LOCAL UNDERSTANDING AND PRACTICES RELATED TO IMCI INTERVENTIONS IN EASTERN TANZANIA

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Prof. Dr. Tanner

Dedicated to

MY WIFE, CALISTER MAYOMBANA

AND

MY CHILDREN JULLIET AND JONSTON MAYOMBANA

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Abbreviations

BOD	Burden of Disease
CHMT	Council Health Management Team
DMO	District Medical Officer
DSS	Demographic Surveillance System
EHIs	Essential Health Interventions
IDRC	International Development Research Centre (Canada)
IEC	Information Education Communication
IHRDC	Ifakara Health Research and Development Centre
IMCI	Integrated Management of Childhood Illnesses
ITNs	Insecticide Treated Nets
KINET	Kilombero and Ulanga Treated Net Project
NGO	Non-Government Organization
TEHIP	Tanzania Essential Health Interventions Project
WDR	World Development Report
WHO	World Health Organization

Glossary

Household An aggregate of persons, generally but not necessarily bound by ties of kinship, which live together under the same roof and eat together or share in common the household food. Members comprise the head of the household, relatives living with him, and other persons who share the community life for reasons of work or other consideration. A person who lives alone is considered a separate household. (National Statistics Office)

Modern care/western medicine Scientific or cosmopolitan medicine refers to the medicine developed by in the western world since the Enlightenment. It starts from the Cartesian dichotomy of body and mind and is characterized by understanding of disease as a fundamentally biological process

Illness A condition of poor health perceived or felt by an individual and interpreted by the social group

Traditional/folk medicine/care The WHO has delineated a working definition of traditional medicine as "including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal, and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness"

Treatment/care-seeking Refers to a process followed by individuals and/or social group for restoring health by using medical resources of all kinds

Self treatmentPerformance of activities or tasks to take care of oneself or one's family and friends during illness.

Folk medicineIs the collection of procedures traditionally used for treatment of illness and injury, aid to childbirth, and maintanance of wellness. Folk medicine is sometimes associated with quackery, and sometimes with witchcraft or shamanism, yet it may also preserve important knowledge from the past. Folk illnesses are those related to the treatment procedures

Herbal medicine Is an aspect of folk medicine - the use of gathered plant parts to make teas, poultices, or powders that purportedly effect cures. Modern medicine has tended to regard herbal medicine negatively, but in recent times has discovered that some of the herbalists' cures were effective.

Uchawi/Sorcery The belief in magical spells that harness occult forces or evil spirits to produce unnatural effects in the world.

Summary

This PhD thesis presents findings of the health seeking component of the Tanzania Essential Health Intervention Project (TEHIP). It was carried out from 1998 to 2001 in two districts of southern Tanzania where Integrated Management of Childhood Illness (IMCI) was introduced in 1997. The rationale is that best IMCI services are of little benefit, if they do not reach community and household levels. Caregivers need to understand and comply with IMCI core principles, i.e. learn to recognize the correct danger signs and seek prompt and effective treatment.

The goal of our study was to contribute to increasing "community effectiveness" (Tanner et al. 1993) of health care in the study districts. Our specific objectives were to generate local knowledge to better adjust the IMCI interventions to local health seeking behavior and to improve the ways in which caretakers identify and manage common childhood illness.

We define health seeking to encompass three dimensions: 1) health concepts including signs and symptoms recognized by the community; 2) aetiology comprising interpretations and explanations of illness; and 3) help seeking referring to home management and all forms of seeking help from experts, whether these are neighbors, traditional healers or health care staff.

We first investigated the local illness terminology and the relative importance of symptom recognition and labeling in care-seeking. We found that local illness terms overlap with biomedical classifications such as "malaria", but this overlap does not constitute direct correspondence. Caregivers rarely see a link between

malaria and convulsions and create new links between convulsions and polio, tetanus and epilepsy. We identified intra-cultural diversity in symptom recognition and severity ranking of the same illness. Caregivers search for illness labels which are not only a name but contain information about treatment. In this search they face difficulties due to two reasons: 1) different illnesses produce similar symptoms, and 2) different persons provide changing and even contradictory advice and information. We introduce the term “fuzzy concept” and suggest that fuzziness can be explained by the diverse manifestations of malaria, by intra-cultural variability and/or by culture change confronting individual persons with multiple meanings.

In a second step we analyze local aetiologies which we consider equally important for appropriate care-seeking as prompt recognition of danger signs and symptoms. Community aetiologies of IMCI related illness encompass a wide spectrum ranging from natural to supernatural causes. Some caregivers act on these notions, others are not interested in causes, and the majority remains ambivalent and pragmatic. A closer analysis of malaria-related aetiology shows that caregivers clearly attribute *malaria* to mosquito bites but have fragmented knowledge about the aetiology of *homa* (fever) and *degedege* (convulsions). We suggest that aetiological uncertainty leads to difficulties in therapy choice and thus to pragmatic ambivalence.

In a third step we assess care-seeking in actual illness episodes. Caregivers make extensive use of formal health care facilities, not only for *homa* and *malaria* but for most other IMCI related illnesses. Exceptions are the folk illnesses *degedege* and *kimeo* (elongated uvula). The basic distinction found in many parts of Africa also applies to our study sites: 1) mild and “normal” malaria is first treated at home and if not cured brought to a formal health care facility; 2) severe forms of the disease presenting convulsions are rarely considered as malaria but as a distinct illness entity requiring traditional treatment at home or from a traditional healer. Our most important finding is that many children who suffer and sometimes even die from convulsions have had not only a history of *homa*

but have even been diagnosed and treated for malaria in a health facility before they developed convulsions.

In the fourth and final step we examine the impact of malaria care-seeking patterns on childhood mortality. Our findings show that nearly 80 percent of malaria-attributable deaths used modern biomedical care as a first resort, both in the form of antimalarial pharmaceuticals from shops or formal health care services. If care was sought more than once in these fatal cases, modern care was included in the first or second resort in 90 percent with convulsions and 99 percent without convulsions.

There clearly is an urgent need for a thorough analysis of what is happening in these cases. Health providers often formulate the problem of recurrent illness in terms of a delay in treatment or a lack of adherence to treatment regimes. We argue that victim blaming does not bring us any further. Our case studies demonstrate that many mothers make an enormous effort in time, energy and money searching for the best care for their child. They should be supported rather than blamed by the health system.

Zusammenfassung

Diese Dissertation stellt die Ergebnisse der Komponente „Gesundheitsverhalten" des Tanzania Essential Health Intervention Project (TEHIP) vor. Sie wurde in zwei Distrikten im südlichen Tansania durchgeführt, in denen das Programm *Integrated Management of Childhood Illness (IMCI)* 1996 eingeführt worden war. Der Leitgedanke war, dass die besten IMCI Dienste von geringem Nutzen sind, wenn sie die Gemeinde- und Haushaltsebenen nicht erreichen. Die für die Pflege kranker Kinder verantwortlichen Personen, meist Mütter, müssen die wichtigsten Prinzipien von IMCI verstehen und befolgen: nämlich die richtigen Gefahrenzeichen und -symptome für erkennen und umgehend eine effektive Therapie aufsuchen.

Das Oberziel unserer Studie ist es, zur Erhöhung der "community effectiveness" (Tanner et al. 1993) von Gesundheitsdiensten in den untersuchten Distrikten beizutragen. Die spezifischen Ziele sind, erstens die IMCI Interventionen besser an das lokale Gesundheitsverhalten anzupassen und zweitens die Art und Weise, wie Mütter die wichtigsten Kinderkrankheiten erkennen und behandeln,zu verbessern.

Gemäss unserer Definition umfasst Gesundheitsverhalten drei Dimensionen: 1) die Gesundheitskonzepte, die in der Gemeinschaft anerkannte Zeichen und Symptome beinhalten; 2) die Ätiologie, das heisst Interpretationen und Erklärungen von Kranksein; und 3) die Suche nach Hilfe, die sowohl Krankheitsmanagement zu Hause als auch alle Formen von Behandlung einschliesst, seien dies Nachbarn, traditionelle Heiler oder Mitarbeiter der Gesundheitsdienste.

Wir haben in einem ersten Schritt die einheimische Krankheitsterminologie sowie die relative Wichtigkeit von Symptomerkennung und –bezeichnung für die

Therapiewahl untersucht. Wir stellten fest, dass lokale Krankheitstermini sich mit biomedizinischen Klassifikationen wie Malaria überschneiden, diese Überschneidungen aber keine direkte Übereinstimmung darstellen. Mütter sehen selten eine Verbindung zwischen Malaria und Fieberkrämpfen, sondern stellen neue konzeptuelle Verbindungen zwischen Fieberkrämpfen und Polio, Tetanus und Epilepsie her. Ferner fanden wir bezüglich derselben Krankheit eine intra-kulturelle Diversität in der Symptomerkennung und der Bestimmung des Schweregrades. Mütter suchen nach Krankheitsbezeichnungen, die für sie nicht nur Namen sind, sondern Informationen über Therapien darstellen. Bei dieser Suche stossen sie auf zwei Schwierigkeiten: 1) unterschiedliche Krankheiten rufen ähnliche Symptome hervor. 2) Verschiedene Personen geben unterschiedliche oder sogar widersprüchliche Ratschläge und Informationen. Wir führen deshalb den Begriff “fuzzy concept” ein und schlagen vor, “fuzziness” durch unterschiedliche Manifestationen von Malaria, intra-kulturelle Variabilität und/oder den Kulturwandel zu erklären, welcher Individuen mit vielfältigen Bedeutungen konfrontiert.

In einem zweiten Schritt analysierten wir lokale Ätiologien, die wir als ebenso bedeutend wie die Symptomerkennung für die Suche nach der korrekten Therapie betrachten. Die Ätiologien von IMCI-verwandten Krankheiten umfassen ein breites, von natürlichen bis hin zu übernatürlichen Ursachen reichendes Spektrum. Einige Mütter lassen sich von den Vorstellungen zur Ätiologie leiten, andere interessieren sich nicht für Ursachen, die Mehrheit aber bleibt ambivalent und pragmatisch. Eine genauere Analyse von Malaria-bezogenen Ätiologien zeigt, dass Mütter Malaria klar Moskitos zuschreiben, jedoch fragmentiertes Wissen bezüglich der Ursachen von homa (Fieber) und degedege (Fieberkämpfe) haben. Diese ätiologische Unsicherheit führt zu Schwierigkeiten in der Therapiewahl und somit zu pragmatischer Ambivalenz.

In einem dritten Schritt beurteilten wir die Suche nach Behandlung in konkreten Krankheitsfällen. Mütter nutzen das formelle Gesundheitsangebot nicht nur für *homa* und *malaria* ausgiebig, sondern für die meisten IMCI-bezogenen Krankheiten. Ausnahmen bilden die so genannten Volkskrankheiten *degedege*

und *kimeo* (verlängerte Uvula). Auf eine grundlegende Unterscheidung, die in vielen Teilen Afrikas vorkommt, trifft man auch in unserem Untersuchungsgebiet: 1) Fälle von milder Malaria werden in einem ersten Schritt zuhause behandelt und erst wenn sie nicht geheilt werden können, in formelle Gesundheitszentren gebracht; 2) schwere Fälle der Krankheit mit Fieberkrämpfen werden selten als Malaria eingestuft, sondern als eine unterscheidbare, eigene Krankheit betrachtet. Diese verlangen nach traditioneller Behandlung zuhause oder bei einem Heiler. Unser wichtigstes Ergebnis zeigt, dass viele Kinder, die Fieberkrämpfe erleiden und manchmal gar daran sterben, vorher aber bereits eine längere Krankengeschichte mit *homa* haben und sogar in einem Krankheitszentrum Malaria diagnostiziert und behandelt wurden.

Im vierten und letzten Schritt untersuchten wir, wie sich unterschiedliche Muster von Behandlungssuche auf die Mortalität der Kinder auswirken. Unsere Ergebnisse zeigen, dass fast 80 Prozent der an Malaria Verstorbenen, moderne Medizin als erste Anlaufstelle nutzten. Entweder wurden den Kindern in den Geschäften Anti-Malariamedikamente gekauft oder die Mütter brachten sie zu formellen Gesundheitsdiensten. Wurde in diesen tödlich verlaufenen Fällen mehr als eine Option genutzt, war die moderne Medizin die erste oder zweite Anlaufstelle in 90 Prozent der Fälle mit, und in 99 Prozent der Fälle ohne Fieberkrämpfe.

Eine eingehende Analyse zur Erklärung dieser Fakten ist daher dringend erforderlich. Gesundheitsanbieter formulieren das Problem wiederkehrender Fieber oft durch einen verspäteten Arztbesuch oder der Nichtbefolgung ihrer Anweisungen bezüglich der Nachbehandlung. Wir halten dem entgegen, dass die Beschuldigung der Betroffenen nicht förderlich ist. Unsere Fallbeispiele zeigen, dass viele Mütter auf der Suche nach der besten Behandlung einen grossen Zeit-, Energie- und Geldaufwand leisten. Das Gesundheitspersonal sollte sie darin unterstützen, nicht mit Anschuldigungen zusätzlich belasten.

Unsere Schlussfolgerung lautet, dass zusätzlich zur Verbesserung des

Krankheitsmanagements zu Hause die wichtigste Herausforderung weiterhin darin besteht, die „community effectiveness“ der modernen Gesundheitsdienste zu stärken. In diesem Prozess sollten Frauen ermutigt, unterstützt und befähigt werden, ihre pragmatische Ambivalenz zu reduzieren. Sie sollten ein besseres Verständnis für qualitativ hochstehende Behandlungen auf allen Ebenen entwickeln können. Dies erlaubt ihnen, eine informierte Wahl zu treffen und die besten zur Verfügung stehenden Optionen effektiv zu nutzen.

1. Introduction

Real progress in health is not just a question of wealth but also of political will and concerted efforts to build stronger health systems based on primary health care. Core principles of primary health care, first formulated in the 1978 Declaration of Alma Ata, encompass universal access and coverage on the basis of need, health equity as part of development oriented to social justice, community participation in defining and implementing health agendas, and inter-sectoral approaches. Although these principles have to be continuously reinterpreted and adjusted with reference to changes in the health field and broader environmental, economic, political and social contexts they remain valid (World Health Report 2003).

1.1 The Tanzania Essential Health Intervention Project (TEHIP)

It is against this background and especially inspired by the World Development Report 1993 “Investing in Health” that the Tanzania Essential Health Intervention Project (TEHIP) - of which this study forms part - has been designed and implemented. TEHIP is a demonstration project on district level which includes both development and research dimensions. It examined the feasibility of institutionalizing a more evidence-based approach to health planning at district level. TEHIP has been funded from Canada and has been conducted from 1997 to 2001 in Morogoro Rural and Rufiji Districts (see Map 1) in cooperation with the Tanzanian Ministry of Health (TEHIP 1996, de Saviginy et al. 2002).

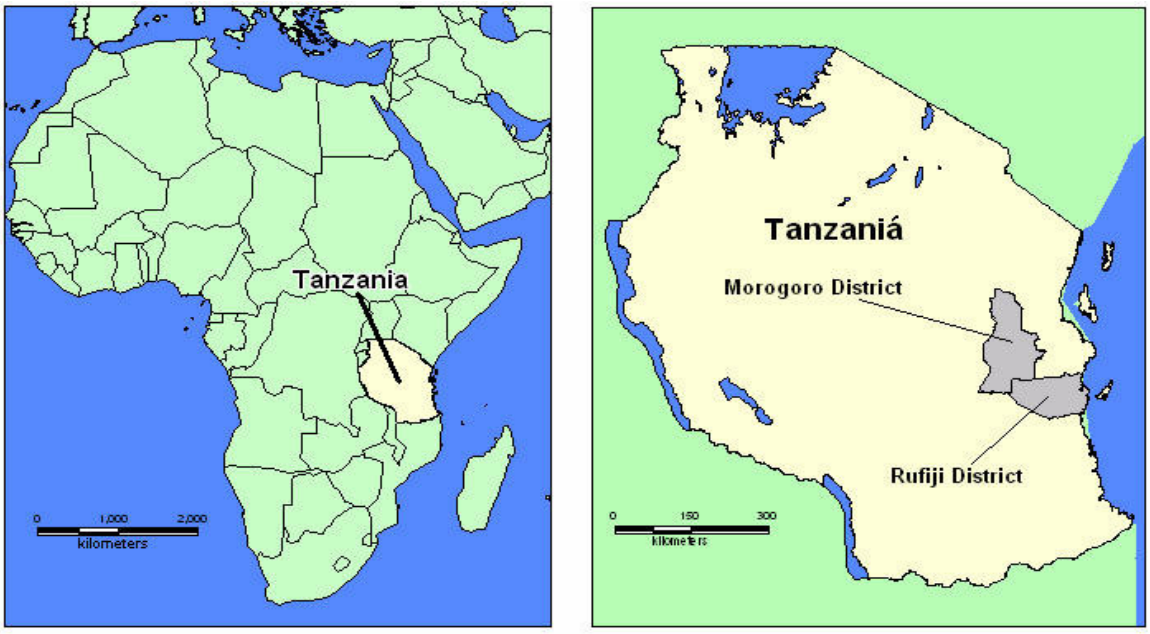

Figure 1. Map of the study area of Morogoro Rural and Rufiji Districts in Tanzania

The conceptual framework bases itself on the premise that the new approach to evidence-based district health planning processes exerts its impact on population health through the interaction between these new processes and the community. It thus focuses on three interlinked domains: 1) health system interventions, 2) community interaction and 3) health impacts. Correspondingly it requires research on three major components:

- District health planning processes
- Household health seeking behavior
- Demographic and epidemiological impact

For a graphic presentation of the conceptual framework of TEHIP see Figure 2.

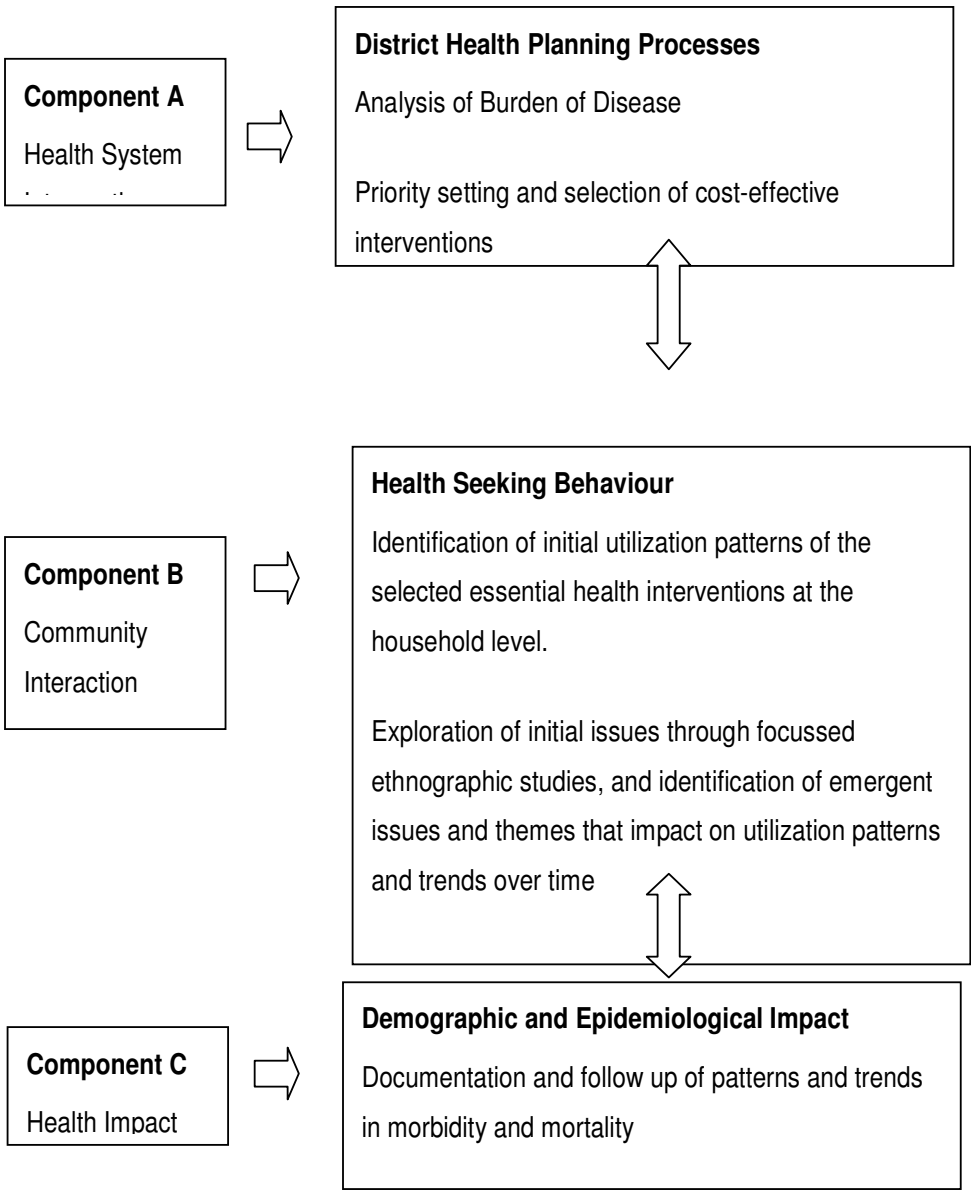

Figure 2. The conceptual framework for TEHIP research

The central idea of this analytical design is that there is an interaction between health system interventions on the district level and health impacts on the population level. Help-seeking behavior of households may influence the nature of district health planning processes and in turn will be affected by district health plans.

This research design is unique in two important and related respects: it not only considers a social science contribution as an integral part of the project from its beginning, it also "moves the wheel" from information, to evidence, knowledge, action and health intervention. The research presented in our study is formative:

it was collected to directly feed the planning and implementation of interventions and to follow the consequences of the plans and interventions on the community and household level.

The basic assumption underlying this design is that health-seeking behavior is key to the success of any intervention. Even if health services are strengthened to provide the best health care possible under given circumstances, these professionals and technologies have little impact, if the local population does not utilize the services. It is on the community and the household level that illness is recognized, interpreted and explained and the seeking of help from experts is initiated. A better understanding of processes on the community and the household level are therefore an integral part “moving the wheel”.

TEHIP decided to monitor change in health development through research focusing on two tracer interventions: Integrated Management of Childhood Illness (IMCI (curative)) and Insecticide Treated Nets (ITN (preventive)). Our study conducted formative research on health-seeking behavior related to both interventions, but in the following chapters, we concentrate on our IMCI related work.

1.2 Integrated Management of Childhood Illness (IMCI)

Every year more than 11 million of children in low- to middle-income countries die before they reach their fifth birthday (Hill et al. 2004). 70% of these deaths are due to malaria, acute respiratory infections such as pneumonia, diarrhea, measles and malnutrition or to a combination of these conditions (WHO/UNICEF 2001). Several prevention and treatment strategies have already proven effective in reducing the burden of disease resulting from these diseases. However, a more integrated approach to managing sick children may contribute to achieving better results.

In response to this problem, the World Health Organization (WHO) in collaboration with the United Children's Fund (UNICEF) and other technical partners developed in the mid-1990s the Integrated Management of Childhood Illness (IMCI) strategy. The strategy includes curative as well as preventive services and addresses children of less than 5 years old as target group, as this age group bears the highest burden of deaths from common childhood diseases. The strategy aims at reducing death and the frequency and severity of illness disability, and at contributing to improved growths and development (Gove 1997, WHO/UNICEF 2001).

As the illnesses mentioned above share many risk factors as well as signs and symptoms, a single diagnosis can be difficult or might not be appropriate. Therefore, instead of addressing single illnesses, the strategy pursues an integrated approach which focuses on the overall health and well-being of the child. Every child is therefore assessed for a set of well-selected clinical signs as well as of symptoms reported by the child's caregiver (WHO/UNICEF 2001, TEHIP 2002).

The strategy includes three main components:

- Improvements in the case-management skills of health staff through the provision of locally-adapted guidelines on integrated management of childhood illness and activities to promote their use.
- Improvements in the overall health system required for effective management of childhood illness.
- Improvements in family and community health care practices.

Cross-cutting the components are three principles which form the core of the IMCI strategy:

- Correct identification of “general danger signs”,
- Routine assessment of other carefully selected clinical signs and symptoms and
- Prompt triage of cases to be treated at the outpatient facility, a referral facility or at home.
- To reach these goals, special guidelines for IMCI training on the health system level have been developed and indicate what actions need to be taken. The guidelines are based on constant underlying principles but need to be adapted when the IMCI is implemented in a country to
- Cover the most serious childhood illnesses typically seen at first-level health facilities;
- Make the guidelines consistent with the national treatment guidelines and other policies;
- Make IMCI implementation feasible through the health system and by families caring for their children at home (WHO/UNICEF 2001).

At several stages of the assessment of sick children, communication with the mother about the child’s problem is critical for effective management. When the child is brought to the outpatient facility, the health staff has to listen carefully to what the caregiver says. Health providers should be able to communicate in a language that the local people can understand, using local words and avoiding medical terminology. Successful communication helps to assure the mother or

caregiver that the child will receive good care. In addition, effective home management depends on how well the mother is informed about danger signs and appropriate treatment. This seems particularly crucial in Africa, where reports suggest that approximately 80 percent of childhood deaths occur at home, many before the child has any contact with a health facility.

Twelve key practices have been identified by UNICEF and WHO to be of crucial importance in providing good home-care for the child (Hill et al. 2004):

- Take children as scheduled to complete full course of immunization.
- Breastfeed infants exclusively for six months.
- Starting at six months of age, feed children freshly prepared energy- and nutrient-rich complementary foods, while continuing to breastfeed up to two years or longer.
- Ensure that children receive adequate amounts of micronutrients, either in their diet or through supplementation.
- Dispose of faeces including children's faces safely, and wash hands after defecation, before preparing meals, and before feeding children.
- Protect children in malaria-endemic areas, by ensuring they sleep under ITN.
- Continue to feed and offer more fluids, including breast milk, to children when they are sick.
- Give sick children appropriate home treatment for infections.
- Recognize when sick children need treatment outside the home and seek care from appropriate providers.
- Follow health workers advice about treatment, follow up and referral.
- Promote mental and social development by responding to a child's needs for care, and through talking, playing and providing a stimulating environment.
- Ensure that every pregnant woman has adequate antenatal care.

IMCI is one of the strategies recommended by the Tanzanian Ministry of Health as the five IMCI target conditions, i.e. malaria, acute respiratory infections such as pneumonia, diarrhea, measles and malnutrition, account for over 70% of the

deaths of children under five years of age. The Tanzanian Ministry of Health started implementing IMCI in 1997 in two pioneer districts, Morogoro Rural and Rufiji Districts with support from TEHIP. The ministry had previously adapted the generic IMCI case management guidelines to reflect national health policies (e.g. first- and second-line treatments for malaria and pneumonia) as well as local terms for illness symptoms and health providers. All material were translated in Swahili and used as the basis for training health workers in a 11-day training (Armstrong Schellenberg et al. 2004, WHO 2001-2004).

The research presented here concentrates on health seeking behavior in response to IMCI diseases in these two pioneer districts. At the centre of interest is the third component of the IMCI strategy, improvements in family and community health care practices, and findings from this level have been continuously fed back to the health system level for further improvements of IMCI training and implementation through health services.

In Tanzania, malaria is endemic. The two study districts are located in an area with stable perennial transmission. Under these circumstances, malaria contributes heavily to the overall disease burden and calls for special attention within the IMCI strategy.

1.3 Malaria

1.3.1 MALARIA AS A WORLDWIDE PROBLEM

Malaria is a life-threatening parasitic disease transmitted by mosquitoes. In Europe, it was once thought that the disease came from fetid marshes, hence the name 'mal aria' (Italian for "bad air"). In 1880, scientists discovered the real cause of malaria – a one-cell parasite called plasmodium. Later, they discovered that the parasite is transmitted from person to person through the bite of a female Anopheles mosquito hence the association with wet lands.

Once also a health threat in Europe, the disease was successfully eliminated from many countries with temperate climates in the mid-20th century. Today, approximately 40 % of the world's population – mostly those living in the world's poorest countries – is still at risk of malaria. The disease remains a leading cause of mortality and morbidity worldwide, especially for pregnant women and children. It causes disease in 300 to 500 million of individuals and results in more than a million deaths each year.

The burden of disease is especially high for sub-Saharan Africa, where at least 90% of malaria deaths occur (Snow et al. 1999, World Bank 2001, WHO/UNICEF 2003). There are several reasons why Africa bears an overwhelming proportion of the malaria burden. This region is the home of the most efficient, and therefore most deadly, species of the mosquitoes that transmit the disease. Most countries in Africa further lacked the infrastructure and resources necessary for sustainable campaigns against malaria; as a result, few benefited from efforts which eradicated malaria elsewhere.

In malaria endemic countries, malaria affects the daily life of families through, significant out-of-pocket resources spent on malaria prevention and cure, reduced schooling because of repeated disease episodes and severe anemia, and reduced work production. Besides the physical suffering, malaria causes retarded physical and cognitive development in children, loss of productivity, depression and increased vulnerability to other diseases.

In Africa today, there is a vicious cycle of disease and poverty: malaria causes poverty, and poverty causes malaria. Together with HIV/AIDS and TB, malaria is

one of the major public health challenges undermining development in the poorest countries of the world (Sachs and Malaney 2002, Murphy et al. 2003a). What makes malaria deaths particularly tragic is that malaria, unlike TB and HIV/AIDS - the other major fatal communicable diseases of Africa – can be prevented and cured by relatively affordable and efficacious drugs.

Over recent years, global attention to malaria has dramatically increased. With the Multilateral Initiative on Malaria (MIM) and Roll Back Malaria (RBM) Programs two world-wide programs have been established and international donor agencies have contributed millions of dollars to malaria research and control. These initiatives also boosted the political commitment of African leaders. In 2000, African Heads of state and their representatives met in Abuja, Nigeria, and signed a declaration endorsing a concerted strategy to ensure that, by the year 2005, at least 60% of those suffering from malaria have prompt access to affordable and appropriate treatment within 24 hours of the onset of symptoms. Following the Abuja Declaration, African countries representing almost half the population at risk have established Country Strategic Plans to achieve the RBM goal and the targets set in Abuja.

1.3.1.1 The nature of malaria

Malaria is a disease usually transmitted by the bite of a female Anopheles mosquito species. By the bite, the disease goes from an infected to a healthy person. The disease is caused by the protozoan parasite Plasmodium, of which four species are distinguished; Plasmodium falciparum, Plasmodium malariae, Plasmodium ovale and Plasmodium vivax. Out of these, Plasmodium falciparum is by far the most common species in practically all parts of Africa. It is also associated with significant morbidity and mortality as it is the only species that can cause the most severe forms of malaria (MOH 2003a).

The symptoms of malaria differ greatly in manifestation and severity. A common and simple classification is to distinguish uncomplicated and severe malaria. The symptoms of uncomplicated malaria infection include fever, headaches, chills and sweats, muscular and abdominal pain, vomiting and diarrhea. The presentation of symptoms is highly variable and mimics that of many other common diseases. The typical attack has three distinct stages: the cold stage,

where the person feels cold, weak, headachy and nauseous; the hot stage where the patient is hot and has intense headaches and the sweating stage where the sick person sweats profusely. This kind of attack can reoccur after a short interval where the afflicted person feels well. Complicated or severe malaria infections are serious and life-threatening, especially in children. Symptoms in children include coma, acute kidney failure, circulatory collapse and convulsions. Adult symptoms include respiratory distress, severe anemia, convulsions and shock (MOH 2003a; Murphy et al. 2003).

Severe forms of malaria can cause a variety of complications such as the following:

- Malaria anemia is the commonest complication of malaria and is due to the destruction of red blood cell containing parasites which can result in heart failure. As a high prevalence of chronic malnutrition and worm infestation often aggravates the anemia, it is of particular importance in African children.
- Breathing difficulties may be presents for patients with severe malaria as a result of different causes such as heart failure resulting from severe anemia.
- Convulsions are abnormal uncontrollable movements of the limbs or of the whole body; sometimes with biting of the tongue and/or fecal and urine incontinence. In very young children convulsions may present as twitches involving the lips or eyes or just an upward or lateral gaze of the eyes. In malaria, convulsions usually occur in those with high fever (febrile convulsions), cerebral malaria or other metabolic disorders.
- Cerebral Malaria is a condition in which the brain is infected by the malaria parasite. Sometimes the term is used as restricted to patient with a coma lasting 30 or more minutes, while for others it means malaria associated with repeated convulsions and unconsciousness.
- Coma may develop either gradually or suddenly or may follow convulsions. It can be moderate or profound. The cause of coma in malaria is not clearly understood.
- Spontaneous bleeding from the gum or the skin is a sign of a severe

coagulation defect (Murphy et al. 2003, MOH 2003a).

1.3.1.2 Strategies to reduce malaria

Prevention and effective treatment of malaria have constituted and still constitute the principal tools for combating malaria. While campaigns in the 1950s and 1960s focused on the eradication of malaria by using top-down approaches, it is understood today that eradication is not an attainable goal given the tools that are at hand. Instead it is proposed that malaria interventions should be delivered through an integrated health system. In 1998, a renewed globally coordinated effort to reduce the disease burden and economic impact has been initiated by the WHO, the United Nations Development Programme (UNDP) and UNICEF; the Roll Back Malaria (RBM) partnership (Mendis et al. 2003, WHO 2002).

The RBM advocates four approaches to reduce mortality and morbidity:

- Prompt diagnosis and access to treatment, especially for young children
- Prevention and control in pregnant women
- Vector control including insecticide treated nets
- Prediction and containment of epidemics.

While experts have been developing tools like new drugs, vaccines, insecticide-treated nets and indoor residual spraying and have generated knowledge about the use of these tools, the key factors that contribute to malarias' burden to disease are insufficient knowledge about the disease, the lack of access to effective tools or the inefficient use of these tools in the target areas. Therefore, the Roll Back Malaria partnership works to integrate malaria treatment into other programs and to strengthen health systems to improve diagnosis, disease management, drug procurement and referral services (Murphy et al. 2003a).

It has further been recognized that – for a variety of reasons - health facility-based treatment does not reach the majority of the population in endemic countries. In Africa, more than 70% of malaria episodes in rural areas and more than 50% in urban areas are self-treated. The relatively few ill patients who have any contact with the health services represent the "ears of the hippopotamus" (Breman 2001, see Figure 3).

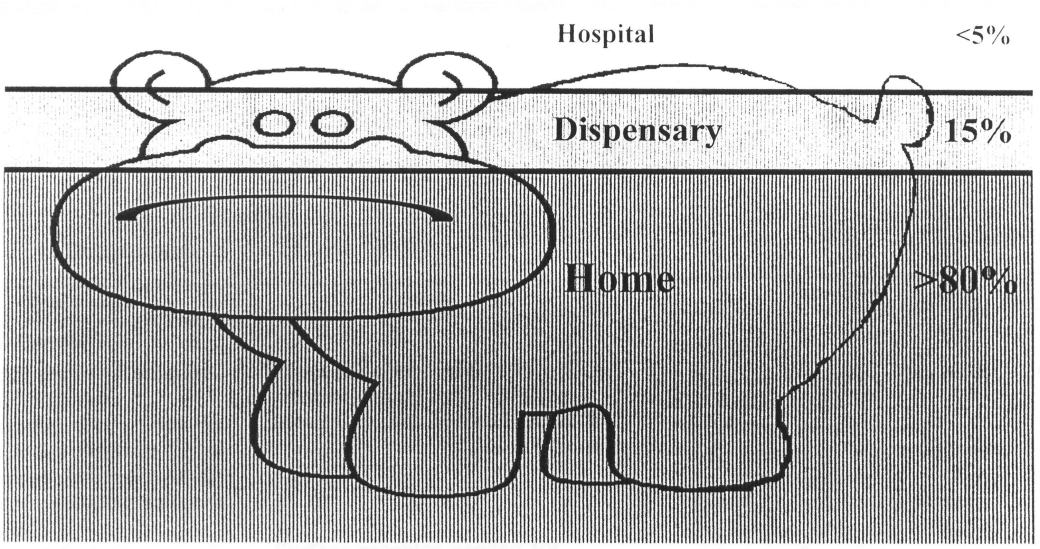

Figure 3. "The Ears of the Hippopotamus" where malaria patients are managed … and die (Breman 2001)

Home-based treatment for febrile episodes usually starts within a day of onset of symptoms and mostly involves the private sector as a major source for drugs and information. Usually fevers in children are treated with simple fever drugs such as Paracetamol or Aspirin, but not with antimalarials. Even when antimalarials are purchased, they are often administered in inappropriate doses. Decisions to seek outside help are made only if home-based treatment is ineffective (WHO 2004).

The nearer the source of appropriate treatment is to the home, the more likely it is that proper treatment will start early. Improved home-based treatment of mild malaria is a key strategy for meeting RBM country targets. Over the past decades, especially with the shift from vertical to horizontal anti-malaria programs involving local communities, a wealth of information and experiences on home-based treatment of malaria has been accumulated in research and demonstration projects. In 2002, a meeting jointly organized by RBM and the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) in Geneva brought together key researchers, health planners and malaria control program managers from African countries to help translate experience into practice and scale up Home Based Management of Malaria (HMM). The program includes training members of the community such as health workers and caregivers as well as people working in the private sector because of the private or informal sectors' importance as an accessible place to

obtain drugs (WHO 2004, Mendis et al. 2003).

The four main elements of the HMM program are to change households' behavior to

- Reliably recognize fever
- Seek prompt treatment
- Comply with instructions
- Seek help in case of progression to severe malaria.

These changes should be made through health education, community mobilization and social marketing activities. Also it is crucial that any behavior change strategy should begin with a situation analysis that looks at local practices related to malaria. The analysis should include the following aspects to find out where obstacles for improved home-based treatments may be found:

- Local concepts of malaria
- The knowledge about malaria people possess such as knowledge about signs and symptoms and causes of malaria,
- The usual health seeking behavior patterns of people
- The process of decision making in and outside the households (WHO 2004).

1.3.2 THE SITUATION OF MALARIA IN TANZANIA

The population of United Republic of Tanzania consists of 34.5 million people who are all at risk of malaria. Malaria is the leading cause of outpatient and inpatient health service attendance at all ages and the leading cause of death in both children and adults in all regions of Tanzania. It is believed that malaria is directly or indirectly responsible for about 16 million annual malaria episodes and 100'000 to 125'000 annual deaths, of which 70'000 to 80'000 occur for children younger than five year old. 70 – 80% of malaria cases are managed at community level where management is often inadequate (MOH 2000, MOH 2003a, b).

