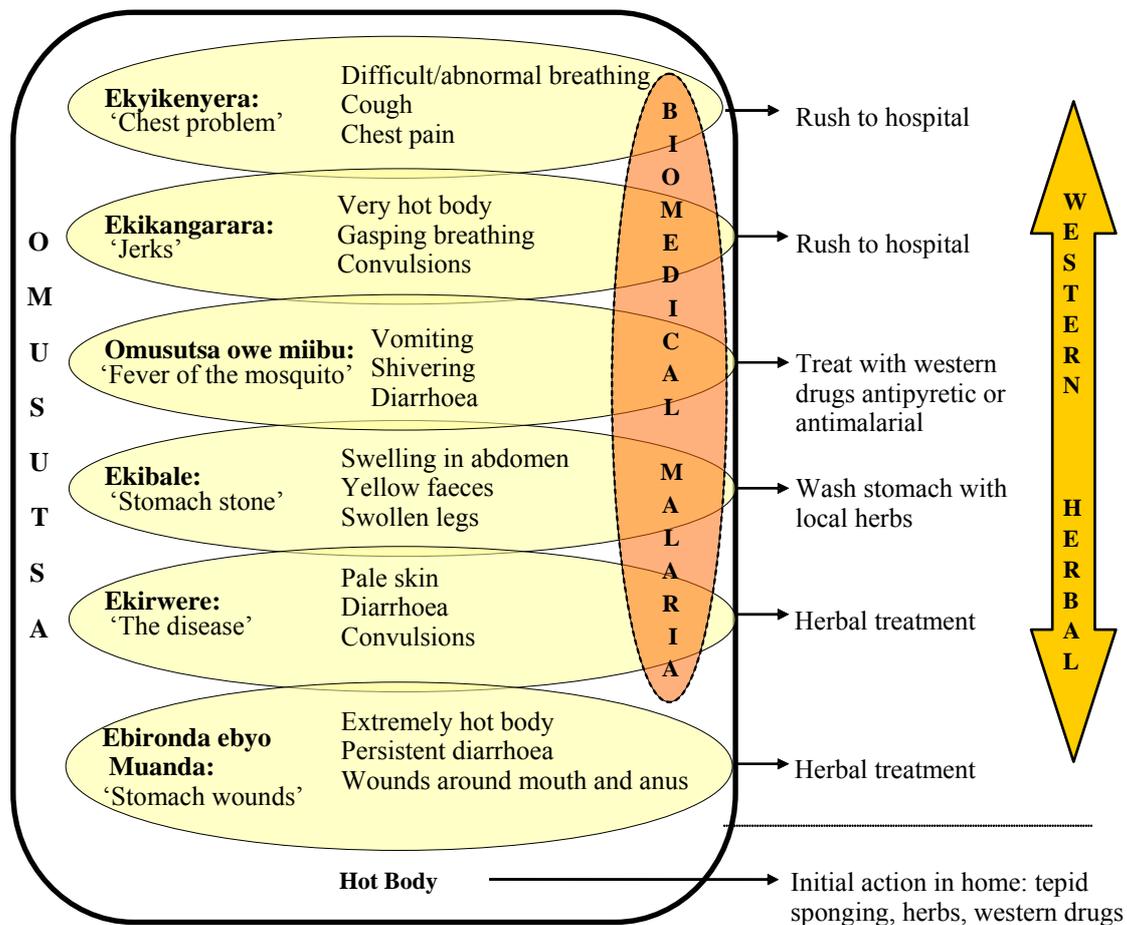


Figure 7. Hot body, local "fever" classifications, associated first-line care seeking actions and possible relation to biomedical malaria.

The treatment process varied according to how symptoms were perceived and classified and how the illness evolved. Some illnesses, such as 'ekyikeneyera' with symptoms of difficult/abnormal breathing and chest indrawings, were considered "for-hospital" whereas others were perceived more effectively treated with herbal medicines. Presence of 'hot body' often prompted home treatment with antimalarials before seeking outside treatment. Caretakers often tried different treatment options, switching between traditional and western. Usually the mothers first consulted the fathers about what type of care to seek, and only in cases where the treatment option did not involve cash outlays, could the mothers decide on the type of treatment to give.

In summary, the local understanding of fever illnesses was complex and although all fever illness classifications could be biomedical malaria, only some were seen to require urgent professional allopathic treatment. One febrile illness concept, 'ekyikeneyera', contained symptoms indicative of severe pneumonia. Although this illness was perceived warranting hospital care, presence of 'hot body' may imply that some children first will be treated with antimalarials.

HOME AND COMMUNITY MANAGEMENT OF ARI (III)

Study III aimed to determine the prevalence of ARI and fever in children at community level, the timeliness in care seeking and the treatments and sources of care sought. Of the 1686 (52%) children who had been sick in the previous two weeks, 19% were reported to have had overlapping symptoms of fever, cough and ‘difficult/rapid breathing’ (DRB) (Figure 8). Of those with fever, 28% were also stated to have had cough and ‘DRB’. Cough with ‘DRB’ occurred equally over the districts but more often in children <1 year than ≥1 year ($p=0.005$). There was no difference across sex.

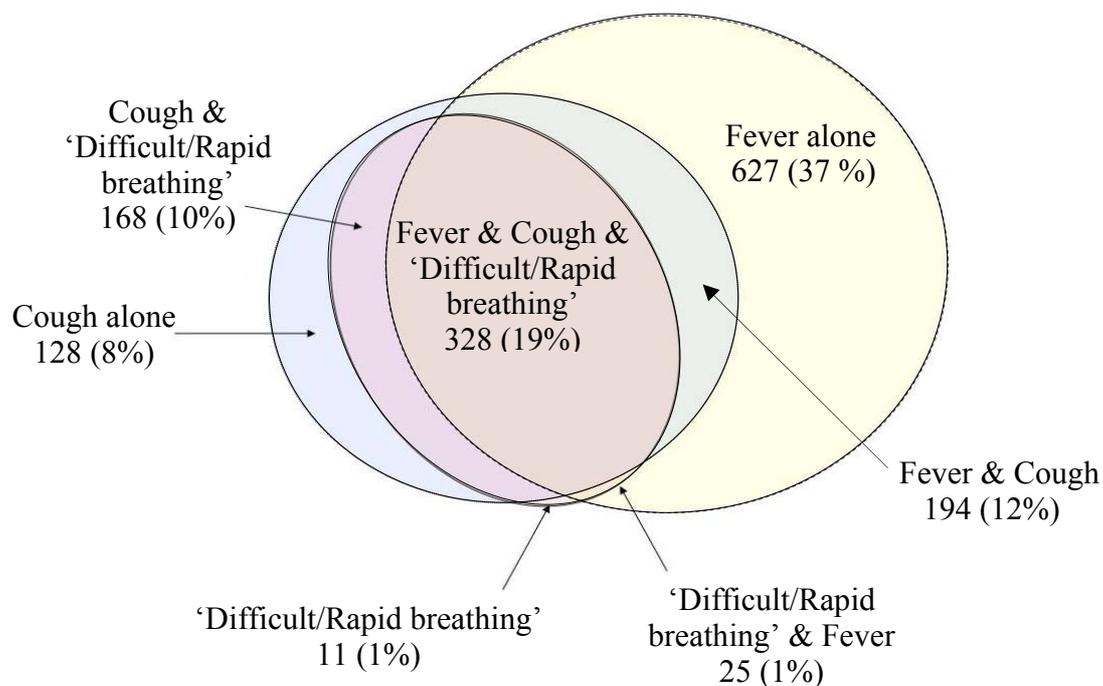


Figure 8. ARI symptom combinations and overlap in 1686 children ≤ 2 years at community level; n (% of children)

More children with cough and ‘DRB’ were taken for treatment within 24 hours if they also had fever (50% versus 37%; $p=0.006$). Private clinics (34%), drug shops (21%) and health centres (20%) were the predominant sources of care sought. Febrile boys were more likely than febrile girls to be taken to a health centre (27% versus 20%, $p=0.004$) and febrile girls more likely to be taken to private clinics (36% versus 27%, $p=0.0009$). Median distance to health centres was 3 km (range 0–35) compared with 2 km (range 0–40) to a private clinic ($p=0.03$). Median cost for consultation and drugs was lower in health centres than in private clinics, US\$ 0.6 vs. US\$ 1.1 ($p<0.001$).

Of children with cough and ‘DRB’, 39% received antibiotics. When fever also was present, antibiotic use dropped to 32% ($p=0.12$) and antimalarial use increased from 11% to 66% ($p<0.001$) (Figure 9). The most commonly used antibiotic for ARI was first line Cotrimoxazole (trimethoprim-sulfamethoxazole) and most common antimalarial used for fever was Chloroquine (CQ) alone – also in line with MOH policy. Most antibiotics were obtained from drug shops or home stocks, often within 2 days of symptom onset.

In summary, every fifth child who had been sick in the previous two weeks in the community had had overlapping symptoms of fever, cough and ‘DRB’. Of children with fever, 28% also

had cough and 'DRB'. Under HBM these should have been referred to a health facility. However, use of health services was low and antibiotic use high - a majority obtained treatment from private sources.