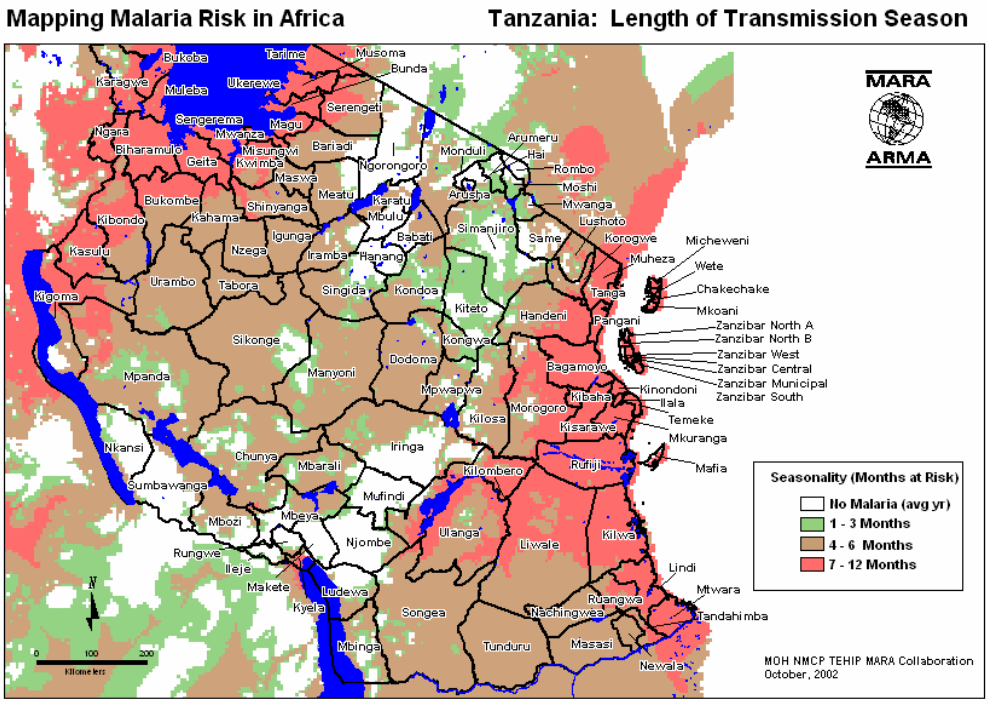

Figure 4. Mapping Malaria Risk in Africa: Tanzania – Length of Transmission Season

Endemicity and risk of transmission vary according to geographical areas (see Map 2). There are areas with unstable seasonal malaria where transmission is not more than 3 months a year and where the effects of malaria on the population are minimal in normal years unless there is an epidemic. These areas feature high altitudes of over 2000 meters above sea level and mean temperatures not exceeding 20°C. In other areas malaria is stable with seasonal variation. The geographical characteristics of these areas are plains at higher altitude with temperatures of 20-23°C. Transmission in these areas occurs from 3 to 6 months. Lastly, there are areas with stable perennial transmission of 6 – 12 months which have a hot, humid climate. Our two study districts belong to this last category and especially Rufiji District (MOH 2003a).

Tanzania is also one of the poorest countries in the world with an annual income of about $282 USD per capita in 2004 (World Bank 2004). Life expectancy at birth dropped from 50 years in 1990 to only 43 years in 2002. Infant mortality remains relatively high with 104 per 1,000 in 2001 (102 in 1990). Malaria is estimated to consume 3.4% of GDP or about $240 million USD annually. Malaria is therefore a major contributor to poverty and poor economic performance in Tanzania (National Bureau of Statistics 2003b).

In recent years, renewed attention has been paid to malaria in Tanzanian national policies. In 2001, the former national first line drug chloroquine was abandoned because of its high drug resistance. Today, the national antimalarial drug policy includes sufladoxine-pyrimethamine (SP) as first line, amodiaquine as second line and quinine as third line antimalarial drugs. The drug of choice for treatment of severe malaria is quinine (MOH 2003a). Also, the National Malaria Control Program developed a strategic plan to reduce the impact of malaria by focusing on four pillars:

- Improved malaria case management
- National scale utilization of insecticide treated nets (ITNs)
- Prevention of malaria in pregnancy
- Malaria epidemic prevention and control (MOH 2003b).

Several research and implementation projects in different districts are carried out to address these issues. The implementation of IMCI and TEHIP are part of these projects.

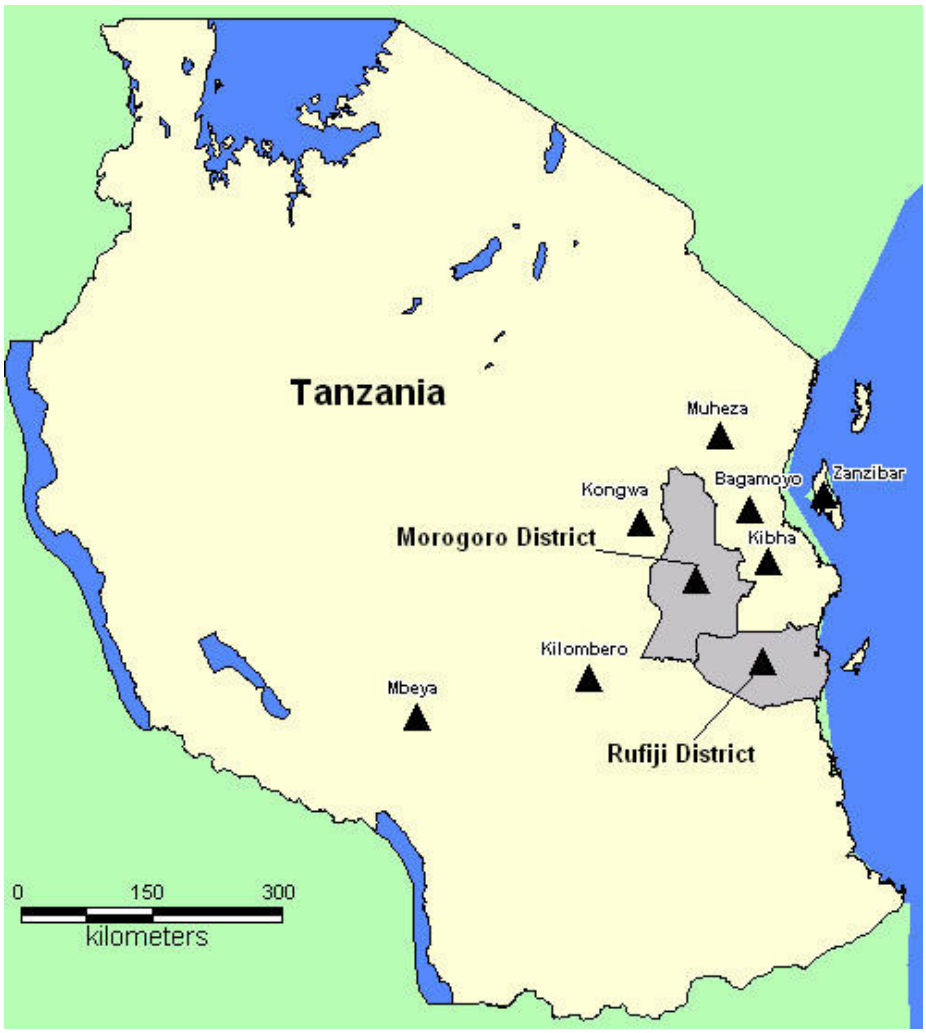

Figure 5. Location of social science research on Malaria in Tanzania

1.3.3 SOCIAL SCIENCE RESEARCH ON MALARIA IN TANZANIA

Social science research on malaria has concentrated on the eastern part of Tanzania (see Map 3). Most studies were carried out in the Kilombero District. A first set of projects concentrated on the anti-malarial potential of medicinal plants and their use by traditional healers (Gessler 1995, Gessler et al. 1995a, Gessler et al. 1995b, Matthies 1998). Subsequent investigations shifted the focus to community understanding of malaria and treatment seeking Hausmann Muela et al. 1998, Hausmann Muela 2000, Hausmann Muela and Muela Ribera 2000, Hausmann et al. 2002) and community responses to the introduction of ITNs (Minja 2001; Minja et al. 2001a; Minja et al. 2001b). In Kibaha District of the Coast Region researchers assessed local knowledge, perceptions and practice among the child caregivers of under five year old children and of health workers in public health facilities (Tarimo et al. 1998, Tarimo et al. 2000, Comoro et al. 2003) as well as the local perception of chloroquine efficacy (Tarimo et al. 2001). In Bagamoyo District studies focused on local taxonomies and terminologies of malaria related illnesses (Winch et al. 1996) and treatment practice (Makemba et al. 1996) as well as experiences with the introduction of ITNs (Winch et al. 1994; Makemba et al. 1995; Winch et al. 1997). In Muheza a study examined the social dynamics and cultural context in health seeking related to malaria (Oberlander and Elverdan 2000). On Zanzibar Island a study was conducted on the local understanding of malaria transmission and causes as a baseline for a project to improve home management of malaria (Alilio et al. 1998). In Kongwa District a local understanding of malaria was assessed and the traditional healer network mapped using GIS techniques (Winch, personal communication). In the Rufiji District a recently published study (de Savigny et al. 2004) documented care-seeking events prior to death of a malaria related illness. Our data is part of ongoing work to understand the local recognition of malaria related illnesses, labeling, aetiological perceptions and care-seeking within the framework of the Integrated Management of Childhood Illnesses (IMCI) in this area of eastern part of Tanzania.

1.3.4 KEY ISSUES IN SOCIAL SCIENCE RESEARCH ON IMCI AND MALARIA

Over the past decade, there has been growing recognition that consideration of social, cultural and behavioral factors is imperative for widespread and effective improvement in IMCI and more specifically in malaria control. Some researchers even speak of a “scientific paradigm shift” (Brown 1997) and link it with the move from vertical to more horizontal approaches requiring citizen participation (Brown 2000, quoted in Heggenhougen et al. 2003). The following paragraphs review some of the most important findings of medical anthropologists, social scientists and other experts who have conducted many studies on social and behavioral aspects of specific IMCI target conditions, especially on diarrhea, acute respiratory infections and malaria. In this review, we focus on those aspects which have been identified as being of particular relevance for interventions:

1) Illness concepts as well as associated signs and symptoms,

2) Interpretations and explanations of illness causes and transmission,

3) Care-seeking including self treatment, home management and resort to expert care.

1.3.4.1 Illness concepts

Health-seeking begins with the recognition of symptoms and their labeling (Hill et al. 2004:65). All societies around the globe have developed systems classifying symptoms into labeled categories and sub-categories. Long history of exposure to malaria, and of course also other conditions, has resulted in a range of different illness terms and categories which may all relate to biomedical concepts but which may not be perceived as such (Heggenhougen et al. 2003:39). This results in a tremendous communication challenge for outsiders who try to bring health development (Inhorn and Brown 1997). For each biomedical disease, several local categories or sub-categories may exist. Since this conceptual distinction is highly relevant, social scientists refer to biomedical concepts as "disease" and to local concepts as "illness". Awareness of the use of a wide range of labels that are related to the variability of symptoms of each disease is highly significant for a better understanding of local health-seeking behavior and the development of socially and culturally appropriate IMCI messages and training.

Supporting evidence for these basic insights come from research on malaria (recently reviewed by Heggenhougen et al. 2003), diarrhea and ARI (reviewed by Nichter 1993) and malnutrition (e.g. Obrist van Eeuwijk 1992, Helman 2000). Many of these studies further show great variation in symptom recognition and labeling within and across groups. Local classifications also change over time because they form part of broader systems of meaning and behavior. There is a need for careful assessment of local recognition of signs and symptoms as well as associated illness labels where- and whenever interventions are planned.

Moreover, illness labels are also diagnostic categories (Heggenhougen et al. 2003:8). They emphasize certain signs and neglect others. Certain signs are given unique names. The boundaries of "semantic fields" of local illness categories often do not correspond with the boundaries of corresponding biomedical concepts. This has been well documented for malaria in East Africa, West Africa and Southern Africa (Williams and Jones 2004:504). Uncomplicated malaria and severe malaria are usually separate and named categories, and

both are clearly distinguished from a condition characterized by convulsions (often caused by cerebral malaria in biomedical perspective). In Tanzania and Kenya, a child with convulsions is said to have ndege ndege (birds, butterfly), an illness which is not associated with malaria and calls for treatment by local specialists (Heggenhougen et al. 2003: 8, 43).

Another and related consequence is that some signs regarded as danger signs in IMCI are not necessarily recognized locally (Hill et al. 2004:66). In some settings, recognition was good, with 65 percent of mothers in Egypt and 73 percent in the Gambia correctly identifying children with ARI as having fast, abnormal or rapid breathing (Herman et al. 1994, Campbell, Byass and Greenwood 1990). In Bolivia, however, only 39 percent of caregivers with fatally ill children recognized that their child was severely ill (Aguilar et al. 1998). Ethnographic studies also report variations in recognition. Studies in Ghana and Sri Lanka found little recognition (Hill et al. 2003, Amarasiri de Silva et al. 2001). In two studies, one in Bangladesh and one in Pakistan, ARI symptoms were recognized but only in Pakistan classified as serious (Hussain et al. 1997, Zaman et al. 1997). These findings and many ethnographic studies document that meanings and behavior related to each of these conditions tend to be local; illness concepts and associated symptoms cannot be assumed, they have to be investigated in each particular locality (Nichter 1993, Obrist van Eeuwijk 1992, Pelto and Pelto 1997).

1.3.4.2 Illness Aetiology

All societies have tried to understand and explain how and why people fall ill. Local interpretations and explanations are thus formed by cultural understanding that has evolved in the course of history. These understandings are, however, not static traditions but continuously reproduced and thus adjusted to personal illness experiences and those of friends and relatives as well as to information provided by health staff and the media. Illness aetiologies provide answers to "how" and "why" questions (Heggenhoughen et al. 2003:7, 38). They form an integral part of care-seeking, but the relationship between aetiology and treatment is neither single-stranded nor unilinear. Etiologies considered poor from biomedical perspective do not always lead to inappropriate treatment, and correct explanations do not always result in good care-seeking.

Explaining illness is only part of the care-seeking pathway, and it is continuously subject to re-interpretation. Often, effectiveness of treatment is more important for treatment decision making than a belief about a specific cause (Williams and Jones 2004:508). On the other hand, illnesses may present with similar symptoms but can be differentiated by cause. Respondents in Tanzania were unable to state how homa illnesses differed from each other in terms of symptoms (Winch et al. 1994:73). Diagnosis relied largely on information about the cause: mosquitoes. In the mosquito season, homa was often attributed to malaria (homa ya malaria); if mosquitoes were few or absent, other diagnostic categories were used to explain fever.

Interpretation and explanation of illness is not only dynamic in a long term as well as short term perspective, it is also marked by intra-cultural variation. It is very important to avoid the assumption that all the people in a community or cultural group share a common set of beliefs about any particular illness (Pelto, Bentley and Pelto 1990:261). This also applies to local understanding of causes of diarrhea (Nichter 1988:42-43) and ARI (Nichter and Nichter 1996:181). For many types of illness, caregivers refer to several causes, ranging from the natural to the supernatural realm. With regard to malaria, a study in the Philippines found that the same person may hold various, seemingly contradictory, views about the

same illness at the same time (Espino et al. 1997).

From a health provider perspective, other understandings of "how" and "why" are not a major problem per se. They may become so, however, if the "how" conflicts with conventional biomedical knowledge about transmission patterns or if preoccupation with the "why" takes precedence in terms of preventive and treatment action, thus delaying or inhibiting effective prevention or therapy (Heggenhougen et al. 2003:7). Unfortunately, reports from around the globe have documented that local views about "how" and "why" often differ from the biomedical view when it comes to the very severe condition of convulsions. Convulsions are often attributed to supernatural forces, probably because it seems plausible to many that a child is possessed by a foreign force (devil or spirit) that makes the child's body twist and shake (Heggenhougen et al. 2003:43).

1.3.4.3 Care-seeking

Care-seeking is a key element of IMCI and a highly complex process, especially in the pluralistic health systems of contemporary societies. Early studies of the 1980s which began to examine health care systems from the patients' points of view came up with various models. A simple model developed by Kleinman (1980) proved useful for many subsequent social science studies on health seeking. This model distinguishes between the popular sector comprising self- and/or home treatment, the professional sector mainly encompassing biomedicine and the folk sector referring mainly to local medical traditions. Kleinman argued that treatment for most illnesses around the globe is initiated in the popular sector. Caregivers or patients prepare their own remedies or buy them on the market or in shops. Of particular interest are the areas in which sectors overlap. Several and diverse types of health care providers can be situated in the intersection of the "folk" and the "professional" sectors: shop keepers selling pharmaceuticals without any formal training, health care staff using local illness terms in their professional practice and healers referring to biomedical disease categories. The central point Kleinman wanted to make with this model was that patients and caregivers actually move between all three

sectors as they seek care which is appropriate in their perspective, and they often borrow from traditions in each sector.

A first step in a study on care-seeking is, therefore, to assess the range of health care options available in a particular community. Such an assessment is usually based on accounts of community members about what they do if they or their children fall sick of a specific illness. Through systematic comparison of their answers the researcher can abstract a composite picture of local health care options.

In a second step, the chronological sequence of events need to be examined. Studies on diarrhea in Sri Lanka and Thailand found, for instance, that caregivers first recur to local remedies and commercially marketed anti-diarrheal medication (Nichter 1988:48-49, Choprawon et al. 1991: 207). This has now also become the common pattern in the treatment of malaria in most of Africa (Williams and Jones 2004:506). If the illness is not cured by treatment at home, people usually seek more qualified care, either in the professional or the folk sector. With regard to malaria, multiple and often simultaneous therapy is common (Heggenhougen et al. 2003:49, Williams and Jones 2004). In cases of diarrhea, medical care from the professional sector, whether in public, NGO or private health facilities, is often considered most efficient but not necessarily also made use of (Choprawon et al. 1991:207). For malaria, the use of health care facilities often overlaps with seeking care from traditional healers.

Early studies of diarrhea already showed that it is not enough to record people's general accounts about illnesses (Bentley 1987, Bentley and Pelto 1990:273). What people say they would do are not necessarily what they actually do in actual illness. Reported behaviour may mirror what they consider as the most appropriate care-seeking, even if they cannot live up to it or it may reflect what they think the investigator wants to hear. For this reason, studies on care-seeking should, in a third step, systematically record case studies of actual illness episodes as comprehensively as possible (Pelto, Bentley and Pelto 1990). These case studies are a crucial component of social science research because they document behaviour when it is most directly relevant to the person they interview.

The recent review of IMCI on the family and the community level identified both

"home treatment" as well as "care-seeking outside the home" as key practices (Hill et al. 2004:58). It acknowledges that home-based management of childhood illness is a popular early treatment option. Not all infections need to be treated by health staff trained in biomedicine. Uncomplicated diarrhea, fevers and local infections can be managed home with efficacious treatment. In their perspective, appropriate home treatment includes prompt and correct procurement and use of relevant treatment and avoidance of ineffective or harmful treatment as well as taking children to a health facility if it does not improve.

Studies indicate, however, that home-based treatment often does not fulfill these criteria. A study in Ghana, for instance, found that fewer than 15 percent of episodes were treated correctly (Dunyo et al. 2000). Most fevers (> 60 percent) were treated with simple fever drugs (i.e. Paracetamol and Aspirin), but not with anti malarials. Even if anti-malarials were given, most of them (>80 percent) were administered in inappropriate doses. Moreover, home treatment often delays appropriate care (Heggenhougen et al. 2003:55). This is a serious problem because early treatment is critical to illness outcome (WHO 2004:11. Mild fever may proceed rapidly to severe malaria and most children die within 48 hours of onset of illness. Treatment must therefore be prompt. A study in Burkina Faso showed that the provision of early treatment within the community reduced progression to severe malaria episodes by 50 percent (Sirima et al. 2003).

Although care-seeking is a crucial element in the management of childhood illness, it clearly relies on a high quality of care (Hill et al. 2004:68). The IMCI strategy emphasizes biomedical training of health staff, but less tangible qualities may be just as important. A study of immunization use in Haiti, for instance, identified five A's as highly relevant: accessibility, acceptability, availability, accommodation and affordability (Coreil et al. 1994:215-216). Accessibility refers to primarily to physical access to services. Acceptability means how well mothers' expectations are met regarding the services they want. Availability in this case included notification about when the campaign will be carried out. Accommodation concerned time issues including opening, commuting and waiting time. Affordability comprised financial and indirect costs in terms of women's time. This framework may also be of use to assess how local communities judge the quality of service provision before and during an IMCI

intervention to improve health care on the system level.

1.3.4.4 Impact

The public health goal is that most malaria cases are treated in formal health services by motivated staff with sound biomedical training following carefully reasoned treatment schedules: treatment is never given without a positive blood slide, and severe cases are always referred to a well equipped hospital if needed. However, for much of the developing world, we are still far from this goal. In 1991, a literature review on malaria in Africa found rates of self-treatment from a low of 19 percent in Guinea to a high of 94 percent in rural Ghana; the average of the 12 studies cited was about 66 percent (Brinkmann and Brinkmann 1991). It is not clear whether these studies counted treatment dispensed by village health workers or community health workers as treatment from the health services or as self-treatment, but Foster (1995) concluded that self-treatment in Africa, especially in rural areas where about 75 percent of the population live, is the rule rather than the exception. McCombie (1996) suggested that more than 70 percent of illness episodes in rural areas and more than 50 percent in urban areas are self-treated.

These findings prompted a series of studies to focus on home-based management of malaria (Ruebush et al. 1995, Lubanga et al. 1997, Diallo et al. 2001, Homedes and Ugalde 2001, Ansah et al. 2001, Agyepong et al. 2002, Ansah et al. 2001). In 2002, Roll Back Malaria and the UNDP/World Bank/WHO Special Program for Research and Training in Tropical Diseases launched a joint effort to up-scale home-based management of malaria (WHO 2004) and thus support the commitment made by African heads of state in Abuja in 2000: to ensure that at least 60 percent of those suffering from malaria have prompt access to affordable and appropriate treatment within 24 hours of onset of symptoms.

The implication of this enormous effort is that, by delaying biomedical treatment, severe disease may be the fault of the mother or caregiver. However, as Williams and Jones (2004:512-13) have pointed out, it has not yet been carefully investigated to what extent caregiver recognition of symptoms, early treatment at home and use of herbal versus pharmaceutical medications contribute to malaria

morbidity and mortality. The results of some studies they reviewed suggest that use of herbal and traditional medicine does not unduly delay the seeking of biomedical care (Alilio and Tembele 1994, Baume et al. 2000, Heggenhougen et al. 2003). In fact, a few studies report high mortality despite good care-seeking behavior. Verbal autopsies in Guinea Bissau showed that 93 percent (n=125) of children who died had been seen in a health care facility within two weeks of death (Sodeman et al. 1997). Matching surviving controls with the deceased children demonstrated that the elapsed time between disease onset to first consultation was shorter for those who died than for those who survived. These results are unsettling and underline that we still have only limited understanding of what happens in severe disease on the household level (Williams and Jones 2004:513). Studies measuring impact have to be carefully designed and require the expertise of epidemiology as well as social sciences.

1.4 Scope and framework of our study

1.4.1 STUDY SCOPE

Childhood illnesses contribute significantly to overall morbidity and mortality in Tanzania, also in the two study districts. A main objective of TEHIP is to reduce this illness burden through improvements in health system planning. Early in TEHIP, the system intervention lead the districts to put high priority and resources on IMCI and ITNs. Both interventions require the active participation of the local communities and caregivers: The best IMCI and ITN services are of little benefit, if they do not reach the community and the household level. Caregivers have to understand and comply with IMCI core principles, i.e. learn to recognize the correct danger signs and seek prompt and effective treatment, and to implement ITN, i.e. to regularly use and re-treat mosquito nets.

However, prior to our study little was known about local understandings of the conditions targeted by IMCI, i.e. malaria, acute respiratory infections such as pneumonia, diarrhea, measles and malnutrition or a combination of these conditions in the two study districts.

1.4.2 CONCEPTUAL FRAMEWORK

In the center of our study is Health Seeking Behavior on the community and the household level. We define health-seeking to encompass the following three dimensions (see Figure 6): 1) Health concepts including signs and symptoms recognized by the community; 2) Etiology comprising interpretations and explanations of illness; and 3) Help-seeking referring to home management and all forms of seeking help from experts, whether these are neighbors, relatives, traditional healers, or staff working in dispensaries or health facilities.

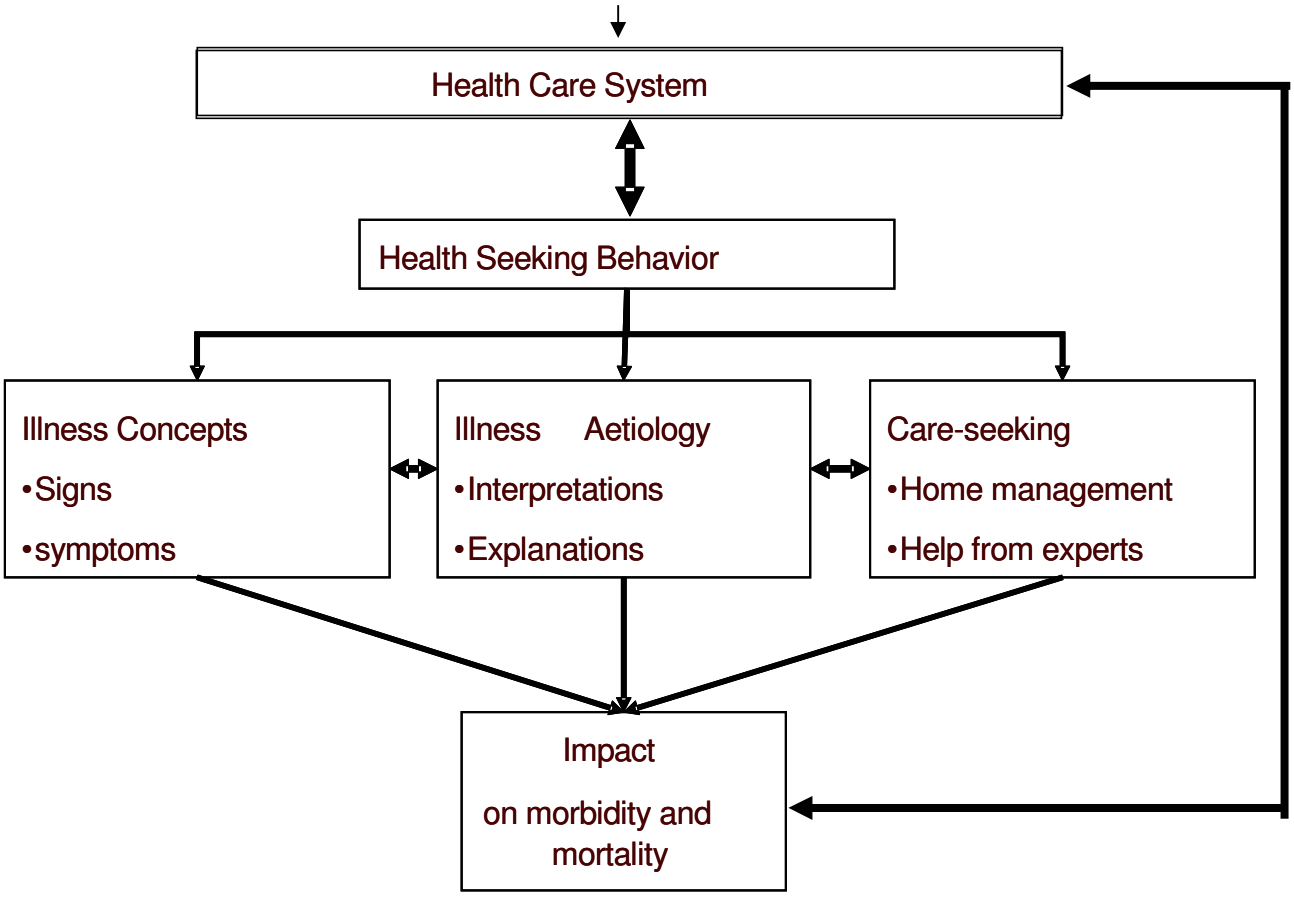

Figure 6. The conceptual framework of this study

1.4.3 OVERVIEW OF CHAPTERS

The structure of this thesis follows our conceptual framework and mirrors our step by step approach. After presenting the goals (Chapter 2), the study setting and methodology (Chapter 3), we discuss the findings (Chapter 4) in four steps: We begin with the illness concepts (Chapter 4.1), move on to illness aetiology (Chapter 4.2), then to care-seeking (Chapter 4.3) and finally to impact (Chapter 4.4.). The thesis ends with a general discussion, conclusions and recommendations.

Each topical area of Chapter 4 – symptom recognition, aetiology, care-seeking and impact - is divided into papers. The first paper presents an overview, the second paper narrows the focus on malaria and conducts a deeper analysis of aspects identified in the first paper. In the overview paper, the analytical focus is on the description of local understanding and behavior relating to IMCI related childhood illness and major preventive and therapeutic consequences that warrant the attention of the planners and implementers on the health system

level of TEHIP. This summary of main findings has been fed back into the district planning to “move the wheel”. The second paper addresses a major concern on the national, district, community and household level, namely malaria. It presents a more theoretical analysis of a particular issue that came out of the descriptive analysis and which we consider as relevant for improving IMCI.

2. Goal and Objectives

2.1 Goal

To identify and analyse trends at household level in the utilization of selected essential health interventions provided through CHMT plans with respect to spatial, social, and economic determinants.

2.2 Specific Objectives

To prepare an evidence base that can be used:

- To better adjust the IMCI interventions to local explanatory models and health seeking behavior
- To prepare an evidence base that can be used to improve the ways in which caretakers identify and manage IMCI related conditions.

2.3 Research Questions

To reach this objective we need to know

- What are the most important health problems in children under five years of age recognized in local communities and how they are the related to IMCI conditions;
- What signs and symptoms of illness are recognized for each of these main childhood illnesses;
- How these signs and symptoms are interpreted; and
- What response is made to them.

In the examination of each of these questions, we first explored health problems in a very broad sense, in a second step narrowed the focus on IMCI-related illness, and in a third step concentrated on malaria which is a main concern for the health-system as well as for local communities and caretakers

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3. Study Setting and Methods

3.1 Study Setting

3.1.1 STUDY AREA

The study was conducted in two rural districts in eastern Tanzania: in the Morogoro Rural District and the Rufiji District. The Morogoro Rural District is part of the Morogoro region and is located about 180 km from Dar es Salaam along the highway from Dar es Salaam to Zambia (see Map 4).

The district covers an area of 19,250 km2. After the completion of our study it has been divided into two districts, Morogoro Rural and Mvomero. The topography is mixed and includes mountains (the Uluguru Mountains) and plains (Mswia 2002). The climate is characterized by hot, dry weather with rainy seasons from October until December and from February until May.

The population averages around 524,445 people (National Bureau of Statistics 2003a) and comprises a wide mixture of ethnic groups (see Map 5).

The main ethnic groups are the Luguru, the Kwere, the Kutu and the Zigua. All these groups are traditionally organised in matrilineal descent groups (Beidelman 1967). Most people are either Christians (41%) or Muslims (57%) with only 2% of the population following other religious beliefs. For their livelihood, people depend mostly on subsistence farming (hoe-cultivation) and small-scale income generating activities. Maize, millet and rice are the staples mainly cultivated. Also, people keep small livestock like chicken. There is a variety of local languages which are spoken in the villages, but Swahili is used as lingua franca throughout the district (Mswia et al 2002).

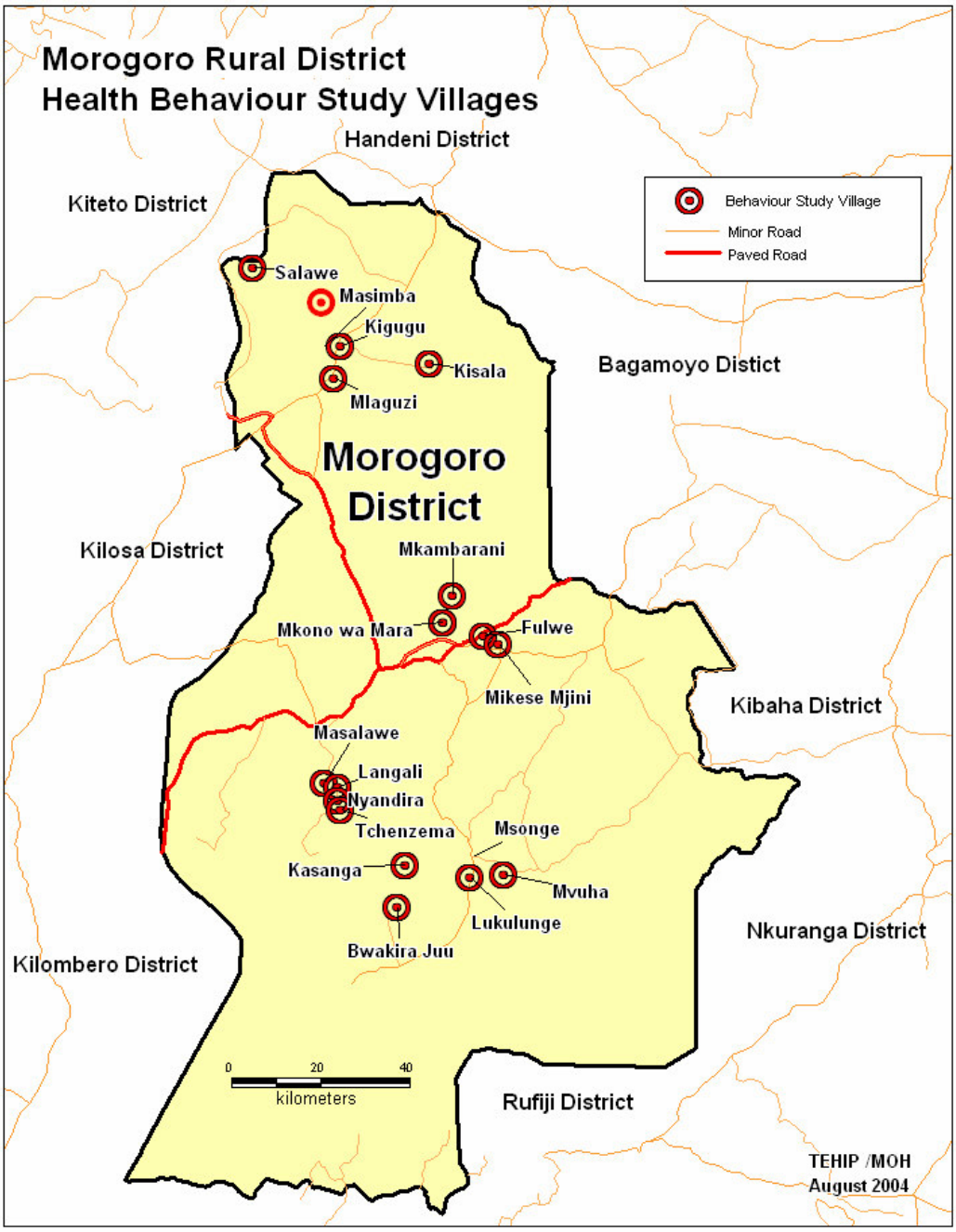

Figure 7. Study villages, Morogoro Rural District

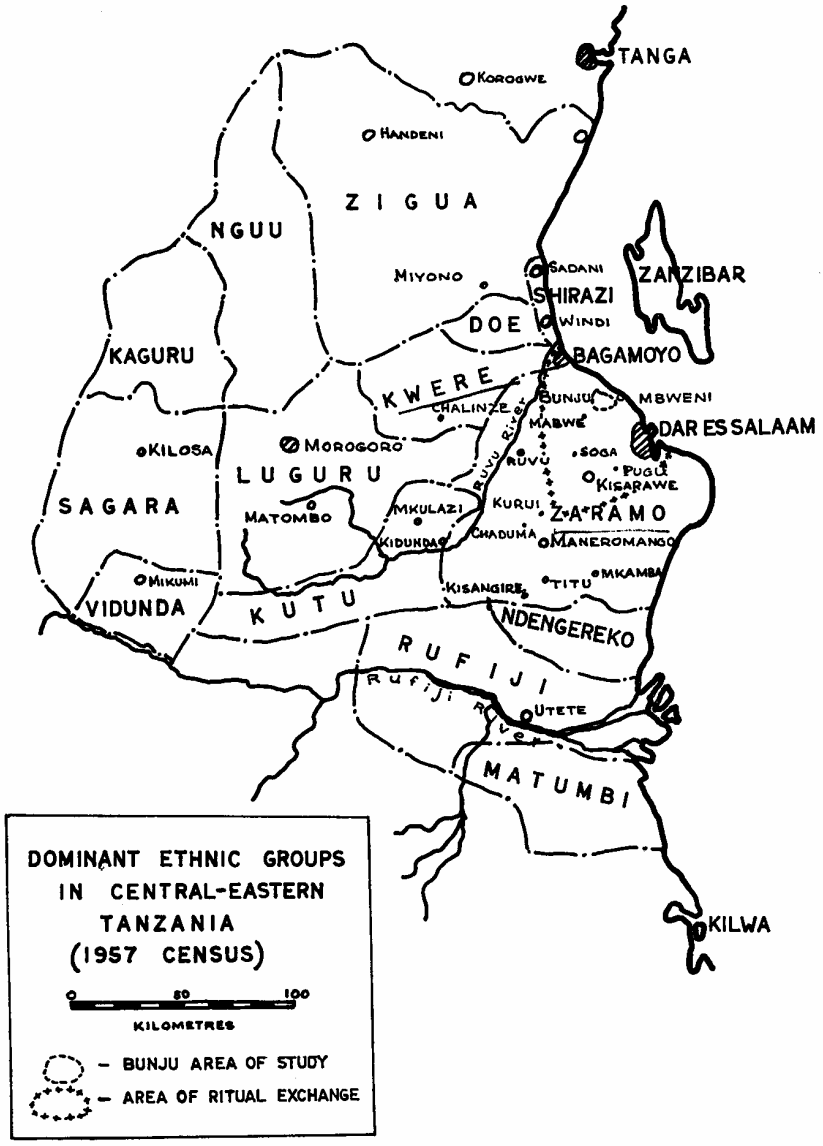

Figure 8. Ethnic groups of the study area (Swantz 1986:430)

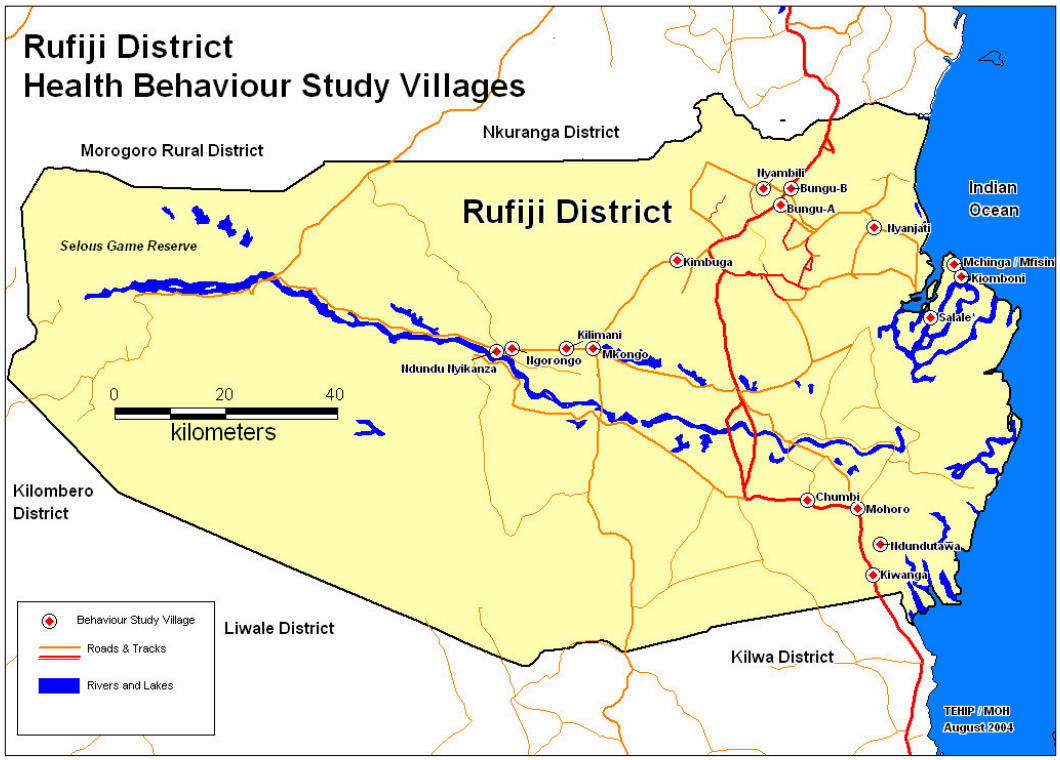

Figure 9. Study villages, Rufiji District

Rufiji District is situated in the southern part of the Coast Region, 178 km South of Dar es Salaam on the coast of the Indian Ocean (see Map 6). The overall mean altitude of the district is less than 500 metres, and its vegetation consists mainly of tropical forests and grassland. A prominent feature is the Rufiji River with its large flood plain and delta (Mwangeni et al 2002). As in Morogoro Rural District the weather is hot and dry except during the two rainy seasons. The district covers an area of 14,500 km2 and the population amounts to a size of about 203,102 (National Bureau of Statistics 2003a).

Rufiji District is home to several ethnic groups. The largest group are the Ndengereko who are said to be the original inhabitants of the area. Other groups include the Nyagatwa who live in the delta area, the Matumbi, Ngindo, Pogoro and Makonde. As in Morogoro Rural District, the majority of people are subsistence farmers. The main crops grown are cassava, maize, rice, millet, sesame, coconut and cashew nuts. Fruit such as mangoes, oranges, pineapples, papaya and jackfruit are also cultivated. Further economic activities include fishing and small-

scale commercial activities like trade. The majority of people are Moslems (>90%) with few Christians and followers of traditional religions. As in Morogoro Rural District, Swahili is widely spoken as lingua franca (Mwageni et al 2002).

3.1.2 ILLNESS BURDEN AND HEALTH CARE SYSTEM OF THE STUDY DISTRICTS

Communicable diseases account for more than 50% of the total burden of disease: 67.4% in Morogoro Rural District and 52.4% in Rufiji District. These illnesses include malaria, diarrhoea, measles and respiratory infections including pneumonia. The remaining burden of disease has been classified into perinatal (11.6% in Morogoro Rural, 15.9% in Rufiji Districs), maternal, (1.7% in Morogoro Rural, 1.3% in Rufiji Districs), nutritional (3.9% in Morogoro Rural, 11.9% in Rufiji Districs) and undetermined (1.1% in Morogoro Rural, 6.2% in Rufiji Districs) problems, injuries (4.7% in Morogoro Rural, 2.1% in Rufiji Districs) and non-communicable diseases (9.6% in Morogoro Rural, 10.4% in Rufiji Districs). A large share of the overall illness burden and especially of the communicable diseases is carried by children of under-five (42.2% in Morogoro Rural District, 53.6% in Rufiji District) (MOH 2001A).

The medical situation in Africa has been described as pluralistic: different systems exist and they may be used in parallel or may compete against each other. The main distinction is made between biomedicine and traditional medicine. These two systems usually work complementary or supplementary to each other (Good 1987, Sindiga et al. 1995, Van der Geest 1997).

According to the Tanzanian national health care system, each district needs to have a hospital that operates as a referral unit for peripheral primary care facilities such as health care centres and dispensaries. There is roughly one health centre for a population of 50,000 and a dispensary for a population of 10,000. All health facilities provide both curative and preventive services. Health facilities include hospitals (3 in Morogoro Rural District, 2 in Rufiji District), health centers (9 in Morogoro Rural District, 5 in Rufiji District) and dispensaries (81 in Morogoro Rural District, 50 in Rufiji District). It is estimated that 85% of the people live less than 5 km from a health unit in both districts (Mwageni 2002; Mswia 2002). Additionally, in both districts over the counter drugs are available from private shops and kiosks.

People also use a variety of traditional healers such as diviners, herbalists, midwives, etc. as well as local remedies.

3.1.3 TRADITIONAL HEALING IN TANZANIA

Traditional healing includes different healing traditions and various mixtures of them. Underlying these are various concepts about ill-health. For Sub-Saharan Africa, Janzen (1997) mentions different basic sets of ideas of health, sickness and healing that can also be found in Tanzania: 1) concepts of balance, equilibrium or harmony between different humors (following the Islamic or galenic tradition), 2) balance between an individual and his or her surroundings or 3) balance between the human, the natural and the spiritual community; 4) notions of the body as an ordered whole whose disruption causes illness, as well as 5) ideas of (ritual) purity versus pollution and coolness and grace versus heat and conflict. Ill health can have a physical or a social base and can be a manifestation of spirit possession or a result of witchcraft (Green 1996, Mesaki 1994).

In Tanzania, witchcraft (uchawi) covers a wide range of forms of mystical and medicinal harm which individuals are thought to bring upon each other (Abrahams 1994). As Green (1994) describes for the Pogoro, witches are motivated by jealousy and use medicine to harm crops and people and to cause sickness, failure and death among their fellow people. Illnesses that are thought to be caused by witchcraft are not treated at health facilities but by anti-witchcraft specialists. The treatment includes divination to find out who has caused the illness and treatment with medicines. Usually, the sick person and the responsible witch are both treated together.

Illnesses can also be caused by spirit possession. In Tanzania, different kinds of spirits are differentiated. There are ancestor spirits, spirits that relate to Islamic beliefs (shetani, jini, ibilisi and ruhani) and spirits that refer to nature (for example spirits that live under ground, under water or in trees as described for the Zaramo). Sometimes spirits are also called pepo, a word which refers to wind. The different names and concepts of spirits vary regionally and are sometimes also used interchangeably. Spirits have different reasons to cause sickness in people: some of them, like ancestor spirits want to get noticed and do this by making people ill. Others are just evil or try to get a body by manifesting in a person. According to

its nature the spirit is appeased or exorcised in order to heal the afflicted person. If a spirit is appeased, the possessed person might benefit by gaining healing powers or knowledge about healing or medicines from it (Erdtsieck 1997, Green 1996, Swantz 1995).

Concepts of witchcraft, spirit possession or balance don't exist as separate categories but can overlap. For example, Erdtsieck (1997) points out, that pepo doesn't only mean spirit but is also considered to be the inner force or inner spirit of a person whose state of balance is essential to the person's well-being. This balance can not only be disturbed by internal but also by external causes as for example by witchcraft.

Illnesses caused by witchcraft, spirits or imbalance are usually treated by rituals and medicine. Traditional medicines are made from plants and trees. As Green (1994, 1996) describes for the plant medicines of the Pogoro, any plant is considered to be potentially medicine as its manufacture depends more on the skill of the person making it than on the innate properties of the plants used. Some knowledge about how to make certain kinds of medicine is passed down within a family. Possession by various spirits can confer the power to make a wide range of medicines and to diagnose the cause of ailments by divination. The medicines work by the transformative power that is ascribed to them. Medicines change the state of the person, by curing, protecting and empowering. On the other hand medicines used by witches drain, weaken and poison.

As Beckerleg (1994) and Whyte (1989) conclude, Swahili medicine is pluralistic and offering sufferers a choice of therapies based on competing theories and religious ideologies. In the context of medical pluralism treatment choices are individual and depend on the assumed underlying causes of the illness. The theories and concepts overlap for both the afflicted and the healers. In her study on the treatment of mental illnesses in Tanzania, Whyte (1989) realised that the most successful healers experimented with creative combinations of Western, Islamic and various African concepts.

3. 2 Methodology

3.2.1 SAMPLING AND METHODS

The research was conducted in three interrelated modules:

1. Module:
   Situational analysis from March 1998 to February 1999
2. Module:
   Longitudinal qualitative assessment from March 1998 to February 2000
3. Module:
   Longitudinal quantitative analysis from May 1999 to April 2002

The districts were stratified into zones, based on geographical, ecological and cultural factors. This stratification was conducted jointly by the researchers and the CHMT from the two districts. For Modules1-2, a purposive sampling procedure was used to select a total of 16 villages in Morogoro and Rufiji districts (see Table 1). They were chosen such that half of the villages had a health facility in their vicinity, the other half didn't. From each village we drew a random sample of 10 households with under-five-year-old children from village registers. The household head and the principal child caregiver were selected and included in the study.

In Modules 1 and 2 we carried out qualitative research using Rapid Assessment Techniques. Members of the research team lived in the study communities. For the first module, they started by using unstructured interviews in order to learn about village life and to gain an initial understanding of local illness concepts. They then selected key informants (child caregivers, household heads, formal and informal health providers and village elders) for in-depth interviews. Initial findings from unstructured and in-depth interviews were used to adjust the guide for focus group discussions which were conducted with additional community representatives.

The second module overlapped with the first in terms of time and content and aimed at a longitudinal qualitative assessment of care-seeking by using case-studies. Field researchers identified children who had recently suffered from an IMCI targeted disease, visited their homes and discussed the illness episode with the principal caregiver against the background information gained in the situational

analysis. While the data of the situational analysis gave an overview of the meaning of illness in the community, the case studies of the second module provided insights into the ways in which individual caregivers refer to these meanings in concrete illness episodes and actual care-seeking.

The research team comprised of 4 senior sociologist, 1 public health specialist and 1 behavior scientist as module leaders or principal researchers. Research assistants whose background was sociology or similar disciplines with minimum education requirement of first degree (e.g. Bachelor of Arts) were recruited and trained for two weeks in field research techniques. During the training the field instruments developed pre-tested and adjusted. In the field, research assistants were assisted by enumerators with minimum qualifications of advanced secondary school education. Research assistants were supervised by the principal researchers. Research assistants and enumerators lived in the study communities for the entire research period for better integration and acceptability in the community.

Morogoro Rural District	Rufiji District
South–Western Zone (Mlali-Mgeta) The zone consists of highland and lowland areas. It is ethnically homogenous (mainly Waluguru). Accessibility variable and economically relatively very strong and is from cultivation and sell of vegetables and legumes. B1: Villages Langali and Nyandira B2: Villages Langali and Nyandira B3: Villages Langali, Nyandira, Tchezema and Masalawe	Upland North Zone (Upland in the North of Rufiji river). The Zone is mostly upland area most, of which are accessible year-rounds and is economically poor. Main ethnic groups are Wandegereko and Wanyagatwa. B1: Villages Bungu and Nyambili B2: Villages Bungu and Nyambili B3: Villages, Bungu, Nyambili and Kimbuga
Eastern Zone (Mikese-Ngerengere) The zone is mostly a lowland area and a large part of it is a forest. It is ethnically homogenous (Waluguru, Wakutu) and most of the area is accessible though with difficult during rain season. It is economically poor. B1: Villages Fulwe and Mikese Mjini B2: Villages Fulwe and Mikese Mjini B3: Villages Fulwe, Mikese Mjini, Mkono wa Mara and Masimbu	Flood Plain Zone (Flood plain along the Rufiji river) The zone is flood plain and accessibility is very difficult during rain season. The area is economically poor. Main ethnic groups are Wandengereko, Wapogoro and Wangindo. B1: Villages Kilimani and Ngororngo B2: Villages Kilimani and Ngororngo B3: Villages Kilimani, Ngorongo, Mkongo and Ndundunyikanza
Southern Zone (Mkuyuni-Mvuha-Bwakira) The zone is mostly lowland areas, ethnically homogenous (Waluguru-Wakutu). Access is difficult during rains, economically poor although rich in fruits such as oranges and banana. B1: Villages Mvuha and Lukulunge B2: Villages Mvuha and Lukulunge B3: Villages Mvuha, Lukulunge, Bwakila Juu and Kasanga	Delta and Coastal Zone (Delta Zone and Coastal Belt) The Zone is the most difficult and isolated part of the district. Ethnically the area is homogeneous and occupied mainly by Wanyagatwa. The area is very poor and can be accessed by boat and movement depends on tides. B1: Villages Kiomboni and Mchinga B2: Villages Kiomboni and Mchinga B3. Villages Kiomboni, Mchinga, Salale, Saninga and Nyanjati
Northern Zone (Mvomero-Turiani) The zone consists of highland and lowland areas. A number of different tribes exist and are (Wazigua, Wanguu, Wapare and Wachagga). Most areas are accessible year round and paddy and sugarcane farming economically strengthen the zone. B1: Villages Kisala and Kigugu B2: Villages Kisala and Kigugu B3: Villages Kisala, Kigugu, Salawe and Mlaguzi	Upland South Zone (Upland in the South of Rufiji river) The zone is ethnically homogeneous and main ethnic groups are Wanyagatwa, Wandengereko and Wangindo. The zone is cut off from rest of northern part of the district due to flooding of Rufiji River in rain season when the ferry is closed up. The zone is economically poor. B1: Villages Muhoro and Kiwanga B2: Villages Muhoro and Kiwanga B3: Villages Muhoro, Kiwanga, Chumbi and Ndundutawa

Table 1. Zones and villages in study district

Source: TEHIP Field research 1998-2002

On the whole, we used the following methods for the first and second module:

A) Interviews (all conducted in Swahili)

89 focus group discussions were carried out, on common health problems with child caregivers, household heads, traditional healers, village health committee members, health-care professionals, community based distributors for family planning.

726 key informant interviews were done on specific illnesses or particular issues of interest (e.g. immunization campaigns, history of health care facilities) with child caregivers, household heads, traditional healers, traditional birth attendants, health-care professionals, elders, village leaders, shopkeepers.

339 case studies of actual childhood illness episodes were performed with caregivers.

B) Observation

Unstructured observation during interviews and informal interactions within the community.

Structured observations at health facilities, traditional healers and traditional birth attendants.

For the longitudinal quanitative analysis in module 3 the sampling strategy was modified. In each zone 4 villages were randomly selected and all households with under-five year children listed. From the list, 20 households were randomly selected for the study. The households formed a cohort, which were examined twice a year by cross-sectional surveys. In these, household heads and caregivers were asked for illness episodes that had occurred to their children of under-five since the last survey. As data collection method we used semi-structured interviews in order to collect quantitative data on childhood illnesses and health seeking. From 1999 to 2001 we recorded 8602 episodes from 80 households in Morogoro rural and 7457 in Rufiji district from 80 households.

3.2.2 DATA MANAGEMENT AND ANALYSIS

The management of qualitative data started in the field. Transcripts were coded in the field using a field guide provided. Transcripts were then brought to the field office and entered into computer by data clerks using word processing software (Microsoft Word,98). In order that textual information in the form of interview and focus group discussion transcripts be accepted and rendered retrievable, the text had to be converted to an ASCII file and formatted after the field codes had been replaced by Word macros as codes e.g. 1a became ID_SEL. This process was essential for the retrieval process to work in Text Base Alpha or Beta, the software that was thereafter used to store, retrieve and analyze the data. The Data Manager who was purposely trained for managing qualitative data did quality control of the data entry. Every tenth file was checked for completeness and consistence. In case of steady errors general feedback to all field staff and data entry clerks was done to address the errors and inconsistence while individual errors were addressed to respective individuals before corrections were done.

Our analysis of the qualitative data was interpretative and based on the approach of grounded theory (Glaser and Strauss 1967). Our interpretation was built from the actual data rather than deductively abstracted from hypothetical assumptions. Text segments keyed to the areas of inquiry within the interviews were retrieved using Text-base Beta. These retrievals formed the basis of our qualitative overview and resulted in a number of analytical categories. These categories were conceptual descriptions of the ideas as expressed by the respondents in interviews and focus group discussions. The themes and categories described were derived inductively - that is gradually and with the aid of constant re-reading and analysis. The themes that emerged were then related to the original objectives and the perceived requirements of the TEHIP research conceptual framework.

For the quantitative data, research assistants supervised the data collection in the field, ensured consistency and accuracy by checking a random sample of filled questionnaire. Filled and checked questionnaires were then sent to the data

processing unit where the data were registered. Each questionnaire was given an identification number. The data were then processed using SPSS version 8 by two experienced data clerks. For logistical reasons double-entry could not be done. Instead the data manager checked the quality of data entry daily and errors were corrected immediately. Checks on quality control and cleaning of the data was further carried out by a statistician who was an investigator and a member of the research consortium. Only descriptive analysis has been done to address essential research questions for TEHIP using SPSS for windows version 10 frequency tables.

The study obtained ethical approval from the Medical Research Coordination Committee (MRCC) and from the Commission for Science and Technology (COSTEC) Tanzania. Informed consent was also obtained from all informants and study participants. Study participants were assured of confidentiality of the information that would be given.

4. Findings: Illness Concepts, Illness Aetiology, Care-Seeking, Impact.

4.1 Illness Concepts: Local Terminology and Ranking of IMCI Related Illness in Morogoro Rural and Rufiji Districts, Eastern Tanzania

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Authors' Contributions

C.M. conceived the study, participated in the design, coordination, data analysis and co-wrote the article. F.T. participated in the design, supervision of fieldwork and initial data analysis. GL. Participated as the Principal Investigator of the project until 2003 when he passed away. N.G. participated in the sampling, quality control of data processing. A.M. co- supervised data collection and initial analysis. J.N. participated in the supervision of fieldwork, initial data analysis. C.M participated in the research management and coordination. DDS conceived the study, managed the project and reviewed the article. MT participated in the design, provided overall support and reviewed the article. BO guided data analysis, interpretation and co-wrote the article.

Keywords: IMCI, symptom recognition, Illness labeling, fever, malaria, convulsions, Tanzania

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ABSTRACT

In order to improve the management of IMCI related illness on the household and community level, it is imperative to understand the relative importance of symptom recognition and labeling in care-seeking. This can only be assessed, if the local illness terminology is known. Our study investigates these critical questions with qualitative and quantitative methods in two districts of Eastern Tanzania, where IMCI was first introduced in 1997. Like previous studies we found that local illness terms overlap with biomedical classifications such as “malaria”, but this overlap does not constitute direct correspondence. On one hand, caregivers rarely see a link between malaria and convulsions; on the other hand they create new links between convulsions and polio, tetanus and epilepsy. The local population does not only appropriate and reinterpret biomedical disease categories, it also recognizes signs and symptoms which are not considered relevant by biomedicine, such as kimeo with the lead symptom of an elongated uvula which is considered highly dangerous. Whether bodily signs are recognized but not assigned to the appropriate biomedical category like convulsions or considered as illness without biomedical correlate like elongated uvula has significant preventive and curative consequences and warrant attention of efforts to improve the management of childhood illness. Particular attention should be paid to differentials in symptom recognition and severity ranking of the same illness within the population including mothers, fathers, elders, traditional healers and village based health staff. IEC messages should be developed to address and correct the identified misperceptions and IMCI training should emphasize the accurate and consistent use of biomedical terms in service delivery.

INTRODUCTION

Every year nearly 11 million children die before reaching their fifth birthday (Hill et al. 2004). Most of these deaths occur in developing countries, and more than half of them are due to acute respiratory infections, diarrhea, measles, malaria and HIV/AIDS. Malnutrition underlies 54 percent of all child deaths. In response to this enormous challenge, the United Nations Children's Fund (UNICEF) and the World Health Organization (WHO) developed the Integrated Management of Childhood Illnesses (IMCI) strategy which focuses on these five conditions (WHO/UNICEF 1995; Gove 1997; Murray and Lopez 1997). The aim of this IMCI-strategy is to move child health programs beyond a single disease approach. Many children present with overlapping signs and symptoms and multiple diseases, and therefore, single diagnosis can be difficult and may not be feasible or appropriate. The strategy therefore focuses on the careful and systematic assessment of common symptoms and well-selected specific signs to guide rational and effective action. Its three main components comprise improving the case management skills of health staff, the health system itself, as well as family and community health-care practices (Gove 1997).

Tanzania introduced the IMCI strategy in 1996. The IMCI guidelines were translated into Swahili (MOH/WHO/UNICEF 1996), and a year later the implementation started in the Morogoro Rural and Rufiji Districts with support from the Tanzania Essential Health Intervention Project (TEHIP), a joint project of the Tanzanian Ministry of Health and the International Development Research Centre (IDRC, Canada).

Both household and health facility levels should be involved in case management of child illness. Appropriate care implies that, on the household level, caregivers know when a disease can be treated at home, and when they should seek professional care in a health facility (Hill et al. 2004). Health providers, on the other hand, should be able to provide high quality care, not only in a technical but also in social sense which refers to communication skills and context specific information (Campbell et al. 2000). The more health providers know about the backgrounds of those who seek care, the better they can interpret patients' explanations and the better they can communicate what they know and do.

Our study forms part of TEHIP and contributed to District efforts to improve the interaction between the two levels. On one hand, it has focused on the household and community level, on the other hand, it has periodically fed back its findings into the planning and implementation on the district health system level.

Appropriate care begins in the household with the recognition of symptoms and illness labeling: caregivers initially recognize that the child is ill, label the illness and thus situate it within the local classification system and in terms of severity, and then either treat the child at home or resort to outside care (Hill et al. 2004). Since Charles Frake's (1969) ethnomedical analysis of local skin disease classification among the Subanun in the Philippines, many studies have shown that symptom recognition is a first step in the process of care-seeking, usually followed by complex decision making, also with regard to diseases targeted by IMCI (Tarimo et al. 2000; Amarasiri de Silva et al. 2001; Hill et al. 2003).

Even if it is the first step, to recognize a sign does not mean that it triggers (appropriate) care-seeking: a study in the Gambia found that mothers recognized fast breathing in children, with high levels of sensitivity and specificity, but mothers did not consider fast breathing very serious and rarely used it as a motivation to seek treatment for their sick child (Gittelsohn et al. 1991, in Pelto and Pelto 1997). Many studies from East Africa, West Africa and Southern Africa have shown that caregivers consider convulsions as a primary symptom differentiating severe from mild illness, but they often fail to link it with malaria (for a review of these studies see Williams and Jones 2004). A study in Ghana showed that the issue may not just be a problem of recognition but different recognition problems within the same communities (Hill et al. 2003).

The relative importance of sign recognition in care-seeking can only be assessed, if the local illness terminology is known. The aim of our study was to elicit and analyze the local illness terminology in the two districts of Tanzania, where IMCI was first introduced.

STUDY SETTING AND METHODS

The study was conducted in two rural districts in Eastern Tanzania: in the Morogoro Rural District and the Rufiji District. The Morogoro Rural District is part of the Morogoro region and located about 180 km from Dar es Salaam along the highway from Dar es Salaam to Zambia. The topography is mixed and includes mountains (the Uluguru Mountains) and plains (Mswia et al. 2002). The population is heterogeneous in terms of ethnic origin. The main ethnic groups are the Luguru, the Kwere, the Kutu und the Zigua. Most people are either Christians (41%) or Muslims (57%) with only 2% of the population following other religious beliefs.

Rufiji District is situated in the Southern part of the Coast Region, 178 km South of Dar es Salaam on the coast of the Indian Ocean. The overall mean altitude of the district is less than 500 metres, and its vegetation consists mainly of tropical forests and grassland. A prominent feature is the Rufiji River with its large food plain and delta (Mwageni et al. 2002). Rufiji District is home to several ethnic groups. The largest group are the Ndengereko who are said to be the original inhabitants of the area. Other groups include the Nyagatwa (who live in the delta area), the Matumbi, Ngindo, Pogoro and Makonde. The majority of people are Moslems (>90%) with few Christians and followers of traditional religions.

In both districts the climate is characterized by hot, dry weather with rainy seasons from October until December and from February until May. For their livelihood, local communities in both districts depend mostly on subsistence farming and small-scale income generating activities. In Rufiji District an additional important income-generating activity is fishing in the river Rufiji. In both districts Swahili is used as lingua franca.

Health facilities include hospitals (3 in Morogoro Rural District, 2 in Rufiji District), health centers (9 in Morogoro Rural District, 5 in Rufiji District) and dispensaries (81 in Morogoro Rural District, 50 in Rufiji District). It is estimated that 85% of the people live less than 5 km from a health unit in both districts (Mwageni et al. 2002; Mswia et al. 2002). Data on the health worker population ratio is not readily available but by 1999, both study district had reached a ratio of one IMCI trained

health worker per 300 children(de Savigny et al. 2002). In addition to government and private health facilities with trained staff, shops and kiosks sell over-the-counter drugs. The local population also seek care from a variety of traditional healers including diviners, herbalists and midwives and use local home remedies to treat illnesses.

In both districts, the planning of IMCI started in 1996-97 and the training started in 1997-98. In Rufiji District, the number of trained health workers reached 60 percent at the end of 1998 and 80 percent at the end of 1999. Morogoro Rural District reached the same targets by 1999 and 2000 (Mbuya et al 2001).

For our health-seeking study, we stratified both districts into four zones based on geographical, ecological and cultural factors. Informed by the design of Focused Ethnographic Studies (Pelto and Pelto 1997), we divided our study into three modules moving from unstructured to semi-structured interviews and observations.

In the first module (March 1998 to February 1999), we conducted a situational analysis employing Rapid Assessment Procedures (Agyepong et al. 1995). With a purposive sampling procedure we selected eight villages in each district, two from each zone, one with and another without health facility. Members of the research team lived in the study communities. They first used unstructured interviews to learn about village life and gain an initial understanding of local illness concepts and then selected key informants (child caregivers, household heads, formal and informal health providers and village elders) for in-depth interviews and ranking techniques like free listing. Initial findings from unstructured and key informant interviews were used to adjust the guide for FGDs with additional community representatives.

The aim of the second and overlapping module (March 1998 to February 2000) was a longitudinal qualitative assessment of care-seeking. It overlapped with the first in temporal terms as well as content and ensured thorough and iterative data collection and analysis. Field researchers identified children who had recently suffered from an IMCI targeted disease, visited their homes and discussed the illness episodes with the principal care taker, usually the mother, against the background of information gained in the situational analysis. While the situational analysis collected data on the meanings of illness in the community, the case studies provided insights into the ways in which individual caregivers refer to

these meanings in concrete illness episodes and actual care-seeking.

The objective of the third module (May 1999 to April 2001) was a longitudinal quantitative analysis. For this purpose, the sampling strategy was modified. In each zone, four villages were randomly selected and all households with under-five year children from the village register listed. From this list, 20 households were randomly selected for the study. The households formed a cohort, which were examined twice a year by cross-sectional surveys. In these, household heads and caregivers were asked for illness episodes that had occurred to their children of under-five since the last survey (recall period ranging from 6 months to 24 hours). Semi structured interviews were used to systematically collect data on care-seeking pathways.

In Module 1 and 2 we conducted a total of 726 key informant interviews, 89 focus group discussions and 339 case studies. In Module 3 we recorded 8602 episodes from 80 households in Morogoro rural and 7457 in Rufiji district from 80 households.

With the permission of the study participants, interviews and group discussions were recorded and transcribed. All interviews and FGDs were conducted and recorded in the lingua franca Swahili to maintain the accuracy and richness of the data. Transcripts of qualitative and textual data were then coded and interpreted following a content analysis method (Silverman 2001) supported by Text Base Alpha qualitative analysis software (Tesch 1999). For the quantitative data descriptive analysis was done to address essential research questions for TEHIP using SPSS for windows version 10 frequency tables.

FINDINGS

The situational analysis found that the local population in the two study districts has many different terms for important health problems in children (see Table 2a and 2b). A systematic comparison of these terms across villages and zones led to eight core illness categories that are related to IMCI conditions: Homa, malaria, degedege, nimonia, surua, kuharisha, utapiamlo, and kimeo (see Table 3). Villagers assign a broad range of signs and symptoms to these illness terms (see Table 4a and 4b); those that were most frequently mentioned are listed in Table 3. While there is much consistency in the overall pattern, differences exist between region and social groups.

Morogoro Rural District			
Eastern Zone	Southern Zone	Northern Zone	South-Western Zone
Degedege, Malaria Homa, Bandama Safura,Utapiamlo, Kimeo Kifaduro, Yevuyevu Kuharisha, Uti wa mgongo Monia, Upungufu wa damu Tetekuwanga	Degedege, Malaria Homa, Bandama, Upele, Pumu Surua,Utapiamlo, Kimeo, Minyoo Typhoid,Yevuyevu, Msokela Kuharisha, Monia, Kifafa, Baridi, Upungufu wa damu, Tetekuwanga, Kwashokoo	Degedege, Malaria Homa, Bandama Safura, Kimeo, Upele Surua, Kuharisha, Kichomi Upungufu wa damu Tetekuwanga, Kichocho	**Degedege, Malaria** **Homa, Safura** **Kuharisha, Monia,** **Upele, Mchango, Kichomi** **Surua, Pafu** **Baridi, Kifaduro** **Tetekuwanga**
Synonyms Degedege: Kuangukiwa, Surua: Galagala,Bunguga Monia: Kichomi	Synonyms Degedege: Magoga, Surua: Galagala, Bunduga, Tandika Monia: Kifua, Kikali,Kichomi, Homa za mbavu Homa: Utamu Kuharisha: Pulenda	Synonyms Degedege:Nyavana,Kichango, Ugonjwa wa kitoto Surua: Sada, Kichomi: Tungwa, Ugonjwa wa mbavu	Synonyms Degedege: Magoga, Mavunyanya, Ugonjwa wa kitoto Surua: Galagala, Bunduga, Kibuhu Nimonia: Kichomi

Table 2. IMCI conditions and local illness terminology, Morogoro Rural District

Rufiji District			
Delta Zone	Upland North Zone	Flood Plain Zone	Upland South Zone
Homa ya malaria, Degedege, Surua, Kuharisha **Ugonjwa wa macho, Mafua** **Homa za kubana mbavu (Kichomi)** **Tumbo, Homa, Homa za matumbo** **Ugonjwa wa kukauka damu, Homa ya ndenguka** **Utapia mlo,Polio, Upele, Safura, Minyoo** **Kifaduro,Homa za vipindi**	**Homa, Homa ya malaria, Homa za kawaida,** **Malaria, Degedege, Kuharisha,Pepopunda** **Upele, Surua, Utapiamlo, Tumbo, Chembe** **Kimeo, Minyoo, Kifua, Kifaduro, Kwashiorkor, Kichango** **Gandama, Monimonia, Polio, Kichango** **Tetekuwanga, Macho, Vidonda**	**Homa, Homa ya malaria, Homa za kawaida, Kuharisha, Degedege,** **Malaria ya pepopunda, Malaria, Upele, Surua, Utapiamlo, Tumbo, Chembe** **Upungufu wa damu, Kimeo, Minyoo,** **Gandama, Monimonia, Kifafa, Polio** **Kilongo (Pneumonia), Vinyangala, Safura** **Tetekuwanga, Macho, Vidonda**	**Homa (konde, liumo), Homa ya malaria, Kifua, Kifaduro, Macho** **Homa za mbavu, Malaria, Degedege, Kupooza (Degedege, Upepo wa shetani)** **Upele, Surua, Utapiamlo, Tumbo, Chembe, Kuharisha** **Upungufu wa damu, Kimeo (kidaka tonge), Upepo, Pumu** **Bandama, Monimonia, Kifafa, Polio, Kilongo (pneumonia), Safura, Kukohoa, Minyoo, Sikio** **Tetekuwanga, Macho, Vidonda**
Synonyms **Degedege: Ugonjwa wa kitoto, Kupooza, Polio, Ugonjwa wa matone, Kuangukiwa** **Surua: Galagala**	**Synonyms** **Degedege: Pepopunda, Kifafa, - Polio, Lyakunani, Ugonjwa wa kitoto, Upepo mbaya** **Surua: Galagala** **Kimeo: Kilimi**	**Synonyms** **Degedege: Pepopunda, Kifafa, Polio, Lyakunani, Ugonjwa wa kitoto, Upepo mbaya** **Surua: Galagala** **Kimeo: Kilimi**	**Synonyms** **Degedege: Reha, Upepo wa shetani, Ugonjwa wa kitoto,** **Surua:Kikukutu, Galagala** **Kimeo: Kidaka tunge**

Table 3. IMCI conditions and local illness terminology, Rufiji District

IMCI Targeted Diseases	Local Illness Concepts
Malaria	Malaria, homa, degedege
Pneumonia	Nimonia, kichomi, kifua, pumu,
Measles	Surua
Malnutrition	Utapiamlo
Diarrhoea	Kuharisha
Pneumonia, malnutrition,	Kimeo

Table 4. Eight core conditions

A general pattern is that the local terminology uses words that are clearly derived from biomedical terms, for instance malaria or nimonia, or their official Swahili translations used by the health staff, like homa, kuharisha, surua and utapiamlo, careful investigation shows, however, that the meanings of the terms are not exactly the same.

The local term malaria, for instance, refers only to some but not all conditions subsumed under the biomedical concept of malaria. The biomedical concept is much broader and encompasses the whole range from mild to severe forms (see Figure 4), while the local usage of the term “malaria” refers only to mild forms. Another local term, homa, is used for fever and is often a clinical sign of mild malaria in highly endemic areas, and a third term, degedege with the lead symptom convulsion with high probability refers to a severe form of malaria in the biomedical sense.

Morogoro District							
Homa	*Degedege*	*Malaria*	*Kuharisha*	*Pneumonia*	*Kimeo*	*Surua*	*Utapiamlo*
Hot body(Fever)	High fever	High fever	High fever,	High fever	Cough and fever	Red eyes	Weight loss
Vomiting	Stiff of body	Vomiting	Limp body	Chest indrawn	Pale skin	Red mouth	Slim legs
Loss of appetite	Rolling of eye balls	Loss of appetite	Rumbling stomach	Difficult breathing	Chronic diarrhoea	High fever	Hair colour changes
Shivering	Twist of mouth lips	Limp body	Crying all time	Loss of appetite	Vomiting	Body rash	Swollen abdomen and legs
Diarrhoea	Twitching of limbs	Yellowish urine	Watery stool	Coughing	Elongated uvula	Limp body	Dry skin
Crying all time	Frothing mouth	Wild talking	Vomiting	Fast breathing	Anaemia	Loss of appetite	General weakness
Child not playing as usual	Stool and urine incontinence	Shivering	Loss of appetite	Flaring of nose	Body wasting	Diarrhoea	Hungry all time
Hotness on head	Limp body	Recurrent fever		Rigidity of body	Loss of body weight	Coughing	
Cough	Tightening of ribs	Persistent fever		Hoarseness	Vomiting	Sleeping all time	
Running nose	Anaemia	Diarrhoea		Anaemia	Chronic fevers	Running nose	
		Anaemia		Twitching	Swelling of legs		
		Sleeping all time			Continuous cough		
		Thirsty					

Table 5. List of signs and symptoms for the Morogoro District

Rufiji District							
Homa	*Degedege*	*Malaria*	*Kuharisha*	*Pneumonia*	*Kimeo*	*Surua*	*Utapiamlo*
Hot body (Fever)	High fever	High fever	Fever	Indrawn chest	Cough	High fever	Hungry
Vomiting	Stiff body	Vomiting	Painful stomach	High fever	Fever	Body rashes	Swollen stomach
Loss of appetite	Limp body	Loss of appetite	Loss of appetite	Shivering	Pale skin	Red mouth	Change of hair
Limp body	Loss of appetite	Feeling cold	Watery stool	Fast breathing	Weight loss	Yellowish urine	Weight loss
Red eyes	Rolling of the eyeballs	Wild talking	Rumbling stomach	Twitching	Vomiting	Coughing	Limp body
Shivering	Persistent fever	Sleeping all time	Limp body	Coughing	Elongated uvula	Diarrhoea	Crying all time
Child not playing as usual	Lips go sideways	Recurrent fever	Crying	Flaring of nose	Pale skin	Vomiting	Slim legs
Cough	Frothing mouth	Persistent fever	Yellowish stool	Loss of appetite	Swollen abdomen	Ulceration of mouth	Swollen legs
Diarrhoea	Fast breathing	Shivering	Bloody stool	Anaemia	Anaemia	Loss of appetite	Coughing
Crying all time	Diarrhoea	Crying all time		Fast breathing	Continuous cough	Bad smell from mouth	
Running nose	Twitching	Diarrhoea		Ribs go in and out	Weight loss		
	Incontinence of stool and urine						

Table 6. List of signs and symptoms for the Rufiji District

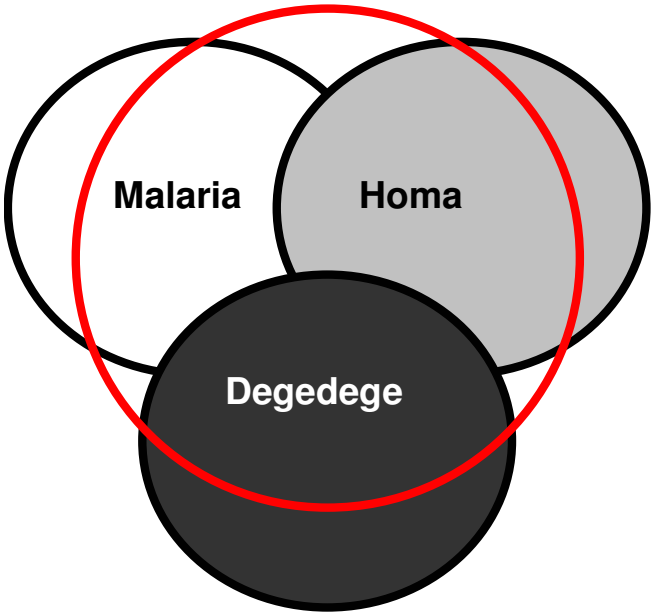

Figure 10. Overlap of the biomedical category" malaria" and related illness concepts

Local people make further distinctions within these illness categories, and most of these more specific concepts were similar across districts, although not across all villages. In Swahili, homa is the name for a symptom (hot body, fever) as well as an illness. Five types of homa have been recorded: homa za malaria, homa za manjano, homa za kila siku, homa za hapa na pale and homa za kawaida. Homa za malaria literally means febrile illness due to malaria. The terms homa za kila siku and homa za hapa na pale refer to the frequency of childhood fevers. The term homa ya kawaida (normal fever) is used for fevers without additional symptoms. These terms were used to insist on how common and frequent the illness was among children in their daily life.

The local illness category degedege refers to the cluster of symptoms called “convulsions” in English. The number of synonyms and conceptual links with other concepts indicate that “convulsions” have high cultural significance: ugonjwa wa kitoto, kuangukiwa, upepo, pepopunda, kupooza or polio kifafa and upepo. These terms were found across the two districts with some difference between zones and villages. Ugonjwa wa kitoto literally means “child’s illness” in Swahili indicating that it only occurs in children. Kuangukiwa is a passive form of the verb kuanguka and refers to the idea that this illness is caused by something,

usually bad wind (upepo), that has "fallen" from a mysterious bird or insect referred to as degedege.

In addition to these understandings that are rooted in local tradition, we found that conceptual links have also been created with the "modern" conditions, on one hand with malaria (see Figure 4), on the other with tetanus, polio and epilepsy (see Figure 5). In Morogoro Rural District the Swahili name for tetanus, pepopunda, was used as synonym for degedege. In Rufiji District, the Swahili term kupooza or the abbreviation "polio" for poliomyelitis was mentioned more frequently. The Swahili term kifafa for epilepsy has been recorded in both districts in relation with degedege.