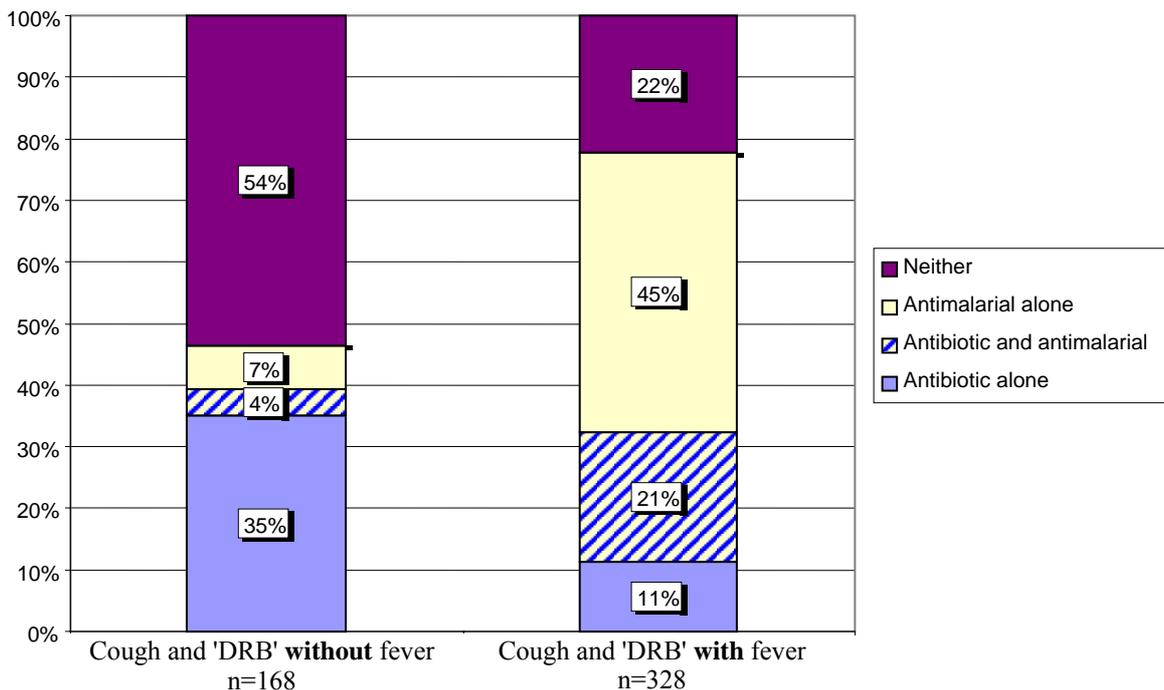


Figure 9. Antibiotic and antimalarial use for different symptoms combinations for 1686 children aged ≤ 2 years who had been sick in the previous two weeks.

COMMUNITY REFERRAL IN HOME BASED MANAGEMENT OF FEVER (IV)

In this case-series study the rate of, the reasons for, and the compliance with referral from community to health centre was studied, as well as reasons for non-compliance, sources of care sought and diagnosis received. Overall referral rate among 1454 children who sought care from DDs was 8%, varying between 3% and 12% across parishes. Sixty-eight percent of caretakers stated seeking care <24 hrs of fever onset. Of those referred, 36% were referred urgently (e.g. for persisting fever or difficult breathing), and 64% were non-urgent (e.g. for cough or diarrhoea). Mothers mainly sought DD care for their child because of fever, general illness symptoms and ARI symptoms. DDs mainly referred persisting fevers, convulsions and vomiting. Of children referred, 32% were stated by the caretaker to have had fast breathing, but only half of these were 'urgently referred'. Thirty percent of caretakers complained of 'ekyikenyerera' (Figure 7), but only 4 DD referrals were due to this illness.

Overall, 87% of caretakers of referred children stated having completed referral (Figure 10). Referral completion rate was 93% for 'urgent referrals' and 84% for 'non-urgent referrals' (p=0.31). Lack of money and child improving were main reasons for non-completion and 5/10 non-compliers instead went to drug shops. Main reasons for delaying to seek referral care were lack of money and waiting to complete malaria drugs. Most referred children were taken to governmental health centres or hospitals. Median out-of-pocket cost of referral was US\$ 10.00 for the NGO hospital, 1.76 for NGO/private health centre and 0.71 for governmental health centres. Overall, 60% of the total cost went to consultation/admission fees. The money was obtained with difficulty for 71% of the caretakers and 62% had sold household assets to finance the referral event.

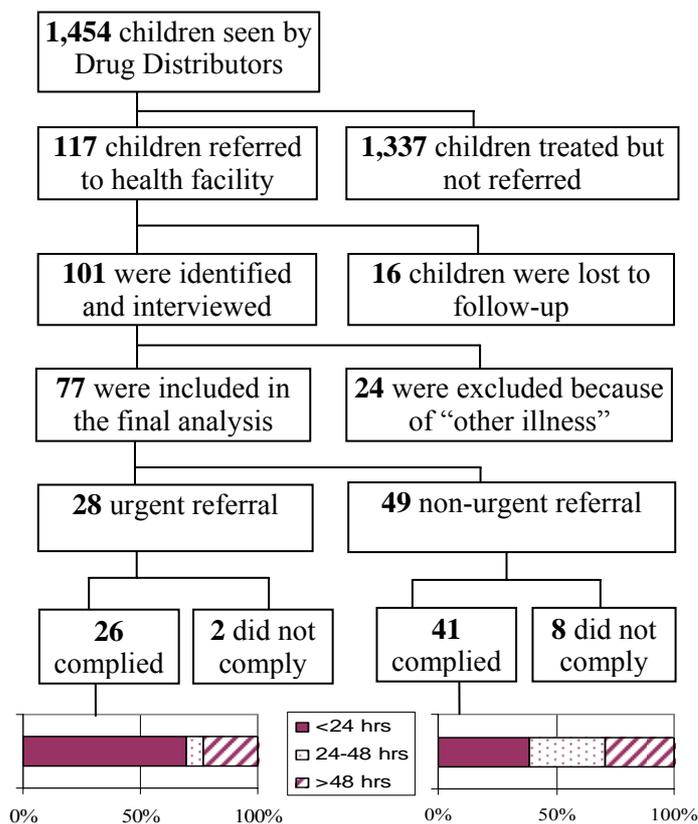


Figure 10. Study sample including referral types, completion and timing for 1454 under-fives seen by DDs.

Of caretakers stating referral completion 82% of children could be identified in health facility registers. Loss-to-follow-up was due to name changes of children, incomplete facility records, legibility of handwriting and, in one known case, incorrect caretaker reporting. Of those tracked in the health facility registers, 84% were diagnosed with malaria and 42% with ARI - 78% of these were prescribed an antibiotic. Twenty-six percent of ARIs were diagnosed as LRI. More than half of the ARIs and 4 out of 6 LRIs accessed referral care after ≥ 2 days.

In summary, referral completion rate was high but ARIs often delayed >24 hours before accessing referral care, mainly owing to lack of money or waiting to complete Homapaks.

COMMUNITY HEALTH WORKER RECOGNITION OF SIGNS OF PNEUMONIA (V)

In the last sub-study, the DDs' ability to count and classify respiratory rate was evaluated, as well as mothers' recognition, terminology and treatments used for ARI symptoms. The proportion of correct DD classification by *impression* was 73% (409/654) with a sensitivity of 62% and specificity 82% (Table 5). Sensitivity of DD classification after *counting* was 75% (95% CI 0.71–0.79) and specificity 83% (95% CI 0.78–0.87). Seventeen percent of DD assessments were identical to gold standard and 71% were within ± 5 breaths/min. Of incorrect assessments, 53% were due to wrong application of cut-off rates and 47% owing to miscounting. Neither sensitivity nor specificity varied with DDs' sex, education or number of children. The composite sensitivity of DD assessment to predict pneumonia was 61–64%[‡] and specificity 60–77%*. Using these projections of DD diagnosis to predict pneumonia, failure-to-treat would be 0-3% and over-treatment ranging from 23% to 40% at low pneumonia prevalence (e.g. $<10\%$).

Mothers used a wide range of respiratory illness concepts which covered most biomedically relevant symptoms. The eight most distinct were summarised (Table 6). Only hot body, cough and fast breathing had analogues in local language. Although fast and difficult breathing were associated to problems in the airways, many ARI illness concepts were frequently related to 'fevers' perceived to require antimalarial treatment.

[‡] Calculated based on the DD sensitivity (75%) and specificity (83%) to assess rapid breathing and the 76-81% sensitivity and 60-89% specificity of rapid breathing to predict pneumonia (Kolstad et al., 1997; Weber et al., 1997).

Table 5. Sensitivity and specificity of assessment by drug distributors compared with researcher gold standard assessment

Drug distributor impression/classification	Researcher gold standard		Total
	Fast breathing n (%; 95% CI)	Normal breathing n (%; 95% CI)	
Impression			
Fast breathing	171 (62; 56–68)	52 (18)	223
Normal breathing	103 (38)	238 (82; 77–87)	341
All observations	274	290	564
Classification			
Fast breathing	204 (75; 71–79)	51 (17)	255
Normal breathing	68 (25)	241 (83; 78–87)	309
All observations	272	292	564

The video footage which showed a six months old child with breathing rate 66 breaths/min and chest indrawings was agreed to have ‘groaning breathing’ (ekyikenyeru). Treatment suggested included ORT, herbs, panadol (Paracetamol) and Chloroquine. The child who breathed through the mouth with a rate 65 breaths/min and looked weak was agreed to have ‘fever’ (omutsutsa) requiring Chloroquine, ORS and tepid sponging. The child with normal respiratory rate and stridor was suggested to have ‘narrow space’ (akafundi) together with ‘abrupt attack’ (obukoni), although some suggested ‘groaning breathing’ (ekyikenyeru). All agreed that the first action would be to rush the child to a hospital.