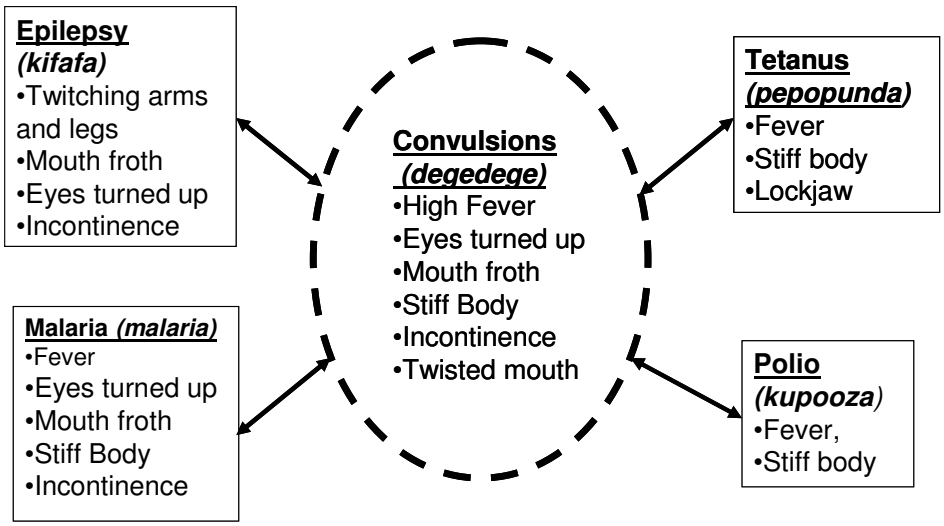

Figure 11. Conceptual links of *Degedege*

The use of the terms kupooza, pepopunda and kifafa as synonyms for degedege has been explained by the similarity of their main symptoms: fever (polio, tetanus), twisting or stiffening of the body (tetanus), twitching arms and legs, mouth froth and incontinence of stool and urine (epilepsy), limp arms and legs and paralysis (polio). The link some villagers in Rufiji make between degedege and polio was further confirmed in interviews conducted during the National Polio Immunization Day at the MCH clinic in Bungu village. To the question "What is polio?" 26 out of 47 (53 percent) of the mothers mentioned degedege.

Similar ideas were expressed in spontaneous statements:

[…] When a woman is pregnant, there are clinical services she is required to attend so that she receives the necessary vaccinations to protect the unborn child. […]. If the mother does not follow up these services and even after she has given birth, she has to take the child for vaccination. […] If she doesn't the child must get an attack of *degedege.* (Female key informant, 49 years, Rufiji)

More specific terms were also identified for the other IMCI related illness categories but these conditions were markedly less culturally elaborated. Nimonia (from pneumonia) and kichomi are used interchangeably in all villages across the two districts. Related terms are kifua, an umbrella concept for many illnesses affecting the respiratory system, and pumu, the Swahili term for asthma. Surua is the Swahili word for measles. Other widely used terms in both districts are galagala and ugonjwa wa jua (illness of the sun). The latter refers to the seasonal occurrence of the illness during the dry season of July and August, when the sun shines almost every day. The illness category kuharisha is Swahili for diarrhea. It was often used in the combination kuharisha na kutapika meaning "diarrhea and vomiting". Malnutrition is referred to as utapiamlo or less frequently as kwashakoo (from Kwashiorkor).

Kimeo means "uvula" in Swahili and refers to the lead symptom, an elongated uvula. The other mentioned symptoms, i.e. vomiting, pale skin, weight loss and anemia, are common for many childhood illnesses.

One problem in classifying symptoms in the local illness terminology was that many illnesses start with fever, but not all febrile conditions fall into same category. Sometimes people find it difficult to attribute a febrile condition to one or the other illness and are aware of the serious consequences for care-seeking.

[…] Because with *homa*, one has to be careful. It could be *degedege* or *pneumonia*. If *pneumonia*, the child needs to be taken to the dispensary because they know how to treat the disease, and if it is *degedege,* the child needs to be taken to the traditional healer first. (Male respondent FGD, Morogoro)

This applies not only to fever. Other signs and symptoms like vomiting, diarrhea or loss of appetite can often not be exclusively assigned to one particular illness category (see Table 2). Caregivers closely observe whether signs and symptoms

persist or change and label the illness accordingly.

[…] The difference between *malaria* and *surua* is that malaria occurs periodically. A child will have fever, and if you give him Aspirin or Chloroquine or Paracetamol, the child gets better, but this is only for a short interval. After some time, the fever is back again. With *surua* the child has a very high fever and rashes all over the body. (Male household head, 44 years, Rufiji)

[…] After noticing that my child had homa, I decided to give him Panadol. He was fine for some time, but later the fever *(homa)* was back again. This time I suspected "malaria", so I decided to take him to the dispensary. (Female caregiver, 35 years, Morogoro)

This shows that symptom recognition and illness labeling is a dynamic process which evaluates actual episodes with reference to a classification system.

The classification of bodily symptoms is not only dynamic, there is also intra-cultural variation in local interpretation, even with regard to the cluster of rather specific symptoms, for instance the combination of fever, yellow urine and yellow eyes. Some women mentioned this cluster as lead sign of *homa za manjano* which literally means "yellow fever", others consider it as sign for malaria.

[…] During the clinic sessions, we are taught how to identify a child suffering from *malaria.* We were taught that if you notice that the child's urine is yellowish in color, the eyes are also yellow, and the child has fever, then that is a *malaria* illness. (Female respondent, 26 years, from Morogoro)

Moreover, these statements linking yellow urine, fever and yellow eyes with "yellow fever" or "malaria" are further indications of how IEC messages have been misunderstood or reinterpreted by the local population.

Patterns in local illness terminologies should not only be assessed in terms of similarities and differences in assigning signs and symptoms to illness labels but also in terms of judging symptoms and/or labels in terms of severity. These meanings were elicited by asking which illnesses were most feared in the study communities. Table 5 shows the ranking for the IMCI related conditions. Much agreement existed between caregivers and household heads. They explained that degedege and to a lesser degrees also kuharisha (diarrhea) and nimonia (pneumonia) were very severe because they caused death within a short time,

while measles ranked third because it leads to permanent disability, namely blindness, or even death. The answers of traditional healers were strikingly different. Degedege and upepo (bad wind) also featured high but in addition they mentioned concepts rooted in “traditional” knowledge like uchawi (sorcery), bahati mbaya (bad luck) and kiharusi (a name of a spirit) as well as terms referring to “modern” diseases like tetanus, chickenpox and whooping cough. While village-based health staff most frequently mentioned malaria, diarrhea, pneumonia and other biomedical conditions, several of them also used the local terms degedege and upepo.

Ranking	Social groups			
	Caregivers	Household heads	Traditional healers	Health staff
1	*Degedege* (severe malaria)	*Degedege* (severe malaria)	*Degedege, uchawi, upepo, bahati mbaya,* chickenpox, asthma, measles, tetanus, whooping cough	Malaria, measles, *degedege*
2	Malaria	Malaria	*Degedege, upepo, kiharusi, kisonono, saha, nimonia, polio,* eye problems, chango, diarrhea, tumbo	Pneumonia, diarrhea, cholera, *upepo*
3	*Surua* (measles)	*Surua* (measles)	*Majini, degedege, bandama, mpogoro, kutenjuke*, blindness, epilepsy	Anemia, malnutrition, diarrhea, *degedege*
4	*Kuharisha* (diarrhea)	*Kuharisha* (diarrhea)	-	-
5	*Nimonia* (pneumonia)	*Nimonia* (pneumonia)	-	-
6	*Utapiamlo* (malnutrition)	*Utapiamlo* (malnutrition)	-	-

Table 7. Qualitative ranking of severity of IMCI related illnesses in both districts

During each round of the semi-structured interviews, caregivers and household heads in Morogoro Rural and Rufiji districts were asked to rank the illness from which any child in the household had suffered since the last visit of the research team (Table 6) by comparing with rest 7 illnesses listed below in table 6. The patterns found in the qualitative data were to a large extent confirmed. In both districts, *degedege* (severe malaria) figured first and malnutrition last across seasons. In Morogoro Rural, malaria came second, followed by *nimonia* (pneumonia), *kusharisha* (diarrhea) and *surua* (measles); in Rufiji, diarrhea and measles ranked higher than malaria. What is important to note is that the local illness concept *kimeo* was consistently mentioned under the top eight health problems in terms of severity. This confirms its cultural significance which is in sharp contrast to the biomedical perspective.

Rank	July-Oct,1999 (Dry 1)		March–May,2000 (Rain 1)		July–October 2000 (Dry2)		March–May,2001 (Rain 2)	
	Illness	**%**	**Illness**	**%**	**Illness**	**%**	**Illness**	**%**
1	*Degedege*	91	*Degedege*	94	*Degedege*	90	*Degedege*	94
2	*Nimonia*	87	*Malaria*	87	*Malaria*	88	*Malaria*	93
3	*Malaria*	86	*Kuharisha*	84	*Surua*	81	*Nimonia*	90
4	*Surua*	85	*Surua*	78	*Nimonia*	80	*Kuharisha*	87
5	*Kuharisha*	82	*Nimonia*	76	*Kuharisha*	79	*Kimeo*	75
6	*Kimeo*	65	*Kimeo*	70	*Kimeo*	62	*Utapiamlo*	65
7	*Utapiamlo*	50	*Utapiamlo*	60	*Utapiamlo*	61	*Surua*	64
8	*Homa*	32	*Homa*	36	*Homa*	38	*Homa*	36

Morogoro Rural District

Rank	July-Oct,1999 (Dry 1)		March–May,2000 (Rain 1)		July–October 2000 (Dry2)		March–May,2001 (Rain 2)	
	Illness	**%**	**Illness**	**%**	**Illness**	**%**	**Illness**	**%**
1	*Degedege*	87	*Degedege*	86	*Degedege*	97	*Degedege*	99
2	*Surua*	74	*Kuharisha*	79	*Kuharisha*	90	*Surua*	96
3	*Kuhaisha*	66	*Surua*	78	*Surua*	89	*Malaria*	93
4	*Kimeo*	63	*Malaria*	76	*Nimonia*	88	*Kuharisha*	92
5	*Malaria*	62	*Kimeo*	68	*Malaria*	82	*Kimeo*	85
6	*Nimonia*	50	*Nimonia*	67	*Kimeo*	74	*Nimonia*	82
7	*Utapiamlo*	50	*Utapiamlo*	45	*Utapiamlo*	47	*Utapiamlo*	50
8	*Homa*	30	*Homa*	40	*Homa*	44	*Homa*	48

Table 8. Ranking of illness with respect to percieved threat, Morogoro rural (top) and Rufiji Districts (bottom)

DISCUSSION

In order to improve the management of IMCI related illness on the household and community level as well as at the health facility level, it is important to gain an understanding on the relative importance of symptom recognition in care-seeking (Hill et al. 2004). A first step in this direction is the assessment of local illness terminologies. In Tanzania, several studies have examined local illness terminologies and symptom recognition with a particular focus on malaria, for instance in Kilombero and Ulanga (Hausmann Muela et al.1998; Hausmann Muela 2000, Minja 2001, Minja et al. 2001), Bagamoyo (Winch et al.1996) and Kibaha (Tarimo et al. 1998; Tarimo et al. 2000; Comoro et al. 2003). Our study broadens the focus to local illnesses relating to the five target conditions of IMCI and investigates this topical domain in a locality for which few previous studies exist.

Previous studies on ARI in the Philippines have shown that a set of local illness terms overlaps with biomedical classifications of ARI, but this overlap does not constitute direct correspondence (Nichter and Nichter 1996). Many studies on malaria from West Africa, Southern Africa and East Africa (Williams and Jones 2004) including those mentioned above for Tanzania have similarly documented that convulsions are an important marker differentiating severe from mild illness, but local caregivers often fail to link it with malaria. This study provides further evidence for this important social feature.

Furthermore, local terminologies often use biomedical terms, but more thorough examination brings to light that the denotations and connotations of the terms are very different (Pelto and Pelto 1997). A well-known example is the term “malaria”. Our findings show not only that the local population rarely sees a link between malaria and convulsions but also that caregivers create new links between convulsions and polio, tetanus and epilepsy. From a biomedical perspective, these perceptions are misguided, but from a community health point of view they illustrate a crucial point, namely that culture is not static but a dynamic process. Our data provide supporting evidence of the phenomenon of interaction, merging and reinterpretation of local and biomedical ideas and logic which has been

called “medical syncretism” (Hausmann Muela et al. 2002).

Local cultures have also produced illness labels as well as diagnostic categories for signs and symptoms which are not considered relevant by biomedicine. In Morogoro Rural and Rufiji districts, the local population considers kimeo as a serious illness, but this condition with the lead symptom of an elongated uvula does not constitute a disease in biomedical terms.

Both cases, whether bodily signs are recognized but not assigned to the appropriate biomedical category like convulsions or considered as illness without biomedical correlate like elongated uvula has significant preventive and curative consequences and warrant attention of efforts to improve the management of childhood illness. These cases provide further evidence that differential recognition problems may exist in the same communities, as a study has already shown for Ghana (Hill et al. 2003). Recognition problems as well as health seeking behavior resulting from them cannot be assumed but need to be investigated in each particular locality.

The lists and ranking of locally recognized danger signs indicate that caregivers in our study area are aware of the most relevant diseases targeted by IMCI. However, the composite picture of knowledge abstracted from households to the community-level does not necessarily reflect actual behavior. In-depth interviews and focus group discussions provide insights into cultural vocabularies and available meanings, but only case studies can demonstrate which signs and symptoms caregivers recognize in actual illness (Nichter and Nichter 1996).

We further found that caregivers sometimes have difficulties to distinguish between diagnostic categories, especially with regard to fever (homa) and have to adjust their assessment as illness progresses through different stages. Moreover, within every community, ambiguity and heterogeneity exists in terms of interpreting and applying cultural vocabularies (Nichter and Nichter 1996). While villagers across the districts agreed that many local illnesses related to IMCI represent severe conditions, not all of them ranked them exactly the same way. During the key informant interviews and FGDs we found surprising consensus on perceived severity among caregivers and household heads, and these data were further differentiated during the semi-structured interviews. Traditional healers elaborated strikingly different views on severe conditions in

key informant interviews and in focus group discussions, and so did village based health workers. Additional analysis of socio-demograhic variables would probably bring further differentiation to light, for instance between elder and less educated women vs. younger women with more school education, as another study has shown in terms of malaria beliefs in a neighboring region (Tarimo et al. 2000).

CONCLUSIONS

Our study demonstrates that local recognition of signs and symptoms and illness labeling present a serious challenge for information education communication (IEC), also in the framework of IMCI. A thorough analysis provides evidence of problems in recognition and labeling, but this evidence then has to be translated into improved quality of care in health facilities as well as improvements in home management of childhood illness. Awareness among health workers of the wide range of labels related to the variability of symptoms is highly relevant for the understanding of local concepts and behavior, for the development of proper IEC messages and for the accurate and consistent use of terms in service delivery. Moreover, specific misperceptions from the biomedical perspective should be addressed and corrected.

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4.2 Illness Concepts: Fuzzy Concepts: Local Recognition and Labeling of IMCI-Targeted Conditions in Eastern Tanzania

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Authors' Contribution

C.M. conceived the study, participated in the design, coordination, data analysis and co-wrote the article. F.T. participated in the design, supervision of fieldwork and initial data analysis. GL. Participated as the Principal Investigator of the project until 2003 when he passed away. N.G. participated in the sampling, quality control of data processing. A.M. co- supervised data collection and initial analysis. J.N. participated in the supervision of fieldwork, initial data analysis. C.M participated in the research management and coordination. DDS conceived the study, managed the project and reviewed the article. MT participated in the design, provided overall support and reviewed the article. BO guided data analysis, interpretation and co-wrote the article.

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SUMMARY

In the late 1990s, the Integrated Management of Childhood Illnesses (IMCI) was implemented in Morogoro Rural and Rufiji Districts in eastern Tanzania. An important aim of IMCI is to improve recognition and assessment of symptoms of common childhood illnesses, both among health staff and community child caregivers. Our study focuses on local illness concepts related to malaria and pneumonia. Like previous studies in other parts of Tanzania and Africa, we investigated which signs and symptoms caregivers recognize and how they assess them. Moreover, we systematically compared danger signs reported by caregivers with those used in the IMCI guidelines. Similar to earlier studies we found that caregivers promptly recognized illness symptoms in their children. If they judged these symptoms as severe or recurrent they called for help outside the household and sought advice from different sources. Our interpretation, however, differs from those of earlier studies in that we emphasize the significance of illness labeling and the fuzziness of illness concepts. It is not enough for caregivers to recognize symptoms, they search for illness labels which are not only a name but contain information about treatment. We argue that these aspects have been neglected in the social science literature on malaria and in the IMCI approach which focuses on signs and symptoms. In our study, caregivers found it difficult to label a given illness because different illnesses produced similar symptoms and different persons offered varied, changing and even contradictory advice and information. This fuzziness is also visible if we compare caregivers' description of symptoms with lead signs used in the IMCI guidelines. We conclude that there is clearly a need for a two pronged approach in IMCI improving 1) communication in health facilities as well as 2) community triage to reduce fuzziness and increase the sensitivity and specificity of illness concepts based on people's everyday language.

INTRODUCTION

In the mid-1990s, the WHO and UNICEF launched a strategy called Integrated Management of Childhood Illnesses (IMCI), which aims at moving child health programs beyond single disease approaches (WHO & UNICEF 1995; Gove 1997). Sick children brought to health centers often show overlapping signs and symptoms of different diseases. Coming up with a single diagnosis can be difficult or may not be feasible or appropriate at all. Therefore, the IMCI strategy focuses on the careful and systematic assessment and classification of common symptoms and on well-selected specific signs which should help health providers to act effectively.

The IMCI was introduced in Tanzania in 1996, and the guidelines developed by the WHO and UNICEF were adapted and translated into the national language Swahili. The two pioneer districts for implementing the IMCI were Morogoro Rural and Rufiji Districts (MOH, WHO & UNICEF 1996; Mbuya 2001). The health profile of both districts is dominated with preventable communicable diseases, which account for 67.4 % in Morogoro Rural and 52.4% for Rufiji of total burden of disease (MOH 2001a). These include malaria, diarrhoea, measles and respiratory infections including pneumonia. The remaining burden of disease has been classified into perinatal (11.6% Morogoro, 14.9% Rufiji), nutritional (3.9% Morogoro, 11.5% Rufiji), maternal (1.7% Morogoro, 1.2% Rufiji), injuries (4.7% Morogoro, 2.7% Rufiji), non-communicable (9.6% Morogoro, 12.5% Rufiji) and undetermined (1.1% Morogoro, 4.9 % Rufiji) (MOH, 2001a). The under-five age group (16% of the population) carries a large share of the overall illness burden (42.2% Morogoro, 53.6% Rufiji) and of the communicable diseases.

To address this high burden of disease in particular of under five children, Morogoro Rural and Rufiji districts adopted IMCI, using support of a simulated sector wide approach (SWAP) and District level health basket funding provided by the Tanzania Essential Health Intervention Project (TEHIP), a joint project of the Tanzanian Ministry of Health and the International Development Research Centre (IDRC, Canada). By 1999, both study districts had reached a ratio of one trained IMCI health worker per 300 children.

When the IMCI-strategy became available to the health system in the two

districts, several questions arose regarding local understanding about common childhood illnesses. Not only people working in different health facilities but also the caregivers of the children have to make decisions upon which they are modelling the actions they are going to take. These decisions are based upon available concepts of illnesses.

Making sense of an illness is done through the labeling of the condition. Illness labels are terms for underlying concepts which give meaning to the experience of illness. By applying these labels, people categorize illnesses according to local illness taxonomies (Lin & Kleinman 1988; Nichter 1993). For naming the illness people often use terms that designate one or several lead symptoms or that are labels for a single or a cluster of symptoms (Frake 1961). In recognizing the illnesses of young children, the signs and symptoms perceived by their caregivers are crucial, as the child often cannot express the symptoms themselves. Caregivers often feel that something is wrong with their children on the basis of subtle cues. These cues include bodily signs perceived through touch and smell as well as the child's eating behavior and activity level (Nichter 1993). According to Helman (2000) the cues refer to people's experience and perception of changes in the bodily appearance or irregular bodily functions, excessive or unusual emotional states, behavioural changes in relations to others and changes in the functioning of the five major senses. How these signs and symptoms are evaluated is largely culturally determined: Culture contributes to shaping diffuse emotional and physical changes into patterns that are recognizable to both the sufferer and his or her surrounding (Helman 2000). As many studies have shown, illness concepts and taxonomies are not rigid but are open to ambiguity and subject to negotiations.

So far, few investigations have been conducted on the local recognition of signs and symptoms and illness labelling in relation to IMCI. A recent study in Sri Lanka found that help seeking by mothers was driven by symptomology (Amarasiri de Silva et al. 2001); another study in Ghana found that caregivers did not recognize several dangerous symptoms at all (Hill et al. 2003). Taking these studies as a lead, our paper examines various dimensions of signs and symptom recognition and illness labelling in eastern Tanzania: we are interested in finding out, which signs and symptoms are perceived as cues for illnesses by caregivers

and how they are evaluated. We also investigated what labels are attached to these symptoms and in which context, and who applies them. We further wish to see if the considerations of symptoms by caregivers correspond with those of IMCI trained staff working at health facilities. Finally we want to point out the implications of these findings for further research and its application in IMCI interventions.

In this paper, we focus on three local illness concepts that are very common among young children: On malaria (an illness which corresponds roughly with the mild form of the biomedical concept malaria and its symptoms such as fever, diarrhoea, etc.), on degedege (seizures which are often caused by attacks of severe malaria but also other illnesses or epileptic fits), on homa (fever illnesses in general) and on nimonia (respiratory illnesses that share their symptoms with pneumonia).

Our research was carried out within the framework of the Tanzania Essential Health Intervention Project (TEHIP). The mandate we received was to examine the health behaviour of the local people in the two districts. By our research we hope to gain insights that may help to improve prompt and appropriate care-seeking when a child is falling ill.

MATERIALS AND METHODS

Study Area

The study was conducted in two rural districts in Eastern Tanzania: in the Morogoro Rural District and the Rufiji District. The Morogoro Rural District is part of the Morogoro region and is located about 180 km west of Dar es Salaam along the highway from Dar es Salaam to Zambia. The topography is mixed and includes mountains (the Uluguru Mountains) and plains (Mswia et al, 2002). The population is heterogeneous in terms of ethnic origin. The main ethnic groups are the Luguru, the Kwere, the Kutu und the Zigua. Most people are either Christians (41%) or Moslems (57%) with only 2% of the population following other religious beliefs.

Rufiji District is situated in the southern part of the Coast Region, 178 km South of Dar es Salaam on the coast of the Indian Ocean. The overall mean altitude of the district is less than 500 metres, and its vegetation consists mainly of tropical forests and grassland. A prominent feature is the Rufiji River with its large food plain and delta (Mwageni et al, 2002). Rufiji District is home to several ethnic groups. The largest group are the Ndengereko who are said to be the original inhabitants of the area. Other groups include the Nyagatwa (who live in the delta area), the Matumbi, Ngindo, Pogoro and Makonde. The majority of people are Moslems with few Christians and followers of traditional religions.

In both districts the climate is characterized by hot, dry weather with rainy seasons from October until December and from February until May. For their livelihood, people at both places depend mostly on subsistence farming (hoe-cultivation) and small-scale income generating activities. In Rufiji District an additional important income-generating activity is fishing in the Rufiji River and Indian Ocean. In both districts Swahili is used as lingua franca.

Health facilities include hospitals (3 in Morogoro Rural District, 2 in Rufiji District), health centers (9 in Morogoro Rural District, 5 in Rufiji District) and dispensaries (81 in Morogoro Rural District, 50 in Rufiji District). It is estimated that 85% of the people live less than 5 km from a health unit in both districts (Mwageni 2002;

Mswia 2002). Additionally, in both districts over the counter drugs are available from private shops and kiosks. People also use a variety of traditional healers such as diviners, herbalists, midwives, etc. as well as local remedies to treat illnesses.

Study Design

The research was conducted in three interrelated modules. The first module examined the initial concepts and understanding of common childhood illnesses before the introduction of the IMCI. The second module put an in-depth focus on central themes identified in the first module, while the third module was concerned with quantifying the patterns and trends that had shown up during the first two modules.

For the study, each district was further divided into four zones according to cultural and geographical criteria. For the first and second module two villages per zone were selected by purposive sampling. In each pair one village had a health facility while the other village was without or situated in a distance of a health facility. A total of 16 villages were selected including one village per district under a Demographic Surveillance System (DSS). From each village, a random sample of 10 households with under-five-year-old children was drawn. From each household the household head and the principal child caregiver were selected and included in the study. The first and the second module were carried-out from 1998 until 2000. Qualitative methods were used, mainly unstructured and semi-structured interviews as well as focus group discussions and case studies. All the interviews were conducted in Swahili and were tape recorded. In all we conducted 726 key informant interviews, 89 focus group discussions and 339 case studies.

In the third module, the sampling strategy was modified for quantitative assessment. For each zone, a multi-stage cluster sampling procedure (village-hamlet-household) was used to select 20 households with children of under-five. The households formed a cohort which was examined twice a year from 1999 to 2001 by cross-sectional surveys in order to assess changes in health seeking behaviour after the introduction of the IMCI at different times and at different seasons. From 1999 to 2001 we recorded 8602 episodes from 80 households in

Morogoro rural and 7457 in Rufiji district from 80 households.

In this paper we present findings from the qualitative analysis with particular emphasis on case studies; the findings from the quantitative data analysis will be presented in a separate paper.

RESULTS

Signs and Symptoms

Caregivers recognize and label illness in young children by observing and assessing signs and symptoms. This paper focuses on locally recognized signs and symptoms associated with illnesses called homa, malaria and degedege in Swahili which are related to fever, malaria and febrile convulsions; in a malaria endemic area, the latter are often a result of the severe form of the disease (see Table 9).

Signs and Symptoms	Illness			
English *(Swahili)*	***homa***	***malaria***	***degedege***	***nimonia***
High fever / hot body / high body temperature/ fever not cooling down (*homa kali / mwili wa moto/ joto kali sana mwilini/ homa haishuki)*	M, R	M, R	M, R	M, R
Hot / feverish abdomen (*joto tumboni / homa tumboni / tumbo la moto)*	M, R	M, R	M	
Hot head *(kichwa cha moto)*	M	M, R		
Delirium *(anaweweseka)*	R	M, R		
Feeling cold / shivering *(anasikia baridi / anatetemeka)*	R	M, R	M	
Crying all the time *(analialia)*	M, R	M, R		M, R
No interest to play/ not happy / sleepy *(hataki kucheza / ananyongea, hana raha / analala)*	M, R	R	R	R
Fast breathing *(anahema kwa kasi)*	M		R	M, R
Coughing *(anakohoa)*	M	M		M, R
Loss of appetite, not breastfeeding *(hapendi kula, hawezi kunyonya)*	M, R	R	R	M
Yellow eyes *(macho yanakuwa njano)*		M, R		
Intermittent / periodic fevers *(homa za mara kwa mara / homa za vipindi)*		M, R		
No strength *(hana nguvu)*		M		
Rolling eye (balls) / eyes turn white *(kupindua macho / macho yanakuwa meupe)*		M	M, R	
Diarrhoea *(kuharisha)*		M, R	M, R	

Vomiting (*akila anatapika)*		M, R	M, R	
Froth coming out of the mouth *(anatoa mate mdomoni)*		M	M, R	
Twitching of arms and legs*(kustukastuka)*		M, R	M, R	M
Body becomes stiff *(kukakama mwili / mwili unakauka)*			M, R	
Kicking leg and arm *(anarusha mkono na mguu / mguu na mkono vimepinda)*			M, R	
Mouth twisted sideways *(mdomo kwanda pembeni)*			M, R	
Falling down *(anaanguka)*			M, R	
Incontinence of urine or stool *(kutokakinyesi na mkojo)*			M, R	M, R
Cannot breathe well / breathes with difficulty *(anashindwa kupumua vizuri / anapumua kwa shida)*				M, R
Breathes very fast and then stops *(anapumua kwa kasi halafu anasimama)*				M, R
Child breathing shallowly *(mtoto alikuwa anahema juju)*				M
Tightening of ribs / the ribs were as if they are breaking *(mbavu zinabana / mbavu unafikiri zinavunjika*				M, R

Table 9. Symptoms recognized by caregivers for homa, malaria, degedege and nimonia in Morogoro Rural (M) and Rufiji (R) Districts (based on case studies)

Homa

The term homa stands for febrile illness in general. As the main symptoms caregivers mentioned: a hot body or fever, a hot abdomen, a hot head, delirium, shivering, crying all the time, loss of interest to play with others, no joy, fast breathing, coughing and loss of appetite.

Caregivers - in most cases the mothers of the children - reported to recognize these symptoms and signs promptly because of their close relationships to the children. A mother would report, for instance:

> I knew Juma had *homa* because, when he is well, is playing with others […]. When he got the *homa,* he couldn't play with others, he wasn't happy at all. The body became very hot and he could not eat. (Female caregiver, 32 years, Rufiji).

The illness homa and its symptoms were considered as a normal childhood illness (homa ya kawaida) that every child must suffer through, despite the fact that some of its symptoms were mentioned to be severe such as high fever (homa kali).

Malaria

Malaria had several symptoms in common with homa. These include high fever, a hot abdomen, a hot head, delirium, coughing, loss of appetite, loss of interest to play, and shivering. Additional symptoms and signs include yellowish coloration of the eyes, intermittent and periodic fever, weakness, diarrhoea and vomiting. A mother might say:

> First, Mwajuma had very high fever, and then she started shivering. She vomited every time I tried to feed her. The vomits were yellowish in color. (Female caregiver, 28 years, Morogoro).

Three symptoms which mothers considered as frightening, i.e. rolling eyes, froth coming out of the mouth and twitching of arms and legs, have been mentioned as indicators of *malaria* and of *degedege* (table7).

Degedege

Degegede is an illness that is – from a biomedical point of view - usually equated with the severe form of malaria marked by convulsions. It includes symptoms that are also mentioned for homa and / or malaria such as high fever, a hot abdomen, difficult breathing, loss of appetite, child not playing, diarrhea, vomiting, shivering, rolling eyes and twitching of the body. These symptoms were usually mentioned when the symptoms were reported to be gradual on the onset of the illness. Additional, characteristic symptoms for degedege are stiffening of the body, falling down, shifting of the mouth to one side, and kicking of legs and arms. In some cases, froth coming out of the mouth and incontinence of urine or even stool was mentioned. The following examples are typical:

Case 1

The body was stiff. The eyes became white: the black spot of the eyes rolled upwards. The child had high fever for one day, but has already had continuous normal fever for a whole week. The fever went so high, and the child became weak. (Female caregiver, aged 27 years, Morogoro).

Case 2

Ramadhan was twitching and then the breathing was difficult. The leg was flexed, the arm too; the leg and arm couldn't be straight. He could not swallow any thing. The body was very rigid, and the mouth turned sideways. The fever was very high. (Female caregiver, aged 18 years, Rufiji).

Case 3

You see a child become rigid. The eyes protrude and become bigger than her usual eyes. She tightens the teeth by locking the jaws. After a while the eyes turn sideway, the lips are pulled sideway too, the arms and legs flex as if becoming short. But there is another type in which the child's body parts become limp until you - the parent - move them. In this case the leg will be paralyzed and the child become stiff after the illness (Female caregiver, aged 33 years, Rufiji)

Nimonia

The symptoms mentioned for nimonia overlap with those mentioned for the other three illnesses: Fever, crying all the time, breathing problems, coughing, child has no interest to play and loss of appetite. Not surprisingly, special emphasis is put on breathing problems. Caregivers use a range of expressions and terms to describe these symptoms such as: cannot breathe well, breathes with difficulty, breathes very fast and then stops, breathing shallowly, tightening of ribs and ribs sounds as if they are breaking.

Case 1

John's chest was tightening and breathing out was difficult. He was breathing like somebody who is running, and when you looked at his ribs they were very tight (Female caregiver, aged 29 years, Morogoro)

Case 2

Mariam was coughing and twitching, the eyes were white and she was not breathing well. This was because her ribs tightened and developed pneumonia (Female caregiver, aged 27 years, Morogoro)

Often the caregivers used more than one of these terms to express the breathing

problems that have occurred during a single illness episode.

Assessing Signs and Symptoms

In sum, these findings show that people use a variety of terms to express the recognized signs. For example, some caregivers referred to fever by calling it “hot body” (mwili wa moto), while others called it “heat in the body” (joto mwilini). These different terms carry slightly different meanings. The latter implies that “heat” is some kind of quality that can move in the body, for instance up and down. Fever sometimes rises to the head, sometimes stays in the abdomen or spreads through the whole body.

The second feature of our findings is the overlap of some of the symptoms mentioned for the different illnesses (table7). Fever, lack of interest to play and loss of appetite are related to all the illnesses while hot abdomen, difficulty in breathing, crying all the time, coughing and shivering are each attributed to three of the illnesses. Making sense of the cluster of symptoms in a systematic way is therefore not easy for the caregivers. Moreover, the illnesses malaria and degedege can both be forms of biomedical malaria, but their symptoms vary in important aspects.

Our findings indicate that there is a locally defined threshold along which particular symptoms or a cluster of symptoms is categorized as “normal” or “dangerous”. Symptoms like a hot body, lack of interest in playing and loss of appetite were often related with “normal fever” (homa ya kawaida). However, the assessment of this cluster of symptoms could change: if the symptoms did not cease after a certain period of time the illness was considered to be more serious. The duration of this time period could vary across the caregivers and might last from a few to several days. Another sign for the caregivers that the illness was more severe than supposed was the intensification of the symptoms, for example if mild fever changed to high fever. Changes in the assessment of symptoms also depend on the development of new symptoms and on the failure of home treatment. The following statements show the dynamics of symptom assessment:

Case 1

There is normal fever caused by keeping the child under the sun for long time. The body becomes hot and when given aspirin or panadol the child gets better. Then there is that fever which - when a child gets it - the body becomes hot, [the child] doesn't want to eat and if you take him to hospital and they investigate, they detect that the child has malaria. (Female caregiver, aged 20 years, Morogoro).

Case 2

After noticing that Mkude had *homa,* I decided to give him Panadol. He was fine for some time, but later the fever (*homa)* was back again. This time I suspected *malaria*, so I decided to take him to the dispensary. (Female caregiver, 35 years, Morogoro)

The findings show that there is an overlap of symptoms and a general fuzziness of symptom clusters that makes it difficult for the caregivers to find out with which kind of illness they are dealing.

Illness labeling

Illness labeling is a dynamic process in which several people may be involved. Previous experiences with particular illnesses of the caregiver and "significant others" are taken into account. In our case studies we wanted to know when caregivers assigned a specific label to an illness, whether they knew it themselves or whether they learnt it from somebody else.

Homa usually was one of the first symptoms by which caregivers recognized that their child was ill, and caregivers themselves used this term as first label to name the illness. Malaria and nimonia were labels caregivers brought home after they had been to a modern health facility. Before going there, they had called their child's illness homa, kifua (coughing) or kichomi (chest infection) or had not labeled the illness at all, as the following statements show:

Case 1

I first thought it was normal fever (homa ya kawaida) and I could see the child had fever. Now, when I took the child to hospital, they examined the child's blood and informed me the child had malaria. […] the child was not playing. I touched the child and the body was as if it was on fire, the body was very hot and was twitching. Now I and actually all the people here we don't have the expertise to know if it is malaria we just term it homa and that is it (Female caregiver, aged 29 years, Rufiji).

Case 2

I did not know at the beginning it was *nimonia* until when we had taken the child to the hospital where they said the child had *nimonia* (Female caregiver, aged 24 years, Morogoro).

Case 3

Doctors told me my child had *malaria*. I could only say my child had *homa*. We who have not been educated, we refer every illness *homa*. When I took my child there, I told them my child had *homa*, and they gave him an injection. (Female caregiver, 24 years, Rufiji).

For degedege, caregivers often relied on past experiences with the illness - either of their own or of other people. Often, the following pattern of illness-labeling emerged: when the caregivers encounter the typical symptoms of degedege like twitching, rolling of the eyes, etc. for the first time, they do not know with what kind of illness they are confronted. During the subsequent help seeking process, other people teach the caregivers the characteristics of degedege. Caregivers described a range of people whom they learned from about degedege for the first time. These include elders of all gender in the community, parents and other members of the immediate household, neighbours and healers.

Case 1

I personally did not know it was *degedege*, Halima my young sister was around when it happened and it was she who confirmed to me it was *degedege* (Female caregiver, 30 years, Morogoro).

Case 2

I was in the hospital admitted for my child. Other women admitted in the same ward saw my child twitching; they then told me that my child was having an attack of *degedege* (Female caregiver, 26 years, Rufiji).

Case 3

My parents told me that if I see the child's eyes roll-up and shivering at a time of having fever then I should know the child has *degedege* (Female caregiver, 25 years, Rufiji).

In addition to learning a particular illness labels for a concrete illness, caregivers also learn about related illness concepts and synonyms. Especially in Rufiji, people often linked *degedege* with poliomyelitis to which they referred either by the abbreviated form *polio* or the Swahili word for "paralysis" *(kupooza), (*see table8). This conceptual link was created by the observation that the arms and legs of children who suffer convulsions often go limp, loose all strength and look as if paralyzed. In one interview, a caregiver said she had learnt the term *polio* from health facility staff and explained that a *polio* vaccine protects children from this illness. To crosscheck this spontaneous statement we interviewed 47 mothers at an MCH clinic in Rufiji on the National Polio Immunization day. Nearly 53 percent of these mothers reported that *polio* was *degedege,* thus confirming the spontaneous information of the caregiver.

Some caregivers also reported that they learned other terms for degedege from their peers and community members. These include expressions like "childhood

illness" (ugonjwa wa kitoto), illness of falling (ugonjwa wa kuanguka), illness of the sky (ugonjwa wa juu), illness due to a worm (ugonjwa wa kichango) and twitching illness (ugonjwa wa kustukastuka).

The findings show that the caregivers cannot make a prompt and precise diagnosis when confronted with a specific illness episode. Discriminating between different febrile illnesses is difficult. In order to label the illnesses the caregivers involve other people from their social network as well as healers and people working at health care facilities. By this process, different experiences and labels are attributed to the illness in question. Therefore, the illness concepts are fuzzy: they include different associations and meanings which can vary regionally, situation ally and from one person to another.

Comparison of ILLNESS LABELS listed by the IMCI and mentioned by caregivers

The IMCI uses labels to name danger signs and illnesses that should be valid for the whole of Tanzania. We were interested to find out if these labels correspond with the local terms used by the caregivers of our study setting.

IMCI guideline	**Local terms used by caregivers**
convulsions *degedege*	convulsions *degedege*
childhood illness *ugonjwa wa kitoto*	childhood illness *ugonjwa wa kitoto*
illness of falling *homa ya kuanguka*	illness of falling *ugonjwa ya kuanguka*
illness due to a worm *mchango*	illness due to a worm *kichango*
-	polio *kupooza*

Table 10. Comparison of labels used for degedege in IMCI guidelines and those mentioned by caregivers in interviews, FGDs and case studies

Table 8 compares the labels used by the IMCI for degedege and those used by caregivers in our study area. The labels partly correspond: most of the labels have been found in both i.e. in IMCI guideline and from interviews with

caregivers. Caregivers from both districts reported additional labels such as polio and kupooza. Signs and symptoms mentioned by caregivers (table7) also differed with those listed in IMCI guidelines such as rolling eye-balls, twisted mouth, incontinence of stool and urine, high fever and froth coming out of the mouth. For them, degedege thus includes more features than those listed in the guideline. However, it should be noted that in general biomedical terms "convulsion" also means a cluster of signs including all of the locally recognized signs, and they are listed in other health education booklets, e.g. the Swahili versions of the Malaria Control Series (MHO 2001b, MOH 2001c). The following two narratives demonstrate the variety of danger signs that caregivers relate to degedege:

Case 1

You see the child becoming rigid. The eyes become much bigger than usual. The jaws lock. After a while the eyes go sideways and so does the mouth, the leg or the arm contracts as if becoming short. But there is also another kind where the child's body goes limp, only the parent can move the limbs. In this condition the leg is paralyzed. Even after recovery the child is mute (Female caregiver, 35 years, Rufiji).

Case 2

The child's body becomes rigid, the eye balls roll upward, the froth is coming out of the mouth, and he throws arms and legs. Before that the child can sit and play well with other children but suddenly you see that the child goes limp after standing upright and see him fall. (Male caregiver, 40 years, Morogoro).

Local concepts for degedege have been included in the IMCI guidelines. As Table 8 shows, they correspond roughly with those mentioned by caregivers in both districts. Only the connection with polio mentioned by caregivers is not included in the IMCI guidelines.

Sign	IMCI guideline	Local signs used by caregivers
breathing problems	fast breathing *mtoto anapumua kwa haraka*	fast breathing *kuhema harakaharaka*
	noisy breathing *pumzi za mtoto zina kelele nyingi*	-
	interrupted breathing *zinakatika katika*	-
	-	difficult breathing *kupumua kwa shida*
	-	forceful, laboured breathing *kuhema kwa nguvu*
	-	slow breathing *anapumua kidogokidogo*
	-	shallow breathing *anathema juju*
	-	superficial breathing *hahemi*
indrawn chest	chest indrawn *kifua kubonyea*	-
	-	ribs go in *mbavu zinabonyea ndani na kurudi / anabanwa mbavu / mbavu zinabana*
	-	chest pain *mbavu zinaingia ndani / kifua inachoma sana*
	-	ribs break *mbavu unafikiri zinavunjika*
stridor	stridor *strido*	stridor *Kupumua kwa sauti ya kukauka*

Table 11. Comparison of danger signs for nimonia mentioned by caregivers with those used in IMCI guidelines

Our findings are similar for nimonia as shown in Table 9. When health workers trained in IMCI ask the caregivers if the child has a cough or difficulty in breathing, the expected answers would fall into the categories fast breathing, noisy breathing or interrupted breathing. Except for the sign fast breathing, the caregivers use different terms, like difficult or laboured breathing. In addition, they sometimes also name symptoms that describe actually the opposite such as slow, shallow or superficial breathing. When health workers examine the child, they look for “indrawn chest” and for “stridor”. When caregivers observe the same signs, they use more descriptive terms. They do not speak of “indrawn chest” but of “ribs go in”, “chest pain” or “ribs break”. The following cases show again the variety of terms used to describe recognized symptoms:

Case 1

First it starts with small, small fever […] sometimes it becomes severe […], its outcome can be two-fold, it can turn out to be *degedege* or it can become *nimonia*. Now the signs of *nimonia* are really like this: shallow breathing until you are confused, yes, he breathes little by little, that *nimonia* that tightens. So, by our local name, they call it *bandama*, now in the hospital they call it stiffening of the body, by the local name they say *bandama.* (Female caregiver, 40 years, Morogoro).

Case 2

It makes you think that the ribs are breaking. He breathes heavily, has breathing problems. You can hear that the child cannot breathe out. Every time he breathes [it] sounds like Nhe! Nhe! Nhe! Body temperature increases highly; the ribs go in when breathing. (Male caregiver, 45 years, Morogoro).

Our findings for nimonia show only partial correspondence of the terms used for danger signs by caregivers and IMCI trained health workers. As the descriptive labels of caregivers express underlying illness concepts that provide meaning to the illness experience, difficulties in communicating or misunderstandings at health facilities are prone to arise.

DISCUSSION

After the introduction of the IMCI strategy in Morogoro Rural and Rufiji Districts, several questions arose: do caregivers of children younger than five years recognize signs and symptoms of common childhood illnesses? Which signs and symptoms do they recognize and how do they assess them? Do these signs and symptoms trigger help seeking actions and what kind of actions? Is there a correspondence between the assessment of caregivers and of the biomedical assessment of the IMCI guidelines? As the IMCI strategy is based on the recognition of signs and symptoms not only of health workers but of the caregivers and families and as the emphasis is on the danger symptoms and signs assessed at the health facilities and at home (Gove 1997; WHO & UNICEF 1995), the answers to these questions are important for the efficient use of the IMCI strategy.

We found that caregivers recognized promptly when their child fell ill. For this they relied on signs and symptoms that served as cues. These sensual cues can be grouped according to Helman's (2000) classification: A first group of signs and symptoms relate to changes in the bodily appearance of the child such as a yellowish coloration of the eyes noticed for malaria. The second group include (unpleasant) physical or physiological changes such as a hot body, loss of appetite or vomiting, while the third group refers to changes in bodily functions like twitching or difficult breathing. The fourth group encompasses behavioural and emotional changes like excessive crying or the refusal to play with others.

Our findings about symptom recognition in *homa*, *malaria* and *degedege* are similar to those of other authors working in Tanzania (Comoro et al. 2003; Hausmann Muela & Muela Ribera 2000; Hausmann Muela et al. 1998; Makemba et al. 1996; Minja 2001; Tarimo et al. 1998, 2000; Winch et al. 1996), in Kenya (Nyamongo 2002) and Ghana (Agyepong 1992). There is a broad category which comprises (mild) febrile illnesses, illnesses in general as well as fever as a symptom for other illnesses. This mild form, called homa in Swahili, is continuously evaluated. Three factors govern the assessment: The duration of symptoms, their intensification and the showing up of new symptoms. How

quickly the caregivers reacted when symptoms did not cease varied from one person to another. Contrary to the mild symptoms, the intensification and the showing up of new signs immediately trigger help seeking actions outside the household. These symptoms are considered to be life threatening; they may indicate degedege or nimonia.

Our interpretation of these findings, however, slightly differs because we emphasize the cultural significance of illness labelling. This fact has been neglected in the social science literature on malaria and in the IMCI approach which focuses on symptom recognition. We argue that the illness label is not just a name but a diagnostic clarification which includes information about treatment. To find the illness label, people seek advice from neighbours, household members, elders of the community, traditional healers and staff at modern health facilities.

Malaria and nimonia are illness labels people have appropriated from modern health providers. In everyday conversation, people nowadays often use these terms. As several studies on malaria in districts nearby our study area (Comoro et al. 2003; Fivawo 1986; Hausmann Muela & Muela Ribera 2000; Hausmann Muela et al. 1998; Minja et al. 2001; Tarimo et al. 1998, 2000; Winch et al. 1996), and elsewhere in Africa (Agyepong 1992; Ahorlu et al. 1997; Brieger 1994; Helitzer-Allen & Kendall 1992; Helitzer-Allen et al. 1993, 1994; Mwenesi et al. 1995; Ramakrishna & Brieger 1987; Ramakrishna et al. 1989) reported, local understandings are not equivalent but correspond in several ways with the biomedical concept of malaria.

Contrary to malaria, the diagnosis degedege usually derives from non-medical sources. This partly explains the conceptual distinction between the labels degedege and malaria (both in the local and in the biomedical sense). The few people in our study who made the link had received some information from modern health providers. In Morogoro and Rufiji District, the illness label clearly pointed to the source of information.

Often caregivers reported to learn different labels from different sources for the same illness as they consulted multiple people with different backgrounds. This often leads to problems in the interpretation and conceptualisation of the illness, as the caregivers have to make sense of sometimes conflicting information.

We thus use the term “fuzzy concept” rather than “medical syncretism” (Hausmann Muela et al. 2002) because the latter emphasizes the integration of illness interpretations which are rooted in different medical traditions. What we observed was rather different. When a child fell ill, the usually female caregivers closely observed the often changing signs and searched for diagnostic clarification but their conceptualizations of illness remained rather vague, fragmented and flexible. Their understandings are not standardized or static, they are discrete and nowadays often isolated bits of folk wisdom.

These findings have important implications for IMCI on the family and community level. Not only the recognition of symptoms but also the labelling of illnesses is a learning process that should be taken into account. Labelling is not simply a matter of perception and naming; it is a complex interactive process of interpretation and evaluation. Innovative and participatory approaches are required to improve caregivers’ understandings, not only of symptoms but also of illness labels and the links between them, and increase the quality of community triage.

In our study we have further compared danger signs for degedege and nimonia used in the IMCI guidelines and by caregivers. We found that despite some overlaps the signs recognized by caregivers differ in critical ways from those used by IMCI trained health workers. In most cases, caregivers mentioned more symptoms than those included in the IMCI guideline. This holds especially true for nimonia: not only do caregivers mention additional signs, but also they describe signs that are the exact opposite of some listed in IMCI guidelines, e.g. “slow breathing” in contrast to “fast breathing”. Another example of critical difference in understanding is the conceptual association of *degedege* and poliomyelitis and the related ideas about vaccination. Fuzziness in this sense leads to misunderstandings at health facilities and to faulty diagnosis.

For counselling, we thus strongly recommend that health professionals should find out first what people already know about the illness, to go through a process of clarifying their knowledge and then add or explain whatever information is needed. A similar strategy is needed for a systematic community IMCI strategy. Such a two-pronged approach will contribute to reducing fuzziness and increasing the specificity and sensitivity of childhood illness concepts based on

people's everyday language.

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4.3 Illness aetiology: Explaining IMCI Related Illness: Intra-cultural Variation in Eastern Tanzania

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ABSTRACT

This paper argues that careful analysis of local aetiologies is equally important for appropriate care-seeking as prompt recognition of danger signs and symptoms, a fact neglected in the current IMCI strategy. “How” and “why” questions are not only a major concern for the afflicted persons and their families, they also direct care-seeking, although they do not determine it in a simple way. Our study assesses the relative importance of local etiologies for IMCI related illness categories in Eastern Tanzania, combining qualitative and quantitative methods. It shows that community etiologies of IMCI related illness span from natural to supernatural causes and refer to pollution, spirits and witchcraft, concepts which cross-cut the biomedical categorization of disease. Nearly all illnesses can be assigned to supernatural causes which require expertise of traditional healers, but only for a small proportion of all caregivers this is the unquestioned first choice. Others do not really worry about causes, and the majority remains ambivalent and pragmatic. They have a rough idea about the “why” and “how” of a specific illness and search for experts who see and know more, either through techniques of divination or through the microscope. We suggest that mothers should be encouraged and supported in their pragmatic ambivalence to make most effective use of the available options. This requires the development of information education and communication (IEC) messages that take women’s questions seriously and answer them in accurate yet simple terms. It also calls for best practice with regard to diagnostics and therapy to convince through the evidence of effective treatment.

INTRODUCTION

Understanding the causes of illness is an integral part of care-seeking. Up to now, this topic has received little attention in the literature on IMCI. Even reviews of research on the family and community level (e.g. Hill et al. 2004) emphasize the recognition of symptoms, illness labeling and treatment seeking but hardly pay attention to the relative importance of local etiologies for care-seeking.

For social scientists, on the other hand, aetiology plays an important role because it responds to the questions of "how" and "why" people fall ill (Heggenhougen et al. 2003). These are questions of high cultural and social significance in every society, also in Africa, especially in cases of "high density", when illness is perceived in a broader context of affliction and misfortune fraught with tension, anxiety, and fear (Janzen 1997: 278). Ethnographic research on "low density" cases, for instance common childhood illnesses like diarrhea, has shown that many societies also refer to a wide range of natural causes like weather, bad food, or dirty water (Pelto, Bentley and Pelto 1990:260-261). Generally speaking, societies around the globe consider illness to be caused either within the individual, in the natural world, in the social world or in the supernatural world (Helman 2000: 91).

Although these lay models are not based on scientifically correct principles, they have an internal logic and consistency which assist the sufferer of the illness – or the caregiver if the patient is a child - to figure out what has happened and why. It is thus one of the first tasks in social science research on IMCI not only to examine local illness categories and diagnostic features but also etiologies for category. Only once they are known can the relative importance of these etiologies for care-seeking be assessed.

While studies on the etiology of IMCI related illness are lacking for Tanzania, several investigations have focused on local etiologies of febrile illness, for instance in the neighboring district to our study area of Kilombero District (Hausmann Muela et al. 1998; Hausmann Muela and Muela Ribera 2000), in Muheza District (Oberlander and Elverdan 2000), in Kibaha District (Tarimo et al. 1998; Tarimo et al. 2000; Comoro et al. 2003), and in Bagamoyo District (Makemba et al. 1996; Winch et al. 1996). All of them have identified local concepts that are related to malaria and found that unfortunately convulsions were

seen as a distinct illness category with its own etiology, directing caregivers to traditional healers and thus causing a delay in appropriate treatment. The aim of our study is to contribute to this strand of research with an investigation in a new geographical region, the Morogoro Rural and the Rufiji districts, widening the thematic focus from malaria to IMCI.

Another strand of research investigated “traditional healing” in Tanzania. Basic sets of ideas of health, sickness and healing found in Tanzania are actually also found elsewhere in Sub-Saharan Africa (Janzen 1997): A central notion can be translated as balance, equilibrium or harmony. Illness is often considered as a state in which this balance has been disturbed either within the body, for instance between different humors (following the Islamic or galenic tradition), between living persons or between a person and the natural and spiritual community. Another set of ideas refers to (ritual) purity versus pollution, often expressed symbolically as coolness and grace versus heat and conflict. Ill health can also be a result of witchcraft (uchawi) or a manifestation of spirit possession (Abrahams 1994, Mesaki 1994, Green 1996).

As Green (1994) describes for the Pogoro, witches are motivated by jealousy and use powerful substances (“medicine”) to harm crops and to cause sickness, failure and death among their fellow people. An illness caused by witchcraft cannot be treated at health facilities. Traditional healers use divination to find out the source of illness as well as the appropriate remedy for the ailment.

Different kinds of spirits can posses people and make them ill. These include ancestor spirits, spirits that relate to Islamic beliefs (shetani, jini, ibilisi and ruhani) and spirits that refer to nature (for example spirits that live under ground, under water or in trees as described for the Zaramo). Sometimes spirits are also called (u)pepo, a word which refers to wind. The different names and concepts of spirits vary regionally and are sometimes also used interchangeably. Spirits have to be appeased or exorcised in order to heal an afflicted person. (Erdtsieck 1997, Green 1996, Swantz 1995).

Swahili medicine, especially along the coast, is pluralistic and offers sufferers a choice of therapies based on various traditions (Whyte 1989, Beckerleg 1994). Concepts of balance, pollution, witchcraft and spirit possession co-exist and sometimes overlap. Pepo does not only mean spirit but is also considered to be

the inner force or inner spirit of a person whose state of balance is essential to the person's well-being (Erdtsieck 1997). This balance cannot only be disturbed by internal but also by external causes as for example by witchcraft. In the context of medical pluralism, individuals and their families move between and draw upon diverse traditions in care-seeking.

Our study also contributes to this research orientation and examines whether the etiology of childhood illnesses draws on any of these local traditions.

STUDY AREA

The study was conducted in two rural districts in Eastern Tanzania, where IMCI has been introduced in 1996. The Morogoro Rural District is located about 180 km from Dar es Salaam along the highway to Zambia. Mountains and plains mark the topography. The population is ethnically heterogeneous. The main ethnic groups are the Luguru, the Kwere, the Kutu and the Zigua. Most people are either Christians or Muslims with only 2% of the population following other religious beliefs (Mswia et al 2002).

Rufiji District is situated 178 km South of Dar es Salaam on the coast of the Indian Ocean. The overall mean altitude of the district is less than 500 meters, and its vegetation consists mainly of tropical forests and grassland. A prominent feature is the Rufiji River with its large floodplain and delta. Rufiji District is home to several ethnic groups. The Ndengereko are the largest group and considered as the original inhabitants of the area. Other groups include the Nyagatwa (who live in the delta area), the Matumbi, Ngindo, Pogoro and Makonde. The majority of people are Moslems with few Christians and followers of traditional religions (Mwageni et al 2002).

The climate in both districts is characterized by hot, dry weather and two rainy seasons from October to December and from February to May. For livelihood, people depend mostly on subsistence farming and small-scale income generating activities. In Rufiji District an additional important income-generating activity is fishing in the river Rufiji. In both districts Swahili is used as lingua franca.

Health facilities include hospitals (3 in Morogoro Rural District, 2 in Rufiji District), health centers (9 in Morogoro Rural District, 5 in Rufiji District) and dispensaries

(81 in Morogoro Rural District, 50 in Rufiji District). It is estimated that 85% of the people live less than 5 km from a health unit in both districts (Mwageni 2002; Mswia 2002). In addition, over the counter drugs are available from private shops and kiosks. Healers drawing on diverse traditions also practice in the study area. Some specialize more in herbal medicine *(mitishamba)*, others perform rituals to appease spirits of nature, ancestral spirits *(mizimu)* or spirits related to Islamic religion *(jini, shetani, upepo)*.

STUDY DESIGN

Field research was conducted in three interrelated modules. We first examined common understandings of IMCI related illnesses on the community level (Module 1). The focus then narrowed on actual cases which were recorded as illness narratives to get a close-up view of care-seeking (Module 2). In the third module, further cases were systematically recorded using semi-structured interview guides to examine the distribution of beliefs and practices in the communities.

For the first and second modules (1998-2000) we divided each district into four zones according to cultural and geographical criteria and selected two villages per zone. In each village, we conducted interviews with the household head and the principal child caregiver in ten households, as well as with a range of key informants including mothers whose child had recently been sick, traditional healers and village health staff. In the third module (1999-2001), we modified the sampling strategy for quantitative assessment. For each zone, a multi-stage cluster sampling procedure (village-hamlet-household) was used to select 20 households with children of under-five. The households formed a cohort whom we visited twice a year to record home management of illness over time.

With the permission of the study participants, interviews and group discussions were recorded and transcribed. All interviews and FGDs were conducted and recorded in the *lingua franca* Kiswahili to maintain the accuracy and richness of the data. Transcripts of qualitative and textual data were then coded and interpreted following a content analysis method (Silverman 2001) supported by Text Base Alpha qualitative analysis software (Tesch 1999). For the quantitative data-descriptive analysis was done to address essential research questions for TEHIP

using SPSS for windows version 10 frequency tables.

Findings

During the in-depth interviews and the FGDs of the situational analysis in Module 1, respondents in both study districts seemed very much concerned about the "how" and the "why" of local illnesses. They often used the word chanzo meaning "source" or *sababu* for "cause".

Morogoro District

Homa	Degedege	Malaria	Kuharisha	Pneumonia	Kimeo	Surua	Utapiamlo
Weather	Bad wind	Mosquito	Contaminated water	Cold weather	Unknown	Bad wind	Inadequate food
Dust	High fever	Bad wind (shetani)	Contaminated food	Spirits	Born with	God's will	Feeding on leftover
Mosquito	Bird	Insects like bedbugs	Dirty environment	God's will	Age related	weather	Early pregnancy
Cold	Insect	Cold	Teething	Witchcraft	God's wish	Dirty environment	Worms
Sun	Spirits	God's wish	Bad breast milk	Dust		High fever	
	"malaria"		Bad food	Heavy worms in body		Sun	
	Worm			Bad air			

Rufiji District

Homa	Degedege	Malaria	Kuharisha	Pneumonia	Kimeo	Surua	Utapiamlo
Weather	Bad wind	Mosquito	Contaminated water	Cold weather	Unknown	Infection	Inadequate food
Bad wind	High fever	Fever	Contaminated food	Spirit	Congenital	High fever	Anaemia
God's will	Bird	Cold weather	Dirty environment	Witchcraft	Age related	Weather	Indigestion
Anaemia	Spirits	High fever	Eating new food			Sun	Congenital
	Witchcraft		New teeth				Worms

Table 12. Qualitative range of explanation of causes of IMCI related illnesses

Those who participated in interviews and discussions identified many causes for the eight core conditions related to IMCI (see Table 10). Most of these causes were not exclusive for any illness, with the exception of mosquitoes and a spirit bird and insect called *degedege* in Morogoro and *kokotolo* in Rufiji. Mosquitoes were only mentioned as cause of malaria, the spirit bird or insect only as cause of convulsions.

Case 1: Mosquito as cause of malaria

The illness was caused by mosquito. […] When a mosquito bites a person with malaria and then bites you, you get it […] although we go into the net, children can get bitten in the evening and get it. (Female caregiver, 32 years, Morogoro)

Case 2: Mosquito as cause of malaria

Malaria is caused by mosquito […] mosquito have malaria parasites (*vidudu vya malaria*) and when you get bitten you get infected. (Female caregiver, 38 years Morogoro)

Case 3: *Degedege* as cause of convulsions

[…] we the Luguru and in fact other tribes we believe that something has fallen over the child (*mtoto ameangukiwa*) when *degedege* occurs […] we mean *degedege* fell on the child. We believe a bird called *degedege* is in the sky, and if it flies over [something] falls on children. (Female caregiver, 45 years, Morogoro)

Case 4: *Degedege* as cause of convulsions

The reason for the illness was a big wild bird which normally flies over at night […] When it flies over the roof of a house, and if it happens that there is a child inside for sure the child will develop *degedege.* (Female caregiver, 42 years, Morogoro)

Case 3: Devil as a cause

> […] In my opinion evil spirits causes *degedege*. There is no other explanation other than evil spirit. If a child happens to pass by a big tree then it is possible for him/her to be attacked by that evil spirit…(Male respondent, 47 years, Rufiji).

For both conditions, malaria and convulsions, as well as for all the others, a range of causes was listed. At one end of the spectrum is the "high density" illness *degedege* marked by sudden convulsions which creates much fear and anxiety in local communities. Causes mentioned cover the whole range from natural (e.g. climate, malaria) to personal (e.g. feeding bad breast milk or dirty food) to social (e.g. evil eye, witchcraft) and supernatural causes (e.g. *upepo*: "bad wind", spirits).

Case 1: *Malaria* fever as cause of *degedege*

> […] It was caused by *malaria* which was still in the body of the child […] because the treatment he got […] I think *malaria* was still in the body. When the *malaria* fever *[homa ya malaria]* increases and temperature goes up, a child develops *degedege*. (Female caregiver, 34 years, Morogoro)

Case 2: Climate change and fever as cause of *degedege*

> […] The cause of *degedege* is fever. Initially we used to live in Zanzibar, and when we moved to Bungu, due to the change in climatic conditions, the child developed fever which resulted in *degedege*….. (Female caregiver, 29 years, Rufiji)

At the other end of the spectrum is the "low density" illness *homa* which is mainly attributed to natural causes, although this may be a methodological bias, as we argue below.

Even though *kuharisha* (diarrhea) and *nimonia* (pneumonia) as well as *surua* (measles) are also considered as very severe conditions often leading to rapid death or disability (see Chapter 1), the "how" and "why" question is not much elaborated in the local tradition, possibly because these concepts are relatively new and associated with the biomedical tradition brought from outside. On the

other hand, not every concept rooted in local tradition is culturally elaborated in terms of explanations. *Kimeo*, a condition with an elongated uvula as diagnostic feature, is said to be either inherited or associated with childhood.

These in-depth interviews and FGDs were conducted with local experts including elderly persons with much experience, traditional healers, village health staff as well as caregivers or household heads whose children had suffered from specific illness or were regarded as knowledgeable people about the illnesses in the community. The aim of the interviews was to learn about local meanings of illness in general (Module 1).

Perceived Cause	Homa n=1018	Degedege n=870	Malaria n=1030	Diarhea n=947	Niumonia n=924	Kimeo n=701	Surua n=376	Utapiamlo n=408
Don't Know	40	52	8	21	26	83	73	12
Mosquito	22	5	84	1	7	0	2	0
Cold	13	1	2	1	57	1	1	0
Bad wind/spirit/witch	1	5	0	0	1	0	1	11
Nutrition	0	0	0	1	0	0	0	71
Contaminated food	1	0	0	33	0	0	0	1
High fever	1	17	1	0	3	1	3	0
Pain in spleen (wengu)	0	0	0	0	0	0	0	0
Weather	15	3	2	3	4	2	6	0
Malaria	0	7	0	1	1	0	1	0
Congenital	0	0	0	0	0	7	1	0
Siting under sun	4	0	0	0	0	0	1	0
Outbreak	1	2	0	1	0	1	4	0
Others	1	6	0	8	5	1	9	2

Table 13. Causes by frequency of mentioning in percentage (%), Morogoro Rural District

Perceived Cause	Homa n=861	Degedege n=715	Malaria n=746	Diarrhoea n=816	Pneumonia n=477	Kimeo n=838	Surua n=565	Utapiamlo n=423
Don't Know	36	41	14	18	37	64	63	16
Mosquito	17	2	78	0	1	0	2	0
Cold	11	0	1	0	46	0	1	0
Bad wind/spirit/witch	0	20	1	0	1	0	2	9
Nutrition	2	0	0	0	1	1	1	67
Contaminated food	0	0	1	38	0	0	1	1
High fever	1	0	2	1	4	0	14	0
Pain in spleen (wengu)	0	0	0	28	0	0	0	0
Weather	17	13	1	1	3	0	8	0
Malaria	0	2	0	0	0	0	0	0
Congenital	0	0	0	0	0	17	0	0
Siting under sun	5	0	0	0	0	0	0	0
Outbreak	5	0	0	3	1	8	2	0
Others	3	9*	0	5	3	6	7	4

Table 14. Causes by frequency of mentioning in percentage (%), Rufiji District. (*ear discharge, bird, bad weather, early pregnancy, god)

The picture we got in Module 1 slightly changes if we examine case studies of concrete illness episodes recorded partly Module 1 but more in Module 2 and 3. The range of causes mentioned for each illness becomes even broader indicating high intra-cultural variation. A closer look at *homa*, for instance, shows that even a "mild" condition is interpreted differently by different people or in different contexts. The most frequently mentioned cause for *homa* was weather, also an explanation recorded in the first module (see Table 11). Either the illness was seen as caused by weather changes, cold weather or the hot sun. Some care takers linked *homa* to mosquitoes without mentioning malaria. They explained that a mosquito bite may lead to *homa*. This finding was consistent across the study districts and with data from semi-structured interviews on the same question. *Homa* has, however, also been attributed to pollution and/or to supernatural causes. Caregivers referred to *upepo* (lit: "bad wind"), *jini* or *shetani* (spirits), and sometimes mixed these beliefs with *uchawi* (witchcraft).

> Case 1: *Homa* caused by dirty blood *(damu chafu)*
>
> The *homa* was caused by dirty blood which was caused by clouds. […] But the *homa* was also caused by the shadow of his late father because the child was still having memories of him. (Female caregiver, 25 years, Morogoro)
>
> Case 2: *Homa* caused by mosquito
>
> […] Mosquito *(mbu)*. If the child gets bitten by mosquito he then develops *homa*. (Female caregiver, 26 years, Morogoro)
>
> Case 3: *Homa* caused by sun
>
> […] playing for a long time under the sun. You know, she can leave in the morning, without coming back for lunch and returns only in the evening. She plays too much, and it is from there she develops *homa*. (Female caregiver, 25 years, Morogoro)

Case 4: “Bad wind”, spirit and witchcraft as causes of *homa*

> […] My child has been hit by evil wind *(upepo mbaya)*, I think he has a *jini* in his body […]. He got hit by the *jini* on his way back home, and this is causing the illness. […] When you have a healthy looking child or because the child is cute, people might decide to harm him by witchcraft […]. The child was attacked by *jini* because I boasted about my child. […] Because I love my child they have decided to kill him so that I won’t have a child anymore (Female caregiver, 48 years, Rufiji).

As a general rule, more serious causes are only considered in cases of recurrent or very sudden and high fever. This also applies to other illnesses that may become reinterpreted as having a “deeper” cause if they cannot be cured.

While case studies in the form of narratives (both Module 1 and Module 2) and semi-structured interviews (Module 3) recorded a broader range of causes, the latter did not elicit certain types of causes. As a cause of homa, *upepo* has been noted only once, and also for other illnesses, *upepo* and other supernatural and social causes have been hardly reported, especially in Morogoro. Only 5 percent of the respondents spoke of *upepo* as a cause of *degedege*. In Rufiji, 20 percent used *upepo* as an explanation of convulsions. These figures provide added evidence for a hypothesis we made based on Module 1 and 2 data, namely that there is a regional difference in terms of illness explanations between inland and coastal regions. However, in neither of the two districts did caregivers explicitly mention the spirit bird and insect *degedege* or the spirit insect *kokotolo*.

Furthermore, in the case studies of Module 3, a relatively high percentage (> 30 percent) of caregivers has been classified as not knowing the cause of the illnesses *homa, degedege, kimeo* and *surua* across both study districts. This picture changes with findings from Module 2 when we recorded case studies in the form of illness narratives. While some caregivers also said they did not know and did not add anything when prompted, others hesitated at first and then articulated their considerations. They underlined their explanatory effort by saying *kusema kweli* (“to say the truth”, to be honest, to be frank).

With regard to *homa*, several women suggested that fevers did not really have a

cause because they were just part of growing up:

> To be frank I don't know what causes this illness. What I know is that this is *homa* and affects mainly children. (Female caregiver, 24 years, Morogoro)

> I don't know what caused it. I presume it is part of the growth process of the child because a child cannot grow up without experiencing an episode of *homa*. (Female caregiver, 40 years, Rufji)

Another woman did not really see a cause as the fever hit suddenly:

> To say the truth I don't know what the cause was because the *homa* was of sudden onset. We had left home in the morning together with the child, and he was not sick at all. (Female caregiver aged 26 years, Morogoro)

In terms of *malaria*, several women felt trapped between contradictory advice (see also 4.1.2).

> I don't see what caused the illness. […] I only realized he was sick. My brother in-law touched him and said it was evil wind *(upepo)*. […] At the dispensary, he was examined, and I was told the child had malaria. (Female caregiver, 24, Rufiji)

Some compared their observations with the teachings about mosquito nets and found the evidence contradictory.

> What I know is that *malaria* can be caused by mosquito when you are bitten. […] Now here at Nyandira [a village], there are no mosquitoes. I don't understand what caused the illness. (Female caregiver, 25 years, Morogoro)

> Some people say it is the mosquito, but I don't think so because there are parents whose children use mosquito nets and yet they suffer from *malaria*. How do they get it? To say the truth I don't understand more than that. […] But in what concerns mosquitoes, I don't agree [with what I am told]. There are people who use mosquito nets and still get *malaria*. If it was mosquito that causes *malaria* then those people shouldn't be getting *malaria.* […] For me I think that sometimes the illness just happens. (Female caregiver, 37

years, Morogoro)

> To say the truth I don't know the cause. Maybe it depends on how each individual was created. I say so because there are some children who do not get the illness until they are grown up¨, while others suffer from it, and we all live in a similar environment. I ask myself "why"? I have no answer. You are an expert. I hope you will educate me on its cause. (Female caregiver aged 30 years, Morogoro).

"Traditional" ideas about *degedege* were sometimes attributed only to "others".

> I don't know the source myself. [...] As I told you, I don't know. They say it comes from an insect like a butterfly (*mdudu kama ngombalima*). […] It is the elders who say so. Even myself, I don't understand fully. […] They say that it is the insect which makes the child get *degedege.* (Female caregiver, 40 years, Morogoro)

As with homa, some women did not really perceive a cause as the child was suddenly seized by convulsions.

> To say the truth I don't know the source of the illness […] because the illness was like a sudden attack without prior illness. (Female caregiver aged 28 years, Morogoro)

Other women pointed out that they are not experts meaning that they do not have the expertise (*utaalam)* to know the sources of illness. In their view, it is up to people who are knowledgeable or who have particular expertise to tell them. In this context, people with expertise include modern care health staff as well as healers.

> This I don't understand because I am not an expert. I only know that my child is sick and what to do may be to go to the hospital or somewhere else in order to get treatment. (Female caregiver, 26 years, Rufiji)

> The devil (*shetan*) is the enemy who aims to harm the child. I can't explain what he looks like because he can't be seen by eye; only traditional healers say they are able to see them […]. It attacks from the toilet. […] That is

where it stays before attacking. (Female caregiver, 30 years, Morogoro)

For malaria, however, most women clearly identified a main cause, namely mosquitoes (84 percent in Morogoro, 78 percent in Rufiji), and a similar consensus existed for malnutrition (inadequate food intake: 71 percent for Morogoro, 67 percent for Rufiji), pneumonia (cold: 57 percent in Morogoro, 46 percent in Rufiji) and diarrhea (contaminated food: 33 percent in Morogoro, 38 percent in Rufiji).

From a biomedical perspective, some of our findings draw attention to misperceptions. In the case of *surua* (measles) most caregivers neither knew the cause nor associated the illness with an outbreak. *Degedege* (convulsions) was hardly ever seen as caused by mosquitoes. About 10 percent of caregivers in both districts considered *utapiamlo* (malnutrition) as having a supernatural cause *(upepo)*. In Rufiji, the local explanation of diarrhea by *wengu* (pain in the spleen) warrants further clarification.

DISCUSSION

While the IMCI strategy emphasizes prompt recognition of danger signs and symptoms, anthropologists and other social scientists consider local aetiologies as equally important for appropriate care-seeking. As they have shown for diarrhoea (Pelto, Bentley and Pelto 1990, Nichter 1993), ARI (Nichter and Nichter 1996) and malaria (Heggenhoughen et al. 2003), the "how" and "why" questions are not only a major concern for the afflicted persons and their families, they also direct preventive and curative action. If, for instance, the mosquito is not considered a vector in malaria transmission, sleeping under an ITN does not make much sense in terms of malaria prevention. While this seems obvious, the link between etiology and care-seeking is far from simple. Aetiology does not determine – in the strict sense of the term - but influence care-seeking. Explaining illness forms part of often complex decision making processes following initial symptoms recognition. This has also been clearly demonstrated for malaria related illness in Tanzania (Hausmann Muela et al. 1998, Hausmann et al. 2002, Hausmann Muela and Muela Ribera 2003). It is therefore imperative to assess the relative importance of local aetiologies for IMCI related illness categories in particular localities.

Our data confirm that local understanding of the "how" and "why" of childhood illness is partly rooted in traditions which differ markedly from biomedicine. Traditions in Morogoro and Rufiji follow a logic which has been reported from many parts of the world (Helman 2000) and centers around four main sources of ill-health: nature, personal behavior, social relations and supernatural powers. In our study, community views of IMCI related illness span from natural to supernatural causes and referred to pollution, spirits and witchcraft, concepts which cross-cut the biomedical categorization of diseas.

A common pattern is that illness is first explained in terms of weather (e.g. *homa*, "fever; *nimonia,* "pneumonia"; *surua,* "measles"), inadequate or contaminated food (*utapiamlo,* "malnutrition"; *kuharisha,* "diarrhea") or just as a normal part of growing up (homa, "fever). Mosquitoes have become a well accepted natural cause, mainly for malaria but also for *homa, nimonia* and *surua*. The second pattern is that these same illnesses are explained with reference to supernatural powers such as *upepo*

(bad wind), *mizimu, jini* or *shetani* (spirits) or *ujiawi* (witchcraft). In our overview this has been documented for all illnesses. A third pattern, linking the first two is that if any of these illnesses do not go away and/or turn into a serious and even life-threatening condition, they are more likely to be interpreted in terms of supernatural causes. Very sudden onset of an illness, for instance in the case of *homa* or *degedege*, has also been taken as an indicator of supernatural inference.

From biomedical perspective the consequences of these patterns warrant attention. If mild illnesses are considered as normal or natural occurrences, these aetiologies may delay proper treatment and foster misguided prevention measures (Heggenhoughen et al. 2003). The same problems arise, if caregivers become too preoccupied with the "why" and, therefore, postpone appropriate treatment. In Morogoro and Rufiji, as in many other parts of Africa and elsewhere (Williams and Jones 2004), this seems to happen in the case of *degedege*, often with fatal consequences.

What key informant interviews and FGDs with local experts on community views of childhood illness do not bring to light is the sequence of events. As our case studies have demonstrated, nearly all illnesses can be assigned to supernatural causes which require expertise of traditional healers, but only for a small proportion of all caregivers this is the unquestioned first choice.

There is remarkable intra-cultural variation, but the caregivers in our case studies fall into three groups: Some attributed a specific cause to a specific illness and acted accordingly, whether this meant to seek help from a traditional healer or a health facility. Others, on the contrary, neither knew the cause nor became very active. And a third group was ambivalent and pragmatic, a pattern found again in many parts of the world (Lock and Kaufert 1998). Explanations available on the community level present different options, but they are not always considered appropriate for a concrete illness episode.

This ambivalence has not been captured in case studies conducted with a semi-structured interview guide, leaving little space for recording narratives. It was mainly during home visits of more informal character during Module 2, when villagers felt more familiar with the researchers who had lived with them for several weeks or months, that they articulated their uncertainty and ambivalence.

To feel uncertain when confronted with illness or another misfortune is neither a new nor a specific experience. It is and has probably been quite common, especially in societies where advanced science and technology are not part of everyday life. This experience creates a world view and an everyday practice which has been aptly called the “pragmatics of uncertainty” (Whyte 1997).

Seen against this background, it seems clear why caregivers often have only a rough idea about the “why” and the “how”. They search for experts who see and know more, either through techniques of divination or through the microscope. Medical pluralism has a long history and continues to create new options, also in contemporary Tanzania and along the Swahili coast, and this is reflected in our findings concerning childhood illnesses. In their search for explanations, caregivers draw on different strands knowledge, recur to a range of available ideas, emphasize certain elements, weigh the relationships between them and construct their individual views.

CONCLUSIONS

Local etiologies should be as carefully assessed as the local recognition of symptoms assigned to illness categories. Such an analysis helps to identify explanations of illness which inhibit prevention or delay appropriate treatment. Mothers should be encouraged and supported in their pragmatic ambivalence to make most effective use of the available options. This requires the development of IEC messages that take women's questions seriously and answer them in accurate yet simple terms. It also calls for best practice with regard to diagnostics and therapy to convince through the evidence of effective treatment.

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4.4 Impact: Care-Seeking Patterns for Fatal Malaria in Tanzania

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ABSTRACT

Background:

Once malaria occurs, deaths can be prevented by prompt treatment with relatively affordable and efficacious drugs. Yet this goal is elusive in Africa. The paradox of a continuing but easily preventable cause of high mortality raises important questions for policy makers concerning care-seeking and access to health systems. Although patterns of care-seeking during uncomplicated malaria episodes are well known, studies in cases of fatal malaria are rare. Care-seeking behaviours may differ between these groups.