Table 6. Biomedical illness symptoms, local terminology and ARI illness concepts among mothers in a rural population in Western Uganda.

Biomedical symptom	Respiratory illness concept							
	Ekiha-hayiro	Erihihira	Ekihu-mira	Erihumayira	Ekyiken-yero	Akafundi	Obukoni	Ekik-uba
	Quick breathing	Shivering breathing	Heavy attack	Unorganised breathing	Groaning breathing	Narrow space	Abrupt attack	Chest
Hot body ^o	√	√	√		√			
Cough ^p		(√)	√	√	√	√		√
Fast breathing ^o	√	√		√	√		√	
Difficult breathing*	√		√	√	√	√	√	
Stridor*						√		
Grunting*					√		√	
Chest indrawing*					√			
Associated illness	Fever	Fever	Cough & flu	-	Severe fever	Cough & flu	-	-
Associated action	Antimalarials	Antimalarials	-	-	Antimalarials	-	-	Antibiotics

^o Local term was Ekibugumu, ^p Local term was Erikohola, ^o Local term was Erihumulha lhuba lhuba

* Described in words

In conclusion, sensitivity and specificity of DD assessment of RR was adequate but diagnostic value was limited by the sensitivity of RR to predict pneumonia. There was consistency in interpretation of severity, cause and treatment of ARI illness concepts – most being related to fever and perceived to need antimalarial treatment.

DISCUSSION

The occurrence of malaria and pneumonia symptom overlap in sick children under-five is substantial both in the studied communities and health centres. Whereas the frequency of this overlap has been studied in hospitals (English et al., 1996, O'Dempsey et al., 1993b), the extent had not been explored previously in primary health care and in communities. Nor had caretakers' and community drug distributors' (DDs) perceptions and actions for indications of co-morbidity been studied. Symptom overlap also occurred in local fever and ARI illness concepts, resulting in delayed care seeking for children with potential pneumonia.

The use of private sources as providers of treatment for sick children is widespread. Generally the labelling of illness influenced the treatment and provider option. Although antibiotics are frequently used for symptoms of mild ARI, presence of fever steered treatment towards use of antimalarials, and sometimes traditional medicine alone. These findings add to a relatively sparse evidence base on antimicrobial drug use in Sub-Saharan Africa, as the majority of these types of studies have been done in Asia (Chuc et al., 2001, Larsson et al., 2000).

DDs already trained in malaria case management can successfully be taught to recognise and classify also signs of pneumonia in children, supporting the WHO/UNICEF recommendation to integrate pneumonia care in community management of malaria (WHO/UNICEF, 2004). While community management of pneumonia has been demonstrated effective in reducing child mortality in Asia (Sazawal and Black, 2003), the feasibility and impact of community management of more than one illness has rarely been evaluated in Sub-Saharan Africa.

METHODOLOGICAL CONSIDERATIONS

Design

The cross-sectional surveys at health facility (I) and household (III) levels and the focus group discussions of fever illness classifications (II) were conducted before the HBM policy was implemented. The case-series study (IV) and study V, which used triangulation of methods, were performed after introduction of HBM. While the "pre-policy" studies describe care seeking patterns and barriers to prompt and appropriate care for children with febrile and respiratory illness, the "post-policy" studies provided valuable information on whether HBM manages to overcome these barriers, or whether additional efforts are needed.

Prevalence rate ratios versus odds ratios in cross sectional studies

Many have used prevalence odds ratios (POR) as effect measures in cross-sectional studies in relation to malaria and other infections (Sintasath et al., 2005, Schwartz et al., 2001). However, some argue that prevalence rate ratios (PRR) are more appropriate measures in situations where the disease is prevalent and the outcome is not strictly a "disease" but rather a construct (Lee and Chia, 1993, Zocchetti et al., 1997). A conversion of the PORs in sub-study I, as recommended by Zocchetti et al (1997), shows that the estimated POR=1.3 for age as a predictor of symptom overlap corresponds to a PRR=1.16 and the POR=1.6 for duration of fever equals PRR=1.3. Hence, we could conclude that age and duration of fever predict the occurrence of overlap in children under-five, even when effect is measured by PRR.

Cluster analysis

The study units sampled in studies I, III and V were clustered. The analyses were adjusted for the cluster effect in studies III and V, but not in study I. Failure to address the cluster effect of health centres in study I likely generated too narrow confidence intervals around the estimate. However, given the very large sample size in this study, the effect is expected to be minor and the confidence intervals of the estimated proportion likely remain narrow.

Sampling bias

The health centre based study (I) unavoidably suffers from sampling bias due to caretakers' care seeking practices, and children included may have later or more severe symptoms with more symptom overlap than sick children in the community. Consequently, these findings cannot be extrapolated to community level. Although the data collected represent 14 facilities from 4 districts reflecting different situations, the sample size and sampling procedures do not strictly allow generalisations to the country level.

The failure to apply probability proportionate to size (PPS) in study III, overrepresentation of smaller districts with differing health infrastructure and disease endemicity may have occurred. However, 5/8 districts had fairly homogenous populations (200,000-500,000 inhabitants) and only one was significantly smaller (Yumbe=99,794 population). The lack of PPS sampling in the 2nd stage may have caused overrepresentation of small villages with less access to health services. However, most Ugandan villages are homogenous in size (50-100 households) and such bias is expected to be minor. Similarly, given the lack of probability sampling of households, overrepresentation of households with better access to roads and health centres could have occurred. But as most villages are small with no clear clustering around a central point, reaching the periphery should not have been a problem.

Another limitation of studies I and IV is that they were carried out during a limited period of the year, spanning the dry season and early/mid part of the rainy. In most parts of Uganda malaria transmission is holoendemic 7-12 months of the year (MARA/ARMA, 2005). Given that the main focus of studies I and IV was to capture many types of childhood fevers it was deemed appropriate to avoid conducting the studies during spiking malaria transmission, but rather when malaria prevalence was at annual average levels.

Interviews, language and information bias

Studies III and IV may be subject to information bias, as they report caretakers' *stated* rather than *actual* practices, and some may have responded to "please" the interviewer (Krause et al., 1998). In study III, most data collectors were students and teachers who did not represent modern medicine (Hardon et al., 2001) and any misreporting on illness symptoms between districts is believed to be non-differential. In study IV, the inability to confirm health facility attendance for 12 children whose caretakers reported referral completion, would have generated lower overall compliance (71%) if all were incorrect responses. However, health facility staff admitted that children coming at night were not always registered properly, and it was noted that caretakers often renamed younger children, explaining why some children could not be identified.

A potential weakness in studies III and IV was the use of a questionnaire in English, rather than local language. Generally, on-the-spot translation has been discouraged since it tends to produce more errors (Hardon et al., 2001). As Uganda is ethnologically diverse, more than 40

languages are in use. The local languages are only used in the first three years of school, followed by English in subsequent grades. The data collectors hence felt more comfortable to read and write in English. During training, standard translation of questions was agreed. In study III, this may have caused variations in illness terminologies used across languages. The inability to directly translate the respiratory symptoms ‘fast breathing’ and ‘difficult breathing’ into local languages further weakens the study. However, the finding of similar proportions of children with the symptom combination across different geographic and language regions supports the conclusion that differential misclassification was not an issue.

Recall bias

Interviews depending on people’s memory pose both reliability and validity bias (Kroeger, 1983). Especially when it comes to proxy reporting by parents, minor incidences may not be reported, creating a source of error. Severe symptoms are remembered longer than mild ones (Linder, 1965) while minor problems may be under-reported during a two week (Roghmann and Haggerty, 1974), or even one week (Martorell et al., 1976) recall period. Shorter recall periods capture more mild and brief episodes (Roberts et al., 1996). Although we cannot exclude recall bias in study III, where use of 2 week recall could have underreported minor illnesses, the validity of caretaker reporting was confirmed in study IV, where caretakers’ stated day of accessing referral care highly correlated with information in health facility records. This may indicate that this period of recall was adequate for the purpose of these studies.

Observation bias

In study I, observation bias owing to reliance on self-recorded information by IMCI health workers’ cannot be excluded. However, all health workers had undergone the 11-day training course in IMCI treatment guidelines, as well as a 5-day refresher training before the study. In study IV observation bias may have influenced attendance, referral and compliance rates. Our results may therefore reflect “better-than-average” performance (Kazdin, 2003). However, despite potential bias introduced, caretakers are still likely to face the same barriers to referral care access. This study design has also been judged most appropriate for the study purpose (Cervantes et al., 2003). In order to minimise bias, DDs and data collectors were informed about the importance of continuing normal routines and not to blame caretakers who failed to comply with advice. In study V, direct observation by the author may have influenced DDs to perform better RR assessment. However, given the aim to test the end-of-training performance, observation bias would not be an issue. For evaluation of field application of DD assessment and treatment of children, such bias could be more problematic, and would require another type of design.