Methods:

This study documents care-seeking events in 320 children less than five years of age with fatal malaria seen between 1999 and 2001 during over 240,000 person-years of follow-up in a stable perennial malaria transmission setting in southern Tanzania. Accounts of care-seeking recorded in verbal autopsy histories were analysed to determine providers attended and the sequence of choices made as the patients' condition deteriorated.

Results:

As first resort to care, 78.7% of malaria-attributable deaths used modern biomedical care in the form of antimalarial pharmaceuticals from shops or government or non-governmental heath facilities, 9.4% used initial traditional care at home or from traditional practitioners and 11.9% sought no care of any kind. There were no differences in patterns of choice by sex of the child, sex of the head of the household, socioeconomic status of the household or presence or absence of convulsions. In malaria deaths of all ages who sought care more than once, modern care was included in the first or second resort to care in 90.0% and 99.4% with and without convulsions respectively.

Conclusions:

In this study of fatal malaria in southern Tanzania, biomedical care is the preferred choice of an overwhelming majority of suspected malaria cases, even those complicated by convulsions. Traditional care is no longer a significant delaying factor. To reduce mortality further will require greater emphasis on recognizing danger signs at home, prompter care-seeking, improved quality of care at health facilities and better adherence to treatment.

INTRODUCTION

Background

Malaria continues to be the largest single component of the burden of disease in sub-Saharan Africa, even though simple, effective and affordable treatments exist. Malaria's pervasive morbidity and high mortality persist because of failed transactions between those at risk of malaria transmission and available preventive and curative health systems. The consequence is not just an intolerable burden for individuals, their families and national health systems, but is also a devastating and continuing impediment to socio-economic development on the continent. Unlike HIV and TB, the other major fatal communicable diseases in Africa, malaria deaths can be prevented by prompt treatment with relatively affordable and efficacious drugs. Yet this goal continues to be elusive. The paradox of a continuing, but easily preventable, cause of high mortality raises important questions for policy makers and health systems in Africa.

Malaria in Tanzania. The United Republic of Tanzania has a population of 34.5 million, all of whom are at risk of malaria. However, endemicity and risk of transmission varies and have recently been mapped by the MARA collaboration [1](Figure 1). This GIS-based analysis reveals that 75% of the population is subject to stable perennial or stable seasonal malaria transmission; 8% to unstable highly seasonal transmission; and 17% to no malaria transmission in the average year, but still at risk of epidemic malaria. Tanzania has the third largest population at risk of stable malaria in Africa after Nigeria and the Democratic Republic of Congo (MARA-Lite Software 3.0.0, http://www.mara.org.za). Malaria is the leading cause of out-patient and in-patient health service attendance for all the ages and the leading cause of death in both children and adults in all regions of Tanzania [2]. In Tanzania, malaria is believed to be directly or indirectly responsible for about 16 million annual malaria episodes and 100,000 to 125,000 annual deaths (70-80,000 in under-fives) [3].

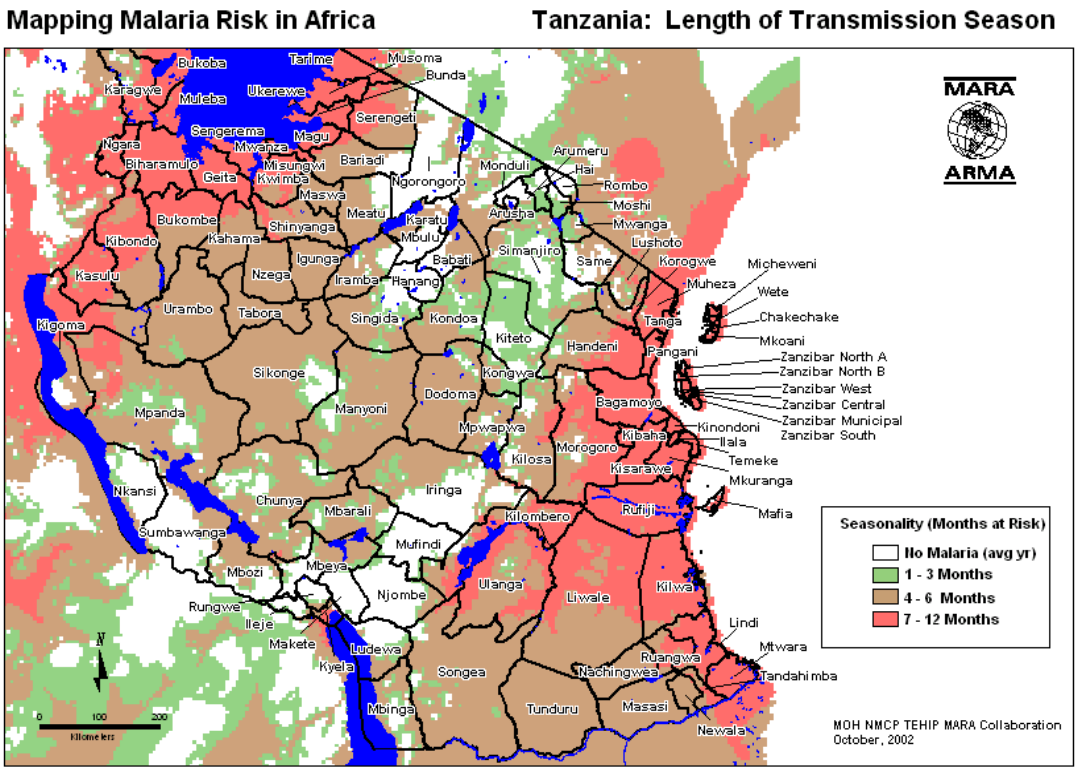

Figure 12. Risk of malaria transmission. Length of malaria transmission season in Tanzania based on the MARA climate model. (Source, Ministry of Health TEHIP and MARA-Tanzania).

National Responses. Increasing global political commitment to malaria control in recent years stimulated by the Roll Back Malaria partnership and the Global Fund to fight AIDS, TB and Malaria, has been reflected in renewed attention to malaria in Tanzanian national level policies, and to a lesser extent, in local government practices. The National Malaria Control Program's strategic plan is built around four pillars: 1) improved malaria case management; 2) national scale use of insecticide treated nets (ITNs); 3) prevention of malaria in pregnancy; and 4) malaria epidemic prevention and control [3]. Integrated Management of Childhood Illnesses (IMCI), intermittent presumptive treatment in pregnancy (IPT) and Insecticide Treated Nets (ITNS) are all part of Tanzania's national package of essential health interventions. In late 2001 the national antimalarial drug policy ceased chloroquine as the first line drug due to high drug resistance. On average there was 52% total treatment failure in sentinel surveillance of antimalarial drug efficacy [4]. The new policy includes sulfadoxine-pyrimethamine (SP) as first line, amodiaquine as second line and

quinine as third line antimalarials. In 1998 a district-scale, and later in 2000, a national-scale social marketing programme for ITNs was implemented by the Ministry of Health and its NGO and donor partners in order to develop and test processes for increasing affordable supply, demand and coverage for ITNs and to stimulate the commercial market for ITNs. As part of the health sector reforms, a sector-wide approach to financing places per capita resources under the control of local government councils at district level where they can be used to support the provision of the national package of health interventions, including malaria interventions at both public and non-governmental health facilities.

Household responses. Tanzanians enjoy relatively good geographic access to primary health services, with 90% of the population within one hour of a government health service [5]. Government health services for children under five years of age and for pregnant women are officially free. However, household health needs and demands are great. Prevalence of overall morbidity is high, with 28.3% of the population reporting illness or injury in the previous four weeks. Utilization of the health system is relatively good and 67.1% of these episodes were reported to attend a health provider (predominantly government). The most commonly reported complaint resulting in a health service consultation is fever or malaria – reported in 69.3% of ill children (less than 15 years of age) and 60% of ill adults (15+ years). Non-governmental health providers are also common and work in partnership with government facilities at rural level. Private-for-profit health providers are relatively new and still largely available only in urban areas and large towns. Over-the-counter drugs are increasingly available in rural settings through private pharmacies, shops and kiosks [6]. Nevertheless, the most accessible health service for the rural household, both in socio-economic as well as spatial-temporal terms, is traditional medicine and traditional healers.

Economic considerations. Coincident with and consequent to having one of the highest malaria burdens, Tanzania is also one of the poorest countries in the world with an annual GDP of $213 USD per capita (2000) and 36% of the population below the basic needs poverty line. Malaria is estimated to consume

3.4% of GDP or about $240 million USD dollars annually [5]. This is stifling for an already fragile economic performance [7]. Tanzania spends about USD $11.37 per person per year on health [8]. Of this, $2.14 is spent on malaria services. About 75% of malaria expenditures are borne by the household, with the government contributing 20% and partners 5% [9]. Of the household malaria expenditure, about one-third is spent on antimalarial drugs and almost half on bed nets, insecticides, coils and other preventive strategies. This burden is greatest on the poorest households and contributes to the continuing cycle of poverty.

Care-seeking. There have been a number of studies of care-seeking for malaria in Africa reviewed by McCombie in 1996 [10] and updated in 2002 [11] with much additional work since then [12-18]. Many of these studies involve qualitative and sometimes quantitative analyses of data from illness narratives for recalling episodes of recent illness. Common themes emerge which can be summarized as follows: almost every study identified local community or folk perceptions, terminology or explanations of illness that overlap with malaria disease in ways that distinguished fever, malaria and convulsions as distinct in aetiology and required treatment. Care-seeking patterns for simple fever or uncomplicated malaria were more likely managed initially at home while cases with convulsions or severe malaria were more likely to seek care from a health care practitioner. Multiple care-seeking events and switching between types of providers were common. Cases with simple fever or uncomplicated malaria were more likely to seek formal, modern biomedical care and antimalarial drugs, while cases with convulsions were more likely to be managed by traditional healers or traditional practices, as well as modern care. The hierarchy of such events is likely to affect timely access to effective care. One feature of much of this prior work is that, because severe and fatal malaria is relatively rare, nearly all studies based on illness recall ask what people *would do* if they/their child experienced a severe illness such as “degedege” (cerebral malaria with convulsions) rather than what they *did do*.

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Basic Indicators	National Mainland	Coast Region*
Household and Housing		
Average Household Size	4.9	4.9
Percentage of female-headed households	23	18
Percentage of households with a modern roof	43	24
Percentage of households with modern floor	25	10
Percentage of households with modern walls	25	1
Percentage of households with electricity	12	6
Percentage of households using a toilet	93	98
Mean distance to firewood (km)(rural households only)	3.1	1.7
Mean distance to a shop (km)(rural households only)	1.8	1.0
Mean distance to a bank (km)(rural households only)	37.5	31.3
Education, Health and Water		
Percentage of adult men without any education	17	24
Percentage of adult women without any education	33	52
Percentage of adults literate	71	58
Primary net enrollment ratio	59	56
Percentage of individuals ill in 4 weeks before survey	28.3	34
Percentage of ill individuals who consulted any health provider	69	83
Percentage of above who consulted a government provider	54	69
Percentage of households within 6 km of primary health facility	75	69
Mean distance to a dispensary / health centre	4.7	3.5
Mean distance to a hospital (km)	25.6	25.9
Percentage of households with a protected water source	57	23

Percentage of households within 1 km of drinking water	55	51
Mean distance to a primary school (km)	1.8	1.7
Mean distance to a secondary school (km)	12.6	13.1
Economic Activities		
Percentage of adults whose primary activity is agriculture	63	62
Percentage of children age 5-14 years who are working	62	57
Mean area of land owned by rural households (acres)	6	2.9
Consumption and Poverty		
Consumption expenditure per capita (2000/01 TZS / month)	10,120	9,922
Percentage of consumption expenditure on food	65	71
Percentage of population below the food poverty line	19	27
Percentage of population below the basic needs poverty line	36	46

* Rural result provided where available.

** Exchange rate, January 2001: TZS/USD = 803

Source: Government of Tanzania, National Bureau of Statistics, Tanzania Household Budget Survey 2000/01

Table 15. General household-level characteristics of Coast Region in comparison to Tanzania rural mainland

Rationale. Although malaria mortality rates are high, fatal malaria is still relatively infrequent when compared to the number of malaria illness episodes. It is possible that the care-seeking patterns of the majority who are ill, but survive, will potentially mask different patterns of those whose care-seeking choices fail and result in a fatal outcome. To understand how best to reduce malaria mortality through improved access to antimalarials, it will be important to examine the care-seeking of individuals who actually died from what they or the health system considered was malaria. No studies in Africa have specifically focused on short-term recall of care-seeking patterns for fatal malaria to see whether and how the general themes above prevail in this sub-group of greatest interest [19]. In this paper an analysis is reported of care-seeking events in a large series of malaria deaths recorded in the course of longitudinal demographic surveillance.

METHODS

Study area. The general context of malaria and malaria control in Tanzania has been outlined in the background. The specific setting of this study is in the stable perennial malaria transmission belt that runs along the coast of Tanzania and up the Rufiji and Kilombero River basins (Figure 1). This transmission risk is typical of that experienced by the majority (75%) of Tanzanians and of sub-Saharan Africa in general. There are two main rainy seasons, October-December and February-May. The specific data for the study comes from a demographic surveillance system (DSS) in the Rufiji District of Coast Region, managed by the Ministry of Health and the Tanzania Essential Health Interventions Project (TEHIP). Details of the study populations, DSS methods, life tables and results are available for the Rufiji DSS [20]. Household characteristics of the Coast Region are provided in Table 1. These are shown to be generally representative of rural mainland Tanzania.

Rufiji District is 178 km south of Dar es Salaam on the Indian Ocean coast and has a population of 203,000 in 2002 in an area of 14,500 km^2. The district is entirely rural with 94 registered villages, no urban areas or towns, and has a

large area set aside as a game reserve. The economy is predominantly subsistence farming and fishing. Rufiji district is home to several ethnic groups. The largest is the Ndengereko who, according to oral tradition, are the original inhabitants of the area. Other groups include the Matumbi, Nyagatwa (concentrated in the delta area), Ngindo, Pogoro and Makonde. The majority of the people are Moslems (98%) with a few Christians (1.3%) and followers of traditional religions. In addition to local languages, Kiswahili is widely spoken; English is not commonly used in the area. The population has access to 57 formal health facilities: two hospitals (one government and one NGO), five health centres with in-patient facilities (all government) and 50 outpatient dispensaries (46 government). Over-the-counter drugs are available from many private shops and kiosks in the villages. People also obtain services from traditional healers including traditional birth attendants. Immunization coverage ranges from 85% for BCG (tuberculosis) to 66% for measles in children 12-23 months of age. Acute febrile illness and malaria are the leading causes of attendance at health facilities, and the largest cause of mortality. For malaria, the district provides Integrated Management of Childhood Illness (IMCI), Intermittent Presumptive Treatment of malaria in pregnancy (IPT), and first, second and third line antimalarial services at all formal health services, as well as social marketing of insecticide-treated nets (ITNs).

Demographic Surveillance. The Rufiji District hosts a sentinel DSS area that covers 1,800 km^2 north of the Rufiji River and west of the Rufiji Delta (7.470 to 8.030 south latitude and 38.620 to 39.170 east longitude). The Rufiji DSS monitors a total population of 85,000 people in 17,000 households in 32 villages. All residents are registered in the system and all births, deaths, in-migrations, out-migrations, pregnancies and other vital events are monitored and registered. Events are recorded in the Demographic Surveillance Area (DSA) by 150 village key informants and verified by DSS staff. Twenty-eight full-time enumerators update the population register every four months by household survey cycles. The field and data system is based on the Household Registration System Software [21]. The database also includes key household level information on household structure, socio-economics and assets, food-security and

environmental features that are updated annually. All households and community structures have been geo-located by global positioning satellite (GPS) systems. The Rufiji DSS is part of the Ministry of Health's National Sentinel System (NSS) for monitoring health and poverty status and serves as a sentinel for rural coastal districts. Annual Burden of Disease profiles are produced by the DSS and used for district planning purposes in the NSS.

Verbal Autopsy. The Rufiji DSS continuously records vital events within households and among individuals over time in a systematic way. The vital events reporting system consists of key informants who notify the system of any death occurring in the DSS area. This information is passed to a DSS key informant supervisor (or DSS enumerator who informs the key informant supervisor). The key informant supervisor visits the households in which death has been reported within two weeks and contacts the DSS data centre for verification of the registry status. A verbal autopsy (VA) (post mortem interview) is then scheduled and administered to one of the deceased's relatives or the individual who is most well informed of events and details of illness of the deceased. A DSS VA supervisor, who is also a trained clinical officer or health officer, conducts the VA interview. Respondents are not aware of the health care qualifications of VA interviewers. Enumerators also ascertain death events at fixed enumeration rounds three times per year, using specific event forms that are reconciled with the mortality database. There is no population sampling. The entire population of the DSS area is in the DSS and all deaths to DSS residents are subject to VA. Population compliance in both the DSS and VA interviews was very high resulting in high completeness of death registration for registered members. Verbal autopsy was available on 97.7% of deaths, missing only those where the family out-migrated shortly after the death or declined the VA interview.

The VA tool used is that of National Sentinel System [22] based on an evolution of forms developed by the Adult Morbidity and Mortality Project (AMMP) [23] and very similar to that proposed by INDEPTH (http://www.indepth-network.net). It

uses individual specific standard questionnaires for: a) children under 31 days of age; b) children under five years but 31 days and older; and c) population aged five years and older. The questionnaires and responses are in Kiswahili. Information such as household ID number, name, age and sex are re-collected for confirmation. In addition, data is collected by open-ended and closed questions on history of events leading to death, together with previously diagnosed medical conditions as well as signs and symptoms before death. Questions about use of health facilities prior to death, reasons for using or not using a particular health facility and confirmatory evidence of medical care and cause of death (if available) are also asked and recorded in the questionnaires. A typical bereavement interview in the course of a VA takes 45 to 60 minutes.

The tentative cause of death is established from the sequence and severity of signs and symptoms, as well as the available confirmatory evidence, by the VA supervisor and recorded on the forms. However, it is physician coding that determines the final cause of death that is subsequently entered in the database. Completed questionnaires are coded independently by two physicians according to a list of causes of death based upon the tenth revision of the International Classification of Diseases. A third physician independently codes the VA in case of discordant results from the first two physicians. Where there are three discordant codes, the cause of death is registered as undetermined (about 6% of cases). A single cause is assigned as the main cause, with contributing causes also indicated. All death coded as the following were included as suspected to be directly or indirectly due to malaria and included in the study: acute febrile illness 1-4 weeks; acute febrile illness <=7days; acute febrile illness including malaria; acute febrile illness with convulsions; acute febrile illness with anaemia; cerebral malaria; fever plus malnutrition; malaria; malaria confirmed; and unspecified acute febrile illness.

Quantitative methods. All data from the DSS and the VA were entered, cleaned and managed using FoxPro (Microsoft Corp). Databases were linked and selected data transferred to Stata 7.0 (Stata Corp) for analysis. The VA

database was linked to the household registration database to obtain other indices, such as the socio-economic status. In a separate study, we determined socio-economic indices for individuals in 14,440 rural households in the Rufiji DSS area for the year 2000. The index was based on principal components analysis of the presence or absence of items from a list of 22 specific household assets and nine household characteristics dealing with household ownership, construction features, water supply, sanitation and type of fuel. Further details on the socio-economic index are provided elsewhere [24]. The household index was applied to each individual in the respective household and all deaths due to malaria were partitioned into socio-economic quintiles by this index. Univariate analyses were used to assess the affect of age, sex, socio-economic status, household headship and severity of malaria on initial choices from 13 potential categories of health care providers. Chi-square was used to identify significant factors associated with choice of care sought during the final illness.

Qualitative methods. The health behaviour research component of the Tanzania Essential Health Interventions Project (TEHIP) investigated the care-seeking and compliance patterns for malaria in a separate study in the Rufiji District from 1998-2001. Eight villages were purposely selected to include four villages with a local health facility and four villages far from a health facility. From these villages 80 households with children under-five years of age were selected by simple random sampling. Ethnographic approaches (semi-structured interviews, case histories and focus group discussions) were used to explore and describe households' responses to childhood illnesses including malaria. A two-step coding strategy was used. In the field, a research assistant, using a provided guide, performed initial thematic coding of the data. Field coding was supervised and consistency checked by a senior social scientist. At computer data entry level, field codes were replaced by corresponding thematic codes written in text macros by experienced data clerks. A data manager supervised the data entry and was responsible for quality and further consistency checks. All qualitative data was processed in a text editor and analysed using text analysis software, Text-Base Beta (Centre for Qualitative Research, University of Aarhus, Denmark). The codes allowed retrieval and compilation of text segments of

interest for thematic analysis.

Terminology. The ethnographic literature on treatment seeking in Africa uses a variety of terms, none of which are wholly satisfactory in capturing the nature and complexity of available health systems. In this paper the term "modern care" is used to describe what conventionally includes biomedical, western, pharmaceutical, professional, official or formal health care and the term "traditional care" is used to describe what conventionally includes traditional medicine, traditional healers, traditional providers, lay providers, traditional practices or folk care.

Ethical Considerations. All household visits, surveys and questionnaires in the DSS and TEHIP surveys were administered with individual informed consent. All individual and household data are confidential. All reports are based on summary data that cannot be linked to individuals or individual households. The Ministry of Health, National Institute for Medical Research's Tanzania Medical Research Coordinating Committee has approved the research protocols of TEHIP and its Rufiji DSS. Information is fed back to the communities concerned on a semi-annual basis and provided to the local council authorities and the Ministry of Health for planning purposes on an annual basis.

RESULTS

Qualitative themes: illness terminology.

Qualitative studies confirmed that the population refers to the signs and symptoms associated with the biomedical condition of malaria as three distinct conditions, each with its own aetiology, treatment-seeking patterns and prognosis. The three conditions are: "homa" (fever, vomiting, feeling cold, loss of appetite, limp body, red eyes, not considered life threatening); "malaria" (high fever, vomiting, loss of appetite, feeling cold, some caretakers considered life threatening) and "degedege" (high fever, loss of appetite, stiffness of body, rolling of eyes, lips twisted sideways, twitching, considered life threatening). These are

well recognized by most households in the study population.

"[…] you are able to recognize an episode of degedege in one day. It begins with mild fever and the next day the fever becomes more severe and results in symptoms of epilepsy. The child opens the eyes wide and the black spot cannot be seen, he begins to twist the arm and leg, and then, even if you pour cold water over the child, does not react…" (Female respondent aged 37 from Bungu - Rufiji).

Although the local population distinguish between the illness "homa" and malaria the distinction is not always very clear to them. Analysis of case studies revealed that the illness term "malaria" has been obtained from modern health care. When mothers take their children to these health services with what had been diagnosed at home as "homa", they are told it is malaria. The following is illustrative of experiences reported:

"I first thought it was normal homa (fever) and I could see the child had homa. Now, when I took the child to the hospital, they checked the child's blood and informed me the child had malaria. […] the child was not playing. I touched the child and the body was like fire (mwili wake ulikuwa wa moto), the body was very hot". (Female respondent aged 29, Bungu, Rufiji).

Anaemia is not often recognized, and where recognized, is not associated with malaria.

Qualitative themes: aetiology.

Although "homa" and especially "malaria" were seen as associated with malaria and mosquitoes, in most cases the signs and symptoms of "degedege" are not attributed to malaria. Life threatening malaria with convulsions is not only perceived as a different illness from malaria through local symptom definition but is attributed to different causes than malaria. Few households mention the mosquito as a cause of the illness described as "degedege". Popular beliefs as to the cause of "degedege" were found to include: fever, evil spirits and a change in weather/wind. The following translation is typical of quotes obtained from respondents on perceived causes of "degedege":

"….Evil spirits or demons cause degedege. If it happens that evil spirits or demons pass in front of the child, then the child is likely to get degedege. This may result in paralysis of the body or leg or arm or any part of the body…" (Male respondent aged 46, from Kilimani, Rufiji).

Qualitative themes: Care-seeking pattern.

"Homa" and "malaria" are seen as conditions that can be managed at least initially at home with modern medicine available from shops and from health facilities. But "degedege" is perceived as a serious life-threatening condition for which prompt treatment-seeking is required. People reported different sources of care they used for the treatment of "degedege". These sources encompass more than the biomedical health system and fall into three broad categories: home treatment, traditional healers and biomedical. Home treatment was reported to include the use of modern medicines, such as aspirin from local shops, in the early stages the illness. If the illness reaches a severe stage (convulsions) people claim to use traditional healers in the home or outside the home. Biomedical care ranging across government hospitals, health centres, dispensaries and equivalent private facilities was used in the later stage, when convulsions had subsided. However, some respondents perceive traditional healers as not competent to deal with such illness and claim to seek care from biomedical providers at the beginning of the illness.

"We use traditional remedies only to treat degedege. They (remedies) must have a very bad smell for this will chase away the evil spirit. It is just like telling you to stay in the latrine; surely you will have to find another place because of the bad smell. This is just the same case for the evil spirit attacking the child because of the bad smell it will have to find another place to stay…." (Male respondent aged 57 years, Kiomboni, Rufiji).

"I had gone to the dispensary for treatment; my child was suffering from homa. The first day he was given panadol tablets and chloroquine injection and was asked to return the next day for chloroquine injection. The next day while I was there at the dispensary waiting for treatment my child started convulsing. This I believed to be a sign of degedege. Immediately I left the dispensary in search of

a traditional healer. Degedege is never treated in the dispensary. Child may die after being injected." (Female respondent, 39 years old, Kiomboni, Rufiji).

"When my child developed degedege I was at Kibiti. I had to look for transport to take the child to Songa Hospital (Mchukwi Missionary hospital). There you have reliable service because you find almost all kinds of investigations. I don't like going to traditional healers because they are not reliable and do not have equipment to investigate well your child. They end up telling you things related to superstition." (Female respondent aged 42, Bungu, Rufiji).

Quantitative results: care-seeking pattern.

In the period January 1999 to December 2001 inclusive, the Rufiji DSS conducted 243,042 person years of follow-up. In this series, 3,023 deaths occurred to resident members and 2,953 (97.7%) verbal autopsies were conducted. Of these, 24.4% (722) had a cause of death suggestive of malaria as the direct or underlying cause, of which 44.3% (320) were in children less than five years of age. Among these child deaths, there was no difference in frequency between sexes, with 51.3% being male and 48.7% female. Of the child malaria-attributed deaths, 282 (88.1%) sought care at least once before death, while 38 (11.9%) did not, or could not, seek care. Convulsions (possible cerebral malaria) were recorded in 30 (9.4%) of these fatal cases.

Level of Care	Provider	Age	
		<5	5+
Government	VHW	0.0%	0.7%
	Dispensary	19.4%	11.2%**
	Health Centre	20.0%	14.4%*
	Hospital	5.3%	5.0%
Home	Mothers	2.5%	2.2%
	Family	9.4%	13.2%
	Drug Shops	8.1%	20.6%**
Non-Government	Dispensary	10.3%	5.5%*
	Health Centre	1.6%	2.0%
	Hospital	2.2%	2.5%
	TM at Practitioner	6.6%	6.5%
	TM at Home	2.8%	1.7%
None	None	11.9%	14.3%
		100%	48%
	Number	320	402
	Total		722

* Significant at 5% level

** Significant at 1% level

TM Traditional Medicine or Practice

Table 16. Level and source of initial care in fatal acute febrile illness / malaria by age group in the Rufiji DSS sentinel area, 1999-2001.

The verbal autopsies contained both an open-ended narrative account of the final illness and a specific chronological account of where and in what sequence care

was sought. There were 13 possible sources of treatment that were collapsed for purposes of certain analyses into three sub-categories of care types (Modern Care; Traditional Care; and No Care) and into six sub-categories of provider types (Government; Home/Shops; Non-Government; Traditional Medicine at Home; Traditional Medicine at Practitioner; and No Care). Table 2 compares the level and detailed source of initial care in acute febrile illness (malaria) for children less than five years of age compared with older cases. The initial treatment-seeking choice for children less than five years of age was modern care (78.7%), whereas only 9.4% used traditional care initially. The remainder (11.9%) sought no care (Figure 2).

Within modern care, government providers were most prominent (44.7%) followed by home care with antimalarials from private shops (20%) (Table 3). Children were statistically more likely to be taken to government health centres and government and non-government dispensaries and less likely to be served by drug shops as the initial resort to care ($p<0.05$). There were no significant differences between treatment-seeking patterns for male and female patients regarding the broad choices of modern, traditional or no care. Even though there was no difference in the proportion of males and females receiving traditional care, within the traditional care group, females were statistically more likely to be kept home to receive traditional medicine, and males were more likely to be taken out of the home to see a traditional healer ($p<0.05$). There were no significant differences in specific or general care-seeking patterns by sex of the household head. There was no difference in treatment-seeking patterns when comparing choices made by households in the poorest quintile and households in the least poor quintile.

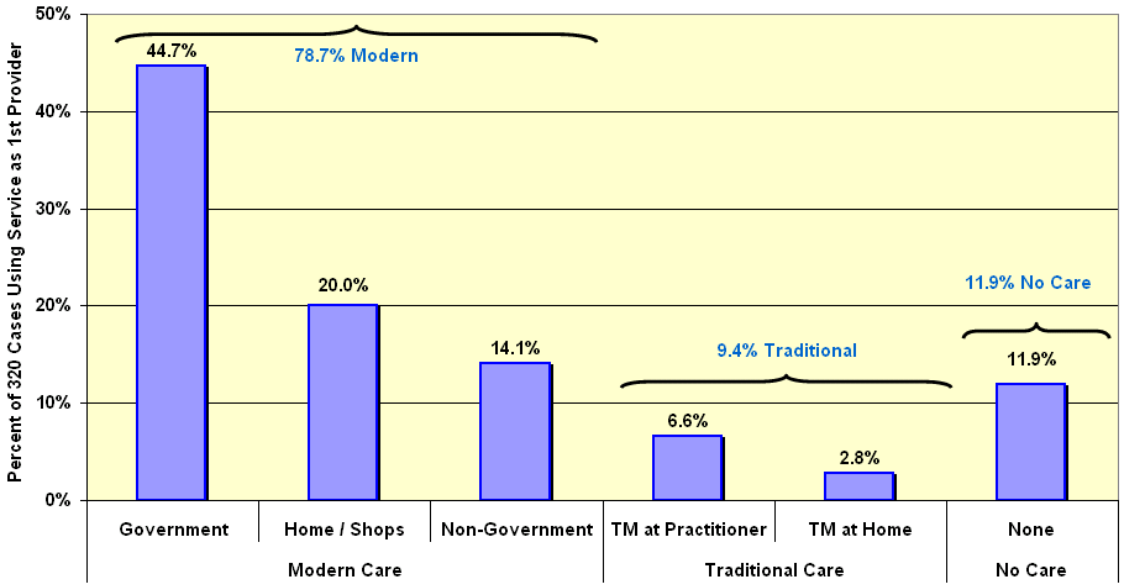

Figure 13 Initial care-seeking patterns. Care of forst resort sought during the final illness by 320 fatal “malaria” cases in children less than five years of age in the Rufiji DSS sebtinel area, 1999-2001.

Table 17. Type and provider of initial care in fatal acute febrile Illness / malaria by age group, sex, socio-economic status, and type of illness in the Rufiji DSS sentinel area, 1999-2001.

Type of Care	Provider	Age		Sex of Child		Sex of HH Head		Poverty Quintiles		Convulsions	
		<5	5+	Male	Female	Male	Female	Poorest	Least Poor	With	Without
Modern Care	Government	44.7 %	31.1 %**	46.4 %	42.9%	38.6 %	33.3 %	42.6 %	51.0 %	55.6 %	43.3 %
	Home / Shops	20.0 %	36.1 %**	21.3 %	18.6%	28.2 %	31.9 %	22.2 %	15.7 %	19.4 %	20.1 %
	Non-Government	14.1 %	10.0 %	12.2 %	16.0%	12.6 %	9.8%	9.3%	9.8%	2.8 %	15.5 %
Traditional Care	TM at Practitioner	6.6%	6.5%	7.3%	5.8%	2.1%	2.9%	7.4%	5.9%	16.7 %	5.3% *
	TM at Home	2.8%	1.7%	1.2%	4.5%	6.0%	7.8%	1.9%	3.9%	0.0 %	3.2%
No Care	None	11.9 %	14.4 %	11.6 %	12.2%	12.0 %	14.3 %	16.7 %	13.7 %	5.6 %	12.7 %
		100 %	33%	100.0 %	100.0 %	100 %	100.0%	100%	100 %	100 %	95%
	Number	320	402	164	156	485	204	54	51	36	284
	Total		722		320		689		105		320

* Significant at 5% level

** Significant at 1% level

TM Traditional Medicine or Practice

HH Household. Note, 33 households had a change in headship during the study period and were excluded from the analysis in the sex of HH Head column.

Cases with convulsions were as likely to receive initial modern care as cases without convulsions (77.8% and 78.9% respectively) (Table 3). However, cases with convulsions were less likely to receive no care. Therefore, although the predominant choice of care was modern, inclusion of care from traditional healers was significantly more frequent in those with convulsions than in those without convulsions ($p<0.05$). All traditional care was provided by traditional healers and no case claimed to give traditional medicine at home, which is contrary to what is often described in non-fatal treatment seeking.

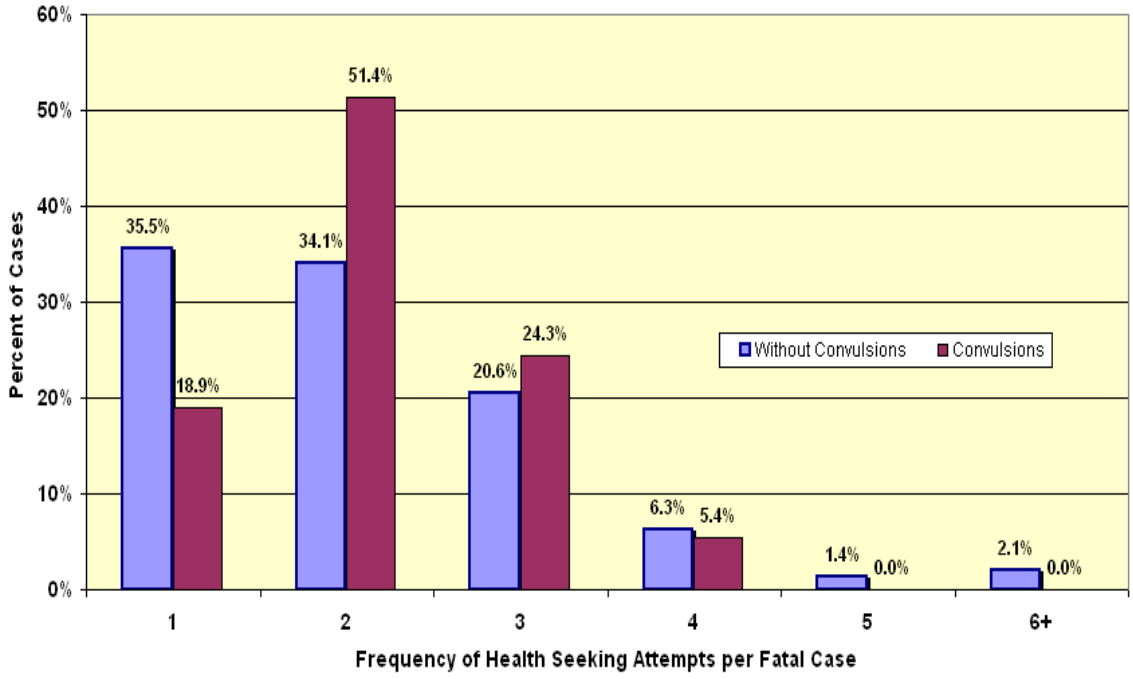

Figure 14. Frequency of care-seeking events. Distribution of frequency of care-seeking events at differing categories of provider among those who sought care during the final illness in fatal episodes of malaria in 320 children under five years of age with (dark shading) and without convulsions (light shading).

Among children for whom care was actively sought, 82.4% of those with

convulsions and 90.3% without convulsions sought modern care as the initial care (Table 3). Multiple episodes of care-seeking were common. More than half of cases had two or more treatment-seeking events for the same illness involving a different type of provider (Figure 3). There is also a difference in pattern when initial care choices and cumulative care choices are compared (Table 4). The latter indicates important switching between providers over time and this phenomenon is most apparent when comparing malaria without convulsions to malaria with convulsions. Multiple provider care-seeking was more common if convulsions were present. These synchronic choices (frequency of use of a particular resort to care) are shown in Figures 3 and 4. In the multiple-care-seeking group, switching between modern care and traditional care can be a factor in the delay of effective care. Of the multiple-care-seeking group that did not have convulsions, 88.4% and 99.4% had used modern care at least once by their first or second choice respectively. In this group, of those who started with modern care, only 0.9% switched to traditional care as the second choice. Of the few who started with traditional care as their first choice, most (94%) switched to modern care for their second choice. For the group that had convulsions, 90% chose modern care as their first choice, but by the second choice, 29.6% switched to traditional as the second provider. Switching did not seem to be based on differences in likelihood of receiving treatment. All provider categories were generally able to supply the expected treatment, the poorest being government providers who were able to give treatment for 94% of cases and the best being traditional healers at 96.8% of cases.

Table 18. Level and source of accumulative care in fatal acute febrile illness / malaria, all ages, in the Rufiji DSS sentinel area, 1999-2001.

Level of Care	Provider	Cumulative Events	
		No.	%
Government	VHW*	5	0.8%

	Dispensary	92	14.5%
	Health Centre	104	16.4%
	Hospital	67	10.6%
Home	Mothers	19	3.0%
	Family	64	10.1%
	Drug Shops	36	5.7%
Non-Government	Dispensary	77	12.2%
	Health Centre	39	6.2%
	Hospital	30	4.7%
	TM** at Practitioner	73	11.5%
	TM** at Home	27	4.3%
	Total care-seeking	633	100.0%

VHW* Village Health Worker

TM** Traditional Medicine or Practice

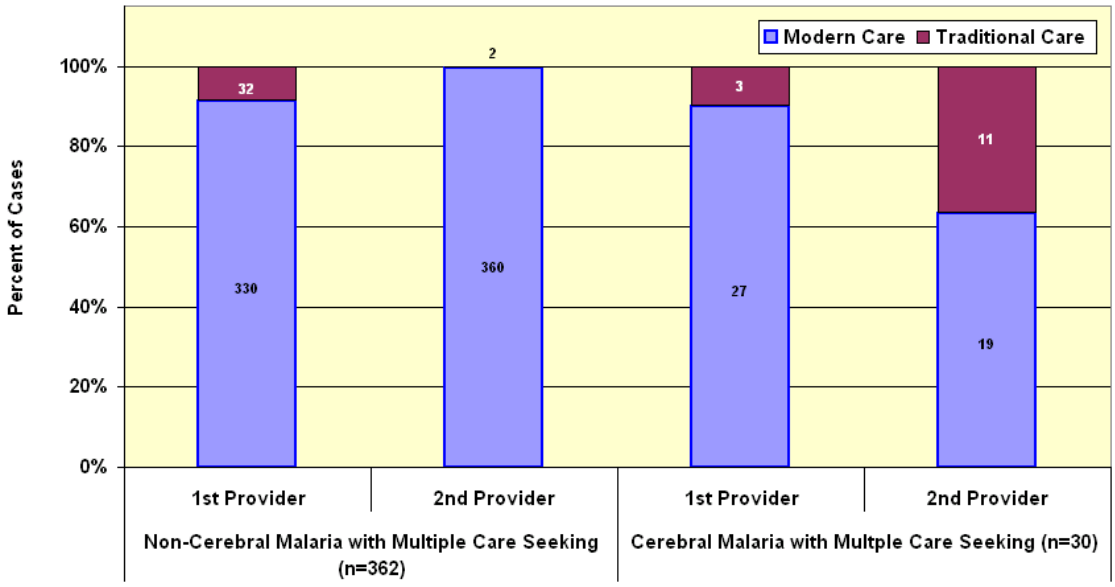

Figure 15. Loyalty to first provider. Comparison of loyalty to first provider of modern or traditional care during the final illness in fatal cases (all ages) that saw two or more providers.

DISCUSSION

Limitations of verbal autopsy methods for malaria deaths have long been recognized, especially with regards to specificity and sensitivity [25,26]. This has provoked efforts to improve and validate verbal autopsy procedures in the settings in which they are used [23,27-34]. The general consensus is that, although imperfect, verbal autopsies are reasonably reliable in determining major causes of death at population level, but may not be suitable for detecting specific impacts of interventions. However, recent work applying adjustments for sensitivity and specificity at differing prevalence levels based on validation studies shows how VA data could be used to monitor progress towards malaria-specific mortality reduction [35].

It must be emphasized that not all of the cases identified as “malaria” in this series are malaria, especially those with unspecified acute febrile illness at older ages. Undoubtedly, some malaria deaths were coded as a cause other than malaria-related. For example, severe and life threatening anaemia, likely to be

due to malaria, is prevalent in young children over six months of age in the study area [36] yet VA coded deaths due to anaemia with malaria are infrequent. Despite improvements in verbal autopsy methods in recent years, any study based on verbal autopsy is subject to bias. The recall abilities of respondents can be faulty, although for major events such as a death in the family, it tends to be better than recall of less significant events [33]. In the current study of care-seeking as reported in verbal autopsy, respondents might inflate the number of care-seeking events or exaggerate the choice of modern care if they perceive the DSS to be an instrument of the modern health system or if they feel guilt regarding the care-seeking decisions they took. This would tend to bias responses in favour of more modern care.

Much has been learnt in recent years concerning treatment seeking for malaria in Africa, largely through ethnographic research on illness recall narratives [10-12,14,37-42]. This literature confirms that, for the majority of cases deemed as uncomplicated malarial fevers, modern care based on antimalarial drugs is favoured over traditional medicine. Usually treatment starts at home using anti-pyretics and antimalarials obtained over-the-counter from local shops or left over from previous episodes. Knowledge of appropriate treatment regimens is lacking on the part of the public as well as on the part of private providers [43,44]. Under-dosing in home-based care is common. Malaria is perceived by adult care givers as a mild disease, and if it becomes serious or life threatening, then, it is generally believed that the perceived diagnosis changes from malaria to something that is more likely to be treated with traditional medicine or practices. These beliefs are not rigid. Every case is subject to a process of continuing debate and re-evaluation such that modern pharmaceuticals are also sought, albeit with delay, when convulsions fail to resolve or reoccur after traditional medicine [16,45].

If this is the case in studies of illness recalls, where most patients recover, the question remains whether this general and widespread pattern of treatment seeking holds in those cases where effective treatment seeking clearly failed and

the patient died. Since most cases of malaria death in Africa occur at home rather than in health facilities, facility-based data and studies cannot answer this question. The increasing use of demographic surveillance field sites to monitor health at population level in Africa [46] presents an opportunity to examine large series of verbal autopsy findings. Modern verbal autopsy goes beyond cause of death data to collect additional contextual data on, for example, care-seeking events prior to death.

This study confirms that the general patterns seen in illness recalls for uncomplicated malaria in Africa also apply to what people actually do in episodes of fatal malaria in a holoendemic area of Tanzania. Modern care is the first choice for children in over 78% of all child malaria deaths. Government health facilities and shopkeepers were the main source of modern antimalarial drugs. Traditional care may have caused delay in modern care in only 9.4% of fatal cases. 11.9% had no care of any kind. This general pattern held over broad age, sex and socio-economic status groups. Among children with and without the complication of convulsions for whom care was actively sought, 82.4% and 90.3% respectively sought modern care as the initial care (Table 3). In the case of convulsions, although the majority of initial care-seeking was modern, the use of traditional healers increased while the no-care group decreased accordingly. Among those of all ages who sought care two or more times in the course of fatal malaria, modern care was included in the first two choices in 99.4% of cases excluding convulsions and in 90% of cases with convulsions.

Clearly, the perceived severity and danger signs posed by convulsions provoke polyvalent treatment seeking. Nevertheless, modern care is now more popular than previous reports and qualitative studies suggest. One other study of care-seeking patterns in a large series of verbal autopsy reports from the mid 1980's from Tanzania analysed a similar number of all-cause child deaths from Bagamoyo District, a nearby district in the Coast Region [47]. In that study, malaria deaths were not analysed separately, but government providers were the choice in only 45% of deaths. At that time government providers were often

without an adequate drug supply and a preference for traditional healers was cited by 41% of mothers as the reason for not using government providers. At the time of the present study in Rufiji, all government providers had adequate drug supplies under the health reforms and offered the integrated management of childhood illness (IMCI) strategy. This could be a factor in the current popularity of government providers.

A relatively small proportion (21.3%) of malaria-attributable child deaths failed to seek modern care (9.4%) or any care (11.9%). This is considerably better than was seen in the mid-eighties, when 55% of children who died had not utilized any modern care [47]. It is also better than seen for deaths in general in the same area during the same period, when 20% of all-cause deaths had no prior care-seeking events [48]. Part of these non-care groups would include those who had sudden death following apparently mild illness, including severe anaemia.

This study shows that most patients now include modern care early in their treatment seeking patterns for eventually severe and fatal malaria, including malaria with convulsions. So why is malaria still the largest single component in the burden of mortality? With belief systems for malaria treatment seeking now firmly on the side of modern care, there is obviously something still failing in 1) the transaction to obtain this care; 2) the quality of the care and referral once it is reached; and/or 3) patient adherence to treatment once it is obtained. This would suggest that policies, efforts and implementation research aimed at improving early recognition of symptoms and danger signs at home, prompt treatment or treatment seeking, the quality and efficacy of the antimalarial available and compliance with the full course of treatment, are now, more than ever, highly justified. When appropriate care-seeking is as high as it is in Tanzania, continuing malaria deaths should be considered as sentinel events deserving of close scrutiny and audit to identify the best remedial strategies for the health system.

There are promising developments. IMCI has recently been introduced in the

study area. It places heavy emphasis on training care-givers on early recognition of danger signs and the need for prompt treatment and on improving quality of assessment and care at primary health facilities [36,49]. Replacement of chloroquine with directly observed treatment with sulfadoxine-pyrimethamine (SP) and its simpler single dosing schedule should result in less under-dosing while the introduction of pre-packaged doses has also been shown to be effective in improving provider and client adherence [50,51]. This study was conducted over the last three years of a policy period that used chloroquine as the first line antimalarial. It will be repeated for a similar time frame over the initial three year period of a new policy that uses SP to see if the care-seeking and care-getting patterns change. A qualitative analysis is also planned for the narrative portion of the verbal autopsy questionnaire to look at categories and sub categories of health care related themes in VA reports. This would focus on reasons for delay in seeking modern care (e.g. tried to treat at home without antimalarials, transport, beliefs, poor recognition of severity, lack of confidence in modern care, no power to decide, insufficient finances); delay in receiving modern care (e.g. outside of working hours, weekends, long queues, satisfaction); ineffective modern care (poor communication, no referral, drugs not available, abusive health worker).

CONCLUSIONS

This preliminary study examined what families of children who died from malaria in a holoendemic setting in Africa actually did in terms of treatment-seeking choices and sequence. It confirms that modern medicine in the form of antimalarial pharmaceuticals from shops or government or non-governmental heath facilities is now the preferred choice in an overwhelming majority of cases (78.7% and 97% as their first or second choice respectively). Traditional medicine could only be implicated in a possible delay of modern care in 9.4% of cases. 11.9% sought no care of any kind. There were no differences in these broad patterns of choice by sex of the child, sex of head of household, socioeconomic status of the household or presence or absence of convulsions. Contrary to what is concluded from much of the historical and qualitative work on

this subject, modern care is now the care of first choice, even for those who seek care for children with malaria with convulsions (82.4%), although traditional medicine also played an important role in later choices. But despite high rates of modern care-seeking for all forms of malaria, and despite relatively high attendance and utilization of modern care as seen in Tanzania, malaria mortality remains high. This must, therefore, be due to excessive delay in seeking modern care, and/or poor quality of modern care (providers and/or drugs) once sought, and/or poor patient adherence to treatment regimens once obtained.

Certain policy and practice implications arise: 1) public messages need to focus aggressively on improving early recognition of malaria and severe malaria at home and improving promptness of treatment seeking (within 24 hours of onset of malaria symptoms or immediately in the case of severe malaria); 2) quality of modern care providers and modern care must be improved in all sectors, private, NGO and Government; and 3) patient adherence with modern care at home must be simplified and reinforced.

List of abbreviations

DSA	Demographic Surveillance Area
DSS	Demographic Surveillance System
GIS	Geographic Information System
HBS	Household Budget Survey
HH	Household
IMCI	Integrated Management of Childhood Illness
ITN	Insecticide-treated netting
MARA	Mapping Malaria Risk in Africa Collaboration
SP	Sulfadoxine-pyrimethamine
TM	Traditional Medicine
VA	Verbal Autopsy

Authors' contributions

DD conceived the study, participated in the design, coordination and quantitative analysis and co-wrote the article. CM conceived, conducted and analysed the qualitative studies and co-wrote the article. HM led the analysis of quantitative data. EM managed the surveillance system and participated in design and coordination. AM managed and cleaned the quantitative data. YM managed the field work. CM, HK and GR participated in the coordination and management of the study.

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4.5 Illness Aetiology: Pragmatic Ambivalence as Barrier to Effective Household and Community IMCI in Eastern Tanzania

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Authors' contributions

CM conceived the study, participated in the design, field research, coordination, and analysis and co-wrote the article. BO guided the data analysis and co-wrote the article. DD conceived, coordinated overall research project and co-wrote the article. AM participated in field data collection and analysis. JN lead field data collection and initial analysis. GN conceived the study and guided the sampling of quantitative study. FT conceived the study and led the quantitative study. GL conceived the study and was PI until his death 2003. CM participated in overall coordination of the research. HM participated in the management of the project. MT participated in the design, backstopped management of the study and edited the article.

Keywords: IMCI, lay aetiology, malaria, Tanzania

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ACCOMPANYING PARAGRAPH

Family and community IMCI emphasizes recognition of signs and symptoms for prompt treatment but neglects aetiology. Malaria research in Tanzania and other parts of Africa has shown that perceived causes of severe malaria (convulsions) influences the relative probability of seeking care from health facilities versus traditional healers.

We argue for the importance of aetiology in care-seeking. Our study shows that about half of the caregivers do not know the causes of homa (mild malaria) and degedege (severe malaria) in concrete illness episodes. We attribute this to the fact that caregivers draw on different sources of information derived from diverging or even conflicting traditions. If they cannot make sense of these bits of information, they respond by pragmatic ambivalence which inhibits effective care.

About 80% of the caregivers use the term malaria for an illness perceived caused by mosquito bites. This finding suggests that social marketing activities for treated bed nets have made an impact on the people living in the study area.

ABSTRACT

Objective: To examine the local perceived aetiologies of IMCI related illnesses with a focus on malaria and to consider the consequences for care-seeking.

Method: We interviewed caregivers with children under five in Morogoro Rural and Rufiji Districts in Tanzania of any episode of malaria occurred between surveys. From 1998 – 2001, 314 caregivers were included in qualitative case-studies and 6636 semi-structured interviews for quantitative analysis.

Results: The local communities made a distinction between three illness categories that correspond with biomedical malaria: homa, malaria and degedege). Homa and malaria share many symptoms but they can be distinguished by its cause: mosquito bites. About 80% of caregivers in both districts identified this cause. For homa and degedege a variety of natural and supernatural causes were mentioned. Also, a big group of caregivers reported not to know the causes of these illnesses at all. Narratives from the qualitative case studies showed that caregivers had only fragmented knowledge about the etiology of these illnesses. It was not consistent enough to make sense of concrete illness episodes. This etiological uncertainty made it difficult for them to decide where to seek treatment.

Conclusion: Etiological uncertainty leads to ambivalent pragmatism and acts as a barrier against effective care-seeking. As part of the IMCI strategy, mothers should be empowered through participatory information education communication (IEC) and best practice in accurate diagnosis and therapy to overcome this ambivalence.

INTRODUCTION

In 1996, the Integrated Management of Childhood Illnesses (IMCI) was introduced in Tanzania. The IMCI is a strategy developed by WHO and UNICEF to provide effective and affordable interventions to reduce child mortality and to improve child health and development (1). Whereas the IMCI strategy focuses on the assessment and classification of signs and symptoms to improve the management of childhood illness (1), social scientists emphasize the added importance of local etiologies for care-seeking (2, 3). Studies around the globe have shown that people distinguished between causes within the individual, in the natural, the social and the supernatural world (4). The health system in Tanzania is pluralistic (5 – 10). In its long history of contact, especially along the Swahili coast, with medical traditions of different origin have partly merged or compete with one another. Apart from biomedicine, they centre around core ideas known from many parts of Africa: ill health is caused by nature, social or spiritual disharmony, spirit possession or witchcraft. In such a pluralistic setting, treatment seeking becomes an individual choice.

Several studies on local taxonomies and concepts of malaria in different areas of Tanzania found that people have illness terms that broadly correspond to the biomedical disease malaria (11 – 20). However, these studies as well as others in East Africa, West Africa and Southern Africa (2, 3) noted that caregivers commonly do not attribute severe forms with convulsions to mosquito bites. Based on these observations, our study focuses on causes local people attribute to the IMCI related local illness concepts homa (fever), malaria (malaria) and degedege (convulsions).

MATERIALS AND METHODS

Study Area

This study was part of research component of the Tanzania Essential Health Intervention Project which test health system intervention to influence priority setting in decentralized settings (desavigny et al, 2004). The study was conducted in two rural districts in eastern Tanzania: in the Morogoro Rural District and the Rufiji District. The Morogoro Rural District is located about 180 km from Dar es Salaam and is part of the Morogoro region. Topographical features are mountains and plains (22). Rufiji District is situated on the coast of the Indian Ocean 178 km south of Dar es Salaam. The overall mean altitude of the district is less than 500 metres and the vegetation is characterized by tropical forests and grassland. A prominent feature is the Rufiji River with its large food plain and delta (21). In both districts the climate features hot, dry weather with rainy seasons from October until December and from February until May. People in both Morogoro Rural and Rufiji Districts rely on subsistence farming and small-scale income generating activities. In both districts Swahili is used as lingua franca.

The health system of the two districts faces primarily communicable diseases such as malaria, diarrhea and respiratory infections including pneumonia. These account for 67.4 % in Morogoro Rural and 52.3% in Rufiji Districts of the total burden of disease. The under-five age group (16% of the population) carries 42.2% in Morogoro Rural (22) and 55.1% in Rufiji District of the overall illness burden (21).

There are various health facilities in both districts: Hospitals (3 for the Morogoro Rural District, 2 for Rufiji district), health centers (5 for each district) and dispensaries (56 in Morogoro Rural District, 48 in Rufiji District). According to an estimate, 85% of the people live less than 5 km from a health unit in both districts (22). Over-the-counter drugs are available from private shops and kiosks in both districts (23). People also consult a variety of traditional healers including diviners, herbalists and midwives, and use local remedies to treat illnesses.

Study Design

The research was conducted in three interrelated modules. The first examined initial concepts and understanding of common childhood illnesses before the introduction of IMCI. The second focused on central themes identified in the first module while the third module was concerned with quantifying the patterns identified during the first two modules and to document trend following IMCI introduction.

For the study, each district was divided into four zones according to cultural and geographical criteria. For the first and second module we selected two villages per zone by purposive sampling, one close and one far from health facility. We chose 10 households for each of the 16 villages by random sampling and included the household head and the principal child caregiver in the study. In the course of these modules, we conducted unstructured and semi-structured interviews as well as focus group discussions and case studies. This paper focuses on case studies eliciting Caregivers' explanations of causes in concrete illness episodes. All the interviews were conducted in Swahili at the people's home and were tape recorded.

In the third module, the sampling strategy was modified for quantitative assessment. For each zone, we selected 20 households with children of under-five by a multi-stage cluster sampling procedure (village-hamlet-household). The selected households formed a cohort that was visited twice a year from 1999 to 2001. During these visits semi-structured interviews were to assess the perceived causes of all illness episodes that occurred between the cross-sectional surveys. in which using semi-structured interviews. By this we also planned to assess trend in health seeking behavior after the introduction of the IMCI.

In this paper we present findings from the qualitative and quantitative analysis on perceived causes recorded from case studies in the form of narratives and semi-structured interviews.

RESULTS

We recorded 8602 episodes from 80 households in Morogoro Rural of which 1018 episodes were homa, 1030 malaria and 870 degedege. In Rufiji 7457 episodes were registered from 80 of which 861 were for homa, 746 malaria and 715 degedege. The remaining recorded episodes in each district were illnesses that were of no interest in the analysis.

A variety of causes were mentioned. We then tried to assess the relevance of the causes by quantifying how often the causes were mentioned in the semi-structured interviews. The findings of the qualitative and the quantitative data for both districts are shown in tables 1, 2 and 3. As can be seen, some of the causes mentioned during the qualitative phase did not surface during the quantitative analysis.

We first present the findings for malaria. This illness label comes from the health care staff and is relatively new for the caregivers. Afterwards we present the findings for homa and degedege, which are local illness concepts.

Causes attributed to malaria

In both districts a majority of caregivers reported that malaria was caused by mosquito bites (84% in Morogoro Rural and 78% in Rufiji Districts). In the case studies some caregivers elaborated this link by describing complex situations where children can get malaria even when mosquito nets are used or when few mosquitoes are found in the area. Others described that malaria mainly occurs during the rainy season as there are plenty of mosquitoes.

A second group of caregivers said they did not know or were not sure about the cause of malaria (8 % in Morogoro Rural and 14% in Rufiji Districts). Closer analysis of narratives, however, demonstrated that even if caregivers first said they did not know, they were usually able and willing to formulate their ideas. Most of them were familiar with various explanations of malaria, but did not find them appropriate for the concrete illness case. Some caregivers for example point out that malaria is caused by mosquito bites but that in their specific case no mosquitoes have been around. Others describe that some people use mosquito nets and still get malaria. This minority concludes that malaria cannot be caused by

mosquito bites. Getting malaria depends on individual characteristics, or it is an illness that just occurs. For us it was interesting to note that even those respondents who claimed not to know the cause of malaria reflected about the link with mosquito bites.

Only few other causes for malaria have been mentioned by caregivers. In the semi-structured interviews around 5% of caregivers in both districts considered cold weather, weather changes or high fever to cause malaria. In the narrative case studies some caregivers from Rufiji District thought malaria was caused by spirits (upepo) or sent by witchcraft (uchawi) or god (mungu). We found that these explanations usually came from relatives, neighbors or local experts who had been consulted after treatment at home or at a health facility had failed to improve the child's condition.

Causes Attributed to Homa

In both districts about 40% of caregivers reported that they did not know the cause of the illness. In the narrative case studies some respondents explained that knowing the illness was homa was more important to them than understanding its cause. Identifying the cause of the illness became relevant only after a lapse of time and if symptoms changed, persisted or became worse. Then, the perceived cause of the illness was one of the aspects that influenced help seeking behavior. Some caregivers also perceived homa as a mild illness which is part of the normal growing process of children and which does not have a specific cause.

A second group of caregivers attributed homa to mosquito bites (22% in Morogoro, 17 % in Rufiji). Interestingly the caregivers reported that a mosquito bite can make a child fall ill with homa, but did not mention malaria. This finding was consistent across the districts. In the semi-structured interviews the weather featured as an important cause for homa: About 15% of caregivers in both districts attributed homa to weather changes, more than 10% in both districts ascribed it to cold weather. This explanation is based on the observation that fever episodes frequently occur during the cool season. Another explanation for homa featuring weather conditions link fever to a prolonged exposure of the child to the sun. While this cause has been mentioned in the case studies only by caregivers in Morogoro, it accounts for about 5% of the explanations offered in the semi-structured

interviews in both districts.

In both districts some caregivers narrated that spirits (upepo in Rufiji, shetani in Morogoro Rural District) have caused homa. These explanations came again from other persons, in this case from healers or diviners whom the caregivers contacted when the child did not get better. During the semi-structured interviews, spirits and other supernatural causes were hardly mentioned.

Causes Attributed to Degedege

When it came to fever with convulsions (degedege), around half of the caregivers reported not to know its cause. Similarly as described for malaria, some caregivers did have knowledge about possible causes but found them inadequate in their specific case. Others have heard about possible causes but did not fully understand the explanation offered to them. Some caregivers also stated that they did not have the expertise to know what causes degedege. They expect experts like health care staff and healers to find the cause and to explain it to them.

In both districts some caregivers of the case studies considered degedege to be caused by high fever or malaria. Some caregivers explicitly mentioned “severe” malaria or malaria “not well treated”. When high fever was reported to be the explanation for degedege, it was usually considered to be the result of another, usually supernatural cause. While in Morogoro Rural District degedege was ascribed to high fever by 17% of the caregivers in the semi-structured interviews and 7% to malaria, only 2% attributed it to high fever and none to malaria in Rufiji District. However, 20% of the caregivers in Rufiji District and only 5% in Morogoro District linked degedege to supernatural causes which have been reported in case studies of both districts. It is possible that this difference can be explained by the fact that the link between high fever and supernatural causes was stronger in Rufiji District.

In Morogoro Rural people either say degedege is an insect or a bird, in Rufiji they speak of a bird called kokotolo. We recorded many stories about this real or spirit insect or bird during the key informant interviews and the focus group discussions. To our surprise, these causes were hardly mentioned in the case studies, neither in the narratives nor the semi-structured interviews. Even though this concept was

widely known, beliefs about how exactly the bird or insect causes degedege were unclear, as statements of the case studies revealed. For some, the bird or insect caused the illness by flying over the child, for some by dropping saliva on the child while for others the bird or insect had to be present during an attack of degedege in order to be its cause. Other supernatural explanations centered around spirits and witchcraft as causes for degedege. Here, too, explanations on how exactly spirits or witchcraft caused the illness varied from one case to another. Also, various different names for spirits were mentioned.

DISCUSSION

Our results show that the causes for “old” illness concepts such as degedege and homa and “new” concepts like malaria differ in significant ways. For malaria the main source of information were health facilities. Moreover, the illness was mainly associated with a single cause: mosquito bites. The fact, that about 80% of caregivers in both districts attribute malaria to mosquito bites indicates a shift in the aetiology of malaria from studies carried out earlier in neighbouring areas (20, 24). This finding corresponds with the results of studies carried out recently in Kilombero, Kibaha and Bagamoyo districts, where a similar strong causal link between malaria and mosquito bites has been found (11, 12, 20, 25). The authors of these studies attribute this change in perception to various anti-malaria campaigns and especially to the social marketing of insecticide treated nets (26, 27) As insecticide treated nets were introduced by social marketing campains in our study districts in parallel to the implementation of the IMCI strategy (28), we conclude that the strong attribution of malaria to mosquito bites can similarly be explained by these social marketing activities. Studies in Bagamoyo and Kilombero districts further describe that the change of perception in aetiology corresponds with appropriate help seeking actions: When malaria is attributed to mosquito bites, it is understood that modern health facilities are the best place to have it treated (12,17, 20).

Degedege and homa are local concepts that correspond partly with the biomedical malaria concept (11 - 14, 16, 20). Contrary to what we found for malaria, there was no strong link to a single cause. A variety of causes were mentioned which derived

from different information sources such as traditional healers or neighbours. Sometimes this information appeared to be confusing or even conflicting. Also, about 40% and 45% of caregivers reported not to know the cause of homa and degedege respectively. This finding contradicts results from earlier studies carried out in neighbouring areas, where caregivers were reported to know and name causes for malaria-related illnesses (11, 12, 14, 16, 18, 20, 27). We attribute this difference to the fact that we asked the caregivers for the cause of a specific illness episode and not of an illness in general. Our assumption is supported by the fact that we did not encounter this uncertainity about causes in additional focus group discussions and unstructured and semi-structured interviews where we asked caregivers for causes of illness in general.

In our case studies we gained the strong impression that the caregivers actually knew of several causes but did not find them appropriate for the specific illness case. Often, they explained what notions they discarded and why. Also, they referred to fragments of knowledge about the aetiology of these illnesses. The little they knew was not consistent enough to make sense in actual illness. This aetiological uncertainty made it difficult for them to decide on a clear course of action. We conclude that this etiological uncertainty leads to ambivalent pragmatism and acts as a barrier against effective care-seeking.

We therefore agree with Heggenhoughen et al. (2) that questions about the “how” and “why” influence appropriate health seeking. This demonstrates that local aetiology influences the effectiveness – and also the efficiency - of health care. In addition to the emphasis on symptom and sign recognition as an important part of care-seeking (30), local understandings of causes should become an essential component in the IMCI implementation. Mothers should be empowered through participatory IEC and best practice in diagnosis and therapy to overcome their ambivalence. Through regular interactions between health workers and caregivers, for instance in community dialogues, but also through effective and efficient delivery of health care, uncertainty about causes will be systematically reduced. For further research, we recommend studies that document and analyze the impact of such interventions to improve care-seeking as a key practice within the framework of IMCI and thus the efficiency of public health care.

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Cause	Illness		
	Homa	Malaria	Degedege
Don't know	M, R	M, R	M, R
Mosquito	M, R	M, R	
Spirits / evil wind (*upepo*)	M, R	R	R
Growing process	M, R		
Witchcraft	R	R	M, R
Rain	M		
Sitting under the sun	M		
Dirty blood	M		
Shadow from dead person	M		
Clouds	M		
God		R	
Moon			M
High fever			M, R
Malaria			M, R
Plant, bird, insect *degedege* / *kokotolo*			M, R
Vegetable (nyanya chungu)			M
Cold weather, weather changes			R
Fever (*homa*)			

Table 19. Causes attributed to homa, malaria, degedege and nimonia by caregivers in Morogoro Rural (M) and Rufiji (R) Districts in the case studies

Cause	Illness		
	Homa n=1019	Malaria n=1029	Degedege n=867
Don't Know	40	8	52
Mosquito	22	84	5
Cold weather	13	2	1
Bad wind / spirits / witchcraft	1	0	5
High fever	1	1	17
Weather changes	15	2	3
Malaria	0	0	7
Sitting under sun	4	0	0
Just happens without reason	1	0	2
Others			
* worm, cigarette, cold, dirty blood, outbreak			
+ cough, nutrition, other illness	2	0	4*

Table 20. Causes attributed to homa, malaria, degedege and nimonia by caregivers in percentage (%) in Morogoro Rural District

Cause	Illness		
	Homa n=861	Malaria n=744	Degedege n=715
Don't Know	36	14	41
Mosquito	17	78	2
Cold weather	11	1	0
Bad wind / spirits / witchcraft	0	1	20
High fever	1	2	0
Weather changes	17	1	13
Malaria	0	0	2
Sitting under sun	5	0	0
Just happens without reason	5	0	0
Others $ new teeth, other illness, god * worm, god + nutrition, worm	5$	1	3*

Table 21. Causes attributed to homa, malaria, degedege and nimonia by caregivers in percentage (%) in Rufiji District

4.6 Care-seeking: Searching for Best Care. Family and Community IMCI in Eastern Tanzania

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Authors' contributions

CM conceived the study, participated in the design, field research, coordination, and analysis and co-wrote the article. BO guided the qualitative analysis and co-wrote the article. DD coordinated the research project and co-wrote the article. AM participated in field data collection and initial qualitative analysis. JN lead field data collection and initial analysis. GN conceived the study and guided the sampling of quantitative study. FT conceived the study and led the quantitative study. GL conceived the study and was PI until his death 2003. CM participated in overall coordination of the research. HM participated in the management of the project. MT participated in the design, backstopped management of the study and edited the article.

Health Intervention Profile and IMCI

In 1997, the health care system of the two study districts was dominated by IMCI targeted preventable communicable diseases, which accounted for 67.4 percent of total burden of disease in Morogoro Rural and for 52.3 percent in Rufiji. These included malaria, diarrhea, measles and respiratory infections including pneumonia and malnutrition (MOH 2001a). The under-five age group (16% of the population) carried a large share of the overall illness burden (42.2% Morogoro, 55.1% Rufiji). To reduce this high burden of disease the districts adopted the IMCI strategy in 1997, using support of sector wide approach (SWAP) District level health basket funding provided by the Tanzania Essential Health Intervention Project (TEHIP), a joint project of the Tanzanian Ministry of Health and the International Development Research Centre (IDRC, Canada). By 1999, both study districts had a ratio of one IMCI trained health worker per 300 children under-five years of age. 1998 was considered IMCI introduction phase while post 1999 was IMCI period.

STUDY DESIGN

The research was conducted in three interrelated modules: module 1 assessed care-seeking patterns for childhood illnesses. Module 2 examined central themes identified in the first module, and Module 3 quantified patterns found during the first two modules.

For the purpose of this study, each district was divided into four zones according to cultural and geographical criteria. For the first and second module two villages per zone were selected by purposive sampling; one village having a local health facility within its boundaries while the other was without or situated at a distance from the health facility. A total of 16 villages were selected including one village per district under a Demographic Surveillance System (DSS). From each village, a random sample of 10 households with under-five-year-old children was drawn. From each household the household head and the principal child caregiver were selected and included in the study.

In the third module, the sampling strategy was modified for quantitative assessment. For each zone, a multi-stage cluster sampling procedure (village-hamlet-household) was used to select 20 households with children of under-five age. The households formed a cohort, which was visited twice a year from 1999 to 2001 for cross-sectional surveys in order to capture changes in health seeking pattern following the introduction of the IMCI at different times and at different seasons.

1998 was considered IMCI introduction phase while post 1999 was IMCI period. The first and the second module were carried out from 1998 until 2000. Qualitative methods were used, mainly unstructured and semi-structured interviews as well as focus group discussions and case studies. All the interviews were conducted in Swahili and tape-recorded. All in all we conducted 726 key informant interviews, 89 focus group discussions and 339 case studies. The recall period for the cases varied and ranged from few days or weeks before interviewed (around 70% of cases) several months (30% of cases).

Semi-structured interviews were used to document sources of care utilized for any under-five illness episode that occurred between the cross-sectional surveys

during the IMCI period. From 1999 to 2001 we recorded 8602 episodes from 80 households in Morogoro rural and 7457 from 80 households in Rufiji district.

We analyzed 190 qualitative case studies of which 62 were *homa* (fever) cases, 48 *malaria* and 39 *degedege* (convulsions). The rest of the 339 case studies were for other illnesses such as measles not included here. The narratives of these cases were recorded between 1998 and 1999. From the quantitative study we analyzed 1766 interviews carried out in the dry season of 1999 (IMCI implementation) as cross-sectional of which 495 were for the illness *homa*, 469 *malaria* and 466 *degedege* from both Morogoro and Rufiji districts.

RESULTS

As discussed earlier (Chapters 4.1.1. and 4.1.2), caregivers in the study district distinguish between three febrile conditions that are related to malaria: homa (fever), *malaria* and *degedege* (convulsions). None of these concepts directly corresponds with the biomedical category malaria. The prevailing local understanding is that malaria is an illness caused mainly by mosquitoes which can only be diagnosed and treated at biomedical health facilities (see Chapter 4.2.1 and Chapter 4.2.2). Homa is the term for fever but is also considered as an illness and often further specified, for instance homa ya malaria (fever of malaria), homa za mbavu (fever of the chest) or homa za matumbo (fever of the belly). Convulsions, in a malaria endemic region probably most often caused by malaria, are the lead signs of degedege, an illness entity classified as separate from the other two and as belonging to the domain of "traditional" treatment at home or by a healer.

Care-seeking for *homa*, *malaria* and *degedege* assessed through semi-structured interviews follows the expected pattern in both study districts (see Table 17). For the first two illnesses, mainly biomedical modern care was used in Morogoro and Rufiji district, respectively: in 85 and 94 percent of *homa* episodes and in 96 and 96 percent of *malaria* episodes. For *degedege* the pattern changes: Although the majority still seeks care from modern health facilities (71 and 41 percent), they more frequently combine modern and traditional health care (39 and 28 percent) or recur only to traditional therapy (27 and 52 percent). Home treatment with pharmaceuticals is probably underreported in these interviews.

	Morogoro Rural District			Rufiji District		
Source of care used	Homa n= 241	Malaria n=243	Degedege n=237	Homa n= 254	Malaria n=226	Degedege n=229
Modern care alone	85	96	32	94	96	19
Traditional alone	2	1	27	1	1	52
Modern + traditional	4	2	39	2	2	28
Self treatment at home	9	1	2	3	1	1

Table 22. Proportion (%) of health care options used in malaria-related illness

Although people clearly make a distinction between *degedege* and *malaria*, a focus on actual cases highlights the dynamic dimension of these concepts. We found that they overlap or intersect in a given illness episode: a fever *(homa)* may be diagnosed as *malaria* in the health facility staff and also turn into convulsions *(*degedege). Caregivers have to observe closely, in which direction a fever develops:

[…] With homa, one has to be careful. It could be degedege or *nimo*nia. If *nimo*nia, the child needs to be taken to the dispensary because they know how to treat the disease, and if it is degedege*,* the child needs to be taken to the traditional healer first. (Male respondent FGD, Morogoro)

Although mothers and other caretakers do not consider *homa* itself as a threat they are well aware of the fact that it may quickly lead into serious illness. Some spoke of *homa* as "the mother of all illnesses" *(homa ni mama wa magonjwa yote)*. The following case shows, how rapidly the condition can change:

Case 1

Halima (fictive name) started with fever (homa). It was around seven in the evening when I detected that her body was boiling with fever (mchemko wa homa). The next morning we went to the dispensary, and it was around six in the evening when we returned from the dispensary. At home, after returning from the dispensary, I put Halima to rest in the open air in order to cool down the body. After a short while her condition changed. I saw the eyes rolling, they became wide open, arms and legs started twitching, and she passed greenish stool. My mother and another

woman said we should take the child immediately to the healer because this was *degedege*. We reached the healer, and the healer went to look for medicinal herbs in the forest. The healer returned from the bush and made effort to treat the child. Halima child could not swallow the medicine because the mouth had locked. She died right there. (Female caregiver, 30, Morogoro)

This case shows how fever within 24 hours turned into a life-threatening condition. It is for this very reason that convulsions are much feared in local communities.

Sadly, this case also documents that convulsions occurred after "good care-seeking". What is in fact alarming is that this is not an exception. Many other cases also began with homa and were brought to a health facility several times before the convulsions occurred. We render a rather long passage of this narrative in order to give a voice to these women.

Case 2

Said became unhappy, feverish and refused to eat and drink milk. High fever (homa) started at night. I gave him half a tablet of Panadol as I could not go to the health centre that night. Here, the health centre is far away; so you have a problem when illness starts at night. Also, when you go there at night, there is normally no staff. [….] I had medicine at home. When you have children, you cannot be without some reserves of medications at home. The medications are of good help, especially when an illness starts at night. […]

The fever went down, and Said could sleep, but I decided to bring him for correct treatment at the Health Centre the next morning. He was given Chloroquine and Panadol tablets. I gave them for three days, and when the treatment was completed, Said became better. After about four days, fever returned, and I went back to the Health Centre. They gave him Chloroquine injection the first day because he was vomiting and Chloroquine tablets for the following two days. I continued to use the medication, and I left to Morogoro town with Said as I had to attend a seminar. His father was in town too, and so we decided to take the child to hospital for investigation [tests in laboratory]. They checked stool and urine and detected nothing. We did not get any medication because they found nothing during the investigation […].

We finished the tablets we had, and after about one week I returned to the village. Fever started at night and continued to increase. I gave Panadol but it did not go down. Said started to talk strangely. At around 3 in the morning, he developed convulsions (degedege). The body started to become rigid (alianza kukakamaa). […] I have seen children with degedege before. He became rigid, the neck was stiff, and the mouth locked, he looked as if in shock, breathed shallowly. I immediately woke up my sister, and we walked down to Health Centre the same night.

At the Health Centre we went to knock at the door of the doctor [clinical officer], and Said was treated. It was the same malaria which was still in the body. Because the child had collapsed, they gave him a first aid before injecting him. They inserted a certain medicine in the anus, and afterwards, when he became conscious, they gave him injections. They prescribed five injections of Quinine every 8 hours. After the injections, he got better. Said has been fine until now. (Female caregiver, 34, Morogoro)

In this case the child luckily survived thanks to prompt and appropriate IMCI treatment at a local dispensary.

This case further documents home treatment with pharmaceuticals, a common practice also in Morogoro and Rufiji. As shown in Figure 10, however, caregivers often buy only fever drugs like Aspirin and Paracetamol at local shops, and much less often anti-malarials like Cholorquine, at the time of the study the first line drug in the treatment of malaria. It should be noted that at this time (1998-1999) chloroquine resistance had reached 52%. The IMCI was not able to provide efficacious 1st line drugs for malaria until January 2001.

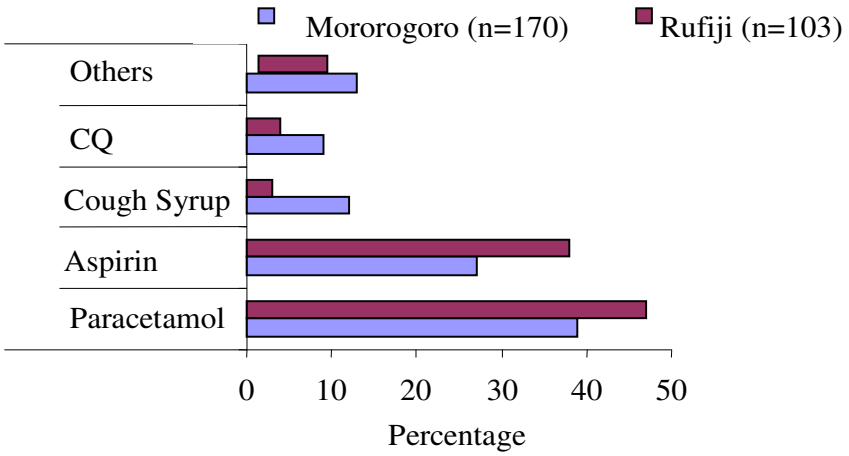

Figure 16. Drugs purchased from retail and drug shops for home use (1999)

When it comes to convulsions, most caregivers provide local remedies. The aim is to stop the convulsions before seeking any other treatment. Local remedies included tepid sponging, sprinkling mother's urine on the child, burning local herbs with pungent smell or bathing with certain herbal solutions. Some caregivers spoke of these measures as first aid (*huduma ya kwanza*). They were performed by traditional healers or experienced and usually elder men and women.

If the fever persisted, this was seen as an illness distinct from *degedege,* the term used for the actual convulsion. As some caregivers put it, malaria was accompanied by *degedege* whereby *degedege* required treatment by traditional methods and malaria by modern biomedical method.

One could thus say that often the three illness concepts were interlinked starting as mild illness (*homa),* turning into malaria when diagnosed as such at a modern health facility and developing into *degedege* if convulsions occurred. What is unsettling also from a public health point of view is that mild illness often developed into fatal illness in spite of home management and treatment in modern health care facilities.

It is not surprising that some mothers lost trust in biomedical treatment in the process, as the following long case study underlines:

Case 3

When Esther developed degedege I was in Dar es Salaam, where I had gone to visit my brother. I took the child to the hospital together with my brother. Unfortunately, none of us knew that the illness had no cure in the hospital as none of our children had degedege before.

Esther started with homa, I touched her body, and it was hot. I informed my sister-in-law who then advised me to buy Aspirin from the shop. I gave the medicine to the child. She slept, but the fever did not go down. My brother decided we should take Esther to Temeke hospital for treatment. At the hospital, they checked her blood and said she had malaria and had to be admitted for treatment.

The second day in hospital while continuing with treatment Esther's condition worsened. She developed twitching of the limbs and fast breathing. Other women admitted in the same ward for their children told me that she suffered from degedege. The fever went up, the mouth twisted sideway and limbs became rigid. This happened on the second day after admission, and the child was given several injections of Chloroquine at short intervals, valium injection and a number of tablets.

We were discharged on the third day in the evening. After discharge I believed Esther had been cured but she continued to have recurrent fevers almost after every few days. Each time I gave Aspirin the fever went down but return a week

later. The child developed high fever for the second time, even higher fever than before for about 3 days and then developed degedege. My sister-in-law and my brother decided we should take Esther again to the hospital. This time we took her to a private hospital expecting better treatment. We got admitted again and this time she was found to be anaemic, and my brother donated blood. […] We did not go back to Temeke hospital because we believed they did not cure the illness completely but gave only short relief. At the hospital the child got an infusion with a medicine that I cannot tell and blood transfusion. We also went to this private hospital because service is quicker than in Temeke where it takes hours to get services. After a week of treatment the child improved a bit and we got discharged.

Back home Esther continued to be unwell. Mild fever kept returning, and I used Panadol syrup to cool it down. My father visited us after the news of the illness reached them back home in Rufiji. After hearing our account he advised that I return to Nyambili [name of home village] saying this was not an illness for the hospital. A few days after returning to Nyambili, the child developed degedege again. It was around midnight when the *degedege* developed. The child had froth in the mouth, rigid limbs and breathed fast. I woke up my mother who then decided we should take Esther to the traditional healer. We were there from 12.00 midnight until 3.00 pm on the next day, and the child had relief. We returned home and she continued to improve, and the illness got cured. I now believe degedege is not an illness for the hospital. The hospital gives temporary relief but the disease keeps recurring (Female caregiver aged 18, Rufiji) From these narratives and others, we see that children who suffered degedege had been diagnosed and treated or still were under treatment by modern health care staff. This treatment, though, does not seem very effective. The treatment failure probably point to chloroquine resistance as reason.

DISCUSSION

Although much has been written about care-seeking in common childhood illness, what happens at the household level, especially in severe disease is still poorly understood (Williams and Jones 2004). Such an understanding is crucial for optimizing IMCI at the facility and at the community and family level. Recently much effort has been put into improving household-based management of malaria (HMM). The rationale is that especially in severe malaria with convulsions local caregivers often delay effective treatment because it is considered as a "not-for-hospital disease" (Hill et al. 2003). This delay is seen as a main reason for increased malaria morbidity and mortality (WHO 2004).

Recent studies, on the other hand, show that mothers often do practice "good" care-seeking (Alilio and Tembele 1994, Tarimo et al. 2000, Baume et al. 2000, Heggenhougen et al. 2003, de Savigny et al, 2004) and even if they do so, mortality remains high (Sodeman et al. 1997). Our study examines these critical issues in two districts of Tanzania for which data are not yet available but were pioneers in the introduction of IMCI.

Mothers in our study area distinguish between three malaria-related conditions. A systematic in-case and cross-case-comparison of the relations between illness concept (recognition and labeling), illness explanation (aetiology) and care-seeking confirms this distinction: caregivers see malaria as caused by mosquitoes and best diagnosed and treated in hospital, while they consider *degedege* as a threatening complication caused by supernatural forces which has to be stopped before the illness can be successfully treated in a health care facility. This basic pattern has also been described for the neighboring area (Hausmann Muela 2000).

A focus on care-seeking as a process or pathway (Chrisman 1977) brings the dynamic nature of *homa*, *malaria* and *degedege* into sharper focus. *Homa,* sometimes called "the mother of all illnesses", is like a quality which can be situated in different parts of the body and perhaps even move up and down within the body. These findings echo similar ideas reported from Swahili communities in Kenya (Beckerleg 1994). Since most conditions of childhood illness start with fever, a more thorough examination of understandings of *homa* is critical for improving care-seeking, not only in case of malaria but also of pneumonia, measles and

other infections.

Our case studies further show what Oberlander and Elverdan (2000) have argued in their study of malaria related illness in Muheza, Tanzania: Illness behavior is not just a system of labeling and treatment. It is rather a step by step process which continuously moves back and forth between explanation, therapy and evaluation. Or as Feierman (1981) has put it a long time ago with reference to north-eastern Tanzania: “Treatment is diagnosis. The only way to know with certainty the cause of a particular illness is to treat that cause and see if the condition improves.”

This process becomes highly confusing and difficult in recurrent illness when drug resistance is common. Recurrent febrile illness- which in many cases is malaria - is common in this region, and its treatment pathway has already been described for the neighboring Kilombero District (Hausmann Muela 2000). Our findings provide additional evidence for this pattern. They show that a focus on care-seeking at the time of convulsions distracts from the fact that this conditions often develops after the caregiver has engaged in “good care”. Our case studies clearly show that many children who suffer and sometimes even die from convulsions have had not only a history of *homa* but have even been diagnosed and treated for malaria in a health facility before they developed convulsions. Only in a few cases did a child develop convulsions without prior signs of serious illness.

There clearly is an urgent need for a thorough analysis of what is happening in these cases. Health providers often formulate the problem of recurrent illness in terms of a delay in treatment or a lack of adherence to treatment regimes. We argue that victim blaming does not bring us any further. Our case studies demonstrate that many mothers make an enormous effort in time, energy and money searching for the best care for their child. They should be supported rather than blamed by the health system. The question thus is how can diagnosis and treatment be improved to provide better services at dispensary and hospital levels? This is, of course, at the center of the IMCI strategy. Our study in Rufiji and Morogoro like the one in neighboring Kibaha (Tarimo et al. 2000) specifies that improvement should include, from the caretakers’ perspective, the provision of high quality diagnostic lab services.

It is not surprising that many mothers lose trust in formal health care and seek help elsewhere if their children do not get well but continue being ill or even

become worse after being diagnosed and/or treated at the health facility. Trust is an essential element of effective health care (Gilson 2003) and takes a continuous effort to build and to maintain. It can best be strengthened by high quality treatment.

The study was conducted at a time when chloroquine resistance was high. Policy change has taken place and chloroquine as first line drug for uncomplicated malaria has been replaced by efficacious drug. There is a need to repeat such a study when an efficacious drug is available.

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5. Discussion

Our study contributes to the rapidly expanding social science literature on IMCI and especially on malaria (Heggenhougen et al. 2003, Hill et al. 2004, Williams and Jones 2004). It is now generally acknowledged that a comprehensive understanding of health seeking patterns and trends is a prerequisite for effective interventions. This is particularly true for programmes that are more horizontally organized and heavily depend on the resident population, for instance interventions at the community and household level to improve home-based management of malaria or effective use of ITNs (Heggenhougen et al. 2003). To paraphrase Bradley (1991:28) the insights of anthropology and education should fully permeate the way in which environmental control is implemented and not just be added on as afterthoughts.

TEHIP was a pioneer program in this regard because it built a Health Seeking Behavior (HSB) component into its very framework (see Chapter 1). The rationale was that any improvements at the health system and health service levels have to be translated into actual health-seeking behaviour at the community and the household level in order to have an impact on morbidity and mortality. To put it simply: the best health care services have limited impact unless the local population makes effective use of them.

TETHIP was further original in its declared goal to move the wheel from research to action. Findings of the HSB component should be fed back into district planning cycle in order to tailor interventions to local needs and to thus increase “community effectiveness” (Tanner et al. 1993). This idea was put into practice throughout the implementation of TEHIP in regular interaction and specific planning workshops.

The design of the HSB component of TEHIP built on the approach of focused ethnographic studies (Pelto and Pelto 1997). Its framework put HSB into the centre of interest and divided it into three parts (see Figure 3): health concepts (symptom recognition and labelling), aetiology (interpretations, explanations) and care-seeking (home management, help from experts). This distinction serves only analytical purposes; in reality all three parts are closely interrelated. Moreover, in our framework health seeking behaviour interacts both with the health system and with impacts on morbidity and mortality. The health system not only frames health seeking behaviour in terms of opportunities and constraints, it can also be influenced by health seeking behaviour, e.g.

if the needs and demands of the local population are not only recognized but integrated into district planning. The ways in which people actually use the options of the health system in turn has an effect on morbidity and mortality patterns: these patterns, in turn, also influence people's responses, for instance in an outbreak of measles or in a case of malaria.

The presentation of our study findings followed this framework. The first two papers concentrated on illness concepts, first in an overview (Chapter 4.1.1) and then narrowing the focus on malaria (Chapter 4.1.2). What other studies have found elsewhere for diarrhoea (Choprawon et al. 1991, Nichter 1993), ARI (Nichter and Nichter 1996, Amarasiri de Silva 2001) and malaria (Agyepong 1992, Ahorlu et al. 1997, Baume et al. 2000) has been confirmed by our findings: local and biomedical categories overlap but do not directly correspond. Of particular public health relevance is the often reported fact (Heggenhougen et al. 2003, Williams and Jones 2004) that the severe form of febrile illness with convulsions is considered as an illness distinct from malaria.

A related but new insight is that biomedical terms become reinterpreted in the process and this may lead to misperceptions: the term malaria has a much narrower meaning in local than in biomedical interpretation, and the local illness degedege with the lead symptom convulsions has become conceptually linked with polio, epilepsy and tetanus, biomedically defined diseases that partially present with similar symptoms as childhood convulsions. This finding also warrants attention of health providers. Widening the perspective from malaria to IMCI further led to the discovery of the local illness concept kimeo which has no biomedical equivalent. Its lead symptom is an elongated uvula. This finding is of public health relevance because local therapy involves removal of the uvula by cutting, a rather dangerous practice given the hygiene conditions in the villages. These findings provide further evidence of an observation made in Ghana (Hill et al. 1993): different problems in terms of illness recognition and labelling exist in the same community, are of varying relative importance to care-seeking and warrant different responses on the side of the health system.

Moreover, in a systematic comparison of danger signs reported by caregivers with those used in the Tanzania IMCI guidelines, we found that caregivers promptly recognized illness signs and symptoms in their children. If they judged these symptoms as severe or recurrent they called for help outside the household and sought advice from different sources. This has also been reported by other studies (Tarimo et al. 2000, Amarasiri de

Silva 2001, Hill et al. 2003). Our interpretation, however, differs from those of earlier studies in that we emphasize the significance of illness labeling. We argue that caregivers do not just "perceive" or "recognize" symptoms, they search for illness labels which are not only a name but contain information about treatment. Up to now, these aspects have been neglected in the social science literature on malaria and in the IMCI approach with its explicit focus on signs and symptoms. Even though or just because illness labels are important to them, they remain often fuzzy, that is blurred or nebulous.

The second paper looked at this fuzziness of illness concepts in more detail. We found that difficulties in labeling a given illness were mainly due to two reasons. 1) different illnesses produced similar symptoms, and 2) different persons offered varied, changing and even contradictory advice and information. Fuzziness may thus be explained by the diverse manifestations of malaria, by intra-cultural variability (Pelto and Pelto 1997) and/or by culture change confronting individual persons with multiple meanings. A similar idea has been formulated by Hausmann Muela and colleagues (2002) in terms of "medical syncretism"; we prefer the concept "fuzziness" because it implies flexibility, plasticity and blurred boundaries.

Our main findings with regard to illness concepts thus are:

- The local illness degedege with the lead symptom convulsions is not only seen as separate from malaria, it is also often linked with polio, epilepsy and tetanus.
- People have a local illness concept kimeo with an elongated uvula as lead symptom and remove the uvula by cutting.
- Caregivers do not just "perceive" or "recognize" symptoms, they search for illness labels which are not only a name but contain information about treatment.
- Meanings attached to labels for a given illness remain often fuzzy for two reasons. 1) different illnesses produce similar symptoms, and 2) different persons offer varied, changing and even contradictory advice and information.

The third and fourth papers discussed issues pertaining to aetiology, first in an overview (Chapter 4.2.1) and then narrowing the focus on malaria (Chapter 4.2.2). Our main argument is that careful analysis of local aetiologies is equally important for appropriate care-seeking as prompt recognition of danger signs and symptoms. The current IMCI strategy for the community and family level (Hill et al. 2004) neglects this point. We propose that questions about the "how" and "why" of an illness (Heggenhougen et al.

2003) are of concern for the afflicted persons and their families because the answers direct care-seeking. We found that community aetiologies of IMCI related illness encompass a wide spectrum ranging from natural to supernatural causes, referring to mosquitoes and cold weather as well as to spirits and witchcraft. While some caregivers put these notions into action, others are not particularly interested in causes, and the majority remains ambivalent and pragmatic while they search for experts who see and know more, either through techniques of divination or through the microscope. Such a position of ambivalence and pragmatism in response to services offered by biomedicine has been reported from many parts of the world (Lock and Kaufert 1998). This evidence may seem contradictory to our proposition, but in our opinion it underlines that in a given case, the important issue for a caregiver is less which cause it is but that a cause is found.

To better understand this ambivalent pragmatism, we conducted a more thorough analysis of the etiology of febrile illnesses related to malaria. Our data show that caregivers clearly attribute *malaria* to mosquito bites, but they mentioned a variety of natural and supernatural causes for *homa* and *degedege* or claim not to know the causes of these illnesses. Indeed, narratives show that many caregivers have only fragmented knowledge about the etiology of *homa* and *degedege*. We suggest that this etiological uncertainty makes it difficult for them to decide where to seek treatment, and they thus resort to pragmatic ambivalence.

Our main findings with regard etiology thus are:

- Community aetiologies of IMCI related illness encompass a wide spectrum ranging from natural causes (e.g. mosquitoes and cold weather) to supernatural causes (e.g. spirits and witchcraft) cross-cutting the biomedical classification.
- While some caregivers put these notions into action, others are not particularly interested in causes, and the majority remains ambivalent and pragmatic while searching for experts who see and know more through techniques of divination or microscopy.
- The critical issue for a caregiver is less which cause it is but that a cause is found.
- With regard to *homa* and *degedege*, an aetiological uncertainty makes it difficult for caregivers to decide where to seek treatment, and they thus resort to pragmatic ambivalence.

The fifth and sixth papers assess care-seeking, first in an overview (Chapter 4.3.1) and then narrowing the focus on malaria (Chapter 4.3.2). A first interesting finding is that caregivers in Morogoro Rural and Rufiji districts make extensive use of formal health care facilities, not only for *homa* (fever), *malaria* and degedege but for most other IMCI related illnesses as well. A major exception are conditions considered as "not-for-hospital" illnesses (Hill et al. 2003), namely *kimeo* (elongated uvula). Like previous studies in East Africa (Heggenhoughen et al. 2003:8 some caregivers in our study area believe injections from the doctor to be fatal when a child has an attack of *degedege*. However, IMCI doesn't prescribe injections for such illness conditions.

Home treatment of malaria related febrile illness has become an important feature around the globe (WHO 2004) and is also widespread in Rufiji and Morogoro districts. Traditional healers mainly play a role in the treatment of *degedege* and *kimeo*. Both home treatment and treatment by traditional healers may cause a delay in seeking care at a formal health facility and thus receives increasing attention (Heggenhougen et al. 2003:55-56, Hill et al. 2004:61-62, WHO 2004:11). To examine delays for the three initial conditions "normal" fever, convulsions and recurrent fever we used the model developed by Hausmann-Muela (2000). Our findings indicate that especially recurrent fever has not yet received adequate attention in the literature. Moreover, in each of these illness trajectories, lack of access to cash and power relations between gender and generational categories has been identified as critical factor influencing care-seeking. The influence of power in shaping treatment choice is well recognized (Cosminsky 1987, Csete 1993, Mwenesi 1993, Tanner and Vlassoff 1998) and calls for further inquiry within the wider context of equity in access to health care (Hill et al. 2004: 509, Heggenhougen et al. 2003).

Other interesting findings concern quality of care from the point of view of local care givers. Apart from commonly mentioned factors like direct and indirect costs as well as accessibility in terms of geographical distance, opening time and competing priorities (Heggenhougen et al. 2003:60-63), our study draws attention to less tangible aspects such as trust and respect.

Previous studies on care-seeking for malaria in Africa highlight two distinct patterns (Foster 1995, McCombie 1996 updated 2002, Heggenhougen et al. 2003, Williams and Jones 2004): 1) Mild and "normal" malaria is first treated at home and if not cured brought to a formal health care facility; 2) severe forms of the disease presenting with

convulsions are rarely considered as malaria but as a distinct illness entity requiring traditional treatment at home or from a traditional healer. Several studies from Tanzania provide supporting evidence (Hausmann et al. 1998, Hausmann Muela 2000, Hausmann Muela et al. 2002, Comoro et al. 2003), including our own. Based on these and other studies international organizations now emphasize the improvement of household-based management of malaria (WHO 2004). The rationale is that especially in severe malaria with convulsions local caregivers often delay effective treatment (WHO 2004). Our data suggest that this is not any longer so important in Tanzania.

Our study and others shows that mothers often practice “good” care-seeking (Alilio and Tembele 1994, Tarimo et al. 2000, Baume et al. 2000, Heggenhougen et al. 2003), and nevertheless mortality remains high (Sodeman et al. 1997). Our data demonstrate that many children who suffer and sometimes even die from convulsions have had not only a history of *homa* but have even been diagnosed and treated for malaria in a health facility before they developed convulsions. Only in a few cases did a child develop convulsions without prior signs of serious illness. Indeed, many mothers make an enormous effort in time, energy and money searching for the best care for their child.

Our main findings with regard to care-seeking thus are:

- Caregivers make extensive use of modern care, not only for *homa* (fever), *malaria* and *degedege* but for most other IMCI related illnesses except the folk illnesse *kimeo* (elongated uvula).
- Recurrent fever causes much confusion among caregivers.
- Lack of access to cash and power relations between gender and generational categories are critical factor influencing care-seeking.
- Home treatment of malaria related febrile illness is widespread and not yet well understood.
- Many children who suffer and sometimes even die from convulsions have had not only a history of *homa* but even been diagnosed and treated for malaria in a health facility before they developed convulsions.

The last paper examines the impact of malaria care-seeking patterns on childhood mortality (Chapter 4.4.1). It shows that nearly 80 percent of malaria-attributable deaths used modern biomedical care as a first resort, both in the form of antimalarial pharmaceuticals from shops or formal health care services. If care was sought more

than once in these fatal cases, modern care was included in the first or second resort in 90 percent with convulsions and 99 percent without convulsions.

In most fatal cases, caregivers had used modern biomedical care, either as first resort (80 percent) or as first or second resort (over 90 percent).

Main findings in terms of methodology:

- Key informant interviews and FGDs: These techniques are useful for eliciting community views representing “ideal” rather than “real” behavior. Especially in combination with ranking techniques like pile sorting, they help to assess local illness terminologies and classifications of symptoms.
- Case studies of actual illness episodes provide insights into real behavior. They bring ambiguity and intra-cultural variability into sharper focus and allow an examination of the process of illness management.

6. Conclusions and Recommendations

6.1 Conclusions

The rationale for the evidence-based syndromic approach of the IMCI strategy is that many children present overlapping signs and symptoms of diseases, so that a single diagnosis is often difficult and may not be feasible or appropriate. To a certain extent, this strategy fits well to the local care-seeking pattern in Morogoro and Rufiji districts which is characterized by a fuzziness of illness concepts and an aetiological uncertainty. Following Feierman (1981) we can say that from both perspectives treatment is diagnosis because the only way to know with certainty the cause of a particular illness is to treat that cause and see if the condition improves.

Aetiology only becomes a primary concern if the treatment has failed. Unfortunately, due to drug resistance (chloroquine) during this study this seems often to be the case in our study districts, especially with malaria. Many children suffer from recurrent fever, develop convulsions and even die after seeking modern treatment at health care facilities. There clearly is an urgent need for a thorough analysis of what is happening in these cases. Health providers often formulate the problem of recurrent illness in terms of a delay in treatment or a lack of adherence to treatment regimes. We argue that victim blaming does not bring us any further. Our case studies demonstrate that many mothers make an enormous effort in time, energy and money searching for the best care for their child. They should be supported rather than blamed by the health system.

We conclude that, in addition to improvements of home-based management, the main challenge is to strengthen “community effectiveness” (Tanner et al. 1993) of modern health care. In this process, women as main caregivers should be encouraged, supported and empowered to reduce their pragmatic ambivalence by gaining a better understanding of high quality care on all levels of the health system so that they can make an informed choice and use the available options most effectively.

6.2 Recommendations

FOR FUTURE RESEARCH

1. Dosage problems in home-management exist in the study districts and should be systematically investigated. This topic is partly taken up by current projects like IMPACT and ACCESS. Of particular interest is whether these patterns change when effective antimalarials are used.
2. *Homa* has been reported to be a complex concept in Swahili communities of Kenya (Beckerleg 1994). Since most conditions of childhood illness start with fever, a more thorough examination of understandings of *homa* is critical for improving care-seeking, not only in case of malaria but also of pneumonia, measles and other infections.
3. There is an urgent need for a thorough and transdisciplinary analysis of recurrent fever and convulsions happening after diagnosis and treatment at health care facilities.

FOR PRACTICAL INTERVENTION

4. IMCI IEC messages should be developed to address and correct the identified misperceptions, to reduce fuzziness and increase the sensitivity and specificity of illness concepts based on people's everyday language.
5. IMCI training should emphasize the accurate and consistent use of biomedical terms in service delivery.
6. IEC messages and communication at health facilities should take women's questions and concerns seriously and answer them in accurate yet simple terms.
7. Our study in Rufiji and Morogoro like the one in neighboring Kibaha (Tarimo et al. 2000) underlines that caregivers formulate a need for high quality diagnostic lab services.

Trust is an essential element of effective health care (Gilson 2003) and takes a continuous effort to build and to maintain. It can best be strengthened by high quality treatment.

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Appendix 1

Local Illness Dictionary Developed by Research Team

(Fork childhood illness terminologies and biomedical/English equivalent from research Districts)

MOROGORO RURAL & RUFIJI DISTRICTS

Biomedical/Englishequivalence	Fold Terminology for childhood illness
• Convulsions	Degedege, kuangukiwa, Kichango, Ugonjwa wa kitoto
• Pneumonia	Monimonia, Mbavu, Limonia, Monia,Hatambulwa
• Fever	Homa, Homa za mkungu homa za baridi homa za vipindi
• Chicken pox	Tetekuwanga, Mama wa Surua, Kanatete, tete
• Abscess	Jipu, tambazi, Mapute
• Enlarged Spleen	Bandama, Wengu, Wambala, Kichomi
• Chronic irritant cough/Uvula	Kimeo, Kimeo cha sindano na kimeo cha mtama, kidaka tonge
• Malaria	Nyondenyonde
• Diarrhoea	Kuharisha, kanamda
• Measles	Surua, Bunduga, Galagala, Ugonjwa wa jua
• Bronciolitis/Asthma	Pumu, Yevuyevu, Kifua cha ng'hunga
• Cough	Kikohozi, Lukololo
• Malnutrition/kwashiorkor	Utapiamlo, Baridi, Safura
• Anemia	Upungufu wa damu Damu, imwisigalo
• Worms	Minyoo, Mizango
• Malnutrition(often regarded as worms)	Safura, Baridi, Mizango
• Typhoid	Homa ya tumbo, Pulenda
• Bilharzia	Kichocho, Kisonono cha damu

- Skin rashes — Upele, Uhele, Ukurutu
- Chronic otitis media/externa? — Sikio linatoa usaha, Lugozo
- Vomit — Kutapika, Kudeka
- Hernia — Ngiri, Chango mshipa
- Conjuctivitis — Malembwe
- Polio — Kuhololа
- Epistaxis — Mfunung'ula
- Cancer — Kansa, Luma, Kifirizi
- Rwingworms — Kisumuni, Maduara kwenye ngozi
- Recto prolapse — Kutoka nyama njia ya haja kubwa, Msoloka
- Enlarged uvula — Kimeo, kimelo
- Cancer — Kansa, Ngage, Luma
- Kwashiorkor — Utapiamlo, baridi, Safura
- Fever — Homa, Utamu
- Brochillitis — Pumu , Muhe, Mhumu
- Skin rashes — Upele, Luhele, uhele
- Blister — Malengelenge Vibakuli, Mabumbuza
- Conjuctivits — Macho, viongezeo, Malebwelelembwe, Meso,Minenge
- Whooping cough — Kifaduro, Udodo
- Epistaxis — Damu kutoka puani, Mfunghunula
- Chronic otitis media/external? — Masikio kutoa usaha, Lugozo
- Abdominal pain — Tumbo kuuma, Tumbo doluma
- Worms — Minyoo, Masengo, Machango

Rufiji District

- Measles — Surua, Kigalagala, Kikukutu, Galagala
- Cough — Kifua, Kukohoa, Lukoko Kukomwa, Kyuba
- Uvula (Elongated) — Kimeo, Kimelo
- Convulsions — Degedege , ugonjwa wa kitoto, dege, Lyakunani, Lidegedege,

	Reha, Kokotolo, Kiharusu, Lyakunani, Homa za Kushtukashtuka, Lidege, Kupooza, Pepopunda
• Kwashiorkor	Kwashakoo, Pashakoo, Lukobo
• Chickenpox	Tetekuwanga Kibangandete, Kingandeta
• Pneumonia	Kichomi, Homa za kubana mbavu, Monia, Limonia , Nimonia
• Asthma	Pumu, Lubela
• Blisters	Malengelenge, Maji moto, Mataruma
• Malaria	Homa ya manjano, upepo mbaya, Ngingamo, Homa kali, Homa ya vipindi
• Conjunctivitis	Macho, Mwangeri, Lipindwa, Ngendo
• Mulnutrition	Utapiamlo, Unyafuzi, Kilibatumbo, Lilogo, Safura, Minyoo, Nging'indo.
• Worms	Minyoo, Kisango
• Enlarged spleen	Ligandama, Gandama, Bandama. Ibandama
• Vomit	Kutapika, Chango la kikwamba, Kingumbukumbu, Mbungurumo.
• Ringworms	Ugonjwa wa ngozi, Mapune
• Kifaduro	Kifua cha mshipa
• Diarrhea	Kuharisha, Kuchelenga
• Vomit	Kutapika,
• Recto prolapse	Chango la mmile, Ugonjwa wa chango la kiuno
• Mulnutrition	Utapiamlo, Kinjombinda, kuyapa tumbo

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Appendix 2

Selected narratives from case studies on help seeking for degedege, Morogoro Rural and Rufiji District.

Case No	Narration
Case 1 Morogoro (Ful B2FCS4)	[…] when the child developed degedege I went to Kingolwila dispensary for treatment as at Mikese dispensary there are no drugs [...] At Kingolwila the child was given some tablets to boost blood and Septrine syrup […] the child's condition worsened and I decided to take the child to Mburahati in Dar es salaam […] At Mburahati, the child got PPF injection (antibiotic) for five days and cough syrup called Koflyn because the sickness was accompanied by chest problem […] The child got better and the child gained appetite […]after the injections the severity of the fever reduced and you know it is the fever that caused the degedege […] Still the fever comes up again but we know it is only mild fever, we give Panadol and Cofllyne syrup and the child got better again […] Afterwards fever persisted and was advised by neighbours that I should give the child valium (diazepam) tablets that could be obtained from medical stores[…] I did not buy the tablets and instead I decided to go back to Kingolwila dispensary straight away for investigation (Male household head and caretaker aged 27, Morogoro).
Case 2, Morogoro (FulB2CS5)	[…] I pushed the child under the bed and splashed urine on her. I then smeared the child with wet soil from the toilet […] I then burned garlic together with dry elephant dung and made the child inhale the smoke and then all over the body by covering the child with a piece of cloth[…] the convulsions stopped […] I was

	advised by the parents to take the child to the traditional healer called Mr. Kassim to get something to protect the child from possible subsequent degedege attack and after to the hospital […] at the traditional healer the child was given a charm on a string to wear around the waist […] the string tiered small pieces of wood and a piece of chicken bone[…] also the child was given herb medicine.. I then took the child to Morogoro hospital as was advised by my parents […] at the hospital the child was investigated and found to have malaria […] the child got treated for malaria and cured (Female caretaker aged 27, Morogoro).
Case 3, Morogoro (FULB2CS6)	[…] when she developed degedege I went to the traditional healer. After presenting my case, the healer went to the bush and returned with some roots that were then boiled and the mixture given to the child together with chicken soup […] The herbal medicine was given three times a day. The child is still under treatment and the healer is the uncle of the child [...] The child is not cured yet because we think the disease is from god […] You should also know that there is witchcraft nowadays. It could be the child has been bewitched (Female Caretaker aged 28, Morogoro).
Case 4, Morogoro (FULB2CS7)	[…] my brothers and sister advised that we should give the child some traditional medicine first because Mr. Sume, the healer is locally known to treat the degedege successfully and we agreed that if the child did not improve we should send the child to the hospital […] we have seen many children getting cured by this healer successfully […] for our child, the treatment by this healer did not work […] It was only a slight improvement and after 2 weeks degedege came again […] the healer had the impression had cured the illness but it was a slight relief […] when the degedege came again it was night and could not take the child to hospital that night […] The child was given the same medicine we got from the healer during previous

	attack as we still had some […] In the morning we decided to take the child to the hospital and before we could board the bus the child died (Female caretaker (age unknown), Morogoro).
Case 5, Morogoro (MIKB2CS42)	[…] the healer went to get the medicine and a chicken that was then mixed together and given to the child to drink [...] the child was better after the treatment and we were assured the child was now protected against subsequent attacks from degedege […] we then took the child to the hospital (dispensary) and got tablets and syrup and the child got cured (Female caretaker aged 33 years, Morogoro).
Case 6, Morogoro (LANB2CS1)	[…] we went to seek help from the traditional healer […] the healer first burned some herbal medicine for the child to inhale […] he assured me the child would be better because the child was still unconscious [...] the healer then smeared the whole body of the child with another medicine which looked like cooking oil of some kind and then he left us inside and went outside of the house but said that when he returns the child would be awake [...] when he returned he called the child by the name [...] the child responded by opening her eyes and looked at the healer without moving the eyes [...] the healer told me to call the child [...] I called the child by the name, she then responded. I asked her if she liked to take something [...] the child replied by saying yes and I asked her again what she would liked to have and replied she liked tea [...] I made a cup of tea for her which she was able to drink […] I saw the child got some relief [...] after few hours around noon I then took the child to the hospital [...] at the hospital the child was checked blood and found to have malaria and anaemia […] the doctor complained to me why I delayed to bring to the child for treatment after developing degedege saying it was treatable [...] they gave her some tablets to raise the blood and chloroquine tablets for malaria [...] they told me I should give the child one tablet twice a day and I realized I

	had given her too little chloroquine at home before the degedege[…] after the treatment she got cured (Female caretaker aged 34 years, Morogoro)
Case 7, Morogoro (LAN B2 CS2)	[…] when the child developed degedege I went to seek help to the traditional healer at Nyempenu village […] the healer boiled some roots and gave the child the mixture to drink at least a table spoon full twice a day and a charm in black piece of cloth for the child wear around the neck […] the treatment did not work and I decided to take the child to the dispensary [...] the child got cured at the dispensary and I decided to go to my parents at Luale. Just a day at my parents' home the degedege returned, the child's limbs became rigid and the teeth closed [...] my mother burned elephant dug for fuming the child […] this did not help and my mother suggested we take the child to Lukunguni for another healer […] the child's condition was serious that I suggested to my mother the healer to be brought at home here instead of us going there […] my mother went to get the healer and my brother went to get the child's father […] the child's father refused to came saying I should have brought the child back home[...] after the resistance to come elders and his mother in law contacted him and he came to Luale[…] he found we had two different healers treating the child, one specialized in degedege and the second for many other illnesses each trying level best to save the child [...] the child wasn't getting any better and we believed the child had been bewitched[…] we then resorted to the hospital where the child got chloroquine injections and thereafter quinine[...]while under the hospital treatment we got another healer for *Bandama* […] the healer used a mixture of an egg and some boiled roots and using a sole of an old sandals (*ndala in swahili*) he pressed on left side of the chest […] after treatment by quinine the child got cured (Female caretaker 40 aged years, Morogoro) .

Case 8, Morogoro (MIKB2CS34)	[…] the child was twitching arms and legs and froth was coming out of mouth […] the child could not speak for three days […] before resorting to the hospital we were giving panadol and aspirin that I thought was relieving pain and fever [...] after the three days without improving we resorted to the hospital [...] we were advised by neighbours to seek help from the traditional healer because they said the child had degedege and can not be cured anywhere else than traditional healer […] we did not take the advise, instead we went straight to the hospital […] we went to Morogoro hospital because Mikese dispensary do not do laboratory investigations but also the child was in serious condition we thought we should rush to hospital […] after staying for about ten minutes at the hospital nurses took me with the child to the doctor after realizing the child was in serious condition […] we stayed with the doctor for about fifteen minutes and they said the child had degedege [...] we were admitted for three days and the child was given four injections […] we were then discharged and the child was cured (Female caretaker aged 40 years, Morogoro)
Case 9, Morogoro (FULB2CS23)	[…] the fever was very high and the child had twitching […] we resorted to the regional hospital in Morogoro […] the blood was checked and they said the child had malaria plus plus (meaning severe malaria) […] the child was first given valium injection to relieve the stiffness and then given chloroquine injection […] after 4 days we were discharged and returned home after the cure […] after that we went to traditional healer to undergo some traditional rituals regarding the illness degedege to prevent subsequent attacks [...] the healer instructed to bring a chicken and it took two days to obtain the chicken that was then slaughtered by the healer, cooked and the soup given to the child [...] in our Zigua culture it is important to undergo the ritual so that the child doesn't get subsequent attack of degedege and we refer to it as "kufunikwa" in our language

	(Female caretaker aged 33 years, Morogoro).
Case 10, Rufiji (NYAB2CS5)	[…] I remember it was July this year the last time my child got degedege […] the child got treated several times […] in between treatment the child got a little bit better but fever and degedege kept returning until the use of current treatment […] the child never got total cure that is why the child had these repeated attacks […] degedege is treated by traditional treatment and I was taking the child to the hospital [...] the child got temporary relief with hospital treatment but the illness returns shortly afterwards [...] before my child got sick I didn't know the cure of the illness was only by traditional healer [...] I understood the illness was treatable in the hospital [...] the child started with homa, I touched the child's body and was hot [...] I reported the illness to my sister in law who advised me to buy aspirin which I gave to the child [...] the child slept but fever (homa) did not go down [....] we decided to seek help from the hospital […] at the hospital, the child had blood checked and the results indicated that the child had malaria […] the child was then admitted to the hospital for treatment [...] the second day in hospital while under treatment of malaria the child's condition became worse[...] the child developed twitching of the limbs, mouth went sideway and limbs became rigid and fast breathing […] the child got several injections of chloroquine, valium injection and a number of tablets [...] we were discharged the third day in the evening […] after discharge I believed my child had cured but the child continued to have recurrent fevers almost after every week [...] each time I gave Aspirin the fever went down but return a later[...] the child developed high fever for the second time, high fever than before for about 3 days and developed degedege [...]my sister in law and my brother decided we should take the child again to the hospital[...] this time to a private hospital in anticipation for better treatment […] we

	got admitted again and this time the child was found to be anaemic and my brother donated blood [...].after a week of treatment the child improved a bit and we got discharged […] back home the child continued to be unwell. Mild fever was still returning and I was using Panadol syrup to cool down the fever [...] my father visited us after the news of the illness reached them back home in Rufiji [...] after listening to the story of the illness he advised that I return to their home saying that was not an illness for the hospital [...] after returning to Nyambili, few days later the child developed degedege again[...] it was around midnight when the degedege developed again[...] the child had froth in the mouth, rigid limbs and breathed fast […] I woke up my mother who then decided we should seek help from the healer[.. .] we were there from 12.00 midnight until 3.00 pm and the child had relief[…] we returned home and the child continued to improve and the illness got cured [I now believe degedege is not a disease for the hospital but the hospital gives temporary relief (Female caretaker aged 18 years, Rufiji)
Case 11, Rufiji (NYAB2CS6)	[…] the child developed degedege while admitted at Mchukwi hospital for an abscess on the thigh […] when the condition developed in hospital parents of other sick children alerted me that the child was having an attack of degedege […] eyes had turned on one side, limbs were rigid and the child had froth in the mouth[…] I lifted my child towards the nurse who in turn informed the doctor […] the nurse and the doctor looked at the child, I could see them writing something[...] after that I was told to return to the bed […] after a while I was called and given powder like medicine that was mixed with water and given to the child to drink […] the medicine was given only once and the degedege stopped (Female caretaker aged 26 years, Rufiji).

Appendix 3

It is the tradition of the Ndengereko people of Rufiji to perform a traditional ritual termed “KUMBO” to a new born baby. The traditional event is performed for seven days by the grand mother during which the child is not allowed to be taken out side and touched by other people. The aim of performing the ritual is to protect the child from evil spirits but also “kumbo” Traditionary

Picture 1. Child being bathed in a mixture of traditional medicine on day seven after birth marking the completion of a traditional ritual locally known as ‘KUMBO” to protect the child from evil spirits, to make the child remain calm especially when the mother is away and other local taboo. The ritual also worn the parents to refrain from sexual intercourse during the tender age as this may harm the child.

Picture 2. The grandmother beside the child and a basin containing the medicine mixture used in the ritual. The child is on the ground waiting for the next step.

Picture 3. The child being bathed in a basin with local herbal solution on top of a pounding mortar. Only female children are bathed this way meaning that in her future age she will a duty of pounding floor for food in the family and also to prevent her from screaming during time of difficulties in her life

Picture 4. The child is lifted and pointed to 4 main directions as follows with the meaning:

To the South, people travel to the capital to buying essentials. To the South Rufiji River is used for fishing, to the west tobacco is obtained and to the east (Indian Ocean) people obtain salt and fish

Picture 5. The child lays on the ground to signify “seeking sympathy” one of the parent to offer some money to the grandmother as demanded by her according to culture after performing the cultural ritual.

Picture 6. Shows the grandmother jumping the child seven times forward and backward meaning that in the future life the child will have to work hard in order to be able to sleep any where and any time.

Picture7. The mixture after the ritual is buried in the farm by the grandmother to mark completion of the ritual.

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