Objectivity across cultures and disciplines

One threat to validity in qualitative studies is the researcher subjectivity bias induced by preconceptions, leading to blinded interpretation of the data (Hegelund, 2005). One way to overcome this innate validity threat is to use triangulation of methods and apply different perspectives from different disciplines and cultures (Malterud, 2001). In particular the combination of biomedical and anthropological perspectives has shown benefits (Sachs and Tomson, 1992). In both studies II and V, our preconceptions were based mainly on the malaria and ARI care seeking literature. In these studies, a multidisciplinary and multicultural research team was formed, consisting of one Ugandan paediatrician, two Ugandan social

scientists, one Swedish epidemiologist and one Swedish public health physician. The team analysed and interpreted the data together, hence minimising subjectivity (Malterud, 2001).

Ethical considerations

In study I, confidential patient records were analysed without patient approval. However, the study focused on routine practices of children managed under standard treatment guidelines and data was already collected by the Ugandan MOH. In study II and V, FGDs were used with possible integrity intrusion by discussion of sensitive issues. However, a trained social scientist with vast experiences was used as a moderator and all participants were informed about the research topic before giving verbal consent. In the caretaker interviews in studies III and IV, an ethical concern involved the sensitivity of asking questions on actions taken, marital status and household assets. Caretakers were assured that they were free to withdraw at anytime during the interview and could refuse to answer the questions. In study IV, where sick children sometimes were detected during household visits, the data collectors had been instructed to provide oral rehydration treatment (ORT) for diarrhoea and to emphasise the importance of seeking public health care which is free of charge. In study V, sick children in a hospital were visually examined by DDs. Each child was observed maximum three times; each time by a group of no more than six DDs. Parental and paediatricians' consent was sought before assessing children on the ward and caretakers were assured that the care offered would not be affected if they refused to participate.

The importance of triangulation

For comprehensiveness, a combination of different research methods was used to explore case management of febrile illnesses. The approach of combining different data collection methods (IV & V) and using researchers from different disciplines (II and V) is known as triangulation (Patton, 2002). In triangulation, results can support, complement or contradict each other and serve as a way of validating and increasing credibility of data (Malterud, 2001). Methods triangulation in study V included the combination of FGDs, video probing and key-informant interviews, yielding rich information on ARI terminology, ARI illness concepts and preferred treatments. In studies II and V, inconsistent findings were obtained for the local illness concept 'chest problem' (ekyikenyerera). In study II, caretakers stated that these children required immediate hospital care, whereas in study V, mothers said that this was a severe illness that first needed antimalarial treatment at home. In addition, the direct translation of ekyikenyerera in study II was found inappropriate and changed to 'groaning breathing' after analysis of results in study V.

LOCAL ILLNESS CONCEPTS AND HOME BASED MANAGEMENT OF FEVER

The emic and etic classification of illnesses

Fever in Kasese district was referred to as "omutsutsa", a term covering a broad symptom complex ranging from 'feeling unwell' to more specific fever conditions (II), as observed also in other parts of Uganda (Kengeya-Kayondo et al., 1994, Adome et al., 1996, Jitta, 1996). The local perceptions and understanding of febrile conditions which steer community treatment and actions (II & V) are not being addressed in the Home Based Management of fever (HBM) strategy. When HBM recommends caretakers to treat fever (Omutsutsa) with Homapak, only one of the local febrile illness concepts identified in this area of Uganda was perceived to need early antimalarial treatment. Preferred treatment of other types of fever, some of which could be biomedical malaria, involved herbs or traditional remedies alone.

For many febrile ARI conditions, antimalarials were perceived to be the most appropriate drug (III). These individual health actions are part of specific socio-cultural belief models which orient local definitions of health, illness and cure (van der Geest, 1997). The perceived efficacy of treatment for locally defined illnesses often diverge from the biomedical concepts of disease and appropriate treatment, explained as the divergence between *emic* (local, e.g. community members) and *etic* (outside, e.g. health staff) perspectives of efficacy (Etkin, 1991, Hausmann Muela, 2000). In this part of Uganda, the etic definition of malaria symptoms and treatment had poor correspondence to the emic definitions of febrile illnesses and how these illnesses should be dealt with. Similarly many ARI related illness classifications overlapped with those for 'fever', explaining why treatment actions for ARI often involved a preference for antimalarials. This underscores the importance of addressing local cultural and symbolic meanings of illness and treatments in policy frameworks (van der Geest, 1987).

Policy diffusion and syncretic models

Our findings imply that HBM is not sensitive to local illness perceptions and cultural practices for febrile illnesses. Failing to incorporate local terminology and understanding of fever in HBM education material may result in non-compliance with therapy and delayed treatment for both malaria and pneumonia (Winch et al., 1996, Hausmann Muela, 2000). Health care policies such as HBM are often formulated at national level by highly trained professionals who lack insight into the local culture context, make assumptions about what can be communicated through simplified biomedical terms, and how this will result in behaviour change (van der Geest, 1987). However, diffusion of innovations in the health system depend on individuals' perceptions of the innovation, characteristics of the individuals who may adopt the change, and contextual factors within the community (Berwick, 2003). Hausmann Muela (2000) has described how introduction of policy interventions are imposed on top of pre-existing beliefs which, after integration, result in an intermix of local and biomedical knowledge - referred to as a syncretic model. It is still unclear what role Homapaks will play in a situation where HBM recommendations are blended with local and biomedical knowledge, but the need for carefully constructed and delivered behaviour change messages is clearly fundamental for convincing people to adopt all aspects of the new intervention (Ford et al., 2005).

Household decision-making, health care seeking and gender

Mothers welcomed the idea of free Homapak in their own village, since it would allow them to access treatment without first asking husbands for permission (II) – similar to observations in a nearby district (Kilian et al., 2003). However, for children with symptoms not catered for by HBM, such as difficult breathing or persisting fever, mothers' lack of cash remained a great barrier to prompt care seeking, resulting in several days delay before children referred from the community accessed care from a formal health facility (IV). Armartya Sen (1990) proposes that women's access to independent sources of income is an enabling factor for them to make decisions - in this case by seeking the treatment they wish for the child without relying on their husband to pay or accepting his decision about treatment seeking. Furthermore, where women take on most of the financial burden of accessing treatment without corresponding access to resources, this may contribute to maintaining their subordination within the household by limiting their ability to accumulate resources under their control (Sen, 1990, Tolhurst and Nyongator, 2005). Strategies should therefore strive to

reduce the financial burden for women's and children's health problems. Although HBM brings free antimalarials, it is nevertheless a vertical programme with wide referral criteria to minimise maltreatment of conditions which need other treatment than antimalarials. Increasing the comprehensiveness of community based treatment would imply less strain on household resources. Further research should be done on women's de facto responsibility for children's health care and healthcare payments as a threat to their medium and long-term economic and social independence, and whether integrated community based management of childhood fevers can facilitate them in this process.

Although gender was an important factor for women's access to household resources, it was not an issue affecting health care and care seeking for boys compared to girls. Neither duration of illness before seeking care, nor referral patterns in the community, nor type, length or timeliness of antimicrobial treatment differed between sexes (I, III, IV). These findings thereby refute the observation of gender differences in care and treatment given to sick under-fives in other cultural settings (Kurz and Johnson-Welch, 1997, Larsson et al., 2000). Although it was observed that febrile boys more frequently were taken to health centres and febrile girls more often to private clinics (III), as also observed elsewhere in Uganda (G. Pariyo, personal communication), this does not necessarily imply gender bias. Given that the private clinics referred to by mothers may be mere drug shops, one explanation could be discrimination against girls, as more time and effort is invested in bringing boys to health centres with more qualified staff. On the other hand, costs for drugs were higher in the private clinic, indicating that more household resources were spent on treatment for girls. More in-depth qualitative exploration of caretakers' and other household members' perceptions of care and well being of children is necessary to elucidate potential differences in the negotiations and care sought for sick boys and girls in Uganda.

MALARIA AND PNEUMONIA OVERLAP

The malaria and pneumonia overlap is a multidimensional problem involving *etic* symptoms overlap in sick children, *etic* symptoms overlap in *emic* illness classifications, malaria and pneumonia disease overlap (co-morbidity) and concurrent use of antimalarial and antibiotic drugs.

Symptom overlap for malaria and pneumonia

The *symptom overlap*, which previously only had been quantified at hospital level (Perkins et al., 1997, Kolstad et al., 1997), was common in both routine IMCI health centres and in the community; 30% (I) and 19% (III) of sick children fulfilled both the malaria and pneumonia classification, respectively. Although the reported symptom 'difficult/rapid breathing' used at community level (III) cannot be equalled with the biomedical symptom 'fast breathing', it is still likely a sign indicating that the child has more than just a simple cough, which potentially indicates, or could result in, pneumonia. The escalation of the overlap rate higher up in the health care system is likely explained by natural disease progression and more severely sick children presenting in hospitals during a later stage of disease.

Of children with pneumonia symptoms in health centres and in the community, 93% and 66% also had fever, respectively (I & III). This likely explains why the majority of children with reported difficult/rapid breathing seen by drug distributors (DDs) received antimalarial Homapaks without referral advice (IV). Waiting to complete these drugs was also the main

reason given by caretakers who had delayed more than two days before accessing referral care for children with a lower respiratory infection diagnosis in the health centre. These findings, along with the reported practice of switching to herbs when western antimalarials fails in curing the fever (II), not only imply that pneumonia deaths may continue unabated, but that care seeking for potential pneumonia could be even further delayed by HBM. In addition, antimalarials failing to treat children with ARI may have a negative impact on people's confidence in the HBM strategy, potentially resulting in decreased uptake of the strategy and poor compliance with treatment.

Disease overlap of malaria and pneumonia

Given the observations that *disease overlap*, or co-morbidity, of malaria and pneumonia occur more frequently than it would by random, a child with rapid breathing in a highly malarious area may have either malaria or pneumonia alone, or both (WHO, 1991a). Although the clinical malaria and pneumonia interaction is insufficiently studied and deserve further exploration, it is clear that children with co-morbidity are more likely to die or end up in hospital with severe disease (Mulholland, 2005). While most studies report a single cause of death, many cases may have co-morbidity (Todd et al., 1994). It has also been noted that symptom confusion result in underreporting of pneumonia in malaria endemic areas (Morris et al., 2003, Black et al., 2003). As both diseases kill under-fives rapidly - often within two days - early and appropriate treatment is of particularly high importance (Greenwood et al., 1987, Reyes et al., 1997). Hence, many argue that the benefits of treating both diseases at an early stage with combined treatment for symptoms of co-morbidity still outweigh the risks, although often resulting in over-treatment with both antibiotics and antimalarials (O'Dempsey et al., 1993b). Dual treatment for children with overlapping symptoms is also the WHO policy under IMCI (WHO, 1997). Consequently, greater diagnostic precision is desirable to differentiate the two diseases. Although more specific assessment guidelines have been tested, showing that e.g. normal chest examination, pallor, splenomegaly and hepatomegaly are good indicators to separate malaria from pneumonia (Yacoub et al., 2005), they were not evaluated in concurrent malnutrition or HIV-infection. As these signs are also likely to be too complicated for first level health workers and CHWs, there is a continued need to identify clinical signs, or develop tests, that can easily be used in health facilities and communities to facilitate differential diagnosis and more appropriate treatment of childhood malaria and pneumonia (Amexo et al., 2004).

Treatment for malaria and pneumonia symptoms

Every fifth child with fever, cough and 'difficult/rapid breathing' in the community was stated to have received a combination of antimalarials and antibiotics, most obtained from non-formal providers (III). In health centres, 30% of children seen should receive dual treatment based on dual illness classifications (I). This "*treatment overlap*" is an issue in countries like Uganda where first-line therapy for malaria is Chloroquine (CQ) + sulfadoxine/pyrimethamine (SP) and first-line treatment for pneumonia is sulfamethoxazole/trimethoprim (cotrimoxazole or CMX). With both Pyrimethamine and trimethoprim being antifolate drugs, co-administration may increase risks of toxicity, potentially resulting in folate deficiency anaemia, neutropenia, and thrombocytopenia - particularly in children with nutritional deficiencies (WHO, 1991a). Consequently, treatment guidelines from the early 1990's, when CMX was recommended for treatment of both malaria and pneumonia, state that concomitant co-administration of SP and CMX should be avoided (WHO, 1991a). This argument lends support to the recommendation to move to more

effective and, in some settings 10-fold more expensive, non-sulpha containing Artemisinin based Combination Treatment (ACT) for uncomplicated malaria in HBM strategies (Amexo et al., 2004, Pagnoni et al., 2005). Due to the few, but quite alarming indications of high rates of pneumococcal resistance to CMX in hospitalised Ugandan children (Joloba et al., 2001), a surveillance system for antibiotic drug sensitivity should be established, including monitoring in communities and first level health facilities. Yet, given the likelihood of co-administration of antibiotics and antimalarials in the sick child, an optimal solution would be the development of a drug which, similarly to CMX in the previous decades effectively can treat both malaria and pneumonia.

ACCESS, RATIONAL USE OF ANTIBIOTICS AND DRUG RESISTANCE

Antibiotic use for paediatric cough is high in Uganda, with more than 40% of episodes receiving an antibiotic drug early after illness onset (III). Although prior studies show that antibiotic self-treatment is common in SSA, most report on its use for sexually transmitted diseases (Adu-Sarkodie, 1997) or children with fever (Watling et al., 1995). The majority of studies on antibiotics for ARI come from Asia (Chuc and Tomson, 1999, Hardon, 1987, Tupasi et al., 1989, Halfvarsson et al., 2000). In SSA, most drug utilisation studies have focussed on antimalarials, demonstrating self-medication rates for fever ranging from 7% in Nigeria to 94% in Ghana (McCombie, 1994, Snow et al., 1992). The wide availability and uncontrolled use of antimalarials and antibiotics in SSA likely led way to the emerging parasitic and bacterial drug resistance (Bloland and Etting, 1999, Schrag et al., 2001). However, whereas self-prescription of antimalarials for fever is a recommendation in malarious areas with low access to medical facilities (WHO, 2000b, Snow et al., 1992), self-treatment with antibiotics is largely discouraged and selling of antibiotics not prescribed by health staff is seen as illicit, yet occurs widely.

While the unregulated prescribing and selling of antibiotic drugs may be seen as biomedically “irrational”, it may be the only realistic option for poor and rural mothers to access prompt antibiotic treatment for sick children (Sachs and Tomson, 1992). Restricting the availability of antibiotics in rural areas where the majority are poor may have negative consequences for children, who are most frequent consumers of health care. On the other hand, loosing cheap and effective first-line antibiotics due to excessive use for non-severe conditions may have severe public health consequences and resistant pneumococcal infections can be 11-90 times more expensive to treat (Schrag et al., 2001). For the poorest households, exhausting household resources on ineffective drugs may result in life-threatening conditions, as further treatment seeking may be too costly. Clearly, urgent action is needed to develop strategies which focus both on improving access to antibiotics for children with potentially life-threatening conditions like pneumonia and on restricting the uncontrolled usage for conditions such as mild cough. These efforts must take into consideration the perceptions of treatments for local illnesses, the availability of antibiotics, and the characteristics of the established health care deliver systems (Kunin et al., 1987).

Antibiotics used in the studied communities were predominantly obtained from drug shops or private clinics (III). These are often manned by untrained staff whose dispensing of incomplete antibiotic doses is argued to be a main contributor to drug resistance development (WHO, 2001, Isturiz and Carbon, 2000). A promising approach which increasingly has received attention is the formation of partnerships between public, non-governmental, and

commercial sectors, where integrated drug supply systems and improved close-to-client health services could improve access while reducing inappropriate use of essential drugs (Axelsson et al., 2003, Tawfik et al., 2002, Gilson and McIntyre, 2005). The possibility of involving drug vendors in providing quality PHC in areas where the health system fails to deliver these services has been recognised previously (Brieger et al., 2004a) and promising results have been observed after training in malaria case management in Kenya (Marsh et al., 2004). The feasibility of using drug vendors and other important private providers (such as traditional healers) in the provision of drugs in community based management strategies should hence be tested. Meanwhile, antibiotic resistance needs to be monitored, and as recent studies in Asia demonstrate that 3-day antibiotic courses for ARI lead to less resistance development and are equally efficacious as 5-day courses (Agarwal et al., 2004), the effects of short course antibiotic therapy should also be evaluated in SSA.

COMMUNITY HEALTH WORKERS IN THE HEALTH SYSTEM

Motivation of CHWs important for coverage and sustainability

The high community referral compliance rate observed (IV) indicate that strategies like HBM can extend the health system to the village to catch likely malaria episodes early, while still sending potentially severe cases to the health facility for assessment (Freedman et al., 2005). This is in line with ongoing discussions arguing that community health workers (CHWs), or Drug Distributors (DDs) in Uganda, are fundamental vectors for improved service delivery for maternal and child health in rural and poor populations affected by weak health systems and lacking manpower (Haines and Sanders, 2005, Paul, 2004). However, programme impact is also dependent on high coverage. Preliminary evaluation data from the study area show that uptake is improving but below the expectations (Nsungwa-Sabiiti J et al, 2005, Nsabagasani et al., 2005). The lack of supervision and support likely explain why DDs are unmotivated to carry out their duties, and lack of community sensitisation why community members were doubtful or unaware of the programme. This highlights the importance of having incentives for DDs – monetary or non-monetary (t-shirts, flashlights or supervisor visits in the village) – to be able to achieve programme impact and sustainability (Walt, 1990, Gilson et al., 1989, Kahssay et al., 1998).

Moving from ‘community based treatment’ to ‘community-directed treatment’

It has often been argued that effective community based health care can be obtained only when the communities themselves are actively involved in the planning and implementation of the intervention (Hanson et al., 2003, Kahssay et al., 1998, Brieger, 1996). Many lessons could be learned from community-directed treatment programmes for control of lymphatic filariasis or onchocerciasis (river blindness) in SSA which, although often failing to integrate with PHC, managed to achieve high treatment coverage levels of Ivermectin distributed free by community based distributors (CBD) (Amazigo et al., 2002, Katarawa and Richards, 2001). Here, the success resulted from changing from ‘community-based Ivermectin treatment’ (CBIT) to ‘community-directed treatment with Ivermectin’ (CDIT), where the communities were more actively involved in the process (Amazigo et al., 1998). Although sustainability and coverage is likely to be more difficult to obtain in programmes where treatment is provided continuously around the year, rather than annually as in the CDIT programmes, the importance of community ownership and high motivation among community volunteers will still be fundamental for success (Kahssay et al., 1998). Ignoring to pay attention to the needs, perceptions and gender roles in the context in which the

programme is supposed to integrate, will likely result in continued low community effectiveness (Nsungwa-Sabiiti J et al, 2005, Clemmons et al., 2002).

Antibiotics in the hands of community health workers?

The Ugandan DDs, who function as CHWs trained in vertical for malaria case management, could successfully count respiratory rate in children and make correct classification of pneumonia symptoms (V). The relatively high specificity of assessment suggests that DDs would be technically capable of distinguishing an upper respiratory infection (URI) from a lower respiratory infection (LRI) and thus have potential to provide antibiotics when necessary and reduce inappropriate antibiotic use. Although similar to findings in Bangladesh (Hadi, 2003) and Bolivia (Zeitz et al., 1993), this has rarely been verified in sub-Saharan Africa. Studies show that expansion of curative activities among CHWs' responsibilities beyond health promotion or treatment of just one condition, is a key factor in increasing their motivation and their acceptance within the community (Curtale et al., 1995, Walt, 1990, Kahssay et al., 1998). Although the ability to treat several illnesses may help CHWs to establish their credibility in a community, some argue that this may involve other dangers, such as CHWs becoming 'mini' doctors who inflate their claim to cure ills for which they have not received training (Walt, 1990, Kahssay et al., 1998). Another worry is that CHW management may involve additional responsibilities for already over-burdened mothers, who will receive more responsibilities to recognise and decide on where and when to go for treatment, instead of relying on formally trained health workers judgement.

The medical profession in many countries has been reluctant to allow CHWs access to their more valued treatments and techniques such as antibiotics, arguing that this would lead to severe misuse of drugs and resistance development (D'Alessandro et al., 2005, Walt, 1990). However, antibiotics are already widely used (III) and the projected risk of over-treatment of pneumonia is still much lower than the over treatment with antimalarials in HBM programmes (V). Given the demonstrations from several countries that adequately trained, supported and supervised CHWs are capable of appropriately dispensing antibiotics, it has been concluded that the benefits of supplying them with antibiotics exceeded the risks involved (Walt, 1990, BASICS II, 2004, WHO/UNICEF, 2004). The feasibility and mortality impact of full-scale implementation of integrated home and community based management of both malaria and pneumonia should therefore be tested, and the effects on drug resistance development closely monitored.

CONCLUSIONS AND POLICY IMPLICATIONS

1. There is frequent malaria and pneumonia symptom overlap in sick children both in communities and in first level health facilities (I & III). Most children with pneumonia symptoms also have fever.
2. Informal providers are important sources of treatment for sick children and self-medication with antimalarials and antibiotics is common for acute respiratory infections (ARI) (III).
3. Local illness perceptions and associated actions for fever and ARI are complex. Categorisation of symptoms into local illness classifications affects the treatment option. The biomedical fever definition used by the Home Based Management of fever (HBM) strategy does not match with the local illness concepts used in the communities (II).
4. Most children referred from the community in this study reached a formal health centre (IV). Referral care access is often delayed as many caretakers wait to first complete antimalarial treatment.
5. After two days training, antimalarial community drug distributors (DDs) could also classify pneumonia based on the child's breathing rate (V). Focussed methods for ARI terminology and symptom labelling can provide a toolkit for the development of context specific communication strategies.

Given the difficulty in separating malaria from pneumonia, addressing just malaria in the community may increase incorrect treatment and delayed care seeking for potential pneumonia. Making DD management more comprehensive beyond vertical management of malaria, and include treatment for other major childhood infections such as pneumonia and diarrhoea, could result in significant gains in child survival – and progress towards the millennium development goals.

Although community management of pneumonia would require a drug policy change to allow antibiotic dispensing by non-medically trained health workers, antibiotic drugs are already widely used in the community. With adequate training, supervision and support of DDs – and possibly also drug vendors - there is potential to rationalise antibiotic use while concurrently increasing access to treatment for those with limited health care access. To achieve optimal DD performance and high community uptake of the programme, the local illness concepts and associated treatment actions need to be addressed in communication strategies. Focused studies to elicit terminology, illness concepts and treatment actions should be included as an adaptation step when taking community based strategies to new geo-cultural zones.

While DDs can operate outside the formal health facilities to identify and treat children early in the disease process, the high referral completion rate demonstrates that links to the formal health system can be maintained. With these findings, the feasibility and impact of full-scale implementation of integrated community management of malaria and pneumonia should be tested.

REFLECTIONS FOR THE FUTURE

A number of issues important for achieving coverage, acceptability and impact of community management interventions remain unresolved:

- The lack of adequate clinical predictors for differential diagnosis leads to over-use of antimalarial and antibiotic drugs for sick children in both health facilities and in the community. Research is needed on better diagnostic criteria or tests to separate malaria from pneumonia, which are simple enough to be handled by primary-level health staff and community based health workers.
- No child health programmes will be introduced in vacuum and their compatibility with pre-existing belief models will determine the success of diffusion and acceptance. Malaria and ARI management recommendations therefore need to be carefully adapted to match with communities' perceptions and traditions.
- Improving access to medicines in the community may involve drug misuse and resistance development, both for antimalarials and antibiotics. However, these drugs are already widely used in communities, even without official sanction. While adequately trained, supported and supervised CHWs have the potential to improve the use of medicines, as well as reduce child mortality, such strategies should not only be evaluated for mortality impact, but also for the long-term effects on antibiotic and antimalarial drug resistance.
- The technical knowledge on interventions that can achieve the child health millennium development goal (MDG) exist, but health systems research is needed on delivery mechanisms which can maximise coverage, empower women and reach the most poor. To give direction, a reinforced child survival agenda needs to be developed by a multidisciplinary team consisting of players from NGOs, private and public sectors.

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APPENDICES

Appendix 1 - Interview questionnaire (IV)

1. IDENTIFICATION

TODAY'S DATE (DD/MM/YY): ___ / ___ / 2004		INTERVIEW STARTING TIME ___:___
SUB-COUNTY: _____		PARISH _____ LC1 _____
NAME OF RESPONDENT _____		
REFERRED BY DRUG DISTRIBUTOR IN LC1 _____		
DATE OF VISIT TO DRUG DISTRIBUTOR (DD/MM/YY): ___ / ___ / ___ (check the DD record form)		
RELATIONSHIP OF RESPONDENT TO REFERRED CHILD:		
(1) Mother [] (2) Father [] (3) Grandmother []		
(4) Brother/Sister [] (5) Mother/father in law [] (6) Other (specify) _____		
SEX OF RESPONDENT: (1) Male [] (2) Female []		
TRIBE: (1) Mukonzo [] (2) Mutoro [] (3) Other (Specify) _____		
CHILD'S NAME _____		
SEX: (1) Male [] (2) Female []		
AGE IN YEARS [] AGE IN MONTHS []		
BIRTH ORDER: 1 ST Born [] 2 ND Born [] 3 RD Born [] 4 TH Born [] Other: _____		
1	How old were you at your last birthday? RECORD age in complete years	AGE IN YEARS _____ WRITE 98 if age not known
2	Are you married, divorced, widowed or separated?	NEVER MARRIED 1 MARRIED CURRENTLY 2 WIDOWED 3 DIVORCED/SEPARATED 4
3	What type of marriage are you in	MONOGAMOUS 1 POLYGAMOUS 2
4	Have you ever attended school?	YES 1 NO 2 IF "NO" → GO TO 7
5	What is the highest level of school you attended?	PRIMARY 1 SECONDARY 2 TERTIARY 3
6	What level of schooling have you completed: NONE=0 P7 = 7 P1= 1 S1/P8 = 8 P2 = 2 S2/J1 = 9 P3 = 3 S3/J2 = 10 P4 = 4 S4/J3 = 11 P5 = 5 S5 = 12 P6 = 6 S6 = 13	HIGHEST GRADE (CODES AT LEFT) YEARS OF TECHNICAL TRAINING YEARS OF UNIVERSITY OR PROF SCHOOL [] OTHER: _____
7	What is the highest level of schooling that your partner completed? NONE=0 P7 = 7 P1= 1 S1/P8 = 8 P2 = 2 S2/J1 = 9 P3 = 3 S3/J2 = 10 P4 = 4 S4/J3 = 11 P5 = 5 S5 = 12 P6 = 6 S6 = 13	HIGHEST GRADE (CODES AT LEFT) YEARS OF TECHNICAL TRAINING YEARS OF UNIVERVITY OR PROF SCHOOL [] OTHER: _____ DON'T KNOW []
8	What is your partner's occupation? That is, what kind of work does he/she mainly do?	PEASANT FARMER 1 SHOP KEEPER 2 UNSKILLED LABOURER 3 PROFESSIONAL 4 CLERICAL 5 MANAGEMENT 6 COMMERCIAL FARMING 7 TECHNICAL 8 OTHER (Specify): _____
9	What is your occupation? That is, what kind of work did you do mainly do?	PEASANT FARMER 1 SHOP KEEPER 2

		UNSKILLED LABOURER.....3 PROFESSIONAL.....4 CLERICAL.....5 MANAGEMENT.....6 COMMERCIAL FARMING.....7 TECHNICAL.....8 OTHER (Specify):
10	How many people live permanently in this house	NUMBER OF PEOPLE: _____
11	How many children less than five years are living permanently in this household	NUMBER OF CHILDREN _____

SECTION 4. REFERRAL ILLNESS EPISODE

12	Who takes care of <<CHILD'S NAME>> most of the time?	MOTHER.....1 FATHER.....2 OLDER CHILD.....3 GRAND PARENTS.....4 NEIGHBOUR/FRIEND.....5 MAID.....6 NURSERY SCHOOL.....7 DAY CARE CENTRE.....8 OTHER (Specify):
13	TELL THE CARETAKER: I WOULD LIKE TO ASK YOU QUESTIONS ABOUT THE LAST TIME YOU WENT TO THE DRUG DISTRIBUTOR WITH (CHILD'S NAME) What was the problem with your child that made you go to the drug distributor?	SPECIFY IN LOCAL LANGUAGE: _____ _____ _____
14	What were the symptoms that made you realize that the child had this problem? How long had the child had these symptoms? READ EACH SYMPTOM ON THE LIST TO THE CARETAKER	Days FEVER/HOT BODY (OMUBIRI ERIGHUHANA).....[] DIARRHOEA (OLHUTURUKO) [] CONVULSIONS (ERIKANGARARA)[] COUGH (EKIKUBA).....[] DIFFICULT BREATHING (AKAHAYIRA).....[] FAST BREATHING ERIHUMULHA LHUBALHUBA.....[] PNEUOMONIA(ERIKENYERA)_[] LETHARGY (ERITSEKA).....[] NOT EAT/DRINK (SYALHIRYA/NERINYWA).....[] VOMITING (ERISALHA).....[] NOT PLAYING (SYALISATA).....[] OTHER (Specify): []
15	Did you treat the child before going to the Drug Distributor?	YES.....1 NO.....2 IF "NO" → GO TO 17
16	From where did you get the treatment? PROBE BY ASKING 'ANYTHING ELSE'?	GAVE WESTERN TREATMENT KEPT AT HOME.....1 GAVE HERBAL TREATMENT AT HOME.....2 DRUG SHOP.....3 HOSPITAL.....4 HEALTH CENTRE/DISPENSARY.....5 TRADITIONAL HEALER.....6 OTHER (Specify):
17	What did the Drug Distributor do?	_____ _____
18	Did the Drug Distributor tell you that you might have to take the child to a health centre or hospital?	YES.....1 NO.....2 DON'T REMEMBER.....3 IF "NO" OR "DON'T REMEMBER" →

		GO TO 20
19	How soon did the Drug Distributor tell you to go there? PROBE caretaker by reading list	IMMEDIATELY OR SAME DAY.....1 FOLLOWING DAY.....2 IF THE CHILD GETS SICKER/NOT IMPROVE.....3 DIDN'T SPECIFY.....4 DON'T REMEMBER.....5 OTHER (specify):..... IF "IMMEDIATELY OR SAME DAY" → GO TO 27
20	Did the Drug Distributor come to see you in your home after you visited him/her?	YES.....1 NO.....2 IF "NO" → GO TO 31
21	How long after you visited the Drug Distributor did he/she come to check on you?	DAYS:.....
22	How was the health of your child when the Drug Distributor came to check on you?	WELL.....1 STILL ILL.....2 DEAD.....3
23	When the Drug Distributor came to check on you, did he/she tell you that you needed to go to a health centre/hospital?	YES.....1 NO.....2 OTHER (specify):..... IF "NO" → GO TO 31
24	What additional symptoms did your child have when the Drug Distributor told you to go to the health centre/hospital?
25	How soon did he/she tell you to go to a health centre/hospital?	IMMEDIATELY OR SAME DAY.....1 FOLLOWING DAY.....2 IF THE CHILD GETS SICKER/NOT IMPROVE.....3 DIDN'T SPECIFY.....4 DON'T REMEMBER.....5 OTHER (specify):.....
26	Did you manage to go there?	YES.....1 NO.....2 IF "YES" → GO TO 33 IF "NO" → GO TO 28
27	Did you manage to go there?	YES.....1 NO.....2 IF "YES" → GO TO 32
28	What prevented you from taking the child to the health centre/hospital? PROBE by asking "ANYTHING ELSE"?	TRANSPORT COSTS.....1 LACK OF TRANSPORT.....2 FEES FOR SERVICES AND/OR DRUGS..... CHILD IMPROVED.....4 NEED PERMISSION FROM HUSBAND.....5 WEATHER.....6 DISTANCE TO HEALTH CENTRE.....7 LONG WAITING TIMES.....8 OTHER (specify):.....
29	Ask caretaker to give the story what prevented her from going to the health centre/hospital
30	What did you do instead and why?	GO TO → 43
31	Where did you take the child?	HEALTH CENTRE (specify which):..... HOSPITAL (specify which):..... OTHER (specify where):.....
32	After how many days after visiting the Drug Distributor did you take the child to the health centre/hospital?	SAME DAY.....1 NEXT DAY.....2 AFTER TWO DAYS.....3 MORE THAN TWO DAYS.....4 OTHER (specify):..... IF "SAME DAY" OR "NEXT DAY" →

		GO TO 36 IF “AFTER TWO DAYS” OR “MORE THAN TWO DAYS” → GO TO 34
33	After how many days after having been visited by the Drug Distributor did you take the child to the health centre/hospital?	SAME DAY.....1 NEXT DAY.....2 AFTER TWO DAYS.....3 MORE THAN TWO DAYS.....4 OTHER (specify): IF “SAME DAY” OR “NEXT DAY” GO TO → 36
34	Why did you delay to go?	WAITED TO COMPLETE HOMAPAK DOSAGE.....1 CHILD IMPROVED.....2 NEEDED TO FIND MONEY.....3 LACK OF TRANSPORT.....4 NEEDED PERMISSION FROM HUSBAND.....5 OTHER (specify):
35	After you delayed to go, why did you decide to go?	_____
36	What transport did you use to get there? CIRCLE all that apply	BUS/MATATU.....1 WALKED.....2 AMBULANCE/FACILITY VEHICLE...3 MOTORBIKE.....4 TAXI.....5 PRIVATE CAR.....6 BICYCLE.....7 OTHER (specify):
37	How far is this place from your home in walking distance?	MINUTES: _____ DAYS: _____ HOURS: _____
38	How much money did you spend to go to the health facility and back? PROBE caretaker by reading list	TRANSPORTATION: _____ Ush LODGING/FOOD: _____ Ush MEDICAL CONSULTATION/ADMISSION _____ Ush DRUGS: _____ Ush OTHER (specify): _____ Ush
39	From where did you get this money?	
40	How easy was it to gather this money? PROBE caretaker by reading list	EASY.....1 WITH DIFFICULTY.....2 WITH A LOT OF DIFFICULTY.....3
41	How much time did you spend waiting before being seen by the health worker?	MINUTES: _____ HOURS: _____
42	What did the health worker say was wrong with your child?	SPECIFY IN LOCAL LANGUAGE:
43	How is the health of your child now?	WELL.....1 STILL ILL.....2 DEAD.....3 IF “WELL” OR “DEAD” → GO TO 47
44	If <<CHILD>> is still sick, what actions will you take?	_____
45	In your opinion, how could the work done by the Drug Distributors be improved in your community? Probe for views on cases that need referral	_____

SECTION 5. HOUSEHOLD ASSETS		
46	What type of house do you live in? NOTE the type of house	INDEPENDENT HOUSE.....1 MUZIGO.....2 SHARED HOUSE.....3 BOYS QUARTER.....4 HUT.....5 UNIPOINT.....6 OTHER(specify):
47	Is your house: READ ALTERNATIVES FROM THE LIST	OWNED BY SOMEONE IN YOUR HOUSEHOLD.....1 RENTED (NORMAL).....2 RENTED (SUBSIDISED).....3 SUPPLIED BY EMPLOYER.....4 PAID BY SOMEONE ELSE.....5 OTHER (specify):
48	How many rooms do you have in this home? RECORD NUMBER, include rooms in other structures on property	NUMBER OF ROOMS _____
49	Note main type of material for the roof RECORD most permanent	GRASS THATCHED/BAMBOO.....1 TIN.....2 IRON SHEETS.....3 ASBESTOS.....4 TILES.....5 CEMENT/CONCRETE.....6 OTHER (Specify):
50	Note main type of material for the walls <u>Record most permanent</u>	MUD AND POLES.....1 BURNT BRICKS W/MUD.....2 BURNT BRICKS W/CEMENT.....3 UNBURNT BRICKS.....4 TIMBER/WOOD.....5 GRASS/BAMBOO.....6 CEMENT BLOCKS.....7 STONE W/CEMENT.....8 OTHER (Specify):
51	Note main type of floor material	EARTH.....1 CEMENT.....2 EARTH AND COW DUNG.....3 BRICKS.....4 WOOD.....5 MOSAIC/TILES.....6 STONE.....7 OTHER (Specify):
52	How many of the following items are owned by members of your household? Regardless of whether the item is on the premise.	PANGA.....1 HOE.....2 GRINDING MILL.....3 RADIO WITH CASSETTE PLAYER.....4 RADIO WITHOUT CASSETTE PLAYER.....5 MOTORCYCLE/LORRY/TRACTOR.....6 WORKING BICYCLE.....7 MOBILE PHONE.....8

SECTION 6: HEALTH CENTRE/HOSPITAL RECORD CONFIRMATION

<p>CHECK IF THE CHILD WAS SAID TO HAVE COMPLETED REFERRAL (Q. 27)</p> <p>IF “YES”, go to the health unit where the child was said to have been referred and look for the child’s name in the records.</p> <p>COULD THE CHILD BE FOUND IN THE HEALTH CENTRE/HOSPITAL RECORDS?</p>	<p>YES.....1</p> <p>DATE (mm/dd): _____</p> <p>DIAGNOSIS (specify): _____</p> <p>TREATMENT (specify): _____</p> <p>OTHER: _____</p> <p>NO2</p>
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Appendix 2 - Themes for FGDs (II)

Recognition of fever (Hot body, loss of appetite, general body weakness, vomiting, joint pain, head ache) and difficulties in breathing (fast breathing, painful breathing, fever)

What illnesses are common in your children under five?

Lets now talk about fever illness. How do you know when your child has fever?

Lets now talk about fever, which has hot body. How would you know if a child has this problem? (if not suggested in question two, please bring it up)

Are there occasions when a child also has problems with fast or difficult breathing? (if not suggested in question three, please bring it up)

Labelling of illness:

Which diseases are associated with a hot body in children?

How can you tell when this child has hot body due to malaria?

How can you tell when this child has hot body due to chest problem?

When a child has fever illness. Which signs indicate severe illness?

Concept of fever in children and how it is managed

What is the first thing you do when a child is noticed to have illness with a hot body?

Suppose the child also has a problem with the breathing or chest. What do you do?

What medicines are usually given in the home for a child who has an illness with hot body?

What about when the child also has a problem with breathing or in the chest?

Where do you get the medicine used at home to treat fever with hot body?

When to start treatment

What signs or symptoms would prompt you to start giving medicine to a child with hot body illness? (Probe for problem with breathing also)

Who decides when to start giving medications when the child has a hot body?

Is delay in treating sick children with fever illness a common problem in your community? If yes then why? (Probe for illness labelling and interpretation of disease severity also)

Making decision on treatment of sick children, mothers role and other household members role

Who is consulted when a child falls ill in a home? Why?

Who decides on the kind of treatment to be given to a young child with hot body? Why?

What about if a child has fast or difficult breathing? Who decides that the child should be treated?

Who decides where a young child with hot body should be treated? Why?

What about if a child has fast or difficult breathing?

Does a mother make decisions on how to treat a child who is ill? If yes, in what situations can the mother of the child decide how to treat her sick child? (Probe also for when and where)

Community reaction to the idea of treating fever at community level using pre-packed drugs

[Show the two Homapak packs and explain that this will in future be distributed to mothers for treating fever in children at home. The red pack is for younger children whereas the green

one is for older ones. It contains two combination drugs. Show free tablets unpacked tablets which are currently in use to the respondent]

What is your opinion about packaging the drugs like this for use at home (probe for ease of use by mothers, understanding how to give the drugs)?

In your opinion, who should distribute these drugs?

Which one would you prefer to use? Why?

What is your opinion on strengthening the treating hot body in the home first?

Now let us talk about cough illness and breathing problem

What symptoms would make you seek treatment for cough outside the home?

When a child has cough illness, which signs indicate severe illness?

Appendix 3 - Themes for FGDs (V)

“Sometimes when children are sick they have difficulty in breathing because they have a blocked nose. But sometimes the problem is in the chest [show location]. I would like to find out what words to use to talk about breathing problems in the chest”.

What are the common breathing problems that children can suffer from?

Do the terms mean different types of breathing problems or do they mean the same illness?

Ask if the participants are familiar with the following terms in case they have not been mentioned: Eryikenyera, Ekyihumweyo, Obukoni, Omuka orifunda omwa kyikuba, Akahahayira, Erihumayira, Erihihira, Erihumulha lhubalhuba

Do any of these terms mean the same thing?

What is the difference between [first word] and [second word]?

If there is no difference

So, if a child is having trouble breathing because of a problem in the chest, I can say either or , is that correct?

You also said [third word]. Is there any difference between [third word] and [first word] and [second word]?

Is there a difference in the severity of the mentioned terms?

When a child has [breathing term 1], is there usually anything else wrong that you can see or feel? What about [breathing term 2, 3, 4 etc]

When a child has a chest problem with difficult breathing, which of signs indicate severe illness?

Ask about each breathing term used:

Now, for [breathing term], what do you think is the name of the illness causing the problem?

- What is the cause of the illness?
- How soon do you need to treat such an illness?
- What drugs do you use?
- Would you use Homapak to treat this illness? Herbs?
- Would you take this child to a Drug Distributor? Traditional healer?
- Is treatment different from [other breathing terms]?

Show video

What do you think is wrong with this child?

What signs and symptoms do you easily see that the child has?

What do you call this illness?

If the do NOT mention the breathing, ask:

- Can you see anything peculiar about the breathing?
- If the child also had fever, would you call it something else?
- If this child also had diarrhoea, would you call it something else?
- Do you find children with this problem here?
- What would you do in case you had such a child?
- Where would you take this child and why?

Appendix 4 - IMCI recording form (I)

MANAGEMENT OF THE SICK CHILD AGE 2 MONTHS UP TO 5 YEARS

Name: _____ Age: _____ Weight: _____ kg Temperature: _____ °C

ASK: What are the child's problems? _____ Initial Visit? ___ Follow-up Visit? ___

ASSESS (Circle all signs present)

CLASSIFY

<p>CHECK FOR GENERAL DANGER SIGNS NOT ABLE TO DRINK OR BREASTFEED LETHARGIC OR UNCONSCIOUS VOMITS EVERYTHING CONVULSIONS</p>	<p>General danger sign present? Yes ___ No ___ Remember to use danger sign when selecting classifications</p>
<p>DOES THE CHILD HAVE COUGH OR DIFFICULT BREATHING? Yes ___ No ___ • For how long? ___ Days • Count the breaths in one minute, ___ breaths per minute. Fast breathing? • Look for chest indrawing • Look and listen for stridor</p>	
<p>DOES THE CHILD HAVE DIARRHOEA? Yes ___ No ___ • For how long? ___ Days • Is there blood in the stool? • Look at the child's general condition. Is the child: Lethargic or unconscious? Restless and irritable? • Look for sunken eyes • Offer the child fluid. Is the child: Not able to drink or drinking poorly? Drinking eagerly, thirsty? • Pinch the skin of the abdomen. Does it go back: Very slowly (longer than 2 seconds)? Slowly?</p>	
<p>DOES THE CHILD HAVE FEVER? (by history/feels hot/temperature 37.5°C or above) Yes ___ No ___ Decide Malaria Risk: High Low • For how long? ___ Days • If more than 7 days, has fever been present every day? • Has child had measles within the last 3 months? • Look or feel for stiff neck • Look for runny nose Look for signs of MEASLES: • Generalized rash and • One of these: cough, runny nose, or red eyes.</p>	
<p>If the child has measles now or within the last 3 months: • Look for mouth ulcers If Yes, are they deep and extensive? • Look for pus draining from the eye • Look for clouding of the cornea.</p>	
<p>DOES THE CHILD HAVE AN EAR PROBLEM? Yes ___ No ___ • Is there ear pain? • Is there ear discharge? If Yes, for how long? ___ Days • Look for pus draining from the ear • Feel for tender swelling behind the ear</p>	
<p>THEN CHECK FOR MALNUTRITION AND ANAEMIA • Look for visible severe wasting • Look for palmar pallor Severe palmar pallor? Some palmar pallor? • Look for oedema of both feet • Determine weight for age Very Low ___ Not Very Low ___</p>	
<p>CHECK THE CHILD'S IMMUNIZATION STATUS Circle immunizations needed today BCG DPT 1 DPT 2 DPT 3 OPV 0 OPV 1 OPV 2 OPV 3 Measles</p>	<p>Return for next immunization on: _____ (Date)</p>
<p>ASSESS CHILD'S FEEDING if child has ANAEMIA OR VERY LOW WEIGHT or is less than 2 years old. • Do you breastfeed your child? Yes ___ No ___ If Yes, how many times in 24 hours? ___ times Do you breastfeed during the night? Yes ___ No ___ • Does the child take any other food or fluids? Yes ___ No ___ If Yes, what food or fluids? _____ _____ How many times per day? ___ times What do you use to feed the child? _____ If very low weight for age: How large are servings? _____ Does the child receive his own serving? ___ Who feeds the child and how? _____ • During this illness, has the child's feeding changed? Yes ___ No ___ If Yes, how?</p>	

ASSESS OTHER PROBLEMS: