GAINING ACCESS TO PROMPT AND APPROPRIATE MALARIA TREATMENT IN THE KILOMBERO VALLEY, TANZANIA:

A HEALTH SOCIAL SCIENCE PERSPECTIVE

Inauguraldissertation

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Basel, den 22. Mai 2012

Prof. Dr. Martin Spiess

Dekan

Dedicated to the memory of my dad

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ACT	Artemisinin-Based Combination Therapy
ADDO	Accredited Drug Dispensing Outlet
ALIVE	Artemether-Lumefantrine in vulnerable patients – exploring health impact
ALu	Artemether-Lumefantrine (trade name: Coartem)
CHMT	Council Health Management Team
DHS	Demographic and Health Survey
EMIC	Explanatory Model Interview Catalogue
FGD	Focus-Group Discussion
GDP	Gross Domestic Product
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HDSS	Health Demographic Surveillance System (also DSS)
HMIS	Health Management Information Systems
HMM	Home Management of Malaria
HPLC	high-performance liquid chromatography
HS	help-seeking
IEC	Information, Education, Communication
IHI	Ifakara Health Institute (former IHRDC)
IHRDC	Ifakara Health Research and Development Centre (today IHI)
IMCI	Integrated Management of Childhood Illness
IMPACT-Tz	Interdisciplinary Monitoring Project for Antimalarial in Tanzania
IRS	Indoor Residual Spraying
IPTi	Intermittent Treatment during Infancy
IPTp	Intermittent Treatment during Pregnancy
ITN	Insecticide Treated Net
KINET	Kilombero Insecticide-Treated Net Project
MCH	Mother and Child Health
MMV	Medicines for Malaria Venture
MoH(SW)	Ministry of Health (and Social Welfare)
MSH	Management Sciences for Health
NIMR	National Institute for Medical Research of the United Republic of Tanzania
NMCP	National Malaria Control Programme
OTC	Over-the-Counter
PMI	United States President's Malaria Initiative

RBM	Roll Back Malaria
RCHC	Reproductive and Child Health Clinics
QIRI	Quality Improvement and Recognition Initiative
RDT	Rapid Diagnostic Tests
SES	Socio-Economic Status
SP	Sulphadoxine (or Sulphametoxipyrazine)-Pyrimethamine
STI	Swiss Tropical Institute (now Swiss TPH)
STIFL	Swiss Tropical Institute Field Laboratory (see IHI)
Swiss TPH	Swiss Tropical and Public Health Institute (former STI)
TEHIP	Tanzania Essential Health Interventions Project
TFDA	Tanzania Food and Drugs Authority
UNFPA	United Nations Population Fund
VA	Verbal autopsies
ZMCP	Zanzibar Malaria Control Programme

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Summary

Malaria is a life-threatening disease causing an estimated one million death annually. Major achievements have recently been noted in Tanzania, child mortality rates are declining. If prompt and effective treatment is initiated, malaria is a curable disease; however, in many places, people still lack access to prompt and effective malaria treatment.

This thesis was carried out during the first phase of the ACCESS intervention program (2004-2008) which aimed at improving access to malaria treatment in the Kilombero Valley, Tanzania. The program had three main areas of interventions: 1) in the community, 2) the drug shops and 3) the health facilities.

This thesis has grown out of the monitoring and evaluation component of the ACCESS program. It specifically focuses on two monitoring and evaluation activities: 1) treatment seeking surveys which assess interventions at community level and 2) mystery shopping studies at drug shop level.

The studies on treatment seeking (Chapters 4-6) investigated whether malaria treatment seeking for children with fever and convulsion has changed during the first phase of the ACCESS program. The key argument is that unprecedented achievements in the availability and affordability of effective drugs do not necessarily imply that people get the medicines they need. Access to medicines is a multifaceted phenomenon: Five dimensions of access (availability, affordability, accessibility, adequacy and acceptability) play an influential role in treatment seeking decisions. Of these dimensions, acceptability has received least attention. This study defines acceptability as the match between local and biomedical understanding and appropriate treatment seeking. Acceptability is of particular relevance if local and biomedical explanatory models of illness differ, as they did, for instance, for severe malaria with convulsions. Previous studies on explanatory models of convulsions have shown that communities may not link convulsions with malaria and prefer local treatment practices. Most of these studies have relied on what people *would* do in cases of illness. It is therefore impossible to assess whether and what proportion of children gain access to appropriate treatment. The studies presented here contributed to closing this knowledge gap by examining *actual* convulsion cases.

The Explanatory Model Interview Catalogue was used to collect information on symptoms, causes and treatment seeking for fever and convulsion among children under-five years of age in four studies: i) a cross-section fever survey (2004, n= 88); ii) a longitudinal *shamba* fever study (2005, n=29); iii) a longitudinal *degedege* study (2004/06 n=135); and iv) longitudinal *degedege* study (2007/08 n=88).

Findings indicated that the match between local and biomedical understandings of convulsions was already high in 2004/06; 68% of caregivers associated convulsion with severe malaria while 85% mentioned mosquito bites as a cause of convulsion. Significant changes were noted in the second round of interviews, specifically on i) 46% point increase among those who reported use of mosquito nets to prevent convulsions; ii) 13% point decrease among caregivers who associated convulsion with 'evil eye and sorcery'; iii) 14% point increase in prompt use of a health facility; and iv) 16% point decrease among those who did not use a health facility. The contrast of these findings with findings from previous studies can be explained by a) differences in accuracy of data collection and b) changes in explanatory models due to long exposure to biomedical research and interventions, also through the ACCESS program.

The studies on mystery shopping (Chapters 7 and 8) examined the usefulness of this methodology for assessing changes in the performance of drug sellers in community pharmacies. Indicators were developed and used to measure the quality of dispensing practices and advice before and after ADDO implementation in 2006. Results showed a 30% increase from 2006 to 2007 among clients who got correct advice and treatment based on the assessed indicators.

This thesis provides the first systematic community-based study of actual treatment seeking for children with convulsions in Tanzania and to our best knowledge also in Africa. The methodology developed in this study should be refined and validated in further empirical and comparative research across regions and countries. Improving the match between local and biomedical understanding of disease is fundamental to ensuring acceptability of health care services and successful control of health problems. The thesis further showed that mystery shopping is a useful technique for assessing the impact of ADDO interventions in retail drug stores. Innovative community based participatory research approaches and more systematic mystery shopping techniques

would allow for comparative community-based assessments of drug shop interventions across regions and countries.

Zusammenfassung

Malaria ist eine lebensbedrohliche Krankheit, welcher etwa eine Million Menschen jährlich zum Opfer fallen. Die meisten Krankheitsfälle passieren in Afrika südlich der Sahara, wo Kleinkinder und Schwangere einem hohen Infektionsrisiko ausgesetzt sind. Grosse Fortschritte wurden kürzlich in Tansania erzielt, wo Malaria-Mortalitätsraten am Sinken sind, vor allem dank erhöhtem Einsatz von Schlüsselinterventionen wie integriertes Management von Kinderkrankheiten (IMCI) und mit Insektizid behandelte Mückennetze (ITNs). Malaria ist heilbar bei sofortiger Behandlung mit wirksamen Medikamenten, jedoch mangelt es der Bevölkerung an vielen Orten noch am Zugang dazu. Der Zugang zu Gesundheitsdiensten und Interventionen, v. a. für Medikamente in Entwicklungsländern, ist Gegenstand einer heftigen Debatte; noch nie war das Interesse an diesem Thema und die finanzielle Unterstützung so gross wie während der letzten Dekade.

Diese Dissertation wurde während der ersten Phase des ACCESS-Interventionsprogramms (2004-2008) durchgeführt, welches zum Ziel hatte, den Zugang zur Behandlung von Malaria im Kilomberotal in Tansania zu verbessern. Das Programm wurde in drei verschiedenen Bereichen durchgeführt: 1) in Gemeinden, 2) in Medikamentenläden und 3) in Gesundheitseinrichtungen.

Das Programm führte in den Gemeinden Sozialmarketingkampagnen durch, um den Bedarf an sofortiger Behandlung von milden und schweren Formen der Malaria mit wirksamen Medikamenten zu fördern. Mehrere Kommunikationskanäle wurden eingesetzt zur Aufklärung über Malaria, d.h. zu Symptomen, Ursachen und Prävention. Kampagnenaktivitäten beinhalteten Strassenshows mit Rollenspielen, Tanz und öffentlichen Vorlesungen und die Verteilung von IEC-Material wie Poster, Plakatwände, Kleber, T-Shirts und Kappen mit verschiedenen Botschaften zu Malaria und Konvulsionen.

Das ACCESS-Programm beinhaltete auch Aktivitäten zur Verbesserung der allgemeinen Pflegequalität in Gesundheitseinrichtungen. Das Programm führte in den Jahren 2004 und 2005 Auffrischungskurse zu IMCI für Gesundheitspersonal durch. Das Programm unterstützte auch das für Gesundheitsmanagement zuständige Team auf Distriktsebene (CHTM), damit es die Beaufsichtigung des Gesundheitspersonals in Dispensarien,

Gesundheitszentren und Spitälern besser wahrnehmen kann. Während Besuchen beurteilten die Beaufsichtigungsteams zum Beispiel, ob sich die Leistungserbringer während ihren täglichen Pflegeaktivitäten an die nationalen Malaria- und IMCI-Richtlinien hielten. Das Programm organisierte in Kliniken auch gezielt Kampagnen zur Mutter-Kind-Gesundheit (MCH) für Schwangere und für Mütter von Kleinkindern.

In den Medikamentenläden arbeitete das ACCESS-Programm zusammen mit einem Programm namens ADDO (Accredited Drug Dispensing Outlets) der Regierung von Tansania, welches von Management Sciences for Health (MSH) und der tansanischen Lebensmittel- und Arzneimittelbehörde (TFDA) umgesetzt wird. Das ADDO-Programm wurde im Untersuchungsgebiet im Jahr 2006 gestartet, um den Zugang zur Malariabehandlung und die Medizinausgabe zu verbessern. Das ADDO-Programm trainiert Medikamentenverkäufer, offeriert Anreize und ist zuständig für Akkreditierung und Regulierung, um den Zugang zu und die Pflegequalität in Medikamentenabgabestellen zu verbessern. Mittels Testkäufen (Mystery Shopping) untersuchte das ACCESS-Programm die Auswirkungen von ADDO-Interventionen vor und nach der Programm-Implementierung im Jahr 2006.

Diese Dissertation entstand aus der Monitoring- und Evaluationskomponente des ACCESS-Programms und hat sich auf folgende zwei Aktivitäten in diesem Bereich konzentriert: 1) Untersuchungen zum Behandlungsverhalten zur Beurteilung der Intervention auf Gemeindeebene und 2) Mystery-Shopping-Studien in Medikamentenläden. Diese Dissertation hat zwei Hauptziele: einerseits zur Evidenzbasis bezüglich der Effektivität der zwischen 2004 und 2008 implementierten ACCESS-Interventionen beizutragen und andererseits das wissenschaftliche Verständnis hinsichtlich der Frage, ob, warum und wie Kleinkinder „Zugang bekommen“ zu sofortiger und angemessener Malariabehandlung, zu erweitern.

Die Studien zum Behandlungsverhalten (Kapitel 4-6) untersuchten, ob sich das Verhalten zur Malariabehandlung von Kleinkindern mit Fieber und Konvulsionen während der ersten Phase des ACCESS-Programms (2004-2008) geändert hat. Das zentrale Argument ist, dass die beispiellosen Erfolge in der Verfügbarkeit und Erschwinglichkeit von wirksamen Medikamenten auf nationaler Ebene nicht notwendigerweise den Zugang dazu und zur dazugehörigen Pflege, welche die Leute benötigen, implizieren. Zugang zu Arzneimitteln und dazugehörigen Dienstleistungen ist

ein vielschichtiges Phänomen: fünf Dimensionen von Zugang (Verfügbarkeit, Erschwinglichkeit, Zugänglichkeit, Angemessenheit und Akzeptabilität) spielen eine einflussreiche Rolle bei Entscheidungen zum Behandlungsverhalten, wobei Akzeptabilität am wenigsten Aufmerksamkeit erhalten hat. Diese Studie definiert Akzeptabilität als Übereinstimmung zwischen lokalem und schulmedizinischem Verständnis und dafür angemessenem Behandlungsverhalten. Diese Studie ergänzt andere Studien innerhalb des ACCESS-Programms, welche a) weitere Determinanten des Zugangs und b) milde Malaria zum Gegenstand hatten. Untersuchungen zur Akzeptabilität sind speziell relevant, wenn sich lokale und schulmedizinische Erklärungsmodelle unterscheiden, so wie das zum Beispiel der Fall war bei schwerer Malaria mit Konvulsionen. Vorherige Studien zum Erklärungsmodell für Konvulsionen haben gezeigt, dass die lokale Bevölkerung die Verbindung zwischen Konvulsionen und Malaria nicht macht und lokale Behandlungsmethoden bevorzugt. Die meisten dieser Studien haben sich auf das, was die Leute im Falle einer Erkrankung *tun würden*, bezogen. Es ist daher unmöglich, zu bestimmen, ob Kinder mit Konvulsionen Zugang zu sofortiger und angemessener Behandlung erhalten und wie hoch deren Anteil sein mag. Die hier vorgestellten Studien haben dazu beigetragen, diese Wissenslücke zu schliessen, indem *tatsächliche* Konvulsionsfälle untersucht wurden.

Der Erklärungsmodell-Interview (EMIC) wurde in vier Studien eingesetzt, um Informationen zu Symptomen, Ursachen, Prävention und Behandlung von Fieber und Konvulsionen bei Kindern unter fünf Jahren zu sammeln: i) eine Querschnittsbefragung zu Fieber (2004, n=88); ii) eine Längsschnittstudie zu Fieber in *shambas* (2005, n=29); iii) eine Längsschnittstudie zu *degedege* (2004/06, n=135) und iv) eine Längsschnitt-studie zu *degedege* (2007/08, n=88). Frühere Arbeiten zu Konvulsionen im Studiengebiet wurden auch berücksichtigt, um den Wechsel im Behandlungsverhalten bei Konvulsionen zu untersuchen.

Die Ergebnisse deuten darauf hin, dass die Übereinstimmung zwischen lokalem und schulmedizinischem Verständnis bei Konvulsionen schon in den Jahren 2004/06 hoch war; 68% der mit der Betreuung beauftragten Personen assoziierten Konvulsionen mit schwerer Malaria und der Anteil an Betreuungspersonen, welche Moskitostiche als Ursache für Konvulsionen anschauten, lag bei 85%. Signifikante Veränderungen wurden in der zweiten Interviewrunde (2007/08) gefunden: 1) ein Anstieg um 46 Prozentpunkte bei der Angabe, dass ein Moskitonetz als Prävention für Konvulsionen taugt; 2) eine

Abnahme um 13 Prozentpunkte bei Betreuungspersonen, die Hexerei und Magie mit Konvulsionen im Zusammenhang brachten; 3) ein Anstieg um 14 Prozentpunkte beim sofortigen Aufsuchen einer Gesundheitseinrichtung und 4) eine Abnahme um 16 Prozentpunkte bei denjenigen, welche gar keine Gesundheitseinrichtung besucht hatten. Die Unterschiede zwischen den vorliegenden Ergebnissen und denjenigen der vorherigen Studien können folgendermassen erklärt werden: durch a) Unterschiede in der Genauigkeit während der Datensammlung, b) neue Erklärungsmodelle, welche lokale und schulmedizinische Ansätze vereinigen und c) Veränderungen in den Erklärungsmodellen durch langes und hohes Ausgesetztsein gegenüber schulmedizinischer Forschung und Interventionen, auch wegen dem ACCESS-Programm. Die letzten zwei Erklärungen verweisen auf eine Erhöhung der gesellschaftlichen Akzeptabilität von Interventionen gegen Malaria in den lokalen Gemeinden.

Mit den Testkauf-Studien (Kapitel 7 und 8) wurde die Brauchbarkeit dieser Methodik zur Untersuchung von Veränderungen in der Leistung von Medikamentenverkäufern in Gemeindeapotheken untersucht. Medikamentenverkaufsläden sind eine wichtige Quelle zur Malariabehandlung und waren im Fokus des ADDO-Programs. Das ACCESS-Programm wandte die Mystery-Shopping-Technik an, um die Änderungen in der Pflegequalität vor und nach dem Start von ADDO in den Studiendistrikten zu evaluieren. Mystery Shopping wurde aus ethischen Gründen angeklagt, da dabei Schein oder sogar Täuschung benützt werden. In den vergangenen Jahren wurden ethische Richtlinien entwickelt, die auch für die Forschung in Afrika adaptiert werden können. Basierend auf den nationalen Malariabekämpfungsrichtlinien und dem von ADDO durchgeführten Training von Abgabepersonen bezüglich IMCI wurden Indikatoren entwickelt. Diese wurden angewandt, um die Qualität der Arzneimittelabgabe und der Beratung vor und nach der Implementierung von ADDO im Jahr 2006 zu messen. Auf den untersuchten Indikatoren basierend, ergaben die Resultate einen Anstieg um 30% zwischen 2006 und 2007 bei Kunden, welche eine korrekte Beratung und Behandlung bekommen hatten. Diese Studienergebnisse weisen auf die Bedeutung der ADDO-Intervention hin bei der Verbesserung der Malariabehandlung in Medikamentenabgabestellen. Trotz den Ablehnungen, mit der die Methode konfrontiert wurde, zeigten die Ergebnisse auf, wie nutzbringend Mystery Shopping bei der Abschätzung von ADDO-Interventionen auf Abgabestellen eingesetzt werden kann. Ein zusätzlicher Pluspunkt, der in der Literatur

noch nicht erwähnt wurde, besteht im Empowerment der Dorfbewohner, die in der Mystery-Shopping-Technik ausgebildet wurden.

Diese Dissertation stellt die erste systematische Studie dar, welche das Behandlungsverhalten bei Kindern mit Konvulsionen auf Gemeindeebene in Tansania, und unseres Wissens auch in Afrika, untersucht hat. Die für die vorliegende Arbeit entwickelte Methodik erlaubte die systematische Analyse von Patienten mit tatsächlich vorliegenden Konvulsionen in Gemeinden. Die Methodik sollte verfeinert und durch weitere empirische und vergleichende Forschung zwischen Regionen und Ländern validiert werden. Die Studienergebnisse zeigen auch auf, dass Erklärungsmodelle durch Kommunikationskampagnen beeinflusst werden können, vorausgesetzt dass deren Veränderung mit den Begünstigten im Einklang steht. Die Verbesserung der Übereinstimmung zwischen lokalen und schulmedizinischen Erklärungsmodellen bezüglich Krankheit ist grundlegend für die Sicherstellung der Akzeptabilität von Gesundheitsdiensten und für die erfolgreiche Bekämpfung und das Management von Gesundheitsproblemen. Diese Dissertation zeigte weiter auf, dass Mystery Shopping eine nützliche Methode darstellt zur Abschätzung der Auswirkungen von ADDO-Interventionen in Medikamentenverkaufsläden. Zusätzlich zeigt das Training einen Empowerment-Effekt auf die für das Mystery Shopping rekrutierten Dorfbewohner. Innovative auf Gemeindeebene und auf partizipativer Forschung basierende Ansätze und systematischere Mystery-Shopping-Techniken können eine vergleichende Abschätzung von Interventionen in Medikamentenläden zwischen Regionen und Ländern ermöglichen.

Muhtasari

Malaria ni ugonjwa tishio unaosababisha takribani vifo milioni moja kwa mwaka. Matukio mengi ya ugonjwa huu yanatokea barani Afrika, kusini mwa jangwa la Sahara. Mafanikio makubwa yameonekana hivi karibuni ambapo vifo vya watoto wachanga vimepungua. Iwapo tiba sahihi na mapema inapatikana, malaria ni ugonjwa unaotibika ingawaje bado kuna maeneo mengi, watu wanakosa huduma ya haraka na sahihi ya malaria.

Utafiti huu ulifanyika kipindi cha awamu ya kwanza ya utekelezaji wa mradi wa ACCESS (2004-2008) ambao ulikua na lengo la kuboresha upatikanaji wa tiba ya malaria katika bonde la mto Kilombero, Tanzania. Mradi huu ulifanya utekelezaji katita maeneo makuu matatu: 1)katika jamii, 2) maduka ya madawa na 3) vituo vya afya.

Utafiti huu umefanyika kama sehemu ya ufuatiliaji na tathmini ya mpango wa ACCESS. Utafiti huu umejikita zaidi katika kazi mbili za ufuatiliaji na tathmini: 1) tafiti katika ngazi ya jamii juu ya utafutaji wa tiba ya malaria 2) tafiti kwenye maduka ya dawa.

Utafiti wa utafutaji matibabu (Sura 4-6) ulichunguza kama utafutaji wa tiba ya malaria kwa ajili ya watoto wenye homa na degedege ulibadilika ndani ya awamu ya kwanza ya mpango wa ACCESS.. Hoja ya msingi ni kwamba mafanikio ya kipekee katika upatikanaji wa madawa katika ngazi ya nchi si kigezo kwamba watu watapata madawa hayo. Upatikanaji wa madawa na huduma ni jambo lenye changamoto kubwa: mambo makuu matano (upatikanaji, uwezo wa ununuaji, ufikiwaji, ubora na ukubalikaji) yanachangia katika maamuzi ya utafutaji tiba. Kati ya haya mambo, ‘ukubalikaji’ umepewa umakini mdogo. Utafiti huu unajikita zaidi katika kuangalia ‘ukubalikaji’ wa tiba ya malaria na unaelezea ‘ukubalikaji’ kama mapatano kati ya uelewa wa tiba sahihi kati ya wagonjwa na watabibu. Ukubalikaji wa tiba ni muhimu zaidi pale ambapo tofauti za uelewa zinaonekana kati ya wagonjwa na watabibu kwa mfano kwenye suala la degedege. Tafiti za awali zilionyesha kuwa watu hawahusishi malaria na degedege ambapo tiba za jadi zilipendelewa zaidi. Tafiti hizi zilielekeza nguvu zaidi kungalia ni nini watu wangefanya iwapo watoto wao wangekumbwa na degedege. Kwa mantiki hiyo ni vigumu kuelewa idadi ya watoto wenye degedege wanaopata huduma ya tiba. Utafiti huu unachangia kuziba pengo hili kwa kuchunguza matukio halisi ya degedege.

Utafiti ulifanyika kwa kutumia zana ya utafiti iliyorakabishiwa kutokana na mazingira halisi. Zana hii ilikusanya maelezo kuhusu dalili, chanzo na tiba ya degedege kwa watoto chini ya miaka mitano kupitia tafiti nne i) utafiti wa papo kwa papo (2004, idadi ya wahojiwa = 88); ii) utafiti fuatiliaji (2005, idadi ya wahojiwa = 29); iii) utafiti fuatiliaji (2004/06 idadi ya wahojiwa = 135); na iv) utafiti fuatiliaji (2007/08 idadi ya wahojiwa = 88).

Matokeo yalionyesha kuwa uelewa juu ya degedege kati ya jamii na wahudumu afya tayari ulikuwa juu mwaka 2004/06, asilimia 68 ya wazazi/walezi walihusisha degedege na malaria kali, wakati asilimia ya wazazi/walezi ambao walitaja mbu kama chanzo cha kuumwa degedege ilkuwa 85. Mabadiliko makubwa yalionekana katika kipindi cha pili ambapo kulioneka kuwa na, i) ongezeko ya asilimia 46% kwa wale walioripoti matumizi ya chandarua kama njia ya kujikinga na degedege ii) punguzo la asilimia 13% miongoni mwa walezi waliohisisha degedege na 'jicho baya na uchawi ' iii) ongezeko la asilimia 14% kwa wale waliotafuta matibabu mapema katika vituo vya afya na iv) punguzo la asilimia 16 kati ya wale ambao hawakuhudhuria vituo vya afya. Tofauti ya matokeo haya na matokeo ya utafiti wa awali inaweza kuelezwa na a) tofauti katika usahihi wa ukusanyaji wa takwimu na b) mabadiliko yanayotokana na kampeni mbalimbali za afya juu ya matibabu ya malaria ikiwemo mpango wa ACCESS.

Utafiti wa ‘ununuzi siri’ katika maduka ya dawa (Sura ya 7 na 8) ulichunguza umuhimu wa mbinu hii kwa ajili ya kutathmini mabadiliko katika utendaji wa wauza dawa. Matokeo yalionyesha ongezeko la asilimia 30% kutoka 2006 mpaka 2007 miongoni mwa wateja ambao walipata ushauri sahihi na matibabu kwa kuzingatia vigezo vya tathmini. Matokeo ya utafiti yanaonyesha umuhimu wa mpango wa maduka ya dawa muhimu katika kuboresha huduma za malaria katika jamii.

Utafiti huu umekuwa wa kwanza kuratibu juu ya utafutaji tiba miongoni mwa watoto waliopatwa na degedege Tanzania na ikiwezekana pia Afrika. Utafiti huu unapendekeza kuwa mbinu zilizotumika hapa, zijaribiwe pia katika maeneo mengine ndani na nje ya nchi. Matokeo ya utafiti yanaoonyesha uelelwa katika jamii unaweza kubadilika kutokana na kampeni za afya. Kuboresha uelewa kati ya wanajamii na wahudunu afya ni muhimu kwa ajili ya udhibiti na mafanikio katika matatizo ya afya. Utafiti huu pia umeonyesha umuhimu wa mbinu ya ‘ununuzi siri’ kwa ajili ya kutathmini mpango mzima

wa maduka ya dawa muhimu. Ubunifu juu ya ushirikishaji jamii katika utafiti na mbinu zaidi za ‘ununuzi siri’ zitaruhusu tathmini ya maduka ya dawa ndani na nje ya nchi.

1. Introduction

Figure 1 Campaigning for malaria control in Kilombero Valley (Photo: M. Hetzel, 2004)

1.1 The global malaria situation

Malaria is a life-threatening disease caused by parasites that are transmitted to people through the bites of infected mosquitoes. In 2010, there were 216 million cases of malaria, of which approximately 81%, or 174 million cases, were in the African Region (WHO, 2011a; WHO, 2011b). There were an estimated 655 000 malaria deaths in 2010, of which 91% were in Africa. Approximately 86% of malaria deaths globally were of children under 5 years of age. The good news is that since 2000, malaria mortality rates have fallen by more than 25% globally and by 33% in Africa.

Malaria is transmitted exclusively through the bites of *Anopheles* mosquitoes (WHO, 2011c). The four parasite species that cause malaria in humans are *Plasmodium falciparum, Plasmodium vivax, Plasmodium malariae and Plasmodium ovale.* P. *falciparum* transmission dominates across Sub-Saharan African populations, while elsewhere both *P. falciparum* and *P. vivax* are found (RBM, 2011). The humid geographical conditions maximize the endurance of *Anopheles* mosquitoes and speed up completion of the parasite life cycle (Craig et al., 1999).

The first symptoms of malaria are nonspecific and similar to the symptoms of a minor systemic viral illness (WHO, 2010). They commonly include headache, lassitude, fatigue, abdominal discomfort, and muscle and joint aches, usually followed by fever, chills, perspiration, anorexia, vomiting and worsening malaise. Because of this non-specificity of symptomatology, malaria is frequently over-diagnosed, especially in endemic areas. If properly diagnosed, prompt and effective treatment can be expected to lead to full and rapid recovery. If, however, diagnosis is inaccurate, ineffective medicines are given or if treatment is delayed, particularly in *P. falciparum* malaria, the parasite burden continues to increase and malaria turns into a severe disease. What makes *P. falciparum* malaria particularly dangerous is that the progression from a mild to a severe stage may occur within a few hours. Severe malaria usually manifests with one or more of the following: seizures and/or coma (cerebral malaria), metabolic acidosis, severe anaemia, hypoglycaemia, acute renal failure or acute pulmonary oedema. In the severe stage of *P. falciparum* malaria, the case fatality in people receiving treatment is typically 10–20%. If left untreated, however, severe malaria is fatal in the majority of cases.

In children with *P. falciparum* malaria generalized seizures are more common than in those with the other forms of malaria (WHO, 2010). This suggests an overlap between the cerebral pathology resulting from malaria and febrile convulsions. As seizures may be a prodrome of cerebral malaria, patients with repeated seizures (more than two seizures within a 24 h period) should be treated as for severe malaria. In endemic areas, *falciparum* malaria is the most common cause of seizures in children, and the risk for seizures in malaria decreases with age (Kariuki et al., 2011). A hospital-based study in the malaria endemic area of Kilifi in Kenya found that children less than five years experienced a very high burden of acute seizure disorders (879/100'000/year) (Idro et al., 2008). The etiology of seizures varied with age. Sepsis was the most important cause of neonatal seizures. Pyogenic meningitis, gastroenteritis and respiratory tract infections were the most common diagnoses in children 2–5 months, while malaria was the most common illness in children 6 months or older, followed by respiratory tract infections and acute gastroenteritis.

Where the transmission of malaria is "stable" (populations continuously exposed to a fairly constant entomological inoculation rate [EIR] >10 per year), partial immunity to the clinical disease and to its severe manifestation is acquired early in childhood (WHO, 2010). Such situations prevail in much of Sub-Saharan Africa. The acute clinical disease described above is mostly confined to children less than five years of age. Adolescents and adults are partially immune and seldom suffer clinical disease, although they may continue to harbour low blood-parasite densities. Immunity is, however, modified in pregnancy (Victora et al., 2003). Infections with malaria during pregnancy might result in adverse consequences, or even death, not only for the pregnant woman, but also for the developing foetus and the newborn. It has been estimated that 75'000 – 200'000 infant deaths are associated with malaria infection in pregnancy (Steketee et al., 2001). Immunity is often gradually lost, at least partially, when individuals move out of the endemic areas for many years.

In uncomplicated malaria, the medical objective is to cure the infection as rapidly as possible, to prevent progression to severe disease, and additional morbidity associated with treatment failure (WHO, 2010). The public health goal of treatment is to reduce transmission of the infection to others, i.e. to reduce the infectious reservoir and to prevent the emergence and spread of resistance to anti-malarial medicines. In severe

malaria, the primary objective is to prevent death with anti-malarial treatment. In treating cerebral malaria, prevention of neurological deficit is also an important objective.

1.2 Global malaria control

Between 2000 and 2010, global control efforts have resulted in a reduction in the incidence of malaria globally by 17% and malaria specific mortality rates by 26% (WHO, 2011a). Although these rates of decline are lower than internationally agreed targets for 2010 (reductions of 50%), they are a major achievement. In 43 of the 99 countries with ongoing malaria transmission, reductions in reported malaria cases of more than 50% have been recorded, and in 8 other countries downward trends of 25%–50% were seen.

The main strategies to control malaria defined by the Roll Back Malaria (RBM) partnership in 1998 are still of relevance (RBM, 2011):

Prevention: Insecticide-treated mosquito nets (ITNs) and Indoor residual spraying (IRS) and Intermittent preventive treatment during pregnancy (IPTp)

Diagnosis and treatment: Prompt and effective malaria diagnosis and treatment

Other interventions: Malaria surveillance, case-finding, infection-finding and transmission containment

With regard to ii) prompt and effective malaria diagnosis and treatment, RBM and WHO recommend to give an effective anti-malarial preferably within 24 hours of fever onset and after confirmed diagnosis by microscopy or Rapid Diagnostic Tests (RDT). Due to widespread resistance of anti-malarial monotherapies such as quinine, sulfadoxine-pyrimethamine (SP) and amodiaquine are no longer recommended and instead artemisinin-based combination therapy (ACT) is recommended for mild malaria (RBM, 2011).

Renewed in interest in severe malaria emphasizes that this is a medical emergency (WHO, 2011c). After rapid clinical assessment and confirmation of the diagnosis, full doses of parenteral anti-malarial treatment should be started without delay. For many

years, quinine was the established treatment of choice in Sub-Saharan Africa. The policy has changed with the publication of the AQUAMAT trial (Dondrop, et al. 2010) which showed that artesunate substantially reduces mortality in African children with severe malaria. Artemisin derivates (artesunate, artemether and artemotil) are now included in the WHO Treatment Guidelines for severe malaria, together with the cinchona alkaloids (quinine and quinidine) and the artemisinin derivatives). Following initial parenteral treatment, once the patient can tolerate oral therapy, it is essential to continue and complete treatment with an effective oral anti-malarial using a full course of an effective ACT (artesunate plus amodiaquine or artemether plus lumefantrine or dihydroartemisinin plus piperaquine) or artesunate (plus clindamycin or doxycycline) or quinine (plus clindamycin or doxycycline). Under certain conditions, parenteral medication is not possible and intramuscular injection impractical. A trial in Bangladesh, Ghana and Tanzania showed that under such conditions, using a single dose of rectal artesunate as pre-referral treatment reduces the risk of death or permanent disability in young children (Gomes et al., 2009). A further study in Tanzania found that with a single dose of rectal artesunate as pre-referral treatment 48 h could be gained and this difference was reflected in less severe symptoms at admission (Gomes et al., 2010). After rectal artesunate pre-referral treatment, the patient should be brought to a facility where complete parenteral treatment with artesunate, quinine or artemether can be instituted (WHO, 2011c).

In the last decade, health equity has emerged as the central value and a guiding principle for strengthening primary health care, also in RBM policy and actions (RBM, 2011). Because malaria typically affects impoverished, rural and disenfranchised people and communities, reaching them is a critical priority among RBM partners at all levels. Equity can be improved through several initiatives, especially through achieving and sustaining universal access to prevention measures and case management in the public sector, private sector and in the communities.

1.3 Malaria situation in Tanzania

In the United Republic of Tanzania, the malaria situation has to be considered separately for the mainland and for the islands of Zanzibar (PMI, 2011a). On the

mainland, malaria continues to be a major public health problem for about 41 million residents. On the islands of Zanzibar, which have a much smaller population of 1.2 million, malaria control efforts over the past five years have dramatically reduced transmission of the disease.

Malaria epidemiology exhibits very different transmission settings on the mainland and on the islands of Zanzibar (PMI, 2011b). The following discussion centers on the mainland, where 93% of the population lives in areas where malaria is transmitted. The malaria endemic areas make up 60% of the mainland and are characterized by stable perennial transmission. In 20% of the country, malaria transmission is stable with seasonal variation, and in the remaining 20% unstable seasonal malaria transmission occurs. *Plasmodium falciparum* accounts for 96% of malaria infection in Tanzania, with the remaining 4% due to *P. malariae* and *P. ovale*. *P. vivax* is a rare parasite in Tanzania.

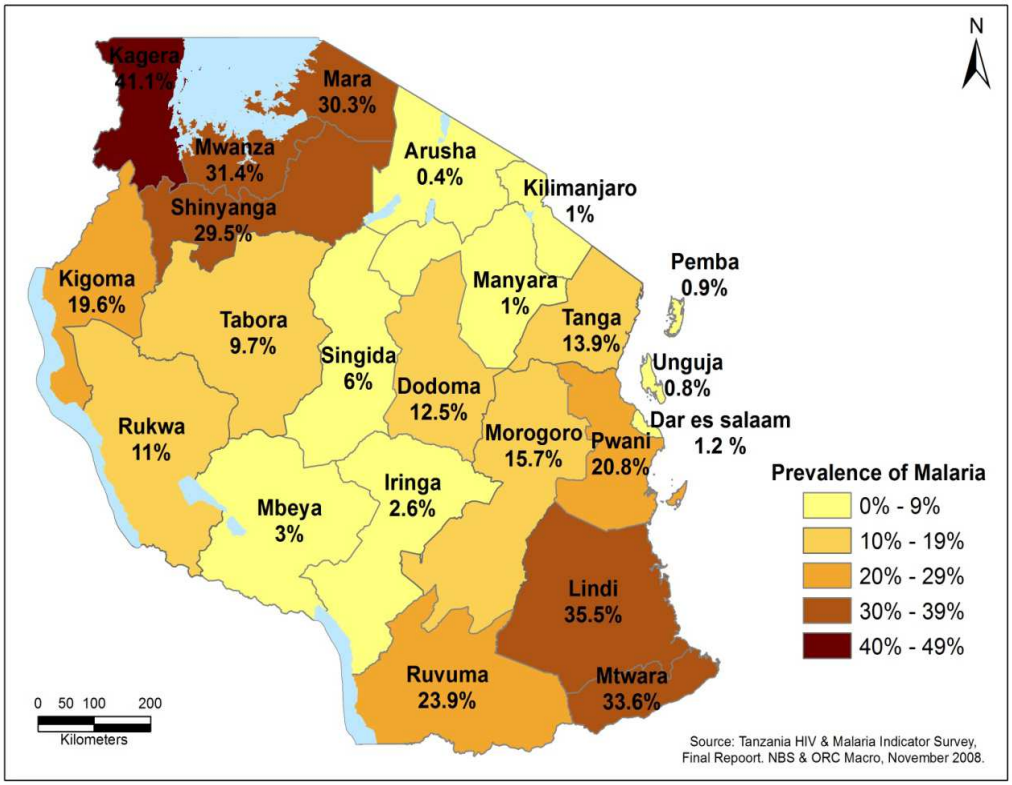
The principal malaria vectors on the mainland are the *Anopheles gambiae* complex and *An. funestus.* The *An. gambiae* complex breeds in clean waters exposed to sunshine, while *An. funestus* prefers to breed in slow-running waters with some vegetation and maintains transmission during the drier months on the year.

The 2007–2008 Tanzania HIV/AIDS Malaria Indicator Survey showed that 18% of mainland children under five had tested positive for malaria, in contrast to 0.8% in Zanzibar (Figure 2) (PMI, 2011b). On the mainland, rural areas had a higher malaria prevalence of 20% compared to urban areas of 8%. The mainland showed marked regional variations in parasitemia, ranging from 0.4% in the highland areas around Arusha to 41% in the northwestern region of Kagera. Malaria prevalence was highest in the north of the country around Lake Victoria and on the coast of the Indian Ocean. Families in the lowest wealth quintile were more likely to test positive for malaria than families in the highest quintile. Children whose mothers had no formal education had a malaria prevalence that was four times higher than those who had received at least a secondary education.

According to the PMI (2011b), more than 40% of all outpatient attendances on the mainland are attributable to malaria, resulting in approximately 12-16 million clinical malaria cases annually. The National Malaria Control Program (NMCP) estimates that

60,000-80,000 malaria deaths occur annually in the mainland among all ages (extrapolated from the under-five mortality rate in 2004–2005 Demographic & Health Survey size of under-five population, and the proportion of deaths attributable to malaria).

Figure 2: Prevalence of malaria in children below five years of age in Tanzania (Source THMIS, 2008)



While malaria remains a public health problem on the mainland, child survival gains in Tanzania since the 1990s are impressive (Masanja et al., 2008). In 1990, mortality in children younger than 5 years in Tanzania was 141 per 1000 livebirths. By 2003, this figure had dropped 24% to 112 deaths per 1000. Such a decline is unlikely to be due to one factor. The authors noted important improvements in Tanzania's health system between 1999 and 2004, including doubled public expenditure on health; decentralization and sector-wide basket funding; and increased coverage of key child-survival interventions, such as integrated management of childhood illness, insecticide-

treated nets, vitamin A supplementation, immunization, and exclusive breastfeeding. Other determinants of child survival that are not related to the health system did not change between 1999 and 2004, except for a slow increase in the HIV/AIDS burden.

And this positive trend in child survival continues: On the mainland and Zanzibar combined, all-cause mortality in children under the age of five fell by 28 percent between 2005 and 2010 (PMI, 2011b). Over the same time period, household ownership of at least one ITN increased from 23 to 64 percent, and ITN use among children under five and pregnant women increased from 16 percent (in both groups) to 64 and 57 percent, respectively. During the same period, the frequency of severe anemia (hemoglobin < 8 g/dL) in children six months to five years of age - shown to be strongly associated with malaria - fell by 50 percent on the mainland.

1.4 Malaria control in Tanzania

Malaria control has a long history in Tanzania and intensified in 1996, when the country introduced the Integrated Management of Childhood Illness (IMCI) strategy in an attempt to reduce child mortality. The IMCI strategy was developed by the WHO and the United Nations International Children's Fund (UNICEF) as an integrated approach to improve child health. It aimed at improving health systems as well as family and community practices regarding the management of childhood illnesses (Gove, 1997). Most life-threatening conditions in children present with fever and other symptoms of respiratory and gastrointestinal system, hence there is a need for an integrated approach for their management (Perkins et al., 1997). In malaria endemic areas, improvements in the diagnostics and treatment of febrile illness potentially caused by *P. falciparum* are a central concern. A survey measuring the effect of IMCI on observed quality of care of under-fives in rural Tanzania conducted in 2000 showed that children in IMCI districts received better care than children in comparison districts: their health problems were more thoroughly assessed, they were more likely to be diagnosed and treated correctly as determined through a gold-standard re-examination; the caretakers of the children were more likely to receive appropriate counseling and reported higher levels of knowledge about how to care for their sick children (Armstrong Schellenberg et al., 2004a).

In the past decade, increasing global political commitment to malaria control stimulated by the RBM partnership and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) has been reflected in renewed attention to malaria in Tanzania national level policies, and to a larger extent, in local government practices. In 2006, Tanzania was among the first three countries in which the US President's Malaria Initiative (PMI) became active. This initiative aims to rapidly scale up malaria prevention and treatment interventions and reduce malaria-related mortality by 50% in 17 high-burden countries in Sub-Saharan Africa (PMI, 2011b). The PMI is led by the U.S. Agency for International Development and implemented together with the Centers for Disease Control and Prevention and in close collaboration with the National Malaria Control Program (NMCP) and the Zanzibar Malaria Control Program (ZMCP) and the participation of many national and international partners involved in malaria prevention and control in Tanzania.

Financing of malaria activities for the mainland is highly dependent on external donors (PMI, 2011b). The Government of Tanzania malaria budget allocation on the mainland has been drastically reduced from a high of US$ 5.2 million in 2006–2007 to US$ 2.8 million in 2007–2008 and US$ 2.0 million in 2008–2009. From 2005-2011, the PMI spent 211 million US$ on malaria control in mainland Tanzania, and other major funding came from many other external sources amounting to US$ 415 million from 2008-2011.

Donor support goes to all four pillars of the NMCP which draws upon the RBM strategic plan: (i) Prompt and effective treatment; (ii) Vector control, especially use of ITNs; (iii) Prevention of malaria in pregnancy; and (iv) Malaria epidemic prevention and control. The emphasis of this PhD is on the first and, to a lesser degree, on the second pillar.

With regard to the first pillar of the NMCP (i) Prompt and effective treatment, three major interventions which directly affect access to malaria treatment have been implemented in Tanzania. Firstly, in 2002, the Tanzanian Food and Drug Administration (TFDA) registered a new class of drug shops known as Accredited Drug Dispensing Outlets (ADDOs) or *Duka la Dawa Muhimu (*in Kiswahili). The ADDO program was part of multi-country initiative of Management Sciences for Health (MSH) who received a grant from the Bill and Melinda Gates Foundation (BMGF) to identify and test innovative approaches for improving access to essential medicines in developing countries through greater participation of the private sector (Center for Pharmaceutical

Management, 2008). Until 2002, about 4600 drug shops known as *Duka la Dawa Baridi* had been licensed to sell nonprescription medicines (legally described as Part II poisons) in Tanzania. An assessment of these drug shops showed a number of problems including illegal availability of prescription medicines and lack of qualified personnel. The ADDO program was designed to address these problems through the development and enforcement of practice standards and licensing requirements, a training program for outlet managers and attendants in appropriate dispensing and stock management, and enhanced supervision and reporting for performance monitoring and adherence. In 2002, the Ministry of Health and Social Welfare (MoHSW) and TFDA worked with MSH to pilot ADDOs in the Ruvuma Region. Since then, the ADDO program has been rolled out in seven other regions, and the MOHSW plans to expand the program to all 21 mainland regions of the country (Rutta et al., 2009; Rutta et al., 2011).

Secondly, in 2006, SP was replaced by an ACT (ALu) as first line treatment for malaria due to high levels of resistance to SP. In January 2007, with funding from the GFTAM, Tanzania began providing ACTs through public and mission health facilities free of charge to all children under age five and at a subsidized price for the rest of the population. In mid-2007, subsidized ALu was made available in the ADDOs. In 2007, with funding from the PMI and technical support from MSH's Rational Pharmaceutical Management Plus Program, TFDA and NMCP began a pilot program to make subsidized ACTs available through ADDOs in 10 districts in the Morogoro and Ruvuma regions (Rutta et al., 2011).

A third intervention which is closely linked with ACTs is the introduction of RDTs for malaria. Since ACTs like ALu are relatively expensive compared to other drugs that were previously used in Tanzania, it is recommended that ALu should be prescribed to only laboratory confirmed cases. However, laboratory services are not available in most parts of Tanzania, especially in rural areas and in places with laboratory facilities, the quality of malaria diagnosis is generally poor (Ishengoma et al., 2009; Ishengoma et al., 2010) or the results are often ignored by clinicians (Reyburn et al., 2007). Studies in Dar es Salaam showed that the introduction of RDTs is safe, feasible and useful for the routine management of fever cases in all age groups and at all levels of the health system (D'Acremont, 2010). Thus, the Tanzanian MoHSW through the NMCP has implemented

RDTs for malaria in 11 regions and roll out was planned to be completed at the end of 2011.

With regard to the second pillar of the NMCP, the vector control strategy, Tanzania has mainly relied on intensive promotion of ITN use (Bonner et al., 2011). In 2004, NMCP initiated the Tanzania National Voucher Scheme, a distribution mechanism supported by a Round 1 grant from the GFATM for delivering subsidized ITN to pregnant women at antenatal visits. In 2006, support from the PMI allowed to add an infant voucher delivered at time of routine measles immunization. Between 2004 and 2007, the proportion of children under five years of age and the proportion of pregnant women sleeping under an ITN increased from 16% to 26% and 16% to 27%, respectively. However, the MoHSW and NMCP considered these increases in ITN ownership and use too low to reach RBM targets of 80% by 2010. In 2008, Tanzania embarked on the Under Five Coverage Campaign which delivered 8.7 million free long-lasting insecticidal nets to all children under five years of age on the mainland (Bonner et al., 2011). From 2010 to 2011, these efforts were followed up by the Universal Coverage Campaign (UCC) which distributed Long Lasting Insecticidal Nets for free across all 21 regions of mainland Tanzania. Funding for the UCC came from the GFATM and, to a minor degree, the USAID through PMI (PMI, 2011b).

In 2007, PMI further launched the "Communications and Malaria Initiative in Tanzania" to address household behaviours such as proper use of ITNs, ACTs, and IPTp. The associated mass media campaign aims to reach 80 percent of the population nationwide. However, within the MoHSW capacity to implement Behavior Change and Communication has been weak. The NMCP has developed a National Communications Strategy that is yet to be disseminated to the field (PMI, 2011b).

Although malaria remains a serious public health problem in Tanzania, major achievements can be noted, also on the mainland. Malaria rates are declining, and this can be possibly attributed to more efficient treatment regimens (ACT) and increased availability and use of insecticide-impregnated bed nets. A remaining challenge is the recurrent national stock-outs of ACTs and RDTs which impede continuous service delivery.

This thesis was carried out during first phase of the ACCESS intervention program (2004-2008) which aimed at improving access to malaria treatment in the Kilombero Valley, Tanzania, during this time of massive efforts and change in malaria control. The next chapter narrows the focus on key issues in access to malaria treatment, with particular emphasis on social science studies.

2. Access to malaria treatment

Figure 3 Drug shop survey for anti-malarials (Photo: M. Hetzel, 2004)

2.1 Key issues in public health and development

Access to health services, interventions and especially medicines in developing countries is a much debated topic and has received an unprecedented level of interest and funding in the past decade. The 12th World AIDS Conference 1998 in Geneva, Switzerland with its slogan “Bridging the Gap” drew global attention to the fact that there are those who have access to treatment (in the North) and those who do not (in the South). A year later, the Médecins Sans Frontières launched a much publicized Access Campaign in the wake of receiving the Nobel Peace Prize.[1] The campaign advocated a push for access to and the development of life-saving and life prolonging medicines, diagnostic tests and vaccines. Also in 1999, the Medicines for Malaria Venture (MMV) was launched with initial seed finance of US$ 4 million from the Government of Switzerland, UK Department for International Development, the Government of the Netherlands, The World Bank and Rockefeller Foundation[2]. At that time, the drugs in use no longer worked, and the pipeline for new anti-malarials was virtually empty. The possibility of profit in anti-malarial drug development was considered too low to attract pharmaceutical investment. Today, the MMV manages the world's largest malaria research and development portfolio and has a number of ACT in its pipeline.

However, resource-limited governments often need support from donor organizations to be able to purchase the newly developed medicines. This is especially the case for ACT. This new generation of drugs can be up to 10-20 times as expensive as conventional anti-malarial monotherapies such as SP and chloroquine. In the past 10 years, the GFATM has developed into the leading international financing institution supporting governments to purchase newly developed malaria medicines.[3]

While these are unprecedented achievements, the availability and affordability of effective drugs at country level does not necessarily imply that people get the medicines and the associated care they need. Surveys conducted between 2007 and 2008 in 11

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[1] For more information see: http://www.msfaccess.org/the-access-campaign
[2] For more information see: http://www.mmv.org/about-us/our-history
[3] For more information see: http://theglobalfund.org

African countries found that despite large increases in the number of anti-malarial treatments supplied through the public health sector, only 15% of children with fever were treated with ACTs (WHO, 2009). Clearly there are many issues that affect access to treatment, even if medicines have reached a country.

Access to medicines and associated services is multifaceted phenomenon. At least four dimensions of access require evaluation (Gulliford et al., 2002). The first is availability. Medicines and associated services have to be available in adequate supply so that the population 'has access' to treatment. But whether and to what extent a population 'gains access' to treatment also depends on financial, organizational, social and cultural factors. Thus access measured in terms of actual utilization is dependent on the additional dimensions of affordability, accessibility and acceptability. Of these dimensions, acceptability has received least attention. More generally, increased emphasis should be given to what attracts patients rather than what deters them (Kizito et al., 2012).

With regard to the treatment of mild malaria, a number of interventions to improve access have focused on the private retail sector. Goodman et al. (2007) examined 16 interventions to improve malaria-related activities of medicine sellers in sub-Saharan Africa (five in Nigeria, four in Kenya, two each in Uganda and Ghana and one each in Tanzania, Madagascar and Zambia). All involved a combination of training and job aids for providers as well as demand generation and consumer information components for users. Some also included pre-packaged drugs. The two key findings from the review were 1) medicine sellers are interested and willing to participate and 2) targeting this sector can have a substantial impact on the quality of care delivered and overall treatment outcomes.

Most interventions target providers and users on the facility, community and household levels. A recent review (Smith et al., 2009) identified 23 interventions to improve provider- and/or user-side behavior in the prompt and appropriate treatment of uncomplicated malaria (with appropriate evaluation design and Roll Back Malaria outcome indicators). 16 studies targeted providers, nine in the public sector and seven in the private sector. Only four interventions were conducted at national scale. Interventions aimed at providers included optimising case-management and services in health facilities or improving dispensing practices of drug shop attendants as well as

training community health dispensers. Initiatives targeting users included health education campaigns and interventions that specifically provided information on how to take anti-malarials, including pre-packaging and pictorial and verbal instructions. The authors conclude that very little is known about what interventions work in improving prompt and effective treatment of malaria. In the context of scaling up effective malaria control and malaria elimination plans and in increasing access to ACTs, increased research in this area is crucial.

2.2 Social science research on access to malaria

Social science research can help to answer the question whether different types of interventions actually reach down to the household level and whether people on the ground actually gain prompt access to the appropriate malaria treatment. However, although many anthropologists and other social scientists have conducted studies on cultural, social and behavioral aspects of malaria and its control (for reviews see McCombie 1996, McCombie 2002, Heggenhougen 2003, Williams and Jones 2004), they have only implicitly investigated access to malaria treatment. Their focus is usually on illness concepts and health seeking behavior. One can argue that - from an anthropological perspective - access becomes an issue once a person recognizes an illness symptom and initiates treatment (Obrist et al., 2007). Communities have their own understandings and definitions of illness as well as their own ways of responding to them. To understand their views and their ways of solving health problems is not only important to assess whether services and interventions reach them but also to learn how initiatives can be improved so that they actually reach and benefit them.

Studies informed by anthropology commonly assume that members of local communities refer to an organized set of ideas and practices when they construct their own “explanatory models” (Kleinman, 1980) in managing concrete illness episodes and gain (or do not gain) access to malaria treatment. Explanatory models encompass:

- Illness concepts as well as associated signs and symptoms;
- Evaluation of symptoms and explanation of causes;
- Treatment seeking including self treatment, home management and resort to expert care.

The clinical manifestations of malaria fever are varied, from episodic shaking chills to intense fevers to drenching sweats. The fact that malaria does not have a distinctive symptomatology means that it can be subdivided by a number of different illness labels (Heggenhougen, 2003). This is has been well documented for malaria in East Africa, West Africa and Southern Africa (Williams and Jones, 2004). Many communities have separate, named categories for mild and high fevers and associated symptoms and clearly distinguish them from the more dramatic condition characterized by convulsions or seizures (Box 1). In biomedical perspective, a seizure represents a clinical symptom of an underlying pathologic process with many possible causes (Friedman and Sharieff, 2006). Seizures are often caused by rapidly raising fever, and in *P. falciparum* endemic regions, rapidly raising fever is often caused by these parasites (see Chapter 1.1).

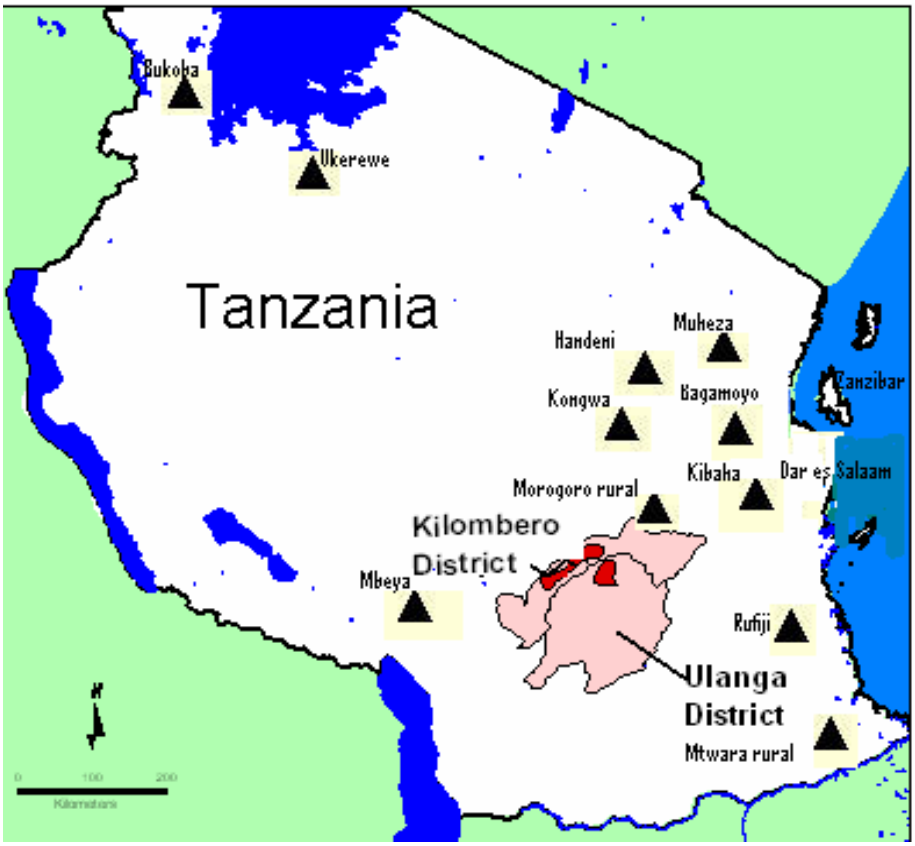
Box 1 Seizures in children

Seizures are involuntary, uncontrollable muscle movements and/or behavior changes. Several types of seizures occur. The child may experience sudden, rapid, repeated shaking of the arms and legs on one or both sides of the body. His or her eyes may be rolled back in the head. The entire body may become very tense or very relaxed. Sometimes there is no movement at all—the child simply becomes unresponsive during the seizure. Parts of the body, such as an arm or leg, may shake or become stiff. Seizures usually last for only a few minutes but can last longer. The child may have other symptoms, such as numbness or pain in a specific area, may make involuntary noises, and may lose control over urination or bowel movements. The child may be conscious or unconscious during the seizure. Afterward, he or she may be very sleepy.
Available at: http://www.sienapediatrics.com/SeizuresWithoutFever.pdf, accessed 10 December 2011.

Studies on illness concepts in Tanzania found the terms *homa* and *maleria* for febrile illnesses and *degedege* for seizures or convulsions in small children (see Winch et al., 1996; Tarimo et al., 1998; Mayombana 2004; Warmsame et al., 2007, see Figure 4). Although there was variation, these terms were widely used and referred to shared underlying concepts encompassing symptoms and their evaluation. In Rufiji and Morogoro Rural districts, the following association was found (Mayombana, 2004): i)

homa (fever, vomiting, feeling cold, limp body, red eyes, loss of appetite: these signs were not considered life threatening); ii) *maleria* (high fever, vomiting, loss of appetite, feeling cold: some care takers considered signs life threatening); and iii) *degedege* (high fever, loss of appetite, stiffness of body, rolling eyes, lips twisted sideways, twitching: signs were considered life threatening). A study in West-Uganda has demonstrated that the symptom of convulsions formed part of five distinct illness terms (all overlapping with biomedical malaria), and this categorization of symptoms into local illness classifications was associated with culturally appropriate treatment actions (Nsungwa-Sabiiti et al., 2004).

Figure 4 Social science research on malaria and convulsions in Tanzania



Further research found that the appearance of convulsions frequently led to the perception that some form of 'supernatural' or 'spiritual' force was, or has become, involved in the illness process and any cure necessitates the involvement of a 'traditional

healer' of some kind. This was a widespread perception and has been well documented for malaria in East Africa, West Africa and Southern Africa (Williams and Jones, 2004). In Burkina Faso, for example, mild malaria is called *sumaya* and distinguished from convulsions *(kono)* thought to be caused by a bird and more amenable to traditional treatment (Beiersman et al., 2007). On the East African Coast, people often resorted to modern medicine for *homa* and *maleria* but considered *degedege* as a life threatening illness that can best be treated by traditional medicine (Mwenesi 1993; Winch et al., 1996; Comoro et al., 2003; Makundi et al., 2006; Warsame et al., 2007; Foster and Vilendrer 2009). In many of these communities, access to health facilities was restricted by the belief that a child with convulsions could die if given an injection.

In-depth studies have demonstrated that the evaluation of illness progression and of treatment effectiveness was often more important than fixed explanations (Hausmann Muela 2000; Nsungwa-Sabiiti et al., 2004; William and Jones, 2004). The Winamwanga of northern Zambia, for example, perceived fever as a natural, tolerable thing that came from God and was unpreventable (Tuba et al., 2002). Prolonged fever was however seen as linked with small malaria. Causes of small malaria included eating some type of relish, bad water, drinking bad water, exposure to wind, getting soaked in cold water and sleeping at the funeral. When the fever classification changed from natural to small malaria, treatment moved outside the home. When children did not respond to treatment of either natural fever or small malaria and had symptoms like persistent fever, vomiting, diarrhea, convulsion and hallucination, the illness explanation changed from natural to supernatural.

The dynamics of symptom and treatment evaluation in *degedege* cases was well illustrated by Case 1 (see Box 2).

Home treatment was widely used as first choice of care for mild malaria (Williams and Jones, 2004). Already in 1995, a multi-country study in Africa found that self treatment, was the rule rather than the exception, especially in rural areas where about 75% of the population lived (Foster, 1995). In addition to tepid sponging and/or use of local herbs, drugs were frequently purchased from informal sources, such as shops, chemists, itinerant vendors, and even other households (Foster, 1995; McCombie, 1996).

Box 2 Home treatment and successful emergency treatment

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) Source: Mayombana 2004.

A study conducted 1998-1999 in Morogoro Rural and Rufiji Districts of Tanzania found that drugs purchased from retail and drug shops for home use were mainly paracetamol, aspirin and cough syrup; the anti-malarial chloroquine accounted for less than 10% of the purchased drugs in both districts (Mayombana, 2004). In the city of Mwanza (Tanzania), a recent facility-based study found that 56% of febrile children had stayed home with fever for 1-2 days and 44% for more than 2 days before presenting to the Health Centre (Mazigo et al., 2011). The majority (76.1%) of the febrile children received different types of treatment for febrile illness at home, such as antipyretics (72%) followed by anti-malarials (11%). The major sources of treatment were the local medical drug stores (94.7%), commonly referred as *duka la dawa baridi.*

When it comes to convulsions, some caregivers started with treatment at home. Mothers in Ifakara reported the following measures to “cool” the child (Hausmann Muela, 2000): They themselves or a women of the generation of grandmothers *(bibi)* would urinate on the child (41%), administer herbal remedies for bathing and drinking (35%), wave a cloth (sanitary towel for menstruation) over the child (12%) and/or prepare a paste of elephant dung to rub on the child's skin (6%). Other remedies included sponging (23%) and administering antipyretics (10%) or chloroquine (2%). The term “first aid” *(huduma ya kwanza)* was often used for such measures, and their aim was to stop the convulsion before seeking any other treatment (Hausmann Muela 2000; Mayombana 2004; Makundi et al., 2006).

The boundary between home treatment and treatment by traditional healers was fluid, also because healers were often relatives who treated the child in the home of the caretaker. The rationale for these measures was explained by an old healer from Handeni District (Makundi et al., 2006):

> Children are normally attacked by spirits which cause uncoordinated movement of eyes and limbs. The disease is better understood traditionally and the spirits easily and quickly leaves the child when urinated on, fumigated with elephant dung smoke and with other herbs as well as washing the convulsed child with herbal water. Mothers know this very well and that is why they bring convulsed children to us for treatment.

More often, however, convulsing children in Tanzania were treated by local experts/traditional healers, either exclusively (Oberlander and Elverdan 2000, Comoro et al., 2003) or in combination with treatment in health facilities (Hausman Muela 2000; Mayombana 2004; Warsame et al., 2007). Box 3 provides an example of exclusive treatment seeking from a traditional healer.

Box 3 Seeking treatment from a traditional healer

> [W]hen 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) Source: Mayombana 2004.

A detailed study of traditional healers in Kilosa District and Handeni District of Tanzania identified five stages of healing for a child suffering from *degedege* (Makundi et al., 2006). Although there were some variations from one healer to another, generally the process involved the following stages, and similar practices for severe malaria have been recorded in other studies (Hausmann Muela 2000, Mayombana 2004, Warsame et al., 2007):

1. Welcoming and listening to the caretaker of the convulsed child.
2. Bathing/sponging the child to get the temperature down.
3. Diagnosing the cause: Most healers were diviners and herbalists. Divination was done by 'ringing the bell' *(kupiga kengele)* or reading the Koran. In five recorded cases the mother needed to be treated first, so as to prepare for a smooth healing for the baby, in the belief that evil spirits possessing the mother are causing illness to her child.
4. Treatment of the child: The healer fetched certain herbs, ground them, mixed them with cold or hot water and administered them to the child. Some herbs were given to the mother of child to be administered at home for three to five days. Generally, the treatment ranged from two to seven hours for healers who do not "hospitalize" the patients, and two to five days for those who do.

5. Final cleansing for prevention of *degedege:* This stage is commonly called "cleaning" *(kufunga)*. Two measures were identified: The first involved the preparation of a chicken soup which the mother and the child drank to cast out bad spirits *(mashetani)* believed to cause misfortunes to the families. After the remains of the chicken were buried a few meters from the healer's compound, all people had to leave the place looking in forward direction to avoid getting again the bad spirit that caused *degedege.* The second measure consisted of tying a black piece of cloth *(hirizi)* around the left hand or the neck as a symbol for barring the evil spirit *(jinni)* from bringing back *degedege* to the child.

According to the healers, failure to abide to the full procedure *(kinyume cha taratibu)* might lead to a relapse of *degedege*. Most healers further claimed that children get *degedege* because the evil spirits were not cast out of them at birth.

Based on all these studies a coherent explanatory model for *degedege* has emerged for the East Coast of Africa which is embedded in a wider set of traditional illness concepts and healing practices (see Bruchhausen, 2006). Broadly speaking, three closely interrelated types of traditional healing have been identified: Herbal medicine, sorcery and possession. Because seizures as the lead symptom of *degedege* is seen as a possession by spirits *(majini, mizuka, mashtani, jinni),* it belongs to those illnesses which have to be treated by a healer *(mganga)*. Moreover, when speaking of spirits, healers often use metaphors (Bruchhausen, 2006:269), and the designation *degedege* which reportedly refers to a bird or a moth may well be such a metaphor. To interpret convulsions in a child as possession by a spirit seems quite plausible if interpreted against this background: the bodily twists and shakes during convulsions are similar as those of an adult person who becomes possessed by a spirit, for instance as a spirit medium in a possession cult (Giles 1987, Larsen 1998).

Many studies of explanatory models are based on in-depth interviews or Focus Group Discussion (FGD) with caregivers and/or community leaders about what they would do if a child had a convulsion (Comoro et al., 2003; Kaona and Tuba 2005; De Savigny et al., 2004; Foster and Vilendrer 2009; Mayombana 2004; Makundi et al., 2006; Warsame et al., 2007). On one hand, this can be attributed to the fact that episodes of childhood illness with convulsions fortunately occur much less frequently than episodes of mild fever. Studies of actual cases which have recorded what caregivers really do when

children have convulsions are thus also much rarer than similar studies of access to malaria treatment in case of mild fever. On the other hand, this lack of evidence is also due to the fact that many of these studies were carried out as formative research or nested studies in projects which had only funds for rapid assessment studies of malaria concepts and health seeking behavior.

One exception is the TEHIP project in Morogoro Rural District and in Rufiji District, Tanzania, with a comprehensive health seeking behavior component (de Savigni et al., 2002). Several studies were carried out within this component (Mayombana, 2004). One of them recorded treatment seeking in actual *degedege* episodes (n=237 and n=229) with semi-structured interviews from 1999-2001 (Mayombana, 2004). It found for Morogoro Rural District that the majority of the caregivers combined modern care4 and traditional care (39%) followed by modern care alone (32%), traditional care alone (27%) and self treatment at home (2%). In Rufiji, the pattern was traditional care alone (52%), modern care and traditional care (28%), modern care alone (19%) and self treatment at home (1%). Also within TEHIP, verbal autopsies (or post mortem interviews) of *degedege* cases (n=30) collected in Rufiji indicated use of modern treatment as the first resort of care for children with convulsion (De Savigny et al., 2004): Modern care (77.8%), traditional care (16.7%) and no care (5.6%). The findings from these studies thus show a trend towards increased use of health facilities and pharmaceuticals.

A recent study of actual care seeking for children with convulsions was nested within an intervention study on rectal artesunate suppositories in Mtwara District (Simba et al., 2009). Caretakers of children with severe malaria received treatment with rectal artesunate suppositories and were advised to proceed to a health facility for further treatment. The study found that the majority of care takers with children who had altered consciousness and / or convulsions adhered to advice to proceed to health facility compared with parents of patients with other symptoms ($P < 0.0001$). More patients with relatively serious symptoms, such as altered consciousness and / or convulsions, went

[4] In these studies, treatment with pharmaceuticals at home or from shops was classified as modern care.

to a health centre; fewer of these patients went to a drug shop and there was no indication that these patients were systematically taken to a traditional healer.

Case studies on actual treatment seeking for children with convulsions thus seem to contradict rapid assessment studies on explanatory models and hypothetical treatment seeking. One possible explanation is that qualitative methods are less reliable than quantitative ones (De Savigny et al., 2004; Simba et al., 2009). Anthropologists would contradict because they are fully aware of the difference between what people say and what they do. They have long been established that people tend to formulate normative ideas and practices in response to hypothetical questions and in group discussions. Anthropological research thus uses a set of ethnographic methods during extended field research which allows for cross-checking of reported and observed practices. However, even during long-term ethnographic field research, it would be difficult to closely follow enough actual cases of *degedege* to see clear patterns because of the comparatively rare occurrence seizures. Other study designs have to be developed to identify enough cases which can then be followed up closely.

A second possible explanation is that people try to integrate the two organized sets of ideas *(degedege* and severe malaria) in actual explanatory models and treatment seeking practice. This argument was developed in an ethnographic study in Ifakara, a community with a long history in malaria research and health education (Hausmann Muela, 2000). This study found that caregivers clearly understood *degedege* as a consequence of malaria (mentioned by 80%, and even 97% when prompted) (Hausmann Muela, 2000). And the first choice of a health service would be the hospital (93%) while the remaining 7% would consult a *bibi.* However, the idea that the illness must first be “cooled down” at home is widespread. Most caregivers who saw *degedege* as a consequence of malaria, and explicitly denied the moth as causal agent, started out with traditional “first aid” practices at home before bringing the child to a health facility (see above).

A third explanation is that individual caretakers may decide not to follow prevailing ideas and practices. This is illustrated with an example in Box 4. Similar examples have been reported in other studies (Warsame et al., 2007). This corresponds with Kleinman’s suggestion that members of local communities refer to – but do not automatically implement - organized sets of ideas and practices when they construct their own

explanatory models in managing concrete illness episodes and gain (or do not gain) access to malaria treatment.

Box 4 Going straight to hospital

[T]he 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 neighbors 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)
Source: Mayombana 2004.

A forth explanation is that a broader change has occurred in a community. Evidence for a change of treatment seeking practices comes from Tanga municipality where doctors, nurses and clinical officers reported that mothers know how malaria, both uncomplicated and severe, presents (Montgomery, 2006):

> But now they come… they'll even come in a car when the child is convulsing, they come in. And they know we'll give them a rectal diazepam, or an IV drip. They know. They say, 'we need the anti-convulsant medicine'. (Doctor, female, government hospital)

Based on previous social science research, it is nearly impossible to assess whether and what proportion of children with *degedege* have gained access not just to a health facility but to prompt and appropriate diagnosis and treatment in specific research sites.

Even for children with mild malaria, Demographic Health Surveys are the only source of information on actual treatment received. According to the 2010 Tanzania Demographic and Health Survey 23 percent of all children under age 5 in Tanzania had a fever during the two weeks preceding the survey, 23 percent in mainland Tanzania and 19 percent in Zanzibar (NBS and ICF Makro, 2011). 65% of children who had fever were taken to a health facility or provider. Children from urban areas were more likely to be taken to a health facility than those in rural areas, as were the children of more educated mothers and mothers who live in households that are in the higher wealth quintiles. There are significant variations by region, ranging from 41 percent in Shinyanga to 96 percent in Morogoro. What is surprising in view of the enormous international and national efforts in malaria control is that the proportion of children who received treatment for fever and the proportion of children who were treated with anti-malarial drugs did not change much in mainland Tanzania since the 2004-05 TDHS, and the proportion of children who were treated on the same or the next day has even decreased significantly, from 51 percent in 2004-05 to 41 percent in 2010. Similar data on actual access to drug treatment for children with convulsions are not available.

There clearly is a need for more accurate data on actual access to malaria treatment, especially for young children. This is not a new concern and applies not only to malaria research in Tanzania but more generally (Williams and Jones, 2004). While it makes sense, from a public health perspective, to focus such efforts on children with mild malaria in order to prevent the progression to severe malaria, there is also a need for more emphasis on children who already show signs of severe malaria, particularly convulsions, both from the perspective of clinicians and of social scientists. Childhood convulsions can be life threatening, and they are certainly frightening events for the parents. Since social scientists aim at studying what really matters to people, they should do their best in systematically study whether and how children with convulsions gain access to prompt and appropriate treatment. To close this knowledge gap, more rigorous and comparative methodologies have to be developed and validated in empirical research.

Although the health care system in Tanzania is well developed compared with those of other sub-Saharan African countries, health services are often inadequate and do not match the needs of the patients. This was already reported a decade ago. In Kibaha District, people's need for laboratory diagnosis of malaria was found to be very high

(98.3%) (Tarimo et al., 2000), and problems in the supply of drugs including anti-malarials have been a recurrent complaint for many years (Nsimba et al.,1999). If medicines are not available at health facilities, patients receive prescriptions and have to buy them in private outlets. In the year 2000, a study in four rural districts (Kilombero, Ulanga Mororgoro, and Rufiji) found that almost all outlets stocked antipyretics/painkillers (Goodman et al., 2004). Nearly all drug shops (n=43) and a third of the general retailers (n=675) stocked anti-malarials. According to the MOHSW (2003), few shopkeepers (15%) were correctly informed about anti-malarial treatment, and none of the kiosk attendants had correct knowledge of anti-malarial dosage. Information Education and Communication (IEC) material on appropriate malaria case management was scarce. To close this second knowledge gap, social science studies are needed which investigate not only steps in treatment seeking but whether children with mild malaria and especially with high fever and convulsions get treated according to the latest national guidelines, in health facilities and drug shops.

The studies presented in this thesis contribute to closing these two gaps in scientific knowledge.

3. Study description

Figure 5 Kilombero River, separating Ulanga and Kilombero districts (Photo: A. Dillip 2008)

3.1 Malaria research in Ifakara

The studies of this PhD project form part of the ACCESS program, a collaborative initiative of the Ifakara Health Institute (until 2008 Ifakara Health Research and Development Centre, IHRDC) in Tanzania and the Swiss Tropical and Public Health Institute (until 2010 Swiss Tropical Institute) in Switzerland, supported by the Novartis Foundation for Sustainable Development. Ifakara has long been a centre of development cooperation and health research (Tanner et al., 1994). Many research and intervention projects focused on malaria, such as the first trial of the SPf66 malaria vaccine in Africa (Alonso et al., 1994), studies on anti-malarial drug resistance development (Mshinda et al., 1996; Mugittu et al., 2005; Mugittu et al., 2006), the social marketing for ITNs through the KINET project (Armstrong Schellenberg et al., 2001; Abdulla et al., 2001), and the efficacy and safety of IPTi with SP (Schellenberg et al., 2001). Ifakara has also been the site of much social science research on malaria, including studies on traditional healers (Gessler, 1995; Gessler et al., 1995a; Gessler et al., 1995b; Matthies, 1998), community understanding of malaria and associated treatment seeking (Hausmann Muela et al., 1998; Hausmann Muela, 2000; Hausmann Muela et al. 2000, Hausmann Muela et al., 2002) and the introduction of ITN (Minja, 2001; Minja et al. 2001; Minja et al., 2005).

3.2 Study area

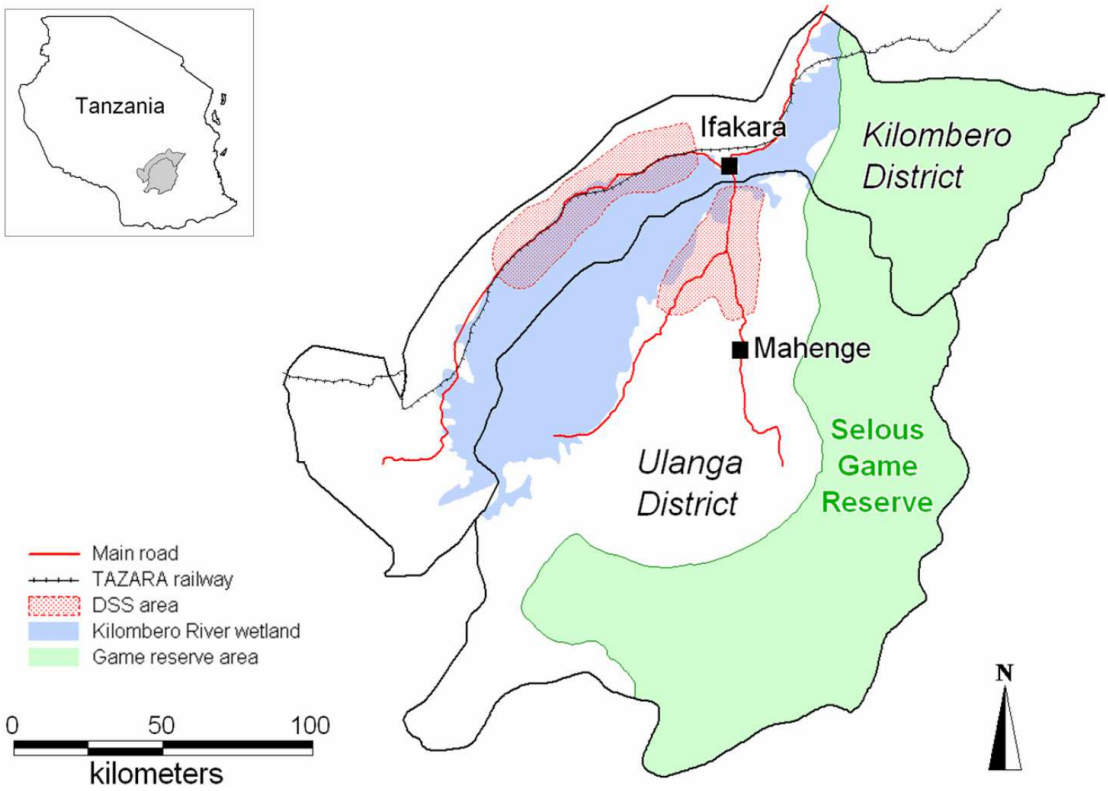
Ifakara is located in the Kilombero Valley (see Figure 6). The Kilombero River separates the Kilombero and Ulanga districts and forms a vast valley which has been described as the largest seasonal freshwater lowland floodplain in East Africa (Wetlands International and Ramsar, 2007). The Kilombero Valley is roughly divided into an inner valley, that is the actual basin, and an outer valley containing the margins of the floodplain and hills. The climate is hot and humid throughout the year. The monsoon from the Indian Ocean causes abundant rains on the windward side of the Great Escarpment from November to April (Kato, 2007).

The valley is delimited by the Udzungwa Mountains belonging to the Great Escarpment in the north and the Mahenge Mountains in the south. Parts of Ulanga's southern and

south-eastern areas, as well as Kilombero's extreme east are part of the Selous Game Reserve (see Figure 6). The Kilombero district is connected to the Tanzania-Zambia highway through a mostly unpaved but well maintained road. To reach the Ulanga district, cars have to cross the Kilombero River by a motorized ferry (see Figure 5).

The majority of the people in the Kilombero Valley lead a rural life. According to the last national Population and Housing Census in 2002, the two districts had a population of 517,000 who lived in 109 villages (United Republic of Tanzania, 2003). Ifakara is the capital of Kilombero district and the commercial centre of the valley, and Ifakara town had a population of about 46'000 in 2004. Ulanga's capital Mahenge is smaller with 7,300 inhabitants (United Republic of Tanzania, 2003). Ifakara attracts many migrants, and its population has increased to 59,497 in 2010 (pers. comm. District Population Officer).

Figure 6 Map of Kilombero and Ulanga districts with DSS area (Source: Hetzel, 2007)



Many villages in the Kilombero Valley are old, others have been created as communal villages in the 1970s (Minja, 2001). As part of his vision for rural development Mwalimu Julius Nyerere, first president of Tanzania, proposed that rural areas be reorganized into collective villages based on his ideal of *ujamaa*, or familyhood In Kilombero valley, many people were resettled in *ujamaa* villages *(vijiji vya ujamaa)* along the newly built TAZARA railway which links Dar es Salaam on the Tanzanian coast with the Copperbelt region of Zambia (Monson, 2009). The first village created for resettlement was Chita, followed by Mchombe, Mngeta and Mkwangawala. Some resettlement also occurred in and near Ifakara and along the all-weather road toward Kidatu. Some *ujamaa* villages were created a existing population centers, such as TAZARA construction camps (Signali village) or railway workshops (Man'gula A and Mang'ula B). Many of these *ujamaa* village inhabitants were migrant railway workers.

Seven ethnic groups consider themselves as belonging to the Kilombero Valley: the Wambunga, Wandamba, Wabena and Wahehe in the Kilombero District, and the Wapogoro, Wandamba, Wangindo, Wabena and Wangoni in the Ulanga District (Gregorius, 1964; Green, 2003). Many others have migrated there in the more recent past. Today, the population of Kilombero and Ulanga comprises representatives from most parts of Tanzania. Incomers can and do marry into the six ethnic groups which are considered as truly belonging to the area. Although cultural differences in terms of language *(lugha)* and custom *(mila)* are recognized, they are balanced in practice by similarities in relation to conceptions of kinship and aspects of common cultural performance, especially among the groups which have migrated from the West (Green, 2003). More recently, an increasing number of nomadic Maasai and Sukuma pastoralists with large cattle herds have moved from the North into the valley, and this continues to cause tensions with the settled communities up to now.

Village livelihoods are based on agriculture, fishing, livestock and small business activities. Most of the villagers cultivate rice in the alluvial fans at the margin of the floodplain and maize on the foothills. The seasonal calendar recorded in the village Itete-Minazini of the Ulanga District (Kato, 2007) is typical for the area: Before the rains begin in November, the villagers start preparing the dry fields on the hills and sow maize seeds immediately after the first rainfalls. Once the rains start, the villagers begin to plow paddy fields with tractors and cast out rice seeds. Weeding is particularly important in the early stages of growth and requires much time, leading many farmers to use herbicides.

Farmers begin harvesting ripe maize in early March and continue until May. Rice plants are now in the booting stage and require high soil moisture for heading. Villagers commonly arrange paddy fields along the tributaries so that they can be flooded in the late rainy season. Rice plants supplied with water can head immediately and ripen. The yield strongly depends on the timing and scale of flooding.

During the ripening stage, the farmers must constantly deter wild birds. Adults migrate to the paddy fields with all their necessities and live in small huts *(lingo)* built on stilts from May to July until all of the work is completed. Because the paddy fields are remote, school age children remain in the village and join the families on the weekend. Once ripe, the rice plants are harvested, gathered and threshed with sticks. Threshing is the hardest work in rice cultivation, and farmers often employ wage laborers. After threshing, the farmers hire trucks to transport rice bags from the paddy fields to the village. By August, they have usually returned to their permanent homesteads.

The cultivation of rice in the Kilombero Valley began already in the mid-19th century (Kato, 2007). It intensified in the 1970s when new technologies like tractors and fertilizers were introduced, and the main research institute for rice in Tanzania, the Kilombero Agricultural Training and Research Institute (KATRIN) moved to Ifakara in 1975. After the political and economic liberalization in the 1990s, rice cultivation expanded rapidly, as it was the only income generator. Currently, the valley is a major rice production area, supplying about 9% of all rice produced in Tanzania

Several other crops in addition to rice and maize are grown in the foothills of the Great Escarpment or the Mahenge Highlands, including sorghum, bananas, and leguminous crops like beans, groundnuts, vegetables and various fruit. Similar findings from Idete and Signali villages in the Kilombero Valley underline that crop diversification is the most important way of coping with food shortages (Kangalewe et al., 2005). It seems to be an important coping strategy not only in the wetland areas of Kilombero Valley but also in other parts in Tanzania and is among the risk-averse behaviors of farmers.

Together with rice, maize and vegetables, fish are the most important part of the diet for many people (KVIEMP, 2000). The Wandamba are the traditional fishermen of the Kilombero Valley. More recently, Wanyakusa have moved into the large, permanent fishing camps on the edge of the Selous Game Reserve. Over the past years,

commercial fishing has become more intensive, and fish from these camps is sold on markets in Ifakara, Mahenge, Kilosa, Morogoro and Dar es Salaam. The most important commercial fish are tilapia *Oreochromis* species, catfish *Clarius, Schilbe* and *Bagrus,* tiger fish *Distichodus.*

The climatic and ecological conditions in the floodplain are also favorable for mosquito breeding. Malaria transmission in the area is perennial and intense with differences between the rural and semi-urban settings. Overall transmission has been declining over the past 10 years. A study in the area between 2001 and 2003 reported an Entomological Inoculation Rate (EIR) of 349 infective bites per person per year (Kileen et al., 2007), but there is evidence of a decline in recent years to 81 infective bites per person per year (Russel et al., 2010). EIR data for Ifakara town suggest that the transmission rate is about a log order smaller than in the surrounding rural areas (Drakeley et al., 2003)

There are six health facilities in the Kilombero HDSS area (three public dispensaries, one public health centre and two faith-based dispensaries) and eight health facilities in the Ulanga HDSS area (five public dispensaries, one health centre and two faith-based dispensaries). The Designated District Hospital in Ifakara serves as a referral centre for the entire area. Government and faith-based health facilities in Kilombero and Ulanga charge user fees.

A Part I Pharmacy is located in Ifakara town, and many shops sell drugs. A study conducted in 2000 found that drugs were stocked by two types of retailer: a large number of general retailers (n=106 in Ulanga and 146 in Kilombero) and a small number of drug shops (n=2 in Ulanga and n=8 in Kilombero) (Goodman et al., 2004). This was a year before the policy change to Sulphadoxine–Pyrimethamine as first line drug against mild malaria. Almost all outlets stocked antipyretics/painkillers. The general retailers who stocked drugs had anti-malarials, usually chloroquine alone. Almost all drug shops stocked anti-malarials, namely chloroquine, quinine, sulphadoxine–pyrimethamine (SP) and amodiaquine. A large number of anti-malarial brands were available. From 2006 onwards, the ADDO program became active in Kilombero Valley.

In addition to health services offering “modern care”, there are also many traditional healers, locally called *waganga wa jadi, waganga wa kienyeji* or simply *waganga.* An

official list of the Cultural District Office listed 63 registrations of traditional healers for Ifakara Division (Matthies, 1998), but this only includes those who have paid the annual license fee and is certainly an underestimation. Alone in Lipangalala (a village of the Ward called Ifakara), more than 20 important *waganga* were counted in the mid-1990s, besides the numerous small ones who only practice sporadically and who have very few clients (Hausmann Muela, 2000). Three different types of healers were identified: diviners, herbalists and "grandmothers" *(bibi).* Diviners were women or men of all age groups and usually charged a considerable to large amount of money. They either used spirit mediumship *(waganga wa mashetani)* or Islamic religious texts *(waganga wa kitabu)* to diagnose illnesses attributed to witchcraft and spirits. Treatments ranged from simple administration of herbal remedies to drum rituals *(ngoma)* lasting several days (Hausmann Muela, 2000). Some of these *waganga* were widely known and charismatic personalities (see Gessler, 1995 for a portrait of *mganga* Charles of Kilama). Interviews with 34 diviners showed that they reportedly treat *degedege* (14%), fertility or pregnancy problems (13%), abdominal problems (10%), spirits (10%), malaria (9%) and mental problems (8%) (Matthies, 1998). Only few, usually elderly men belonged to the second type of healers. They treated minor ailments attributed to natural causes and charged low fees. The third group was the most numerous but least known of healers, commonly referred to as grandmothers (Hausmann Muela, 2000). Their specialization was the treatment of local "folk illnesses" like *degedege* (convulsions), *bandama* (enlarged spleen) and *moto* (heat associated with sexual intercourse). They charged no or small fees and treated mainly patients of the neighbourhood. In treating degedege, their main aim was the "cooling down" already described in Chapter 2.2.

An ethnographic study in Katindiuka and Mofu villages in the Kilombero District over a period of 3 months in 1996 confirmed many of the findings in Ifakara (Minja, 2001). They showed that the prevention of *degedege* involved amulets *(hirizi)* prepared by traditional healers to protect small children from bad spirits. These amulets or charms were given 40 days after delivery. Another measure was a herbal concoction administered in early infancy to protect the child from the "heat" of parents after having sexual intercourse or from attacks by bad spirits. Generally speaking, studies on understandings of mild and severe malaria, prevention and associated treatment seeking in Kilombero Valley show close similarities with those conducted in other parts of Tanzania (see Chapter 2.2).

Preliminary to the ACCESS program, and inspired by the study on drug shops by Goodman et al. (2004), a more focused social science study was carried out in the Ward Ifakara, namely in Ifakara town and Lipangalala, and Katindiuka and Kiyongwile hamlets, from Novermber 2003 to January 2004 (Msechu, 2004). The aim of this study was to examine self-medication and people's attempts to manage malaria at home. For qualitative research 70 patients with diagnosed malaria as well as 14 health workers and 16 drug vendors were selected for in-depth interviews, to collect illness narratives and for FGDs. An additional 100 respondents were randomly selected from the four hamlets for a quantitative study. The study found that more than half (52%) of all households reportedly stocked some pharmaceutical drugs. Most drugs stocked in households came from shops (75%), only 15% from health facilities. Home-management through self-medication was the first resort of about 80% of respondents. Of these, only one person reported home treatment with SP. Shortly after the policy change from quinine to SP as first-line drug for mild malaria, perceptions of SP ranged from confusion to fear. Treatment seeking differed extensively between cases in children and in adults. More children than adults received prompt treatment at home and health facilities (90% and 12%) respectively. Quality of care at health facilities was the main barrier to proper treatment-seeking.

Based on available background information and a literature review of malaria research, the ACCESS program was designed 2003 in a series of workshops in Tanzania.

3.3. Malaria research and interventions in the ACCESS program

The aim of the ACCESS program (2004-2011) was to improve access to prompt and effective malaria treatment with a set of integrated interventions which target both users and providers. The program was implemented in two phases. During the first phase covered in this thesis (2004-2008), the ACCESS program carried out interventions in the two districts of Kilombero and Ulanga in the south-east of Tanzania. In the second phase it extended its activities to the adjoining Kilosa District.

Research

The research on which this PhD is based was conducted in an interdisciplinary team of epidemiologists and anthropologists/sociologists. Three PhD theses and three MA thesis carried out with the ACCESS program have already been accomplished: Manuel Hetzel (2007) and Sandra Alba (2010) were my Swiss counterparts and analyzed studies of the Monitoring and Evaluation component of the ACCESS program from a public health perspective. We collaborated very closely in data collection, management and analysis as well as in writing papers. Two papers which are directly linked to my own studies and to which I contributed as a co-author are included in this thesis (Chapters 5 and 7). My understanding of treatment seeking has further been influenced by the PhD thesis of Karin Gross (in press) on Intermittent Preventive Treatment during pregnancy and antenatal care in practice, the MA thesis of June Msechu (2004) on home management of malaria, Mariette Frankhauser (2006) who conducted a cohort study of treatment seeking during the seasonal migration to the *shamba* (fields) and by Iddy Mayumana (2007) on malaria case management in the light of rural livelihood and vulnerability.

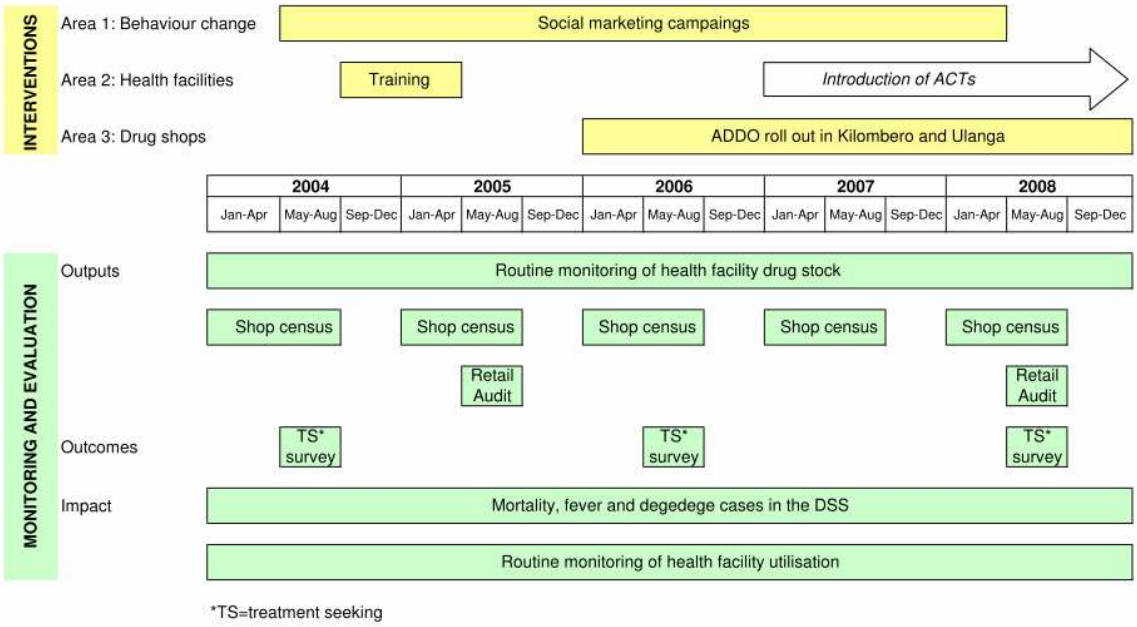
Interventions

Malaria research within the ACCESS program was closely linked with interventions (see Figure 7) and considered access to malaria treatment from a user and a provider perspective. The interventions of ACCESS program use a three pronged approach targeting communities, health facilities and drug stores (Hetzel et al., 2007).

At community level, the program applied a social marketing approach to improve awareness and promote prompt and effective treatment of mild and severe forms of malaria. The main focus of the health communication campaign was to

- Increase awareness and improve malaria knowledge among the community
- Encourage prompt recognition of signs and symptoms of mild and severe malaria
- Promote effective treatment seeking from competent sources and the need to comply with the treatment regime.

Figure 7 Timeline with ACCESS interventions and monitoring and evaluation activities (Source: Alba, 2010)



The ACCESS program recommended first-line drugs in accordance with the national malaria treatment guidelines, i.e. SP until the end of 2006 and ALu from 2007 onwards. As competent sources for proper treatment and advice it promoted health facilities and licensed drug stores (pharmacies, part II drug stores and ADDOs from 2006 onwards).

Target audiences included mothers, fathers and other care takers of children below five years of age, pregnant women, community leaders, school children and teachers, health workers, drug sellers and the general public. The campaigns employed a mix of communication channels ranging from small to mass media. These included road shows package, football tournaments, special promotion at Reproductive and Child Health Clinics (RCHC), posters, brochures, paper flags, folders, banners, caps, T/shirts, public address through ACCESS branded vehicle.

The road show was the main vehicle to convey ACCESS key messages to the target populations. The package comprised of public lectures, comedies and role-plays,

dancing competitions and cinemas. Under role plays for example the local ideas linking convulsions with spirits and '*degedege* bird' were discouraged and new understanding linking *degedege* with severe malaria was promoted. T-shirts were produced and distributed carrying corresponding messages, such as: "Convulsion is a sign of severe malaria and can be treated at the health facility" *(Degedege ni dalili ya malaria kali na inatibika vituo vya afya).* In other messages, local treatment practices were discouraged and alternatives were recommended, for instance: "Do not urinate on a convulsed child but take her to a health facility immediately" *(Usimkojolee mtoto mwenye degedege ila mpeleke kituo cha afya mara moja).*

Mothers of young children and pregnant women who are more likely not to attend social marketing campaign were targeted through Mother and Child Health (MCH) Clinics. The aim of the promotion was to increase and improve awareness of new malaria treatment regime including reasons for frequent change of malaria treatment policy, dosage instructions, importance of complying with full treatment course, use of Insecticides Treated Nets (ITNs) and the importance of Intermittent Preventive Treatment in pregnancy (IPTp).

Other communication channels like posters, brochures, stickers, banners were simultaneously distributed or placed to the prominent public places like health facilities, general shops, drug shops, market places, public transport terminals, schools and other strategic eye catching places.

Between 2004 and 2008 the ACCESS social marketing road shows were conducted in 96% (78/81) of the villages in the Kilombero District and 95% (62/65) in the Ulanga District.

At the health facility level, the main emphasis is on the improvement of quality of care. As a result of the social marketing activities, the demand for quality services can be expected to increase. In order to meet this demand, health facility staff must be in a position to deliver good quality of care. Key activities of the ACCESS program in this component included refresher training for health facility staff. This training was developed and carried out in close collaboration with the Council Health management Teams (CHMT) of both district. From 2004-2005, 93% (39/42) of clinical officers in

Kilombero District and 91% (94/97) of all health workers in the Ulanga District were trained.

Similarly, since 2007, the ACCESS team and the CHMT have worked out and implemented the Quality Improvement and Recognition Initiative (QIRI) in health facilities in the Kilombero and Ulanga districts. QIRI offers an integrated approach for the evaluation of quality of care combined with a strategy to establish the root causes of performance gaps and to develop strategies to address them. Six performance indicators are measured in QIRI as part of the evaluation of health care: Job expectations, skills and knowledge, provider motivation, performance feedback, physical environment and tools, and client satisfaction.

With the QIRI, the project team supports the CHMT in improving the supervision of health staff in dispensaries, health centers and hospitals in Kilombero and Ulanga districts. In the course of their visits, the supervisory teams assess, for instance, whether health providers adhere to the national malaria guidelines and the IMCI guidelines in their day-to-day case management. Health providers are also provided with refresher trainings on malaria case management and use of new diagnostics tools i.e. rapid diagnostic test for malaria.

The intervention at the drug shop level – the ADDO program (see Chapter 1.4) - is carried out by a public-private partnership led by the Ministry of Health and Social Welfare (MOHSW) through the Tanzanian Food and Drug Authority (TFDA) and Management Sciences for Health (MSH). Its aim is to improve access to affordable, quality medicines and pharmaceutical services in drug retail outlets in rural and peri-urban areas where there are few or no registered pharmacies (Rutta et al., 2009).

The main components of the ADDO program are activities to change the behavior of shop owners and dispensing staff through the provision of education, incentives and regulatory coercion (Rutta et al., 2009). The program trains drug dispensers, for instance to listen carefully to the client's description of the signs and symptoms and to advise him/her thoroughly, recommending and providing appropriate medicines, providing advice on the use of preventive tools like treated bed nets and seeking hospital care if no improvements are observed). It also entails efforts to positively affect client demand and expectation of quality products and services. For the districts of Kilombero and

Ulanga, ACCESS could successfully negotiate an early roll out of the ADDO in January 2006 and the introduction of highly subsidized ALu in ADDOs in July 2007. Between 2006 and 2008 135 ADDO were opened in the Kilombero district and 55 in the Ulanga district - equivalent to approximately three shops per 10'000 people in both districts (Alba, 2010). The ACCESS program through its social marketing activities promotes the use of ADDOs as a source of quality and appropriate malaria treatment.

Monitoring and evaluation

The monitoring and evaluation component aims at assessing the impact of interventions on the overall health impact based on a plausibility examination of a before-after study design. Various monitoring and evaluation activities were carried out in the Kilombero and Ulanga HDSS which served as an epidemiological framework for the study;

1. Routine monitoring of health facility utilization data: In patient and out patient diagnosis from Health Management and Information System (HMIS) were collected on a monthly basis in all private and public health facilities in the HDSS area. Standard forms allowed rapid transcription of data from the health facility records. These data were used to estimate rates of fever and malaria cases in health facilities.

2. Routine monitoring of drug stock and supply in health facilities: Data on drug stock and supply were collected in all public health facilities after every other month. Validated data collection tools were used by trained field workers to collect such information from the Health Management and Information System (HMIS) ledger books.

3. Shop surveys: Cross sectional shop surveys were carried out every year to record anti-malarials stocks and shop location in the HDSS area and Ifakara town (see Figure 3). Drug outlets include all potential sources of anti-malarials like kiosks, general shops, pharmacies, ADDOs and Part II drug shops.

4. Mystery shopping studies: Parallel with the shop surveys, performance and quality of services in drug selling shops was monitored annually through mystery shoppers who visited and bought drugs from local commercial outlets. Standardized guidelines were used to obtain relevant information for different simulated case scenarios.

5. Treatment seeking surveys: EMIC interviews were used to collect qualitative and quantitative data on patterns of distress, perceived causes and help seeking for fever and convulsion cases. The surveys have been carried out in 2004, 2006 and 2008 in the HDSS area and in Ifakara town. The interviews focused on adults and children below five years of age who had recovered from a fever or convulsion episode.

6. Monitoring of morbidity and mortality rates: Through the Ifakara HDSS, ACCESS collected community reported fever and convulsion cases. Moreover the HDSS provided ACCESS with under 5 mortality trends in area.

This thesis has grown out of the monitoring and evaluation component of the ACCESS program. It specifically built on monitoring and evaluation activities 4) mystery shopping studies and 5) treatment seeking surveys.

3.4 Aims and objectives of this study

The overall aim of this thesis is twofold: On one hand, it intends to contribute to the evidence base to assess effectiveness of the ACCESS interventions implemented between 2004 and 2008. On the other hand, it aims at increasing scientific understanding of whether, why and how young children “gain access” to prompt and appropriate malaria treatment.

The focus is on the two knowledge gaps identified in Chapter 2. The first gap concerns the lack of case study data on access to treatment for children with mild malaria and especially severe malaria (convulsions). The thesis aims to address this gap through a systematic analysis of case studies. It evaluates whether access to biomedical understandings of malaria and associated treatment seeking and prevention practices has improved in the course of the ACCESS program. Special attention is given to considering acceptability as an important access dimension of malaria interventions. The second knowledge gap pertains to a more accurate understanding of the malaria knowledge and practice of health workers. Since drug sellers have become an important source for malaria treatment and have been targeted by the ADDO program, changes in their performance will be assessed.

The specific objectives are

1. To investigate whether malaria treatment seeking for children with fever and convulsion has changed during the first phase of the ACCESS program (Chapters 4-5).

2. To examine whether 'acceptability' is an important access dimension in treatment seeking for childhood convulsions (Chapter 6).

3. To assess the usefulness of mystery shopping methodology for assessing changes in the performance of drug sellers in community pharmacies (Chapters 7-8).

3.5 Methodology and frameworks

In the study of explanatory models of malaria, the thesis draws on the medical anthropology approach developed by Kleinman (1980). This approach distinguishes between general beliefs about sickness and care held by members of a community and the explanatory models individual members of a community come up with in order to cope with a concrete case of illness. Such explanatory models try to give answers about 1) etiology, 2) time and mode of onset of symptoms, 3) pathophysiology, 4) course of sickness and 5) treatment.

To operationalize this approach for epidemiology, Weiss (1997) developed the Explanatory Model Interview Catalogue (EMIC). This is a framework for semi-structured, in-depth interviews with a specific format. The aim of this method is to reliably assess and compare explanatory models within and across groups. Guided by Kleinman's contributions, the EMIC focuses on 1) patterns of distress (e.g. names of illness and symptoms), 2) perceptions of cause and 3) help seeking and treatment.

The EMIC differs from classical epidemiological questionnaires by the way it is developed and structured: qualitative studies provide the basis for the development of the answer categories. For the EMIC interviews used in the ACCESS program, the project team reviewed the existing social science literature on malaria for the study area and carried out in-depth interviews and FGDs to elicit local terms for febrile illnesses, associated symptoms and causes and to identify the help seeking and treatment options

(Msechu, 2004). Based on these findings, the answer categories for the three main sections of the EMIC interviews (see Appendix A) were developed. To examine patterns of distress, for instance, the question was: How did you first know that something was wrong with the child? The answer categories which can be ticked off included 1) hot body *(mwili wa moto),* 2) hot head *(kichwa cha moto),* 3) periodic fevers *(homa za vipindi),* 4) no strength *(hana nguvu),* 5) twitching *(anastuka)* and 6) body becomes stiff *(mwili unakauka)*, among others.

This procedure draws on standard social science practice. Open-ended questions and screening queries on locally identified categories of answers allow an in-depth assessment of the representation of symptoms, etiology and treatment seeking. What is particular to the EMIC framework is that it aims at analyzing relationships between illness-related beliefs and practices, and outcomes of clinical significance. It thus provides a foundation for a cultural epidemiology.

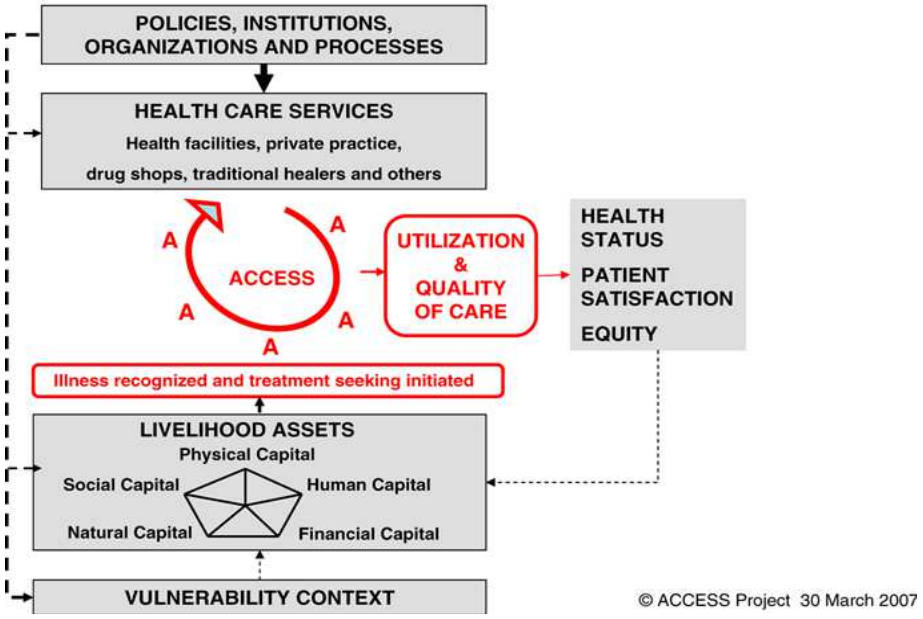
In this thesis, the EMIC approach was chosen to assess the relationships between local concepts related to malaria and the actual treatment practice (see Chapters 4-6). The specific design of each sub-study will be explained in the respective chapters.

Data collected with the EMIC interview were also used for a closer examination of acceptability, the dimension of access which has so far received little attention in treatment research (see Chapter 6). This dimension was identified as highly relevant and included in the Health Access Livelihood Framework (Obrist et al., 2007) developed in the course of the ACCESS program (see Figure 8 and Table 1).

The aim of the ACCESS framework was to link social science and public health research with wider development approaches to poverty alleviation. It started from two key ideas: 1) Access becomes an issue once illness is recognized and treatment seeking is initiated; and 2) To improve equitable access, innovative and community-based approaches are needed to better align health care services with poor people's needs, expectations, and resources. The second idea draws on the access concept of Penchansky et al. (1981). Access can be examined in terms of five dimensions that influence treatment seeking: availability, affordability, accessibility, adequacy and acceptability (the five As). What degree of access is reached along the five dimensions depends on the interplay between (a) the health care services and the broader policies,

institutions, organizations, and processes that govern the services and (b) the livelihood assets people can mobilize and combine in particular vulnerability contexts. Hence, access improves as health care services become better aligned with clients' needs and resources. However, improved access and positive treatment outcomes have to go hand in hand with utilization of health services and good quality of care. The outcomes can be measured in terms of health status (as evaluated by patients or by experts), patient satisfaction, and equity.

Figure 8: The Health Access Livelihood framework (Source: Obrist et al., 2007)



According to the literature review and findings from the ACCESS program, people in Tanzania considered the **availability** of essential drugs a prerequisite to the credibility of health services (Obrist et al., 2007). Problems of **accessibility**, including long distances to nearest dispensary or health center, scarce public transport, and lack of bicycles and other private means continued to be major access barriers. Issues related to **affordability** were also major obstacles: complaints about fees were frequent, and even if official fees were exempted (e.g., for children under fives) or waived (e.g., for persons temporarily unable to pay), people often ended up paying for drugs, small charges, kerosene, and even ambulance transport. Poor people had to resort to short-term coping strategies like selling critical assets such as crops to pay for health care, especially in times of emergencies. **Adequacy** in terms of the organization of health services also

played an important role. A dispensary is of little use to farmers, if services are offered only for a few hours per day and waiting times are long. **Acceptability** refers to the question whether characteristics of providers and clients match. Striking differences existed between the views of caretakers and health providers about the causes of treatment of high fever and convulsions *(degedege)*. Taking up the last point, this PhD thesis investigates acceptability as a "fit" or match between providers and clients with regard to their understanding of malaria.

Table 1 Dimensions of Access to Health Care Services

Accessibility	The location of supply is in line with the location of clients	What is the geographical distance between the services and the homes of the intended users? By what means of transport can they be reached? How much time does it take?
Affordability	The prices of services fit the clients' income and ability to pay	What are the direct costs of the services and the products delivered through the services? What are the indirect costs in terms of transportation, lost time and income, bribes and other "unofficial" charges?
Adequacy	The organization of the health care meets the clients' expectations	How are the services organized? Does the organizational set up meet the patients' expectations? Do the opening hours match with schedules of the clients, for instance the daily work schedule of small-scale farmers? Are the facilities clean and well kept?
Acceptability	The characteristics of providers match with those of the clients	Does the information, explanation and treatment provided take local illness concepts and social values into account? Do the patients feel welcome and cared for? Do the patients trust in the competence and personality of the health care providers?

In addition to the in-depth semi-structured interviews which examined relationships between illness-related beliefs and treatment (EMIC framework) and the influence of acceptability on access to treatment (Health Access Livelihood framework), this thesis used the methodology of “mystery shoppers” to assess treatment knowledge and practices of drug sellers (see Chapter 7-8).

Mystery shopping has its origin in the commercial sector and marketing research, where it is used to evaluate the quality of services offered to customers (Jesson, 2005). It has also been successfully applied to evaluate pharmacy practice (Jesson, 2004). The technique itself may include not only observation and visits but also the purchase of a product (ESOMAR, 2005).

An important aspect of mystery shopping is covert observation, and this raises the question of informed consent. Anthropologists also use covert observation to document what is happening in a certain community. Since they usually spend a long time within the community they are studying, informed consent is usually bargained and re-bargained over time, as part of the everyday interaction between a researcher and the study community (Murphy et al., 2007). However, covert observation in ethnography differs from covert observation in mystery shopping (Jesson, 2005). The mystery shopper has a pre-defined set of issues that he would like to measure to assess the efficiency of a particular intervention. In this regard mystery shopping resembles methods applied in quantitative social science research although the technique does not feature in classic social science text books (Jesson, 2004).

In market research, the technique is regarded as valid and legitimate when conducted in a professional manner and the rights of study participants are protected (ESOMAR, 2005). After careful consideration, the American Medical Association’s Council on Ethical and Judicial Affairs approved mystery shopping as a method to improve and sustain quality of health care services in medical field (Levine, 2008).[5] The limitations of

[5] In June 2008 the American Medical Association's Council on Ethical and Judicial Affairs released a recommendation on the use of "secret shopper patients". The Recommendation: "Physicians have an ethical responsibility to engage in activities that contribute to continual improvements in patient care. One method for promoting such quality improvement is through the

the mystery shopping methodology can be tackled when programs are well designed (Lazaraus, 2009).

It seems useful to distinguish between two types of mystery shopping studies: 1) mystery shopping research and 2) mystery shopping projects. Mystery shopping research is conducted for the purpose of research only, and individual data are protected and not accessible by unauthorized people. In mystery shopping projects the data collected are used for other purposes like training or rewarding the organization of employees (ESOMAR, 2005). This PhD study used mystery shopping for research only.

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use of secret shopper 'patients' who have been appropriately trained to provide feedback about physician performance in the clinical setting." (Levine 2008:250)

4. Socio-cultural factors explaining timely and appropriate use of health facilities for *degedege* in south-eastern Tanzania

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4.1 Abstract

Background

Convulsions are one of the key signs of severe malaria among children under five years of age, potentially leading to serious complications or death. Several studies of care-seeking behavior have revealed that local illness concepts linked to convulsions (referred to as *degedege* in Tanzanian Kiswahili) called for traditional treatment practices while modern treatment was preferred for common fevers. However, recent studies found that even children with convulsions were first brought to health facilities. This study integrated ethnographic and public health approaches in order to investigate this seemingly contradictory evidence. Carefully drawn random sample were used to maximize the representativity of the results.

Methods

The study used a cultural epidemiology approach and applied a locally adapted version of the Explanatory Model Interview Catalogue (EMIC), which ensures a comprehensive investigation of disease perception and treatment patterns. The tool was applied in three studies; i) the 2004 random sample cross-sectional community fever survey (N=80), ii) the 2004-2006 longitudinal *degedege* study (N=129), and iii) the 2005 cohort study on fever during the main farming season (N=29).

Results

71.1% of all convulsion cases were brought to a health facility in time, i.e. within 24 hours after onset of first symptoms. This compares very favorably with a figure of 45.6% for mild fever cases in children. The patterns of distress associated with less timely health facility use and receipt of anti-malarials among children with *degedege* were generalized symptoms, rather than the typical symptoms of convulsions. Traditional and moral causes were associated with less timely health facility use and receipt of anti-malarials. However, the high rate of appropriate action indicates that these ideas were not so influential any more as in the past. Reasons given by caretakers who administered anti-malarials to children without attending a health facility were either that

facilities were out of stock, that they lacked money to pay for treatment, or that facilities did not provide diagnosis.

Conclusion

The findings from this sample from a highly malaria-endemic area give support to the more recent studies showing that children with convulsions are more likely to use health facilities than traditional practices. This study has identified health system and livelihood factors, rather than local understandings of symptoms and causes relating to *degedege* as limiting health-seeking behaviors. Improvements on the supply side and the demand side are necessary to ensure people's timely and appropriate treatment: Quality of care at health facilities needs to be improved by making diagnosis and provider compliance with treatment guidelines more accurate and therapies including drugs more available and affordable to communities. Treatment seeking needs to be facilitated by strengthening livelihoods including economic capabilities.

4.2 Background

Malaria continues to be a major public health problem worldwide and one of the leading causes of morbidity and mortality in sub-Saharan Africa, despite global and national control efforts. Malaria is one of the five life-threatening conditions causing more than half a million deaths of African children annually (WHO, 2008). In Tanzania, malaria is responsible for 34% of deaths among children under five years of age (MOH, 2000). The global strategy for malaria control mainly focuses on case management, through early diagnosis and prompt treatment of all fever cases in malaria endemic areas (WHO, 2008). Prompt diagnosis and timely malaria treatment within 24 hours after onset of first symptoms can reduce illness progression to severe stages, and therefore, decrease mortality.

Recent studies point out that before referral rectal artesunate can be given to patients who can not be treated in time and are several hours away from facilities (Gomes et al., 2008). If patients can not access injections or be treated orally, a single artesunate suppository at the time of the referral can reduce the risk of death or permanent disability. Nevertheless the same multi-country trial showed that there was only a reduction of mortality of patients that were treated no later than 6 hours. Reaching clinics in time still remains crucial. However, prompt malaria treatment is a major challenge in many developing countries (Hetzel et al., 2007).

Before developing a partial immunity, children below five years of age in endemic countries are at a high risk of acquiring a severe form of malaria. Besides contributing to death, severe malaria amongst children under five years of age may cause serious complications, including brain damage and anaemia. The standard treatment of severe malaria is an intramuscular injection or an intravenous infusion of quinine (WHO, 2000).

Convulsions are one of the main manifestations of severe malaria. Several studies on childhood illnesses as reviewed by Williams and Jones (2004) have provided contradictory evidence with regard to treatment of convulsions. Research in sub-Saharan Africa has revealed that conditions with convulsions as leading symptoms were not linked to malaria, and were primarily treated with traditional practices, as opposed to common fever cases for which modern biomedical treatment was preferred (Mwenesi et

al., 1995a; Mwenesi et al., 1995b; Ahorlu et al., 1997; Snow et al., 1998; Hill et al., 2003; Adongo et al., 2005; Beiersman et al., 2007).

In Tanzania, the Kiswahili term used for convulsions in children is *degedege*. '*Degedege*', meaning 'bird bird', is believed to be an evil spirit that takes form of a bird and casts its shadows on children who eventually become ill, develop convulsions and may die (Makemba et al., 1996; Hausmann Muela, 2000; Comoro et al., 2003). Fever cases are referred to as *homa*, and are commonly associated with malaria. Although the link between malaria and convulsions is recognized, *degedege* and *homa* tend to be treated differently. *Degedege* is reported more likely to be managed by traditional practices, while *homa* is mainly treated by the formal health system (Winch et al., 1996; Minja et al., 2001; Comoro et al., 2003; Mayombana, 2004; Warsame et al., 2007). On the other hand a study conducted in Kilosa and Handeni Districts in Tanzania (Makundi et al., 2006) found that traditional healers encouraged modern treatment seeking for convulsing children by referring severe cases of malaria to health facility. A recent study using verbal autopsy methodology indicated that 78.7% of malaria deaths in Southeastern Tanzania used modern treatment as the first resort to care (De Savigny et al., 2004a). Similarly, vignette interviews in Ghana revealed that more than 90% of respondents identified convulsions as severe conditions and recognized the need to seek modern treatment (Ahorlu et al., 2005).

Some studies on the other hand showed that children with *homa* and/or *degedege* did not attend health facilities due to a number of access related factors, including availability and affordability of services (Kazembe et al., 2007). Health service studies focus on health system factors and reducing supply barriers to ensure access to health care (Andersen, 1995; Gulliford et al., 2002; Ensor et al., 2006). Such studies concentrate on improving the quality of care through ensuring availability of supplies, skilled staff, and quality of service (Obrist et al., 2007).

The present study compared the local understanding and treatment of children under five years of age with *degedege* with fever cases in rural areas of Southeastern Tanzania. Children under five years were selected because they are most at risk of contracting malaria. Within the study, interviews with caretakers (parents/guardians) were conducted. The objective of the study was to describe and explain first treatment-

seeking for *degedege,* and to explore how understanding of symptoms and causes related to *degedege* influence response strategies of care takers.

This study was conducted within the framework of the ACCESS Program, a malaria intervention aiming at understanding and improving access to prompt and effective malaria treatment in rural Tanzania (WHO, 2008).The study complements previous research (Hetzel et al., 2008c) carried out within the same program to investigate access obstacles to malaria treatment.

4.3 Study description

Study area

This study took place in the Kilombero and Ulanga Districts in Southeastern Tanzania. The research site is part of the local Health Demographic Surveillance System (HDSS) covering 25 villages in the two districts. The program conducts its monitoring and evaluation activities through this HDSS. Every four months HDSS staff monitor and register all births, deaths, pregnancies, socio-economic indicators, and in- and out-migrations of all residents through household surveys (Hetzel et al., 2007). This allows on one hand the tracking of all individuals and most importantly for this work, to draw an almost perfect random sample, which is essential for the representativity of the results. In 2004, the population of the 25 HDSS villages in Kilombero and Ulanga Districts was 74,200 inhabitants, with an additional 45,700 people living in Ifakara town, the main settlement in the districts (United Republic of Tanzania, 2003).

In 2004 there were 14 public and private health facilities in the study area (Hetzel et al., 2007). Moreover over 400 drug shops were present (general shops selling drugs: 454; shops stocking anti-malarials: 54); from 2006 onwards these included among which Accredited Drug Dispensing Outlets (ADDOs), which are allowed to sell a limited range of prescription-only medicine, and so-called Part II drug stores, which offer over-the-counter (OTC) drugs. General shops provide antipyretics, although in some villages they illegally dispense anti-malarials as well. There are many traditional healers providing

varying kinds of services ranging from protection of disease, to treatment of illness and other misfortunes associated with witchcraft and spirits (Hausmann Muela, 2000).

The most common activities are subsistence farming, fishing and small scale trading, with rice and maize being the predominant food crops. Families spend several months in their farming site (*shamba* in Kiswahili), located at an average 7.5 km away from the main houses in the fertile lower wetlands (Hetzel et al., 2008a).

Instruments

The present study used a cultural epidemiology approach, and applied a locally adapted and constructed version of the Explanatory Model Interview Catalogue (Weiss, 1997). EMIC interviews allow for assessing specified health problems from the local perspective of affected individuals, their families, and/or community members (Ahorlu et al., 2005). The interviews aim to gather information on people's knowledge, understanding and experience of diseases such as malaria (Hausmann Muela, 2000; Mayombana, 2004). As a semi-structured interview, the EMIC was applied in the ACCESS Program in order to collect both quantitative and qualitative information on illness experience, its meaning and related behavior for fever and *degedege*, mostly referred to as patterns of distress (PD), perceived causes (PC) and help-seeking (HS) (Weiss, 1997). EMIC interviews extract explanatory models of respondents in their own terms (Weiss, 1997) and explain how such models influence particular behaviors. For the purpose of this study, EMIC was employed to understand how explanatory models for *degedege* influence treatment-seeking behaviors.

Study design

A similar EMIC was applied in three different studies (for details see Table 2):

A random sample cross-sectional community fever survey drawn from the HDSS and Ifakara Town areas (N=80)

The Longitudinal *degedege* community study with cases drawn from the longitudinal HDSS surveillance (N=129)

Longitudinal *shamba* fever study in which a random sample of households was followed during the time spent in their *shamba* (N=29).

All studies only included children who had experienced either an episode of fever or of *degedege* in the past 14 days. For ethical reasons, children who had not recovered the day before the interview were excluded from the study, and those who were still sick at the time of the interviewer's visit were advised to attend a health facility. The EMIC was administered to caretakers of the children immediately after finding the case, except for the longitudinal *degedege* study, in which interviewers visited the household of the child two to four weeks after a HDSS field worker had identified and reported the illness episode. A caretaker was defined as the parent/guardian who provides the daily essential needs of the child, such as bathing, feeding, clothing, or sending the child to school or to the hospital when sick.

Interviews were conducted in Kiswahili by HDSS field workers and by two trained local interviewers of the ACCESS program, one doing the interview, a second one recording the answers. All interviews, except those done by the HDSS field workers, were tape-recorded, transcribed and entered into their respective sections in the EMIC. The HDSS interviews were entered directly into the interview questionnaire (EMIC) without being recorded.

For the purpose of adhering to these ethical requirements, all participating individuals who were involved in this project were informed about its aim, the interview procedures, and about their rights as informants before they were asked for their verbal consent. Participation in data collection was voluntary and participants were free to leave at any time.

Sample

(1) For the HDSS community fever survey, a village stratified random sample was drawn. The number of households sampled was proportional to the total number of households in the village. In total, 318 households were drawn from the registered 16,220 households in DSS villages (Hetzel et al., 2008c). Only households with at least one child under five years of age were included in the study. Of all 318 households, 58

reported a fever episode in the past 14 days for a child under five years of age, These households were visited between May 2004 and August 2004 for an EMIC interview.

In Ifakara town, there was no updated household list available for sampling purposes. With the support of village and hamlet leaders, the majority of households could be identified and a two-stage random sampling of 223 households performed. Since every household is supposed to be under a ten cell leader a list of all 329 ten cell leaders was established with support from local government officials (Hetzel et al., 2008c). A random sample of 35 ten cell leaders was visited for the purpose of setting up a complete list of households within their ten-cells. Six households from each ten cell were then randomly sampled. Only 22 households with children under five years of age met the selection criteria and were visited between May 2004 and August 2004 for an EMIC Interview.

(2) The longitudinal *degedege* study was conducted from November 2004 to March 2006 in the HDSS area. A total number of 129 households whose children had *degedege* were extracted continuously from DSS records and followed up for an EMIC interview.

(3) For the *shamba* study, data were collected between January and August 2005, to examine treatment-seeking patterns during the farming season. Ten out of 25 HDSS villages were randomly chosen for the study. A list of villagers (5,912) who had reported to own a farming plot was obtained from HDSS records. A two stage random sample of 159 households was drawn in proportion to the relative size of the village. Altogether 100 households were eligible for the study, but only 29 households had children below five years of age who had recovered from a fever episode. These households (29) were identified and followed to their farming fields on a monthly basis for an EMIC interview.

Table 2 Characteristics of the three studies

	Cross-sectional Community fever survey	**Longitudinal *degedege* community study**	**Longitudinal shamba (farm sites) fever study**
Aim of the study	To examine treatment seeking behavior for fever	To explain treatment-seeking behavior for *degedege*, and identify how symptoms and causes related to *degedege* effect first response strategies	To examine treatment seeking for fever during farming season
Study setting	HDSS area of Kilombero and Ulanga	HDSS area of Kilombero and Ulanga	HDSS area of Kilombero and Ulanga

Sample size	80	129	29
Sampling Procedure	A total number of 318 households were random-sampled from the registered 16,220 households in the DSS villages. Only households with at least one under five years of age child were included in the study. Of all 318 households, 58 under five years of age households reported a fever episode in the past 14 days. In Ifakara town, a two stage random sampling of 223 households was performed. Of all 329 ten-cell leaders, a random sample of 35 ten cell leaders were visited to obtain a complete list of their ten cells. Six households per each ten-cell were randomly sampled. Only 22 households with children under five years of age met the selection criteria.	129 *Degedege* cases were continuously extracted from DSS records between November 2004 to March 2006 and followed up for an EMIC interview	Ten out of 25 HDSS villages were randomly selected. A two stage random sample of 159 households was drawn in proportion to the relative size of the village. Altogether 100 households were eligible, but only 29 households included children under five years of age who had recovered from a recent fever episode. These households were therefore followed for an EMIC interview on monthly basis
Study respondents	Caretakers of children under five years of age	Caretakers of children under five years of age	Caretakers of children under five years of age
Interviewers	ACCESS and HDSS Staff	ACCESS Staff	ACCESS Staff

Data Management and Analysis

Quantitative data from the EMIC interviews were double-entered using Microsoft Fox Pro, and analyzed using SAS software (Statistical Analysis of Software Institute, Cary, NC, USA). The analysis was re-computed with reference to illness labels: *homa, malaria* and *degedege.* Referring to the national malaria treatment policy, which recommends treatment of malaria within 24 hours of onset of symptoms, children were classified with respect to three outcome variables: (1) 'Timely health facility use' (HF use), defined to include health facility use within 24 hours; (2) 'Timely health facility and anti-malarial use' (HF AM) meaning health facility and anti-malarial use within 24 hours; (3) 'Timely anti-malarial not from the health facility' (AM not HF) refers to children who used timely anti-malarial not received from a health facility. The correlation of socio-demographic variables, patterns of distress (illness experiences), and perceived causes (meaning of illness) with the outcome variables were analysed and adjusted in a multivariate logistic regression model.

To clarify the nature of the explanatory model variables and how these explain the outcome variables, we used MAXQDA software (MAXQDA, 2001). A coded template for each study was prepared in Microsoft Word, through which qualitative narratives from EMIC interviews were entered before being imported into MAXQDA. Relevant variables were imported from the quantitative data set to select records of particular interest. Content analysis of illness narratives detailed the meaning of categorical codes, and explained the character of correlation identified from quantitative analysis.

Table 3: Demographic Characteristics of Caretaker Respondents (%)

	Degedege n=135	Malaria n=72	*Homa* n=28	Total n=235
Relationship to the child				
Mother	85.9	77.8	78.6	82.6
Father	10.4	15.3	17.9	12.8
Grandmother	0.7	4.2	0.0	1.7
Other	3.0	1.4	0.0	2.1
Not specified	0.0	1.3	3.5	0.8
Marital status				
Never married	9.6	13.9	10.7	11.1
Married	83.0	77.8	71.4	80.0
Separated, divorced	5.9	8.3	14.3	7.7
Widowed	0.7	0.0	0.0	0.4
Not specified	0.8	0.0	3.6	0.8
Income				
Regular and dependable	40.0	30.6	42.9	37.4
Possibly	17.0	8.3	7.1	13.2
Uncertain	10.4	6.9	0.0	8.1
Not regular and dependable	32.6	54.2	50.0	41.3
Occupation				
Farmer	94.8	94.4	96.4	94.9
Trade/Business	3.7	4.2	3.6	3.8
Labourers	1.4	0.0	0.0	0.8
Teacher	0.0	1.4	0.0	0.4
Illness recognition				
Home	79.3	72.2	50.0	73.6
Shamba	20.7	27.8	50.0	26.4

4.4 Results

Sample Characteristics

The socio-demographic characteristics of respondents from the three studies are presented in Table 3. The analysis included 235 children whose caretakers identified the condition as *malaria, homa* or *degedege*; three cases that did not fall into any of the above illness labels were excluded. The majority of family caretakers interviewed were women (82.6%) and married (80%). 41.3% of respondents disclosed that their income is not regular or dependable. The majority (94.9%) depended on farming as the main source of income and livelihood. Regarding the place of illness recognition, 73.6% of caretakers recognized the illness of the children at home.

With regard to treatment options for the children, 60.9% of all children with *homa, malaria* or *degedege* were reported to have 'timely health facility' use (HF use). Out of these, 57% obtained anti-malarial medicines from the facility (HF AM), and 23 % used 'timely anti-malarials not from health facility' (AM not HF) (Table 4).

Treatment-seeking for *homa*, malaria and *degedege*

The demographic characteristics of children in correlation with the outcome variables are presented in Table 4. The sex of the child (female) was associated with less timely health facility use and receipt of anti-malarial medication from the health facility. Being a farmer was also a factor associated with less timely health facility use, but since 95% were farmers, this could be expected. It was surprising that health facility availability was associated with timely anti-malarial use not from health facility (AM not HF). This is also reflected in the fact that a lack of immediate use of a health facility was observed among children who reported 'timely used anti-malarials not obtained from health facility'. Illness narratives revealed that health facility availability did not motivate caretakers to seek prompt treatment, if they believed that the health facilities would be out of drug stock.

Most of the determinants for 'HF use' and 'HF AM' are similar (Table 4). For the categories of distress, 'no interest to play', 'cough' and 'difficult breathing' were associated with timely health facility use and receipt of anti-malarial from the facility (HF AM), while 'hot abdomen' related more to timely health facility use (HF use).

Table 4 Demographic and socio-cultural features of children with *degedege*, malaria and *homa* (N=235)

	HF Use [1] n=143 (60.9%)		HF AM [2] n=134 (57%)		AM not HF [3] n= 54 (23%)	
	Estimate	P-Value	Estimate	P-Value	Estimate	P-Value
Demographics						
*Degedege**	0.69	0.00	0.41	0.06	-0.39	0.19
HF availability					0.61	0.04
HF immediate use (only for AM not HF)					-1.69	0.00
Female Sex	-0.78	0.02	-0.82	0.02		
Never Married					-1.98	0.02
Sep/Div					-1.14	0.21
Farmer	-2.89	0.02	-1.91	0.04	-1.57	0.10
Categories of Distress						
No interest to play	0.88	0.01	0.89	0.01		
Not happy					1.41	0.03
Sleeps					-1.29	0.00
Loss of appetite			-0.24	0.16	-0.42	0.09
Crying all the time	-0.37	0.15				
Hot body					0.28	0.07
Hot abdomen	0.44	0.04	0.39	0.07	-1.68	0.00
Cough	0.65	0.02	0.69	0.01		
Difficult breathing	0.53	0.02	0.60	0.01		
Yellow eyes					0.71	0.08
Diarrohea	0.29	0.07			0.49	0.00
Shivering					0.59	0.05
Body becomes stiff	0.39	0.05	0.33	0.09		
Froth in the mouth					-1.15	0.05
Easily startled	-0.34	0.27				
Perceived Causes						
Impure water			0.38	0.07		
Eating leftover food	1.19	0.00	1.51	0.00		
Breast feeding					2.59	0.00
Worms	-0.56	0.13	-0.50	0.19	0.92	0.08
Stage of child growth	0.76	0.01	0.83	0.01	0.60	0.09
Constitution / blood weakness	0.77	0.13	1.14	0.03		
Hereditary	-1.87	0.01	-1.85	0.01	-1.99	0.05
Sanitation / dirty environment					-0.45	0.08
Contamination - contact			-1.09	0.03		
Wind					1.02	0.11
Failure to abstain from sex (parent)	-0.91	0.13	-0.75	0.16	-1.41	0.06
Bird/ insect called *degedege*	-0.31	0.05	-0.37	0.02	-0.80	0.04
Other mention			0.16	0.16	-0.17	0.43
Don't know					0.94	0.01

Note: Model fitness based on the likelihood ratio (all models with p< 0.0001)

[1] Model outcome: health facility immediate use (HF use) (same day or next day)

[2] Model outcome: health facility and antimalarial immediate use (HF AM) (same day or next day)

[3] Model outcome: antimalarial immediate use (AM not HF) (same day or next day) not from the health

*illness identified with *degedege* in the illness narratives even though identified primarily with *homa* and malaria

For the perceived causes, people stated that ‘eating leftover food’ and ‘stage of child growth’ were more associated with ‘HF AM’ while ‘hereditary causes’ and ‘bird *degedege*’ were associated with less use of ‘HF AM’. On the other hand ‘blood weakness’ was related to ‘timely health facility use and receipt of anti-malarial’ (HF AM), while those who mentioned ‘contamination’ as the cause were less likely to use ‘timely health facility and receive anti-malarial’ (HF AM).

For the outcome variable ‘AM not HF’, the categories of distress associated with this response included: ‘not happy’, ‘diarrhoea’ and ‘shivering’. Whereas, the categories of distress of: ‘sleeps’, ‘hot abdomen’ and ‘froth in mouth’ were the symptoms related to less use of timely anti-malarial not from the health facility (AM not HF). The perceived causes related to the same outcome variable were comprised of: breast-feeding and ‘do not know the cause’, while bird ‘*degedege*’ was associated with less use of ‘AM not HF’.

Treatment-seeking for *degedege*

More specifically, the study narrowed its focus on treatment-seeking patterns for children with *degedege* (Table 5) compared to *homa*. For a general fever case definition, the same children had been studied within the ACCESS Program by Hetzel et al. (2008c), whose interest was to capture the general obstacles to prompt malaria treatment. The present study focuses on how illness experiences and meanings given to *degedege* influence treatment-seeking patterns.

‘Timely health facility use” and “timely health facility and anti-malarial use’

The study found some similarities in determinants of the outcome variables ‘HF use’ and ‘HF AM’ among children with *degedege*. About 71.1% of all *degedege* cases were ‘timely brought to health facility’ and the majority (66.7%) received anti-malarial medication from the facility. In comparison, 45.6% of children with *homa* used timely health facility and 42.7% of them received anti-malarial from the facility. Respondents in these groups also mentioned malaria (p=0.04) and *homa* (p=0.03) when talking about the symptoms, indicating that caretakers made a link between convulsions and *homa* or malaria (Table 5).

Table 5: Demographic and socio-cultural features of children with *degedege* (n= 135)

	HF Use 1) 71.1%		HF AM 2) 66.7%		AM not HF 3) 10.4%	
	Estimate	P-Value	Estimate	P-Value	Estimate	P-Value
Demographics						
Malaria*	1.14	0.04	1.18	0.03		
*Homa***			1.44	0.03		
HF availability					1.24	0.10
Age			0.43	0.06		
Categories of Distress						
No interest to play	1.16	0.12	2.52	0.00		
Not happy	1.55	0.10				
Sleeps	-1.37	0.02	-1.05	0.06		
No strength	0.52	0.15				
Hot abdomen	0.79	0.02	0.56	0.05		
Periodic fevers					-2.63	0.03
Cough	1.50	0.01			1.56	0.06
Difficult breathing	0.87	0.04	1.55	0.00		
Diarrohea			0.55	0.14	1.50	0.02
Vomiting	-0.55	0.05			0.72	0.04
Shivering					0.78	0.09
Twitching					1.44	0.00
Body becomes stiff			0.42	0.09		
Easily startled					-5.97	0.00
Perceived Causes						
Impure water			0.82	0.13		
Starchy food	-2.41	0.05				
Stage of child growth	1.05	0.09	0.81	0.07		
Constitution / blood weakness	3.03	0.01	2.95	0.00		
Sanitation / dirty environment	1.54	0.00				
Personal hygiene / not keeping clean					4.19	0.01
Cold weather					1.39	0.05
Spirits	-1.72	0.03				
Failure to abstain from sex (parent)	-2.84	0.03	-1.13	0.17		
Bird/ insect called *degedege*			-0.60	0.00		
Other mention					-0.55	0.08

Note: Model fitness based on the likelihood ratio (all models with p< 0.0001)

[1] Model outcome: health facility immediate use (HF use) (same day or next day)

[2] Model outcome: health facility and anti-malarial immediate use (HF AM) (same day or next day)

[3] Model outcome: anti-malarial immediate use (AM not HF) (same day or next day) not from the health facility

*Illness identified with malaria in illness narratives even though identified primarily with *degedege*

** Illness identified with *homa* in illness narratives even though identified primarily with *degedege*

Symptoms associated with ‘HF AM’ included: ‘hot abdomen’, ‘cough’, ‘no interest to play’ and ‘difficulty breathing’. The following narratives indicate how caretakers explain such symptoms and the need to seek prompt treatment: *“The child’s fever was very high, you know always the fever starts in the abdomen then goes to the head then comes degedege, the only thing is to rush the child to health facility”* (female respondent aged 38 from Minepa village). Another caretaker explained, *“the child was coughing and struggling hard to breathe like somebody who has asthma, you know the life of any human being depends on breathing so I was scared that the child might die and took him straight to health facility”* (female respondent aged 24 from Mngeta village). The patterns of distress that were associated with ‘less health facility use’ were ‘vomiting’ and ‘increased sleeping’. These symptoms were viewed by caretakers as unserious and manageable in the household, by purchasing drugs from drug stores.

The perceived causes associated with ‘HF use’ and ‘HF AM’ were ‘blood weakness’ and ‘sanitation/dirty environment’. The following narratives explain the perceived causes of *degedege* by respondents: *“Dirty environment around the house like bushes, grasses, pit, and stagnant water are breeding grounds for mosquitoes causing malaria”* (male respondent aged 35 from Kichangani village). Some caretakers believe that some children are born with weak blood, and that makes them more vulnerable to various diseases, including malaria. As a respondent had put it*: “My child’s blood is weak that is why he is prone to many diseases, the only thing I can do is to try and protect her from contacting different diseases otherwise there is nothing I can do”* (female respondent aged 40 from Lupiro village).

‘Spirits’ (mostly referred by respondents as *shetani* in Kiswahili or witches) and the bird/insect called *‘degedege’* were the perceived causes of *degedege* associated with ‘less timely use of health facility and receipt of anti-malarial’ among *degedege* children. This reveals that ‘traditional beliefs’ about the cause of *degedege* do influence timely treatment-seeking of health facility. However, illness narratives also revealed that caretakers did not see the importance of prompt treatment at health facilities, since they believed that medical facilities were frequently out of medications. The following translation is typical of quotes from respondents on the reasons not to take *degedege* children to a health facility*: “When I saw my child twitching, I went to the drug shop to buy some anti-malarials, I could not go to the health facility since the drugs are always out of stock”* (female respondent aged 37 from Iragua village).

Another respondent said: *"You see, it is waste of time going to the dispensary hoping to get some drugs and being told to get them from drug shops; sometimes you are also told to buy some syringes and bring them to the dispensary for injection, so when the child started twitching and becomes stiff, I with my mother rushed the child to the drug shop and got some quinine"* (female respondent aged 30 from Mbingu village).

Illness narratives show that caretakers are well informed about the importance of prompt treatment at a health facility, particularly for young children. The knowledge of this had been acquired from various sources, including: MCH (Mother and Child Health) clinics, previous experience with *degedege* cases, HDSS staff and the extensive social marketing activities in the study area (Armstrong Schellenberg, 1999). The following is typical of for narratives identifying the sources through which caretakers acquire knowledge about malaria:

> "I myself know that whenever the child has various symptoms, I have to take her to the dispensary because when we attend the MCH clinic, we are told how to identify malaria symptoms through which we can promptly seek treatment at the dispensary" (female aged 28 from Idete village).

> "My child had high fever, his stool was red and the eyes used to go up - you know I lost one of my children with the same symptoms, so this time I decided on my own to take the child to the dispensary because the other child passed away while my grandfather was trying to sponge him with traditional medicines. I did not want something bad to happen to my child, I immediately rushed him to the dispensary, he got some treatment and he was healed" (female respondent aged 34 from Iragua village).

> "People from STIFL (Swiss Tropical Institute Field Laboratory, currently known as Ifakara Health Institute) are doing a wonderful job, you see every house has a number, they visit us frequently and educate us about health issues including malaria and the importance of seeking treatment at a health facility" (male respondent aged 46 from Mbingu village).

‘Timely anti-malarial, not from the health facility’

About 10.4% of children who had *degedege* used ‘AM not HF’ compared to 38.8% of those who had *homa*. The patterns of distress associated with this category include ‘diarrhoea’, ‘twitching’ and ‘vomiting’. Typical *degedege* symptoms were grouped together and included ‘twitching’, ‘stiff body’, ‘delirium’, ‘eyes turn white’, ‘kicking of legs and arms’, ‘froth in mouth’, ‘mouth twisted sideways’, ‘falling down’ and ‘easily startled’. Yet, ‘twitching’ was the only typical *degedege* symptom associated with timely anti-malarial, not from the health facility (Table 5). On the other hand, ‘easily startled’ was the pattern of distress that has a negative correlation with “timely anti-malarial receipt but not from the health facility” (AM not HF). The perceived causes that were associated with ‘timely anti-malarial use not from the health facility’ (AM not HF) were ‘personal hygiene’ and ‘cold weather’.

Representative narratives revealed that the major reasons for children with *degedege* receiving timely anti-malarial without seeking care from health facility include a belief in ‘lack of drugs’ and ‘poor diagnosis at health facility’. ‘Lack of money to pay for treatment’ was also pointed out as a reason not to attend a health facility. The following narratives indicate how caretakers explained reasons for not attending health facility*: “I went straight to buy drugs at drug shop, I can not go to the dispensary since there is no diagnosis there, they do not take your blood to see what you are suffering from, so even the doctor does not know what he is treating”* (male respondent aged 41 from Mpofu village). A woman explained: *“There is no need to go the dispensary because in the end you will be told to purchase drugs from drug shops since the dispensary is always out of stock”* (female respondent aged 21 from Lupiro village). Another caretakers explained*: “I did not have money, I have no work that gives me any income, how can I go to the dispensary with only 100 shillings?, I just went to drug shops, still the money was not enough for the drugs “* (female respondent aged 18 from Ikule village).

Although some caretakers also used traditional treatment as the first aid for *degedege*, they recognized the importance of timely modern treatment to cure *degedege*. The following quote illustrates the experience reported: *“When I saw my child twitching, I went to the bush and got some leaves called ‘manunganunga’, which I used to sponge the child, after few minutes the twitching stopped so I took my child to the drug shop and we got an anti-malarial”* (female respondent aged 39 from Mpofu village).

4.5 Discussion

The study examined local understandings and treatment practices of *degedege* compared to fever for children younger than five years of age, from the perspectives of their caretakers. This study applied an integrated methodology that examined health system, livelihood, as well as cultural epidemiological determinants of behavior. The strength of this study lies in the fact that it does not only describe "conventional" factors influencing treatment seeking behavior for malaria (e.g. socioeconomic characteristics), but also elucidates the significance of illness experiences, meanings and resulting treatment seeking behavior, in combination with perceptions on health service delivery. A combination of factors explains treatment seeking behavior and is hence key for targeted disease control.

Findings from this study provide both parallel and diverse ideas to previous studies about the role of illness experience, and its meaning for treatment practices of *degedege* and fever cases. The link between *degedege* and malaria, that respondents make, is certainly confirmed in this study, unlike other studies in sub-Saharan Africa, as reviewed by Williams et al. (2004), and in Tanzania in particular, where the two conditions were perceived as distinct (Makemba et al., 1996; Winch et al., 1996; Minja et al., 2001; Comoro et al., 2003; Mayombana, 2004).

The majority of children with *degedege* were taken to health facilities in a timely manner (71.1%), compared to those who had *homa* or malaria (45.6%). The finding confirms the study by De Savigny et al. (2004a) which indicates modern care as the first choice of treatment for 78% of fatal malaria cases, and that by Ahorlu et al. (2005) where 90% of respondents identified convulsions as severe condition and recognized the need to seek modern treatment. This finding supports that at least in the selected research area there has been a shift in the practices for first treatment of *degedege*, compared to what has been reported in previous studies for the same area (Makemba et al., 1996; Winch et al., 1996; Minja et al., 2001; Comoro et al., 2003; Mayombana, 2004; Warsame et al. 2007). Moreover, the results provide information on the differences between the treatment patterns for fever *(homa)* and *degedege*: Fever cases have been reported as resorting more to modern treatment approaches than *degedege* cases (Makemba et al., 1996; Winch et al., 1996), while our study found a higher percentage children with *degedege* (71.1%) than children with fever (45.6%) accessing modern treatment. A number of

studies have shown that treatment delay for fever/malaria is due to the perception that this illness is a 'normal everyday illness', and thus not a serious one (Mwenesi et al., 1995a; Thera et al., 2000; Kamat, 2006).

While *degedege* symptoms were regarded as belonging not to the modern treatment field (Winch et al., 1996; Comoro et al., 2003) this study attests the use of modern treatment for *degedege* cases. However, these results can also be attributed to the fact that people in the study area have been exposed to multiple health education campaigns since 1970, including the national 'Mtu ni Afya' (meaning "Man is Health") campaign, which provided intensive information about symptoms, causes, treatment and prevention of malaria (Hausmann Muela, 2000). Moreover, in 1996, the study area was marketed via the thorough insecticide-treated nets social marketing campaign (Minja et al., 2001). That campaign was preceded by a study which revealed that communities did not link malaria with *degedege*, and as a result these findings were incorporated in the social marketing to correct the knowledge on linkage between the two. On the other hand, accurate knowledge does not essentially translate into appropriate behavior, since treatment-seeking is also influenced by a number of other factors (Hausmann Muela et al., 2002).

Caretakers of children with *degedege* who did not use health facilities at all, were less driven by local ideas with regard to the importance of traditional treatment as indicated by various studies (Mwenesi et al., 1995a; Makemba et al., 1996; Winch et al., 1996; Ahorlu et al., 1997; Snow et al., 1998; Minja et al., 2001; Comoro et al., 2003; Hill et al., 2003; Mayombana, 2004; Adongo et al., 2005; Beiersman et al., 2007; Warsame et al., 2007) but instead, by the fact that the health facilities do not always provide adequate treatment options, including drugs and proper diagnosis, or that communities lacked the money to pay for treatment, confirming results of a study by Thera et al. (2000). That health facilities are more often used may result from traditional ideas having become less pervasive, or from the fact that in the past there were fewer, or even no health facility options. Yet, the number of health facilities in Tanzania has been comparably high since 1991, when private health facilities were allowed to operate on their own. It is also possible that in areas where a health facility had previously been available but not used, the association of traditional causes, however valid, was not as influential on behavior even then.

A number of studies reported delayed health facility attendance and anti-malarial injection for various *degedege* related symptoms, including eye rolling, body stiffening and foaming at the mouth, which was regarded as fatal and therefore required traditional treatment (Winch et al., 1996; Comoro et al. 2003). On the contrary, our findings demonstrate that illness experience of *degedege* did not hinder caretakers to timely approach health facilities and receive anti-malarial medications. Instead, rather symptoms related to *homa*, including vomiting and increased sleeping, correlated more with less timely use of health facility than *degedege*. This particular finding corresponds with results presented by Muela (2000), who found that for uncomplicated malaria, vomiting was perceived as a sign of relief, rather than a symptom showing an ascending to complicated malaria, and therefore treatment delay was common.

Spirits, the insect '*degedege*', and non-abstinence from sex were the perceived causes of *degedege*, and associated with less timely use of health facility and receipt of anti-malarial. This finding confirms views from previous studies, where *degedege* was related by respondents to spiritual causes and hence less likely to trigger the use of health facilities (Mwenesi et al., 1995b; Makemba et al., 1996; Winch et al., 1996; Ahorlu et al., 1997; Snow et al., 1998; Minja et al., 2001; Comoro et al., 2003; Hill et al., 2003; Mayombana, 2004; Adongo et al., 2005; Beiersman et al., 2007; Warsame et al., 2007). However, these ideas were not so influential as to keep the majority of children with *degedege* from accessing health facilities and receiving anti-malarial medication. More importantly, the so called dirty environment (bushes, grasses, stagnant water) were considered as contributing to breeding sites for mosquitoes, which were recognized as the cause of *degedege* and accelerated the need for prompt treatment. This confirms a study conducted within the same program (Hetzel et al., 2008c), which found that for fever and *degedege* cases, mosquito bites were the most cited perceived cause.

More generally, the findings indicate that symptoms rather than causes are now the drivers of health seeking behavior. This may at least partly be attributed to the many health interventions and campaigns carried out in the study area emphasizing the importance of recognizing and responding to danger symptoms. The present study took place two years after the 2002 introduction of IMCI (Integrated Management of Childhood Illnesses) devoting training to caregivers on early recognition of dangerous symptoms among children, through which prompt treatment at health facility was highly suggested (Armstrong Schellenberg et al., 2004b). The social marketing of insecticide

treated nets (KINET) and of prompt and appropriate treatment seeking (ACCESS) program have certainly also contributed.

However it is important to point out that the results of the study are context-based and cannot be generalized. Firstly, the sample size of the study was restricted since it focused on first treatment and was based only on reported fever and *degedege* cases. Secondly, the study site was influenced by extensive malaria research activities and interventions that have been taking place in Kilombero and Ulanga Districts since several decades. While the results might not reflect the situation in other parts of the country, they provide insights into the effects of interventions such as the ACCESS program in this area, and may thus inform research, policy and practice.

4.6 Conclusion

This study examined caretakers' treatment seeking patterns for children with *degedege* and *homa*, and then compared the findings with results from previous studies focusing on the same theme. Findings suggest that intensive community health education on causes and danger symptoms can trigger seeking of appropriate and timely treatment, and had positive influence on changed health-seeking behavior in the study area. Health facility use was even higher among *degedege* children compared to children with normal fever. Furthermore, findings revealed that traditional ideas are no longer a significant influence in delaying health facility use for children with *degedege*. Even for children with *degedege* who did not use a health facility at all, reasons associated with this had more to do with poor services in the respective facility, and/or lack of money to pay for consultation and/or treatment, than the belief that *degedege* is better managed by traditional practices.

The main reasons why services were considered as inadequate were a lack of drugs and competence as well as equipment to make accurate diagnosis. Communities are exposed to insecurities when they lack financial capital, a significant livelihood asset in seeking care, especially when the exemption of children under the age of five who are supposed to receive free treatment in health facilities is not effective (Hetzel et al., 2008c). In order to further encourage people to seek timely and appropriate treatment,

quality of care at health facilities needs to be improved, through making diagnosis and provider compliance with treatment guidelines more accurate, as well as therapies including drugs more available and affordable to communities. Initiatives for strengthening livelihoods including economic capabilities are also relevant in ensuring prompt and timely malaria treatment. Moreover, further education needs to focus on proper causes of malaria, specifically to correct the inaccurate association of malaria with *degedege* bird and hereditary causes. Finally, the correlation between female children and less use of timely health facility certainly needs to be explored in more depth since this may reflect a gender bias with regard to early treatment.

Competing Interests

The authors declare that they have no competing interest.

Authors' Contribution

AD was involved in the design and implementation of the study, field work, data management, analysis, interpretation and writing of the manuscript. AS, BO, CL, HM conceived the program and its components, provided technical support and supervision, and commented on the manuscript. MW was involved in the design and analysis of the EMIC, interpretation and discussion of the findings. BO was involved in the conception and design of the study, data analysis, interpretation and writing of this paper. CP was involved in data analysis, interpretation and writing of this paper. MH was involved in the design and implementation of the studies and IM contributed to data collection and discussion of the findings. DG was in charge of statistical support and contributed to the analysis of the data. FK, AM and CM were responsible for the development and implementation of the interventions.

Ethical Review

This paper was published with the permission of Dr. Andrew Kitua, Director General, National Institute for Medical Research. Ethical Clearance of the ACCESS Program proposal was granted by the National Institute for Medical Research of the United Republic of Tanzania (NIMR/HQ/R.8a/Vol.IX/236, September 16, 2003).

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5. Improvements in access to malaria treatment in Tanzania following community, retail sector and health facility interventions – a user perspective

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5.1 Abstract

Background

The ACCESS programme aims at understanding and improving access to prompt and effective malaria treatment. Between 2004 and 2008 the programme implemented a social marketing campaign for improved treatment seeking. To improve access to treatment in the private retail sector a new class of outlets known as Accredited Drug Dispensing Outlets (ADDO) was created in Tanzania in 2006. Tanzania changed its first line treatment for malaria from sulphadoxine-pyrimethamine (SP) to artemether lumefantrine (ALu) in 2007 and subsidized ALu was made available in both health facilities and ADDOs. The effect of these interventions on understanding and treatment of treatment was studied in rural Tanzania. The data also enabled an investigation of the determinants of access to treatment.

Methods

Three consecutive treatment seeking surveys were conducted in 2004 2006 and 2008 in the rural areas of the Ifakara Demographic Surveillance System (DSS) and in Ifakara Town. Each survey included approximately 150 people who had suffered a fever case in the previous 14 days were interviewed.

Results

Treatment seeking and awareness of malaria was already high at baseline, but various improvements were seen between 2004 and 2008, namely: better understanding causes of malaria (from 62% to 84%); an increase in health facility attendance as first treatment option for patients older than five years (27% to 52%); higher treatment coverage with anti-malarials (86% to 96%) and more timely use of anti-malarials (80% to 93-97% treatments taken within 24 hrs). Unfortunately, the change of treatment policy led to a low availability of ALu in the private sector and therefore to a drop in the proportion of patients taking a recommended malaria treatment (85% to 53%). The availability of outlets (health facilities or drug shops) is the most important determinant of whether

patients receive prompt and effective treatment, whereas affordability and accessibility contribute to a lesser extent.

Conclusions

An integrated approach aimed at improving understanding and treatment of malaria has led to tangible improvements in terms of people's actions for the treatment of malaria. However, progress was hindered by low availability of the first line treatment after the switch to ACTs.

5.2 Background

The cornerstone of the World Health Organisation's malaria control strategy is prompt and effective treatment for all episodes of malaria (WHO, 2008; RBM, 2008). Largely thanks to international support through the Global Fund to Fight AIDS Tuberculosis and Malaria (GFATM) and the World Bank's Malaria Booster programme, most sub-Saharan African countries have now switched to the highly efficacious artemisinin-combination therapies (ACT). International initiatives such as Medicines for Malaria Venture (MMV) are increasingly speeding up the development of new anti-malarials. However, the public health impact of such drugs relies to a large extent on patient's ability to access them and little progress will be made unless broader access issues are tackled. Despite large increases in the number of anti-malarial drugs supplied internationally, surveys conducted between 2007 and 2008 in 11 African countries found that only 15% of fever cases were treated with ACTs (WHO, 2008).

Several strategies have been proposed and tested to improve access to malaria treatment by targeting providers or users. Smith et al. (2009) recently conducted a systematic review of the effectiveness of various such interventions in improving prompt and effective treatment of malaria. Interventions reviewed included optimising case-management and services in health facilities (Ofori-Adjei et al., 1996; Yeboah-Antwi et al., 2001; Armstrong Schellenberg, 2004b; Gouws et al., 2004; Bradley et al., 2005) or improving dispensing practices of drug shop attendants and private practitioners (Marsh et al., 1999; Tavrow et al., 2003; Obua et al., 2004; Marsh et al., 2004; Tawfik et al., 2006; Nsimba, 2007) as well as community based approaches (Pagnoni et al., 1997; Winch et al., 2003; Nsungwa-Sabiiti et al., 2007). Two general approaches to improving user malaria treatment practices have been pursued 1) health education campaigns (Menon et al., 1988; Nkuo Akenji et al., 2005) and 2) interventions that specifically provide information on how to take anti-malarials (Kaona et al., 2003), including pre-packaging and pictorial and verbal instructions (Ansah et al., 2001; Okonkwo et al., 2001; Afenyadu et al., 2005). The main finding from the review is that most interventions so far have been conducted on a rather small scale and that few have been appropriately evaluated. As a consequence, despite the wealth of research conducted on the topic, little is known about interventions that can promote sustained change.

The ACCESS programme in the Kilombero and Ulanga Districts in southern Tanzania aims to improve understanding of and access to prompt and effective malaria treatment through an integrated approach targeting both users and providers (Hetzel et al., 2007). The programme's activities are based on a conceptual framework which defines access as the degree of fit between the needs and means of patients (users) and the existing services (providers) along the five dimensions of availability, accessibility, affordability, adequacy and acceptability (Obrist et al., 2007). Interventions are carried out at three levels: 1) the community, 2) the formal health sector and 3) the private retail sector for drugs. A comprehensive monitoring and evaluation plan accompanied each of these interventions. The implementation of the programme started in 2004 and the second phase will be completed in 2011.

Between 2004 and 2007 the ACCESS programme's main intervention at community level was a social marketing campaign for improved recognition of the disease and more effective care seeking. It followed on the work by the KINET project which used a social marketing approach to promote the use of insecticide treated nets in the same area (Armstrong Schellenberg et al., 1999). Various communication channels were used and material developed to disseminate information on malaria transmission, symptoms and prevention as well as to stress the importance of prompt and effective treatment. Road shows were the main activity and included role plays, public lectures and quizzes. In addition, promotional materials (e.g. stickers, leaflets, t-shirts) were distributed, and billboards and posters displayed in public places. The programme also organised special campaigns targeted at pregnant women and mothers of young children in Mother and Child Health (MCH) clinics. Social marketing campaigns were conducted in 96% (78/81) of the villages in the Kilombero District and 95% (62/65) of the villages in the Ulanga District. More detailed information on the ACCESS social marketing campaigns can be found elsewhere (Hetzel et al., 2007).

The ACCESS programme also intervened in the public health sector to improve quality of care. Key activities included strengthening of routine supervision and refresher training for health facility staff based on Integrated Management of Childhood Illness (IMCI) algortithms (Hetzel et al., 2007). In 2004 and 2005 91% (94/103) of all health workers in the Ulanga District and 93% (39/42) of clinical officers in the Kilombero District attended a refresher training. In addition the study period saw a change of first line treatment for malaria. In 2006 the Government of Tanzania switched from

sulphadoxine pyrimethamine (SP) to artemether lumefantrine (ALu). Actual introduction of ALu in health facilities was delayed until 2007, with resulting stock-outs in the transition period (Alba et al., 2010a).

In parallel the Accredited Drug Dispensing Outlets (ADDOs) programme was rolled out in the study area from 2006 onwards to improve access to treatment and quality of care in the private drug retail sector (Rutta et al., 2009). ACCESS undertook the local evaluation and monitoring of the programme. The private retail sector plays a very important role in the delivery of anti-malarial treatment in most African countries as retailers tend to be more accessible and flexible, especially with regards to opening hours and charges (McCombie, 2002; Williams et al., 2004). The aim of the ADDO programme is to improve access to basic medicines by upgrading all existing drug shops to well regulated and properly operated outlets manned by specifically trained personnel (MSH, 2008). The intervention involved a combination of private drug shop dispenser training, incentives, accreditation and regulation. The ADDO programme greatly improved the availability and accessibility of drug shops and, most importantly the quality of advice and dispensing (Dillip et al. unpublished data). ALu was made available to the programme at a very highly subsidised price towards the end of 2007, but this did not result in widespread availability of the drug, allegedly because of low profit margins and long distances to the wholesalers (Alba et al., 2010a) between 2006 and 2008 55 ADDOs were opened the Ulanga District and 135 in the Kilombero District (equivalent to approximately three shops per 10,000 people in both districts).

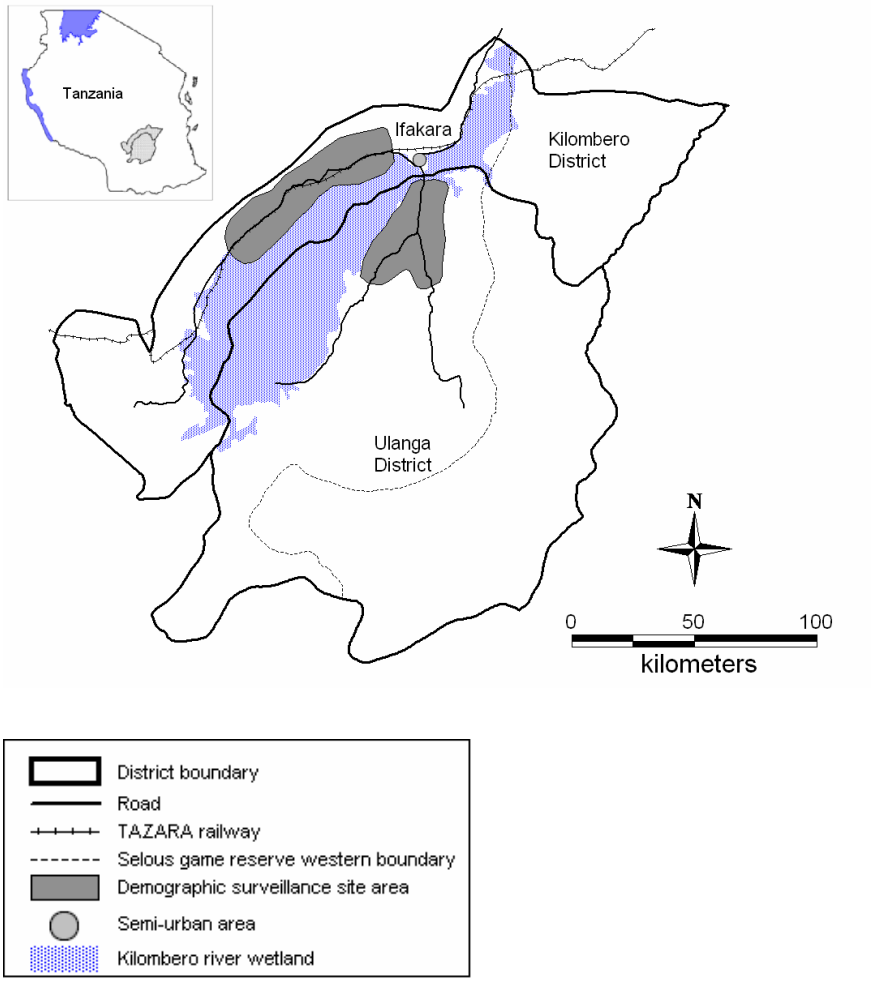
The primary aim of this study was to evaluate changes in understanding and treatment seeking for malaria in the Kilombero and Ulanga Districts during the period 2004-2008 and to assess how such changes could be attributed to the three interventions evaluated by the ACCESS programme. The results presented here are complemented by a study which focused on changes in availability, accessibility and affordability of treatment over the same period (i.e. the provider perspective) (Alba et al., 2010a). The data also provided a unique opportunity to apply a recent analytical framework on access to treatment (Obrist et al., 2007) in a real-life situation and to assess the determinants of access to prompt and effective treatment.

5.3 Methods

Study setting

The study was carried out in the Kilombero and Ulanga Demographic Surveillance System (Ifakara Rural DSS) and in the semi-urban setting of Ifakara town between 2004 and 2008 (Figure 9). In the DSS area every household is visited every four months to collect a set of basic demographic data. As a result, a comprehensive and continuously updated database of the resident population is maintained for the study area. The Ifakara Rural DSS covers 25 villages (13 in Kilombero and 12 in Ulanga). The population in 2004 was almost 74,000 and just over 92,000 in 2008. The population of Ifakara Town was 45,700 according to the national census of 2002 (United Republic of Tanzania, 2003). A study conducted in the area between 2001 and 2003 reported an Entomological Inoculation Rate (EIR) of 349 infective bites per person per year (ib/p/y) (Killeen et al., 2007), but according to recent data it has declined to 81 ib/p/y (Russel et al., 2010). EIR data for Ifakara town suggest that the transmission rate is about a log order smaller than in the surrounding rural areas (Drakeley et al., 2003). The area has been described in more detail elsewhere (Armstrong Schellenberg et al., 2002; Hetzel et al., 2007).

Figure 9 Map of Kilombero and Ulanga Districts showing Ifakara Town and the Demographic Surveillance System (DSS). Source: Hetzel et al., 2006.



The formal health sector **-** There are six health facilities in the Kilombero DSS area and eight health facilities in the Ulanga DSS area. The Designated District Hospital in Ifakara serves as a referral centre for the entire area and there are also two other health facilities in town. Government and faith-based facilities in Kilombero and Ulanga charge user fees. In the Ulanga District the Community Health Fund (CHF) offers a form of risk protection to its members but very few people were enrolled during the study period (around 3% of the population in 2005 - personal communication from the District Medical Officer). Children under five years of age, pregnant women and elderly people should receive services and drugs free of charge but there is ample evidence that the exemption mechanism is not properly implemented (Manzi et al., 2005; Hetzel et al., 2008c).

Retail sector for drugs - By 2008 90% (49/54) of drug shops in the study area were ADDOs. Between 2004 and 2008 the number of shops per 1000 people increased from 0.24 to 0.39 and as a result the proportion of people living within 5km from a shop increased from 71% in 2004 to 87% in 2008. The roll out of ADDOs coincided with a stark decrease in the availability of anti-malarial drugs in non-licensed general shops. Mystery shopper surveys showed that the proportion of customers with malaria symptoms who got correct advice and treatment in drug shops increased from just above 30% to nearly 80% between 2004 and 2008 (Dillip *et al*., unpublished data) after the introduction of ADDOs. Although ALu was made available in ADDOs in mid 2007 with a high level of subsidy by 2008 it was only stocked by a third of shops. SP and other older anti-malarials remained much more widely available and sold (Alba et al., 2010a).

Treatment seeking surveys

Three cross sectional surveys were conducted in the DSS areas and Ifakara Town in 2004, 2006 and 2008 to investigate treatment seeking for malaria and understanding of the disease. The interviewees included children and adults who had recently suffered a fever episode (caretakers responded to questions for children under the age of 12). Data collection was carried out every other year between May and August, a time of the year which coincides with the dry season and is characterised by a lower intensity of transmission. An analysis of the baseline study in 2004 was published by Hetzel et al. (2008c) and the results presented here provide a longitudinal assessment of the changes between 2004 and 2008.

Sampling procedure - Different sampling procedures were applied in the DSS area and in Ifakara Town. In the DSS area, a village-stratified random sample of households was drawn from the existing comprehensive DSS register. Only households with at least one child under the age of five years were eligible. In Ifakara such a sampling frame was not available. Therefore, the local administrative structure was used to draw a two-stage random sample of households, using ten-cell leaders (*balozi*) as first level of sampling. Given a background of decreasing fever incidence rates, every year a greater number of households were sampled to ensure that approximately 150 fever cases could be followed up (Table 6). All individuals from the sampled households who reported an episode of fever within the previous 14 days were included in the study. Patients who had not recovered clinically were not included and they were instead advised to seek

care from a health facility. More details on the sampling and interviewing procedure can be found in the baseline paper (Hetzel et al., 2008c).

Table 6 Sample size and number of fever cases followed up in each survey round

	DSS areas		*Ifakara Town*	
	Households sampled [1]	People interviewed	Households sampled (ten-cells x households per ten-cell) [2]	People interviewed
2004	318	110	223 (40 x 6)	44
2006	561	103	410 (50 x 9)	50
2008	750	86	739 (75 x 10)	41

[1] Village-stratified sampling proportional to number of households per village
[2] Two-stage sampling of households within ten-cells. The final number of households is lower than the product of the parts as some ten-cells have less than the chosen number of households

Data collection tool: The tool for data collection was a locally adapted Explanatory Model Interview Catalogue (EMIC) (Weiss, 1997) based on FGDs and prior research carried out in the study area (Hausmann Muela, 2000; Minja et al., 2001). This semi-structured questionnaire provides qualitative and quantitative data on patients' signs and symptoms associated with the fever episode (patterns of distress), as well as perceived causes and treatment seeking. Patients were also asked to label the disease according to their own understanding. In the study area most cases were labelled as malaria, *homa* (fever) and *degedege* (fever-related disease with neurological involvement (Minja et al., 2001).

Distance from households to nearest point of care: Distances from households to nearest health facility or drug shop were calculated by combining the Global Positioning System (GPS) locations of households from the DSS database and GPS positions of outlets obtained from providers surveys (Alba et al., 2010a). The households GPS values were available for 91% (100/110) households in 2004 97% (100/103) in 2006 and 87% (73/87) in 2008.

Measuring socio-economic status:- A relative index of socioeconomic status (SES) was calculated for the households in the DSS villages using asset ownership and household characteristics data stored in the DSS database. A principal components analysis (PCA) defined the weights of an SES index (Filmer et al., 2001; Vyas et al., 2006) for the households in the survey, relative to all other households in the area. Households were

divided into five wealth quintiles based on their SES score. The score was available for 97% (107/110) households in 2004, 93% (96/103) in 2006 and 93% (81/87) in 2008. The variables included in the analysis and the weight given to each is shown in Table 7.

The variables collected for SES assessment in 2004 differed from the ones collected in subsequent years but this was not considered to bias analyses. Comparing SES quintile groupings in the DSS households showed similar year on year comparability across all years in the poorest and richest category. Indeed 40% (871/2157) of households categorised as poorest in 2004 were categorised as poorest in 2006 and 47% (1256/2686) households categorised as richest in 2004 were categorised as richest in 2006. Similar, albeit higher values were found comparing categories in 2006 and 2008, that is 53% (1341/2540) and 61% (1752/2882) respectively. As year on year comparability in the three middle quintiles was poor, the middle quintiles were grouped into one category which resulted in 66% (4470/6813) of household categorised as middle in 2004 also categorised as middle in 2006 and similarly 73% (5930/8104) comparing the 2006 and 2008 groupings. With these regroupings it was assumed that the difference in the type of assets collected would not introduce substantial bias.

Table 7 Results of principal components analysis of socio-economic status (SES) variables

Item	*2004*		*2006*		*2008*	
	Mean	weight	Mean	weight	Mean	weight
Meals consumed per day in past 2 days	2.31	0.42				
Days per week that the following is consumed:						
Meat	0.71	0.29				
Rice	3.92	0.23				
Tea	2.37	0.42				
Main source of food:						
Market	0.52	-0.34				
Own farm	0.44	0.37				
Source of water : 1=tap 2=well with pump 3=well 4=river	2.49	-0.06				
Household owns at least 1:						
Bicycle	0.45	0.32	0.57	0.42	0.65	0.44
Radio	0.49	0.34	0.65	0.38	0.66	0.42
Animal			0.09	0.17	0.10	0.23
Mobile phone			0.07	0.28	0.28	0.42

Corrugated iron roof			0.32	0.35	0.34	0.34
Small business as source of income			0.09	0.09	0.11	0.13
Rented accommodation			0.10	-0.02	0.10	0.02
Number of mosquito nets			1.97	0.46	2.03	0.35
Number of rooms	2.09	0.17	2.18	0.45	2.23	0.38
Toilet or latrine			0.92	0.15	0.93	0.06
Number of households included	14515 / 14997		16762 / 16888		17764 / 18813	
Variation explained by first principal component	24%		23%		24%	

Ethical clearance - All study participants provided oral informed consent prior to the interview. The National Institute for Medical Research of the United Republic of Tanzania granted ethical clearance for the study (NIMR/HQ/R.8a/Vol.IX/236, 16th September 2003).

Analyses

Various indicators were constructed and compared between 2004 and 2008. Indicators of understanding of malaria focused on perceived causes and patterns of distress.. Indicators of treatment included: actions, sources and type of drugs used for the treatment of fever and links of the community effectiveness chain based on the approach developed by Hetzel et al. (2008c). The community effectiveness chain breaks down the full Roll Back Malaria (RBM 2008) indicator into its primary components (MOHSW 2006) and includes: the proportion of fever cases 1) treated; 2) treated with a drug; 3) treated with an anti-malarial; 4) treated with a recommended anti-malarial; 5) treated with a recommended anti-malarial on the same or next day; 6) treated with a recommended anti-malarial the on same or next day and following the correct regimen (correct number of tablets, timely intake and duration), i.e. the full RBM indicator; 7) treated with a recommended anti-malarial on the same or next day, following the correct regimen and appropriately considering reported symptoms (with quinine if symptoms of severe malaria are reported). Since the change of treatment policy only effectively took place one year before the last 2008 survey, two scenarios were presented for 2008. The first scenario is strictly according to guidelines, following which only ALu qualifies as a

recommended treatment, whereas the second scenario also allows for SP as a recommended treatment. Logistic regressions estimated the effect of changes over time from 2004 to 2008 with time entered in the model as a categorical variable. Estimates of change over time were reported crude as well as adjusted by SES groupings since SES score was higher in the last two surveys compared to the first survey.

The recently developed access to treatment framework (Obrist et al., 2007) was applied to the data to estimate the determinants of access in the study area. The framework defines five dimensions of access, namely availability, accessibility, affordability, adequacy and acceptability. Availability refers to the existence of appropriate service. Thus, an indicator of availability was defined as the presence of an outlet (health facility or drug shop) stocking anti-malarial drugs in the village of residence of the patient. Accessibility refers to the geographical distance between the services and the homes of intended users. The main indicator of accessibility was thus defined as the distance from the patient's main residence to the nearest outlet stocking anti-malarials (health facility or drug shop). But since patients in the study area often spend a significant amount of time in farming fields far away from households and outlets (Hetzel et al., 2008c), a secondary indicator of accessibility was defined as whether the patients were in their main residence or away in farming fields at onset of fever. Affordability refers to whether the prices of services fit the patients' income and ability to pay. The patient's SES quintile was taken as a surrogate indicator for income and how much they spent on their treatment (drug and consultation) as an indicator of their ability to pay. The data necessary to construct indicators of acceptability and adequacy were not available The analysis only included patients from the rural DSS villages as data on SES and distances to nearest shop or health facility were not available for households in Ifakara town. Univariate logistic regressions assessed contribution of each of the access indicators on the odds of the patient receiving of prompt and effective treatment within 24 hours. A multivariate model was built (by backward elimination of variables with a log-likelihood ratio test greater than 0.2) to assess the relative contribution of each of the access indicators.

Epi Info 6 and Intercooled Stata 9 (College Station, Texas, USA) were used for random sampling procedures. Data were double entered in Microsoft FoxPro and Microsoft Access (Microsoft Corp.) and checked for coding errors and consistency. Statistical

analysis was done with Intercooled Stata 9. Distance calculations were carried out with ArcMap Version 9.1 (ESRI Inc.)

5.4 Results

The cross-sectional samples were similar over the three years of observation in terms of age, sex, residence, religion and years of formal education. Despite being marginally wealthier, households in 2008 were located further away from drug shops and health facilities (Table 8).

Table 8 Sample characteristics

	2004		*2006*		*2008*	
	N	n (%)*	N	n (%)*	N	n (%)*
Age group	154		153		127	
Under 5 years		81 (52.6%)		76 (49.7%)		50 (39.4%)
Over 5 years		73 (47.4%)		77 (50.3%)		77 (60.6%)
Sex	154		153		127	
Male		71 (46.1%)		63 (41.2%)		54 (42.5%)
Female		83 (53.9%)		90 (58.8%)		73 (57.4%)
Residence	154		153		153	
Ulanga DSS		61 (39.6%)		41 (26.8%)		40 (31.5%)
Kilombero DSS		49 (31.8%)		62 (40.5%)		46 (36.2%)
Ifakara		44 (28.6%)		50 (32.7%)		41 (32.3%)
Religion*	154		152		125	
Muslim		63 (40.9%)		51 (33.5%)		50 (40.0%)
Christian		91 (59.1%)		101 (66.4%)		75 (60.0%)
Years of formal education**	137		150		125	
< 7 years		56 (40.9%)		45 (30.0%)		38 (30.4%)
= 7 years		70 (51.1%)		99 (66.0%)		80 (64.0%)
> 7 year		11 (8.0%)		6 (4.0%)		7 (5.6%)
SES score ***	107		96		81	
Poorest		20 (18.7%)		6 (6.3%)		10 (12.4%)
Middle		63 (58.9%)		62 (64.6%)		52 (64.2%)
Richest		24 (22.4%)		28 (29.2%)		19 (23.5%)
SES score *** [mean (SD)]	107	0.09 (1.53)	96	0.41 (1.28)	81	0.44 (1.45)
Distance to nearest health facility (km) *** [median (IQR)]	105	1.69 (2.74)	100	1.67 (3.43)	73	2.25 (3.83)
Distance to nearest Part II or ADDO drug shop (km) * [median (IQR)]**	105	1.70 (4.13)	100	1.79 (3.30)	73	2.49 (1.94)

* unless otherwise stated

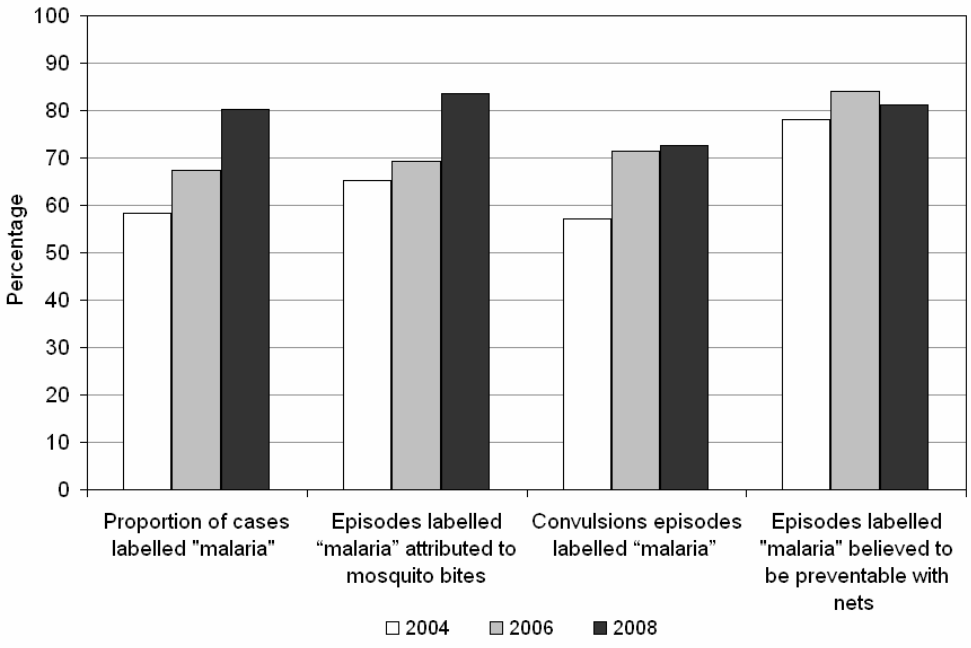
** of caretaker if patient <12 years

*** DSS only (110 observations in 2004, 103 in 2006 and 86 in 2008)

Understanding of malaria

The population appears to be more aware of malaria, its causes and its prevention in 2008 compared to 2004 (Figure 10). While in 2004 57% (80/137) of people labelled their fever case as malaria, the proportion rose to 80% (102/127) in 2008 (crude OR=3.14 p<0.001, adjusted for SES OR=2.31 p=0.008. The proportion of cases labelled malaria attributed to mosquito bites significantly increased from 62% (79/127) to 84% (97/116) (crude OR=3.10 p<0.001, adjusted for SES OR=2.02 p=0.056). The proportion of fever episodes with symptoms of convulsions (twitching, stiff body, delirium, white eyes, kicking limbs) labelled as malaria also consistently increased from 57% (16/28) to 73% (8/11), although not significantly so due to the small number of cases with such symptoms (OR=2.00 p=0.373). The proportion of fever cases believed to be preventable with the use of mosquito nets did not increase, most likely because of the already very high value of 81% at baseline.

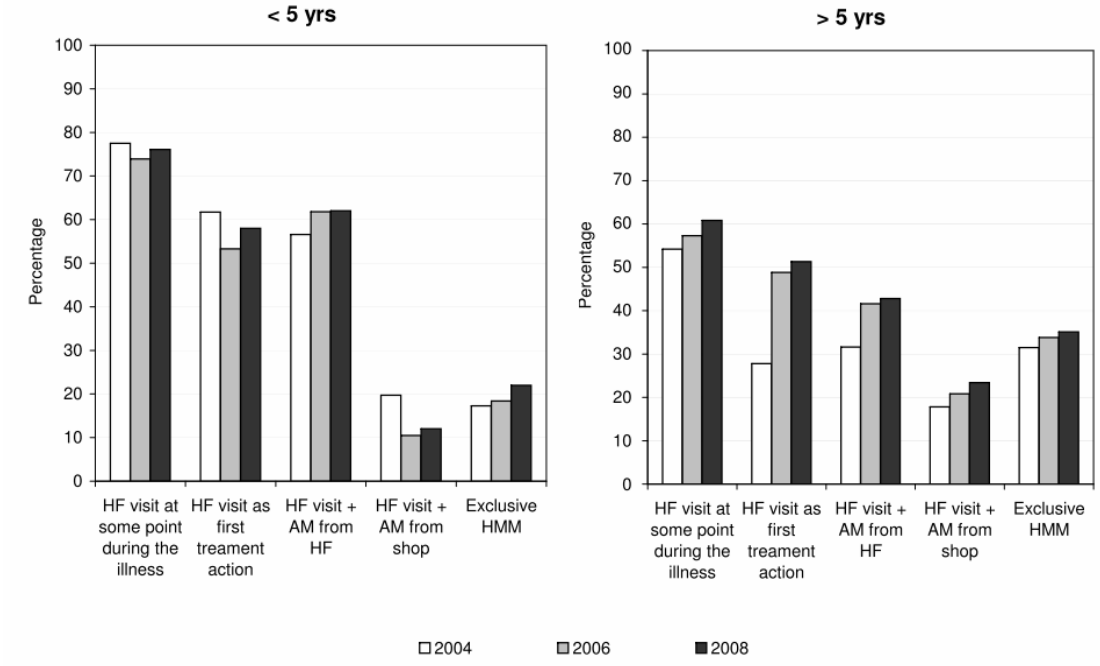
Figure 10 Changes in understanding of malaria



Treatment of fever

There was no difference in health facility attendance and treatment in children, but the proportion of older patients who sought treatment in health facilities increased significantly. Health facility attendance and treatment was already very high at baseline in children and did not change over the study period (health facility attendance at some point during the illness 148/195 i.e. 76%; health facility attendance as first treatment action 119/201 i.e. 58%; treatment with anti-malarial from a health facility 123/207 i.e. 59%). Conversely the odds of older patients attending a health facility as a first treatment option increased three-fold between 2004 and 2008 (from 20/73 i.e. 27% to 40/77 i.e. 52% OR=2.9 p=0.002) crude and nearly 5-fold adjusting for SES (OR=4.6 p=0.001). The odds of older patients being treated in a health facility also increased although not significantly (from 23/73 i.e. 32% to 33/77 i.e. 43% OR=1.63 p=0.152) crude and nearly three-fold adjusting for SES (OR=2.9 p=0.012).

Figure 11. Sources of treatment for fever and actions undertaken (Note: HF=Health facility; AM=antimalarial; HMM=home management of malaria



The receipt of treatment from the private retail sector increased over the study period. Overall the proportion of cases treated with an anti-malarial from a drug shop significantly increased from 31% (47/154) in 2004 to 31% (47/153) in 2006 and 43% (54/127) in 2008 (OR=1.68, p=0.038). Three points should be highlighted with regards to this. Firstly, this effect is confounded by SES (adjusted OR=1.18 p=0.632). The proportion mainly increased in the three middle wealth quintiles from 19% (12/63) to 26% (12/46) and actually decreased in the poorest quintile from 25% (5/20) to 20% (2/10) whereas it stayed stable in the richest quintile (20/74 i.e. 27%). Secondly the increase was mainly in patients over the age of five (38% in 2004 to 52% in 2008) and not in children (25% in 2005 to 28% in 2008). Thirdly the increase in the use of the private sector in patients older than five was due more to an increase in people who attended health facilities and obtained treatment from a shop (23/73 i.e. 31% in 2004 to 33/77 i.e. 43% in 2008) than in people who treated themselves directly from shops without ever visiting a health facility (23/73 i.e. 32% in 2005 to 27/77 i.e. 35% in 2008). Few patients were treated from a general shop (30/434 i.e. 7%) (Table 9)

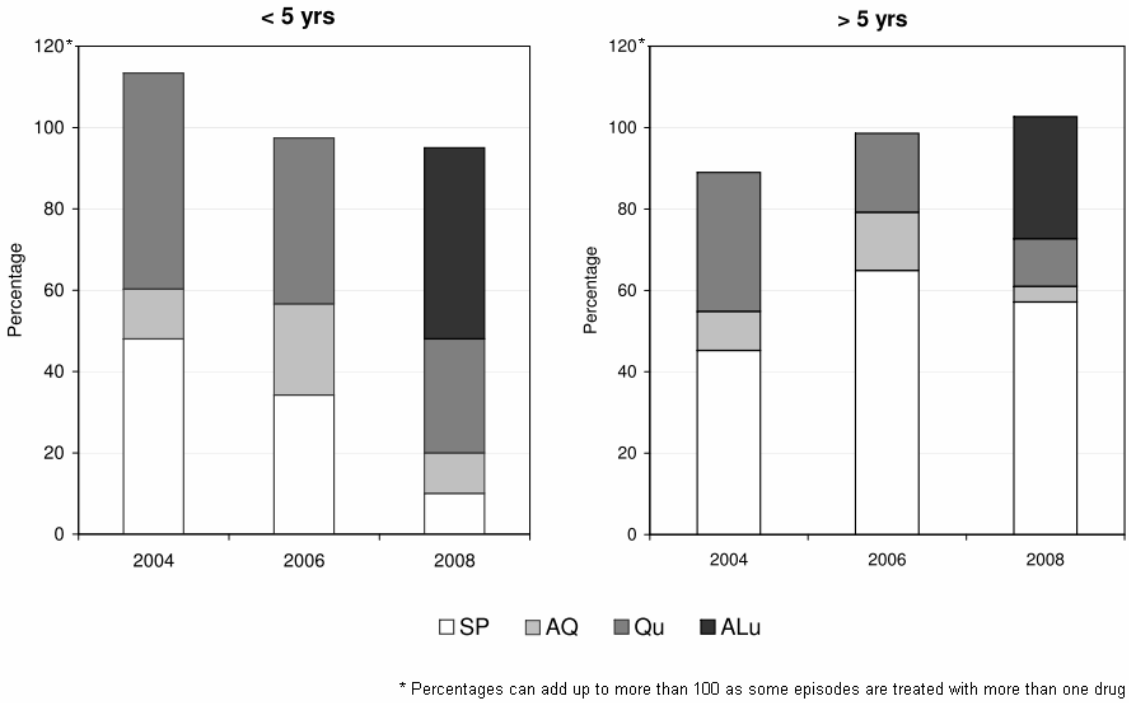
Table 9 Breakdown of types of anti-malarials received from each of the sources of treatment (number of cases and percentages)

	2004			*2006*			*2008*		
	Health facilities	Drug shops	General shops	Health facilities	Drug shops	General shops	Health facilities	Drug shops	General shops
Chloroquine*		1 (2.1%)							
Artemether-Lumefantrine							40 (62.5%)	7 (13.0%)	1 (16.7%)
Sulphadoxine-Pyrimethamine	40 (58.5%)	20 (42.6%)	10 (90.9%)	41 (51.2%)	33 (70.2%)	10 (83.3%)	11 (17.2%)	35 (64.8%)	3 (42.9%)
Amodiaquine	10 (14.7%)	9 (19.2%)		16 (20.0%)	9 (19.2%)	1 (8.3%)	4 (6.3%)	4 (7.4%)	
Quinine	38 (55.9%)	26 (55.3%)	3 (27.3%)	24 (42.5%)	13 (27.7%)	3 (25%)	12 (18.8%)	11 (20.4%)	2 (28.5%)
Total	68	48	11	80	47	12	64	54	6

* 2 patients took chloroquine in 2004 but information on source of treatment was available for 1 patient

A breakdown of the types of anti-malarials taken also shows some improvements over time although the low uptake of ALu is disappointing (Figure 12). Treatment coverage with anti-malarials is extremely high in the study area. In 2004 the use of multiple anti-malarials to treat a single fever case in children under the age of five was common but it decreased in 2006 and 2008. The most commonly used drug over the study period was SP. In 2008, more than a year after the change of treatment policy, only 39% (48/124) of cases were treated with ALu. The low uptake of ALu is partly explained by the fact that even in health facilities not all cases received ALu (only 63%) and partly because most of the people who were treated in shops either received SP (65%), quinine (20%) or amodiaquine (7%) and only 13% received ALu (Table 9). Children were more likely to be treated with the new drug than older patients but not significantly so (23/50 i.e. 46% of children and vs. 23/77 i.e. 30% older patients OR=1.28 p=0.439). Interestingly, patients in the middle quintiles were the least likely to be treated with ALu (poorest to middle quintiles OR=3.56 p=0.029, richest to middle quintiles OR=3.15 p=0.004)

Figure 12 Types of antimalarials taken for treatment of fever (note: SP=Sulphadoxine-Pyrimethamine, AQ=amodiaquine, Qu=Quinine, ALu=Artemether-Lumefantrine)

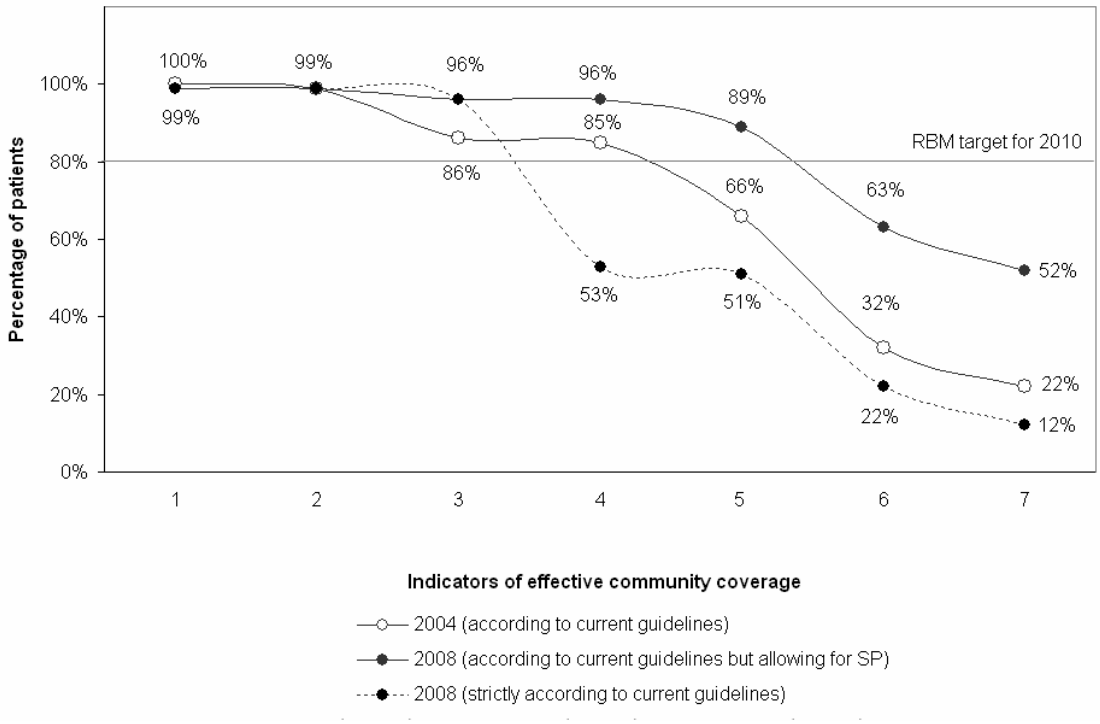


Community effectiveness of malaria treatment

The comparison of the community effectiveness of malaria treatment in 2004 and 2008 shows a clear improvement over time (Figure 13). Despite a sharp fall in the proportion of people taking a recommended treatment for malaria after the switch to ALu, there were appreciable improvements in terms of timeliness of treatment. Comparing the number of people who took an appropriate anti-malarial (indicator 4) and the number who took it within 24 hours (indicator 5) shows that whereas in 2004 80% (101/127) of were treated promptly, in 2008 this figure rose to 97% (65/67) of patients who took ALu or quinine (crude OR=8.36 p=0.005, adjusted for SES OR=6.39 p=0.018), and 93 % (113/122) of patients who took a ALu, quinine or SP (crude OR=3.23 p=0.004, adjusted for SES OR=4.23 p=0.015).

The self-reported adherence to the recommended drug regimen. only marginally improved. Adherence to SP treatment regimens improved over time (55/72 i.e. 76% in 2004 vs. 41/49 i.e. 84% in 2008). However, just over two thirds of patients completed their courses of ALu (22/32 i.e. 69%). Quinine treatments were always under-dosed because the course was not taken for the full seven days. Overall, comparing the number of people who took an appropriate anti-malarial within 24 hours (indicator 5) and those who took it adhering full to its regimen (indicator 6) shows that in 2004 32% (32/101) of timely treatments were taken following regimen and in 2008, although this figure rose to 51% (58/113) of patients who took ALu, quinine or SP, only 31% (20/65) of patients who took quinine or SP fully adhered to their regimen (strictly according to guidelines: crude OR=1.12 p=0.809, adjusted for SES OR=0.94 p=0.910; allowing for SP as appropriate treatment in 2008: crude OR=1.63 p=0.212, adjusted for SES OR=1.40 p=0.475).

Figure 13 Estimated effective coverage of fever treatment based on patients' or caretakers' accounts. Percentages are the proportion of fever cases 1) treated; 2) treated with a drug; 3) treated with an anti-malarial; 4) treated with a recommended anti-malarial; 5) treated with a recommended anti-malarial on the same or next day; 6) treated with a recommended anti-malarial on the same or next day and following the correct regimen (correct number of tablets, timely intake and duration), i.e. the full RBM indicator; 7) treated with a recommended anti-malarial on the same or next day, following the correct regimen and appropriately considering reported symptoms (quinine if symptoms of severe malaria are reported).



There were some difference between adults and children. Generally coverage was higher in children under the age of five compared to the rest of the population. The proportion of cases treated with a recommended anti-malarial (including SP) within 24hrs increased from 73% (59/81) in 2004 to 88% (44/50) in 2008 in children under the age of five (OR=1.30, p=0.030) and from 57% (42/73) in 2004 to 90% (69/77) in patients over the age of five (OR=1.56 p<0.001). The proportion of cases treated with either ALu or quinine within 24hrs in 2008 was 72% (36/50) in children under the age of five and 38% (29/77) in all other patients. However the proportion of cases treated promptly and effectively and following the recommended regimen tended to be slightly lower in children under five than in adults. Allowing for SP the proportion in children under five

increased from 37% (16/43) to 56% (19/34) and in adults from 28% (16/58) to 67% (39/58) between 2004 and 2008. Strictly according to guidelines, i.e. excluding SP and conforming to the full RBM indicator for prompt and effective treatment of malaria, the figure in 2008 is 39% (13/33) for children and 12% (7/58) in adults.

Determinants of access

An analysis of the contribution of each of the access dimensions suggests that the **availability** of anti-malarials thanks to the presence of a drug outlet (health facility or drug shop) is the main determinant of whether people get prompt and effective treatment for malaria (Table10). There was no significant difference in promptness of treatment between patients who had been treated in health facilities and those treated in drug shop (OR=1.28 p=0.613), but patients treated in drug shops were less likely to be treated with the appropriate drugs (OR=0.14 p=0.001). Patients living in villages with either a drug shop or a health facility were four times as likely to get prompt and effective malaria treatment than people from villages without outlets (OR=4.10 p<0.001 adjusting for differences in affordability and accessibility). The presence of outlets influenced promptness (OR=5.83 p<0.001) and appropriateness (OR=4.75 p<0.001) of treatment to a similar extent.

Affordability contributed to a lesser extent to receipt of treatment. Both the univariate and multivariate model showed no difference in receipt of prompt and effective treatment across socio-economic groups. However, people who paid more for their treatment were more likely receive it promptly and effectively (OR=1.74 p=0.008). This implies that even poorer people manage to find the resources to afford treatment. The cost of treatment influenced the appropriateness of treatment (OR=3.34 p<0.001) more than the timeliness (OR=1.67 p=0.017). It is worth recalling here that a somewhat un-expected pattern of ALu uptake was observed in 2008 whereby the three middle quintiles were less likely to be treated with ALu (cf. results in “Treatment of fever”).

Accessibility is a determinant of access to treatment, but only if people are in far away farms at onset of their disease. People were twice as likely to be treated promptly and effectively if they were residing in their main homestead rather than in the farming fields

at the onset of their fever (OR=2.08 p=0.032 in the multivariate model). The location at onset of disease mainly influenced the receipt of a recommended anti-malarial (OR=2.48 p=0.004) rather than the timeliness of treatment (OR=1.63 p=0.133). However, if people were in their main homestead at onset of disease, the distance to the nearest outlet did not have a major impact on treatment provided the outlet was present in their village (OR=0.88 p=0.082).

Table 10 Determinants of receiving prompt and effective antimalarial treatment according to current guidelines from either a health facility or a drug shop in the rural DSS villages between 2004 and 2008

		Univariate model			Multivariate model (n=264)	
		N	OR (95% CI) *	p	OR (95% CI) *	p
Availability	Presence of outlet in the village of residence **	297	3.32 (1.96 to 5.63)	<0.001	4.10 (2.17 to 7.73)	<0.001
Affordability	SES (baseline: middle quintiles)	282		0.951		
	Poorest		0.94 (0.44 to 2.03)	0.893		
	Richest		1.07 (0.59 to 1.95)	0.803		
	Cost of treatment *** (TSh1000)	297	1.73 (1.26 to 2.43)	0.002	1.74 (1.16 to 2.60)	0.008
Accessibility	Distance household to nearest outlet ** (1km)	276	0.84 (0.73 to 0.95)	0.006	0.88 (0.75 to 1.01)	0.082
	Location at onset of fever (home vs. farming site)	295	1.83 (1.03 to 3.27)	0.039	2.08 (1.07 to 4.09)	0.032

* Adjusted for the effect of year of study
** Presence/distance to health facility for those treated in a health facility and presence/distance to drug shop for those treated in a drug shop
*** Drug + consultation

5.5 Discussion

The results presented here show improvements in understanding and treatment seeking for malaria in two rural districts in Tanzania after the implementation of the ACCESS programme. Specific improvements include a better understanding of the causes of malaria, an increase in health facility attendance and treatment in patients older than five

years, and more timely use of anti-malarials. Unfortunately, the change of malaria treatment policy from SP to ALu during the same period led to a lower availability of the first line drug in the private retail sector. As a consequence the proportion of patients taking a recommended malaria treatment dropped significantly in 2008.

Given the before-after nature of this study and the absence of a control group it is difficult to attribute specific improvements to ACCESS interventions. However, plausible explanations can be given on the basis of accepted frameworks (Habicht et al., 1999; GFATM, 2009). With this type of design improvements are attributed to the programme if improvements are found in every step of the causal pathway between intervention and outcomes and all other explanations can be formally discarded. In this study the main outcome of interest is prompt and effective treatment and steps in the causal pathway include :1) changes in understanding of malaria; 2) changes in actions for the treatment of malaria and; 3) changes in access outputs, i.e. the accessibility, availability and affordability of treatment, which were reported in a separate study (Alba et al., 2010a).

It seems reasonable to credit the ACCESS social marketing campaigns for the observed changes in the understanding of malaria and the increased use of health facilities as a first treatment action. Indeed, no other efforts of this magnitude took place concurrently in the area. With regard to the lack of increase in health facility attendance in children, it is important to bear in mind that health facility attendance in this age group was already very high for a rural African setting with over 75% of children visiting a facility at some point during their illness. The high level of action already undertaken by mothers of small children at the start of ACCESS is undoubtedly the result of a long-standing effort in the area to improve comprehensively malaria control parameters (Armstrong Schellenberg et al., 1999; Armstrong Schellenberg et al., 2001). It is especially worthy of note that increases in health facility attendance were higher once adjusted for SES status. This would suggest the ACCESS social marketing campaigns were able to target even the less well off, which is far from always being the case (Mugittu et al., 2005). This result is consistent with data from the evaluation of the Tanzania National Voucher Scheme, which found that road shows are able to disseminate messages more equitably than any other means of communication such as radios and billboards (Hadji Mponda, unpublished data).

The more timely use of anti-malarials can be attributed to the combination of the ACCESS social marketing campaigns and the ADDO intervention. On one hand the ACCESS social marketing campaigns stressed the importance of prompt and effective treatment for malaria. On the other hand following the ADDO intervention treatment became more available and accessible (Alba et al., 2010a). The good availability of ALu in health facilities in 2008, combined with the increase in health facility visits as a first treatment action is likely to also have contributed to the improved timeliness of treatment. It is worth highlighting here two positive outcomes with regards to the role of ADDOs and health facilities which emerged from this evaluation. Firstly self treatment at home did not increase significantly in neither children nor older patients suggesting that ADDOs did not undermine the role of the formal health sector, but rather complemented it. Secondly, after the introduction of ADDOs, the proportion of children who were taken to a health facility and received an anti-malarial from a shop did not change (10-12%), which refutes claims that health facility staff refer patients to outlets in which they have a financial stake. It is important the ADDOs continue to be adequately supervised for these gains to be sustained.

The results presented here largely compatible with findings from the Smith et al. (2009) review, which concluded that interventions targeted at private sector providers generally show a good impact on provider practices. Similarly to the Kilifi Shopkeeper programme in Kenya (Marsh et al., 1999; Marsh et al., 2004) and other studies targeting the private retail sector (Tavrow et al., 2003; Tawfik et al., 2006; Nsimba et al., 2007) (but contrary to results by Winch et al. (2003) in Mali, the ADDO programme has achieved notable gains in terms of the quality of advice given by shopkeepers. Ignoring the treatment policy change, the increase in the proportion of patients treated promptly and effectively according to the recommended regimen in the present study (from 32% to 63%) is comparable to the outcomes in Kilifi (from 2% to 29% treated promptly and effectively with the right dosage and duration) or in Mali (from 2% to 42% treated effectively with the right dosage and duration). However, this study has shown for the first time that improvements can be sustained even at much higher levels. Therefore key parameters can continue to be improved with targeted interventions, up to the 80% levels targeted by the Roll Back Malaria Partnership (RBM 2008).

The results presented here also confirm the reviewers' conclusion that improving user practice is more challenging. Noticeable gains were made in terms of people's actions

for the treatment of fever (health facility attendance for patients older than five years, timeliness of treatment) but there was no clear improvement in the proportion of cases following the recommended regimen of anti-malarials. This appears to be the result of poor patient adherence, since mystery shopper surveys showed a substantial improvement in provider practice (Dillip et al, unpublished data). It is likely to be due to: 1) the introduction of a new treatment (ALu) with a more complicated regime than the previously recommended SP combined with; 2) the absence of messages targeted at users specifically focusing on the importance of adhering to treatment regimens (although ALu was pre-packaged with clear instructions and pictograms).Future social marketing campaigns in the area should put more emphasis on this component.

The community effectiveness chains show that treatment coverage with anti-malarials is very high in the study area, but the change of treatment policy led to a significant drop in the proportion of patients taking a recommended malaria treatment. Despite high levels of ALu stock in health facilities, the proportion of patients treated with ALu remained low partly because the drug was not widely available in drug shops. The decrease in the proportion of patients treated strictly according to guidelines should be seen in the light of the fact that already in 2003 SP had a treatment efficacy of 50% (Mugittu et al., 2005), while ALu had a treatment efficacy of more than 95% (Makanga et al., 2006). The low availability of the first line drug in the private retail sector following the change of treatment policy from SP to ALu, coupled with the multiple stockouts of SP in public health facilities during the treatment transition clearly indicate that malaria treatment policy changes need to be considered in a more comprehensive way. Fortunately, ACTs will be made available in ADDOs in Tanzania in 2010 in the frame of the Affordable Medicine Facility for malaria.[6]

Strategies to improve access to treatment should focus especially on the availability of points of care. The presence of a health facility or drug shop in the village of residence was the strongest predictor of prompt and correct treatment, whereas affordability (within the observed range of prices) and accessibility indicators contributed to a lesser extent.

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[6] Affordable Medicines Facility – Malaria, available at: http://www.theglobalfund.org/EN/amfm/ , accessed 14 January 2012.

These results differ from those presented in a paper, which focused specifically on the farming season, and according to which fever cases which occurred in the farming sites were as less likely to be treated promptly and effectively as those which occurred in the main homestead (Hetzel et al., 2008a). This discrepancy is probably because of design issues, but the considerations from this analysis are largely consistent with a qualitative study on livelihood and health care which revealed that patients make considerable efforts to access treatment, including walking long distances and selling important livelihood assets (Mayumana, 2007). Hence future interventions aimed specifically at improving access to treatment should focus on extending the network of health facilities and ADDOs to underserved villages and ensuring that drugs are available.

The main limitation of this study is the selection of cases on the basis of reported fever only, since not every fever case is due to malaria. However considering every fever as a potential malaria case is consistent with the Integrated Management of Childhood Illness (IMCI) guidelines for treatment in areas of stable malaria (Gove et al., 1997). This approach was warranted when the survey was designed in 2003 and the area experienced very high levels of transmission. This is no longer justified in the study area since 1) recent data suggest a drastic change in the epidemiology of malaria in the study area, and 2) a recent study piloting the use of Rapid Diagnostic Tests (RDT) for malaria in local health facilities found that only 40% of fever cases were actually due to malaria (D'Acrémont *et al*. unpublished data). It is difficult to assess how much the presence RDTs at the time of our surveys would have changed our observations.

Another limitation concerns the variability observed in the samples and the inconsistency of a finding with another study conducted in the area. Despite a random sampling from the comprehensive DSS database households in 2008 were located further away from health facilities and drug shops despite an increase in the accessibility of these outlets (Alba et al, 2010a). Furthermore the distribution of patients across SES appeared to be unequal over the years, with wealthier households over-represented in the 2006 and 2008 samples. To account for differences in SES across years all ORs of significant effects were reported crude and adjusted for SES.

Finally, it is worth pointing out that additional positive patterns of treatment emerged from this analysis which are not consistent with conclusions one might draw from provider survey carried out in the study area (Alba et al., 2010a). Firstly, no patient in

Ifakara was reported treated with artemisinin monotherapy although they were available in 10-20% of shops. And secondly, the severe stockouts of SP in the study area in 2006 did not appear to have an impact on treatment since the proportion of patients who obtained the drug did not decrease as a result. The reason for this apparent paradox is that availability data from health facilities is based on end-of-month balance in the store rooms. Hence, stocks may be delivered at the beginning of the month and dispensed in their entirety by the end of the month or drugs may not be in the store-room but still present in the dispensing room.

5.6 Conclusions

An integrated approach aimed at improving understanding and treatment of malaria has led to tangible improvements in terms of people's perception and actions for the treatment of malaria. The positive results testify that even in a poor and remote African setting, the Abuja targets for access to treatment can be achieved. A higher impact on prompt and effective treatment according to treatment guidelines was hindered by a change of treatment policy, which led to low availability of the first-line drug (ALu) in the private retail sector. This shows clearly that ensuring consistent stocks of ALu in the private retail sector is crucial to improve prompt and effective treatment for malaria. Future interventions aimed at improving access to treatment by targeting users should have a focus on adherences to treatment regimens. Interventions targeting providers should aim at extending the network of health facilities and ADDOs to underserved villages.

Competing interests

AS is employed by the Novartis Foundation for Sustainable Development (NFSD) which funded the ACCESS programme. The Foundation works independently from the company's business and supports not-for-profit health programmes in developing countries.

Authors' contributions

SA participated in the supervision of the data collection in 2008, analyzed the data, drafted and finalized the manuscript. AD participated in the supervision and training for the data collection in 2006 and 2008 as well as contributing to the manuscript. MWH participated in the design of the survey, coordinated the data collection in 2004 and 2006 and contributed to the manuscript. CM and AM designed and conducted the social marketing campaigns. MA was responsible for the DSS, performed the sampling for the DSS surveys and supervised the data collection. IM participated in the data collection and contributed to the discussion on the manuscript. CM and AM implemented the social marketing campaigns and contributed to the manuscript. MA did the sampling of households, supervised the field work and contributed to the manuscript. BO and AS participated in the design of the surveys and contributed to the discussion on the manuscript. HM and FK provided overall coordination and contributed to the discussion on the manuscript. CL contributed to the study design, the data analysis and the manuscript. The final manuscript was approved by all authors.

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6. Acceptability – A Neglected Dimension of Access to Health Care: Findings from a study on childhood convulsions in rural Tanzania

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6.1 Abstract

Background

Acceptability is a poorly conceptualized dimension of access to health care. Using a study on childhood convulsion in rural Tanzania, we examined social acceptability from a user perspective. The study design is based on the premise that a match between health providers' and clients' understanding of disease is an important dimension of social acceptability, especially in trans-cultural communication, for example if childhood convulsions are not linked with malaria and local treatment practices are mostly preferred. The study was linked to health interventions with the objective of bridging the gap between local and biomedical understanding of convulsions.

Methods

The study combined classical ethnography with the cultural epidemiology approach using EMIC (Explanatory Model Interview Catalogue) tool. EMIC interviews were conducted in a 2007/08 convulsion study (n=88) and results were compared with those of an earlier 2004/06 convulsion study (n=135). Earlier studies on convulsion in the area were also examined to explore longer-term changes in treatment practices.

Results

The match between local and biomedical understanding of convulsions was already high in the 2004/06 study. Specific improvements were noted in form of (1) 46% point increase among those who reported use of mosquito nets to prevent convulsion (2) 13% point decrease among caregivers who associated convulsion with 'evil eye and sorcery', 3) 14% point increase in prompt use of health facility and 4)16% point decrease among those who did not use health facility at all. Such changes can be partly attributed to interventions which explicitly aimed at increasing the match between local and biomedical understanding of malaria. Caregivers, mostly mothers, did not seek advice on where to take an ill child. This indicates that treatment at health facility has become socially acceptable for severe febrile with convulsion.

Conclusion

As an important dimension of access to health care ‘social acceptability’ seems relevant in studying illnesses that are perceived not to belong to the biomedical field, specifically in trans-cultural societies. Understanding the match between local and biomedical understanding of disease is fundamental to ensure acceptability of health care services, successful control and management of health problems. Our study noted some positive changes in community knowledge and management of convulsion episodes, changes which might be accredited to extensive health education campaigns in the study area. On the other hand it is difficult to make inference out of the findings as a result of small sample size involved. In return, it is clear that well ingrained traditional beliefs can be modified with communication campaigns, provided that this change resonates with the beneficiaries.

6.2 Background

Acceptability is a neglected and poorly conceptualized dimension of access to health care. In earlier papers, we presented a new framework for the study of access to health care in contexts of livelihood insecurity), and examined three dimensions of access, namely availability, affordability and accessibility, in the case of fever and mild malaria episodes in rural Tanzania (Hetzel et al., 2006; Hetzel et al., 2008c; Alba et al., 2010b). The present paper examines acceptability as a dimension of access, using convulsion episodes in under-five-year-old children in the same study area.

Drawing on the seminal paper of Penchansky et al. (1981), we understand “access as a concept representing the degree of ‘fit’ between the clients and the system”. In this view, acceptability can be seen as “the relationship of clients’ attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients” (Penchansky et al., 1981). The term acceptability was used to describe consumer reaction to personal characteristics of providers like sex or ethnicity, to the type of facility, to the religious affiliation of the facility or provider or the neighborhood of the facility. Providers, in turn, were described as having attitudes with regard to preferred attributes of clients or financing mechanisms, showing for instance unwillingness to serve welfare patients.

More recently, studies examine the acceptability of products, technologies and associated services or campaigns, for instance hormonal contraception methods (Halpern et al., 2011) or the mass vaccination campaign against A/H1N1 2009 pandemic-influenza in France (Schwarzinger et al., 2010). The term social acceptability is used in studies examining whether preventive measures or treatments are perceived as acceptable by the general population (Negrini et al., 2006). This study is however based on the idea that the concept of ‘acceptability’ has not been well defined and studied in the context of trans-cultural societies and with regard to what attributes constitute the concept.

Guided by perspectives developed in medical anthropology, we use the term social acceptability to emphasize that individual perceptions are influenced by social representations and modified in social interactions. As indicated in Penchansky et al.

(1981), we suggest that a 'fit' or match between providers and clients with regard to their understandings of disease is of particular relevance. The usefulness of such an approach is most obvious if striking differences exist in providers' and clients' views about the causes and treatment of health problems, as has been reported, for instance, for high fever and convulsions in Africa and Asia (Williams et al., 2004; Nsungwa-Sabiiti et al., 2004). In areas of high malaria endemicity, health providers with biomedical training treat fever and convulsions with anti-malarials and antibiotics, while local communities traditionally considered convulsions as distinct illnesses which are more amenable to local treatment practices (Williams et al., 2004; Mwenesi, 2005; Warsame et al., 2007). Recent studies in Tanzania have also indicated use of modern treatment for convulsion (De Savigny et al., 2004; Dillip et al., 2009). In Tanzania, the KiSwahili term *degedege* is used for convulsions in children and certain preventive and treatment practices were associated with this well-known illness category (Comoro et al., 2003; Makundi et al., 2006; Winch et al., 1996).

According to the current guidelines for malaria control (WHO, 2011c) and Integrated Management of Childhood illnesses (WHO, 2005a), children above one month of age with convulsions are treated with diazepam at clinics, while phenobarbitone is advised for young infants less than one month of age. In cases of severe febrile disease or severe malaria, intramuscular quinine, antibiotics and paracetamol have to be administered at clinics and follow up referral to a hospital is recommended.

Over the past decades, the Tanzanian health system, often supported by projects and programs, has made great efforts to control malaria. In the study area, three initiatives explicitly aimed at increasing the match between biomedical and local understanding and treatment of malaria: the Kilombero Treated Net (KINET) Project (1996-2000), which implemented a social marketing distribution system for insecticide treated nets to prevent malaria (Minja et al., 2001); the training of health providers in Integrated Management of Childhood Illnesses introduced in 2002 which explicitly refers to *degedege,* its symptoms, causes and treatment; and, since 2004, the ACCESS program, which aims at improving access to prompt and effective treatment for malaria among children, pregnant mothers and the community at large (Hetzel et al., 2007).

The ACCESS program directs interventions to the community (i.e. the home), the drug shops and the health facilities. In the *community,* the ACCESS program conducts social

marketing campaigns for prompt and effective treatment of mild and severe forms of malaria. The campaign activities include road shows with role plays, dancing and public lectures and the distribution of Information, Education and Communication (IEC) materials like posters, billboards, stickers, T-shirt and caps with malaria-related messages. Role plays address, local ideas, linking convulsions with spirits, the '*degedege* bird' and evil eyes and promote a new understanding linking *degedege* with severe malaria. For example, an IEC message on a T-shirt reads, "Convulsion is a sign of severe malaria and can be treated at the health facility" ("*Degedege ni dalili ya malaria kali na inatibika vituo vya afya*"). Similarly, local counterproductive treatment practices were discouraged and alternatives were recommended, for instance a public health advises message: "Do not urinate on a convulsed child but take her to a health facility immediately" *("Usimkojolee mtoto mwenye degedege ila mpeleke kituo cha afya mara moja").* The importance of using Insecticide Treated Nets (ITNs) as a measure to prevent malaria has also been emphasized in the campaigns.

In *drug shops*, the ACCESS program collaborates with the Accredited Drug Dispensing Outlets (ADDO) program of the Government of Tanzania which is implemented by Management Sciences for Health (MSH) and the Tanzania Food and Drug Authority (TFDA). This program provides not only training for drug sellers but also assistance in the up-grading of the part II drug shops (allowed to sell over the counter medicine only) including mechanisms for proper storage of medicines.

In *health facilities,* the ACCESS program supports the Council Health Management Team in improving the supervision of health staff in the 75 dispensaries, 7 health centers and 4 hospitals of the Kilombero and Ulanga districts. In the course of their visits, the supervisory teams assess, for instance, whether health providers adhere to the national malaria guidelines and the IMCI guidelines in their day-to-day case management.

The study presented here has grown out of the monitoring and evaluation component of the ACCESS program. It explores changes in the social acceptability of biomedically recommended malaria treatment, paying particular attention to the match between providers' and clients' understanding of convulsions in children under the age of five. The assumption is that the understandings of the clients, or more precisely of the sick children's caregivers, manifest themselves in their recognition of symptoms, interpretation of causes and health seeking behaviour. The better the reported

symptoms, causes and treatment seeking correspond to the biomedical guidelines, the closer the match and the higher the social acceptability of the biomedically recommended treatment for severe malaria.

6.3 Methods

Study area

The study was conducted in the Kilombero Valley in south-eastern Tanzania, a rural area with villages lined up along the borders of a flood plain formed by the Kilombero River. Most villagers rely on agriculture for their livelihood and grow rice, maize and cassava as main crops. The main administrative and commercial centre is Ifakara, a bustling town with a population of about 59,497 in 2010 (pers. comm. Kilombero District Planning Officer). The malaria transmission was perennial and intense in the nineties (Smith et al., 1993), but there is evidence of a decline in recent years (Russell et al., 2010).

The study was confined to the twenty-five villages covered by the Kilombero and Ulanga Health Demographic Surveillance System (HDSS) with a total population of about 74,000 in 2004 and over 92,000 in 2008 (Alba, 2010). The area is covered by 13 public and private health facilities (11 dispensaries and 2 health centres) with 55 and 135 ADDOs in Ulanga and Kilombero districts respectively (Alba et al., 2010b).

Study design

The study combined classic ethnography with cultural epidemiology as defined by Weiss (1997; 2001). The aim was to investigate the social acceptability of anti-malarials with a focus on the understanding convulsions from the perspective of the caregivers of under-five-year-old children. To capture potential changes in the course of the ACCESS program, two rounds of interviews were carried out:1) from November 2004 to March 2006 (Dillip et al., 2009) and 2) from September 2007 to November 2008. This paper compares the findings of both sub-studies and examines them with reference to the

ACCESS framework (Obrist et al., 2007). Earlier studies on convulsion in the study area were also examined to explore changes in treatment seeking for convulsion.

In each sub-study, a semi-structured interview guide called Explanatory Model Interview Catalogue - EMIC (Weiss, 1997; Weiss, 2001) was administered to caretakers two to four weeks after a HDSS field worker had identified and reported the convulsion episode. The study followed the same sampling approach as for the previous study (Dillip et al., 2009) where a total of 88 convulsion cases were continuously extracted from the HDSS records for the period of 15 months and followed up by trained ACCESS field staff who conducted the EMIC interviews in KiSwahili. They only interviewed caretakers whose children had recovered from convulsion episodes; if a child was still ill, they advised the caretaker to seek treatment from a health facility. The first author conducted a quality check for the EMIC; she revisited 15% of all households to assess the validity of the responses and all responses corresponded what had been earlier collected by the field staff. Households were geo-located and the information was linked with the data from a previous study (Alba et al., 2010b) in order to calculate average distances from households to health facilities and from households to ADDOs.

Data entry and analysis

STATA 10.0 was used to analyze quantitative information while MaxQDA was applied for content analysis of illness narratives from the EMIC. The analysis followed the plan for the first convulsion study (Dillip et al., 2009) with exception that the current study concentrated on only convulsion cases and not mild malaria. Differences in proportion between the 2004/06 and 2007/08 studies were compared using the two sample-binomial tests for proportions. Three outcome variables were defined to include 1) ‘Timely health facility use’ (HF use) 2) ‘Timely health facility and anti-malarial use’ (HF AM) and ‘Timely anti-malarial not from health facility’ (AM not HF). Multivariate logistic regression model was applied for the correlation of covariates with outcome variables. Distance calculations were carried out with ArcMap Version 9.1(ESRI Inc).

Ethical Review

This paper was published with the permission of Dr. Mwele Malecela, Director General, National Institute for Medical Research. Ethical Clearance of the ACCESS Programme

proposal was granted by the National Institute for Medical Research of the United Republic of Tanzania (NIMR/HQ/R.8a/Vol.IX/236, September 16, 2003)

6.4 Results

Sample characteristics

During the second round of interviews, we found fewer cases of *degedege* (88 in 2007/08 as compared to 135 in 2004/06) although the seasonal coverage and the duration were nearly the same (17 and 15 months, respectively). The samples include 6 and 5 children from the fever studies (Hetzel et al., 2008c, Alba et al., 2010b) respectively in the 2004/6 and 2007/8 studies, whose illness had been identified as *degedege* by their caretakers. The samples were similar in terms of demographic characteristics (see Table 11): most of the interviewed caregivers were the mother of the sick child, married and depended on agriculture for their livelihood. However, there was a significant increase in households reporting uncertain or irregular income from 58/135 (43% 95%CI= 34% to 51%) in 2004/06 to 64//88 (73% 95%CI= 63% to 82%) in 2007/08 ($p<0.001$). More caretakers stayed in the village at the onset of the illness (83/88 94% 95%CI= 89% to 98%) in 2007/08 compared to 2004/06 (107/135 79% 95%CI=72% to 85%). In the second round of interviews, the average distance from the home to a health facility was 3.7 kilometers and 1.5 kilometers to a drug shop.

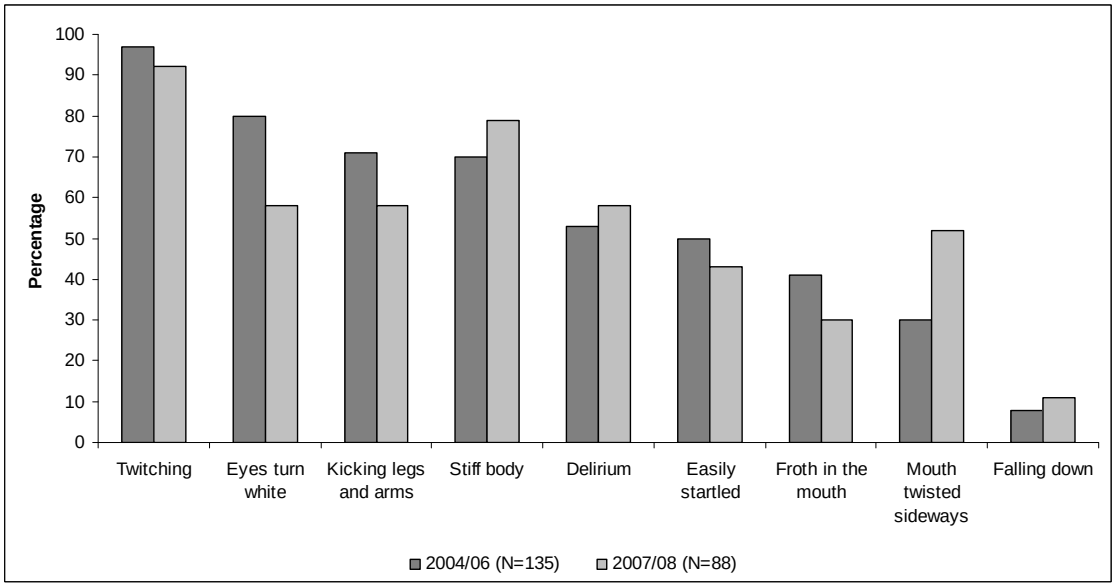
Table 11 Similarities and differences in the two study samples

	First study 2004/06 N=135*	Second study 2007/08 N=88*
	n (%)	n (%)
Relationship to the Child:		
Mother	116 (85.9%)	72 (81.8%)
Father	14 (10.4%)	10 (11.4%)
Grandmother	1.0 (0.7%)	4(4.5%)
Other	4.0 (3.0%)	2 (2.3%)
Marital status:		
Never married	13 (9.6%)	6 (6.8%)
Married	112 (83%)	72 (82.0%)
Separated, divorced	8 (5.9%)	5 (5.6%)
Widowed	1(0.7%)	4(4.5%)
Not specified	1(0.8%)	1(1.1%)
Income:		
regular and dependable	54 (40.0%)	21(24%)
Possibly	23 (17%)	3(3.4%)
Uncertain/irregular	58(43.0%)	64(72.6%)
Occupation:		
Farmer	128(94.8%)	85(96.7%)
Trade/Business	5(3.7%)	1(1.1%)
Laborer	2(1.5%)	1 (1.1%)
Teacher	0(0.0%)	1(1.1%)
Location at time of Illness recognition:		
Main village of residence	107(79.3%)	83(94.2%)
Temporary shelter in rice field *(shamba)*	28(20.7%)	5(5.8%)

Degedege symptoms

The experience of convulsions articulated in terms of five lead symptoms were nearly the same in both studies: "twitching" *(kustuka),* "eyes turn white" *(macho yanakuwa meupe),* "kicking of legs and arms" *(kurusha mikono na miguu),* "stiff body" *(mwili kukakamaa)* and "delirium" *(kuweweseka)* (see Figure 14).

Figure 14 Reported symptoms



Note: Multiple answers were possible.

The illness narratives showed that the percentage of caregivers who associated *degedege* with severe malaria was already high in the 2004/2006 study and rose, although not significantly, from 92/135 (68% 95CI=60% to 76%) in 2004/2006 to 66/88 (75%, 95CI= 66% to 84%) in 2007/2008 (p=0.261) (not shown in Table). Most caregivers (86/135 64% 95%=CI 55% to 72%) in 2004/06 and in 2007/08 (53/88 60% 95%CI=50% to 70%) reported that the *degedege* episode started all of a sudden, without prior symptoms of an illness. As two women reported:

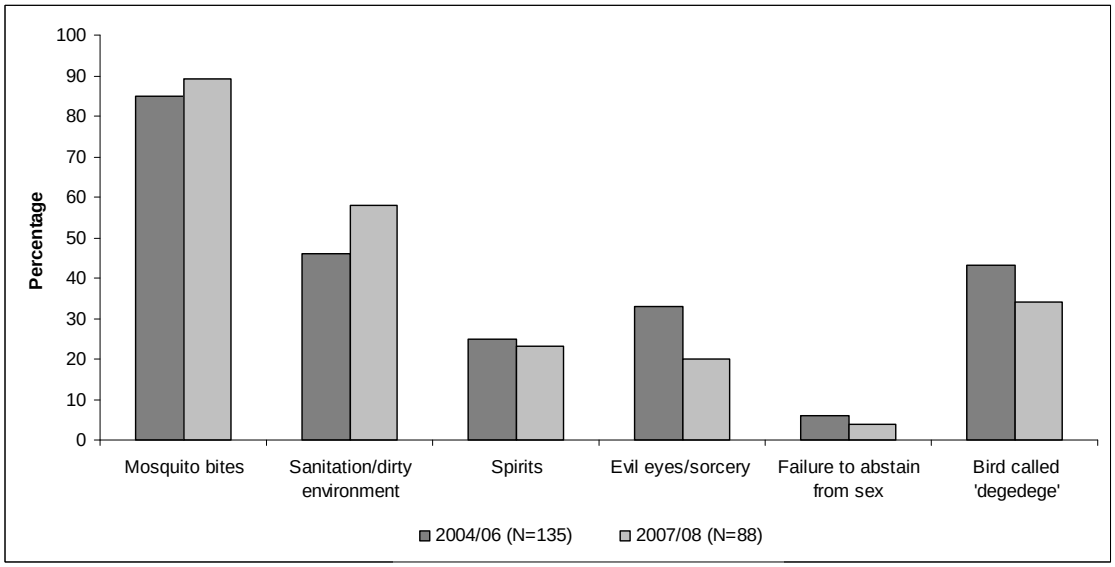
> "I woke up at 2 a.m. to find my child kicking her legs and arms. She had also high fever, and she was twitching" (mother aged 28 from Mbingu village, 2004/06).

"In the morning suddenly my child's body was very hot. He started stretching his legs and arms, froth started coming out his mouth, his eyes were rolling. I carried him and rushed to the health facility" (mother aged 24 from Iragua village, 2007/08).

Perceived causes

Already in the first interview round, the percentage of caregivers who mentioned mosquito bites as a cause of *degedege* was high (115/135 85% 95CI=79% to 91%); and the percentage has further increased though not significantly (78/88 89% 95CI=84% to 96%) in 2007/2008 (p=0.27) (Figure 15).

Figure 15 Perceived causes



Note: Multiple answers were possible.

A slightly higher but insignificant percentage of study participants saw a causal link between "sanitation/dirty environment" and convulsions (62/135 46% 95% CI 37% to 54%) in 2004/06 compared to 2007/08 (51/88 58% 95% CI 48% to 68%) (p=0.07). The qualitative data show that people consider toilets as well as grass, bushes and water pools around the house as breeding sites for mosquitoes causing *degedege*.

"People are not used to keep the environment around houses clean. You see now, the grass around the houses is not cleared and there are many water pools. This attracts mosquitoes to breed" (mother aged 28 from Iragua village, 2007/08).

At the same time, we see a small but consistent decrease in the percentage of "traditional" understandings of causes which have often been associated with *degedege,* such as the 'insect *degedege*' from 58/135 (43% 95%CI=35% to 51%) to 30/88 (34% 95%CI =24% to 44%) (p=0.18) "evil eye and sorcery" *(macho mabaya na uchawi)* from 45/135 (33% 95%CI=25% to 40%) to 18/88 (20% 95%CI=11% to 28%) (p=0.03), "spirits" (*mapepo)* from 34/135 (25% 95%CI=17% to 32%) to 20/88 (23% 95%CI=14% to 32%) (p=0.73), or "failure to abstain from sex" (*mzazi kushindwa kuacha vitendo vya ngono)* from 8/135 (6 % 95%CI= 1% to 10%) to 4/88 (4% 95%CI =<0.1% to 8%) (p=0.51).

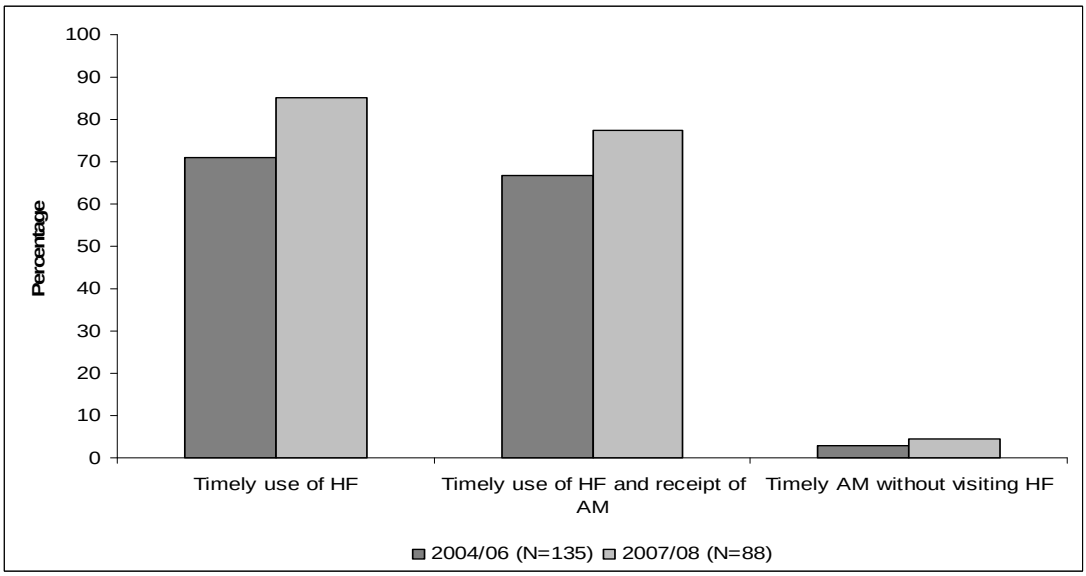
These findings match with a significant increase in caregivers' awareness (not shown in the table) that convulsions can be prevented with insecticide treated bed nets from 46/135 (34% 95%CI=26% to 41%) in 2004/06 to 70/88 (80% 95%CI=71% to 88%) (p<0.001) in 2007/08 and environmental measures from 40/135 (30% 95%CI=22% to 37%) in 2004/06 to 53/88 (60% 95%CI=49% to 70%) (p<0.001) in 2007/08.

> "Yes…to be honest majority of villagers now know that mosquito treated nets can prevent them from malaria and convulsion, we now have bed nets that have been treated for so many years and at least we can prevent ourselves from malaria" (mother aged 24 from Igota village, 2007/08).

Treatment seeking

In the second round of interviews, more caregivers brought children with convulsions to a health facility (see Figure 16) within 48 hours from the onset of symptoms 75/88 (85% 95%CI=77% to 92%) compared to 96/135 (71% 95%CI=63% to 78%) (p=0.02) in 2004/06. There was also an increase, although not significant, in the number of those children who received an anti-malarial 68/88 (77% 95%CI=68% to 85) compared to 90/135 (67% 95%CI=59% to 74%) (p=0.10) in 2004/2006. The percentage of caregivers who bought medicines from drug stores without prior visit to a health facility remained consistently low 4/135 (3% 95%CI= <0.1% to 5%) in 2004/06 and 4/88(4% 95%CI= <0.1% to 8%) (p=0.69) in 2007/08 even though ADDO provide anticonvulsive medicine.

Figure 16: Treatment seeking



Caregivers explained their choice of health facilities as follows:

> "Where else could I take my child for treatment? I carried her and went straight to the dispensary; this is where she could be treated" (mother aged 27 from Kivukoni village, 2007/08).

> "After he [the child] started twitching the legs, I knew it was degedege because his body was also very hot. What I did is to rush him to the health facility because there are professionals who could treat him" (mother aged 26 from Lupiro village, 2007/08).

Mothers evaluate the treatment of their children:

> "It started with high fever then twitching, I knew this was degedege, I rushed my child to the dispensary….I believed she would get proper treatment there….After a week the child was back to normal health" (mother aged 24 from Igota village, 2007/08)

> "Yes she got treatment at Lupiro health centre…we were admitted for four days, they also gave us some tablets to take home….after about six days Mkeli (the child) was healthy again" (mother aged 22 from Lupiro village, 2007/08)

Symptoms, causes and treatment outcome

We further examined whether reported symptoms and/or perceived causes predict treatment outcomes (Table 12). All covariates were adjusted for potential confounders (i.e. age, sex, socio-economic status, marital status, health facility availability in the village and occupation) and only significant associated variables are presented. With regards to the treatment outcome "timely health facility use", in the first round of interviews (Dillip et al., 2009) we found a significant association with the reported symptoms "hot abdomen" (Estimate=0.79) (p=0.02) and "difficult breathing" (Estimate 0.87) (p=0.04). However, neither these two nor any other reported symptoms turned out to be significantly correlated with "timely health facility" use in 2007/08. The main perceived cause which showed a significant correlation with "timely health facility use" in the first study (Estimate 1.54) (p<0.001) also did so in the second study (Estimate 1.43) (p=0.04): "sanitation/dirty environment". In the first study, the more "traditional" understanding of what causes convulsions such as "spirits" (Estimate-1.72) (p=0.03) and "a failure to abstain from sex" (Estimate -2.84) (p=0.03) tended to keep caregivers from prompt help seeking at the health facility. A similar association was not found in the second study.

The second treatment outcome, "timely health facility and anti-malarial use", was associated with the symptoms "no interest to play" (Estimate 2.52) (p<0.001) and "difficult breathing" (Estimate1.55) (p<0.001) in the first study. However, it was not associated with any symptom in the 2007/08 study. With regard to the perceived causes, one showed a significant association in the first study, namely "constitution/blood weakness" (Estimate 2.95) (p<0.001) while "sanitation/dirty environment" (Estimate 1.39) (p=0.03) did so in the second study. Only in 2004/06, caretakers who reported the 'bird *degedege'* as the cause for convulsion were less likely to use health facility timely and receive anti-malarials (Estimate -0.60) (p<0.001). Findings do not show any difference in treatment seeking patterns between caregivers who recognized the child's illness at home as compared to those who did so in their farms *(shamba)* (data not shown).

The percentages for the last treatment outcome, 'timely anti-malarial not from the health facility', were too low to be included into a more detailed analysis.

Table 12 Reported symptoms, causes and treatment outcomes for convulsion

	2004-2006						2007-2008					
Percentage of respondents who mentioned the outcome	HF Use[1] 71%		HF AM[2] 67%		AM not HF[3] 3%		HF Use 85%		HF AM 77%		AM not HF 5%	
	Estimate	p	Estimate	p	Estimate	p	Estimate	P	Estimate	p	Estimate	p
Reported Symptoms												
No interest to play	1.16	0.12	2.52	<0.001								
Hot abdomen	0.79	0.02	0.56	0.05								
Difficult breathing	0.87	0.04	1.55	<0.001								
Degedege symptoms[4]					−2.65	0.04					15.16	<0.001
Perceived Causes												
Constitution/blood weakness	3.03	0.01	2.95	<0.001								
Sanitation/dirty environment	1.54	<0.001					1.43	0.04	1.39	0.03		
Bird/insect called *degedege*			−0.60	<0.001								
Spirits	−1.72	0.03										

Note: Model fitness based on the likelihood ratio (all models with $p < 0.0001$)
1 Model outcome: health facility immediate use (HF use) (same day or next day)
2 Model outcome: health facility and anti-malarial immediate use (HF AM) (same day or next day)
3 Model outcome: anti-malarial immediate use not from the health facility (AM not HF) (same day or next day): the definition of this category differs from the definition used in Table 4 of the baseline study [12] because we regrouped this category to include only AM from the drug shop without prior visit to health facility
4 Grouped degedege symptoms include

Affordability and traditional medicine

The proportion of caregivers who delayed attending a health facility until the third day remained similar in 2007/08 with 9/88 (10% 95%CI= 3% to 16%) compared to 11/135 (8% 95%CI=3% to 12%) (p=0.61) in 2004/06, but the percentage of those who did not use a health facility at all dropped remarkably, from 28/135 (21% 95%CI=14% to 27%) in 2004/06 (these include 3% who received anti-malarials from another source) to 4/88 (5% 95%CI= <0.1% to 9%) (p<0.001) in 2007/08. A closer look at the illness narratives shows that affordability and/or acceptability dimensions of access played a role in delaying treatment:

> "We gave the child *manunganunga* medicine (traditional medicine) to decrease the speed of that mdudu degedege (the degedege insect), we sponged him with the medicine and also we gave him some medicine to drink. We could not go straight to the health facility as we did not have money. On the third day, we were able to reach the facility with cash" (mother aged 30 from Idete village, 2007/08).

> "When you take a convulsed child to a health facility and he receives an injection, he experiences a lot of pain. So we decided to sponge him with traditional medicine first to calm down the degedege and went to the hospital on the third day" (mother aged 21 from Iragua village, 2007/08).

> "I went to the traditional healer, this is where *degedege* is treated. The healer sponged the child with some medicine. Then the convulsions calmed down. He also used a piece of cloth filled with elephant dung and tied it around the child's wrist: We went home, and the child was healed. We didn't take her to the health facility" (mother aged 28 from Idete village, 2007/08).

> "We have been to the hospital more than three times for convulsions this year. I think their medicines are not working. This time, I chose to go straight to the traditional healer, and my child is doing fine now" (mother aged 18 from Idunda village, 2007/08).

The cases document that opting for traditional treatment is one thing, and the reasons for doing so is another: In the first case, the caregivers had to mobilize money before they could obtain health facility treatment for their child, in the second case, they first recurred to local treatment because they wanted to spare the child from a painful injection. The third mother did not see a reason to bring the children to the clinic because the symptoms disappeared after "traditional" treatment. The fourth mother decided based on previous experience that her child's convulsions could not be cured with biomedicine.

Gender and treatment decision making

In both interview rounds, most caregivers 131/135 (97% 95% CI= 94% to 99%) and 72/88(82% 95%CI= 74% to 90%), respectively, reported that they did not consult anyone for advice on where to take the child. They said they knew themselves what illness their child suffered 68/135(50% 95% CI= 41% to 58%) and 66/88(80% 95%CI= 71% to 88%). None of the mothers in either study mentioned that they had consulted the husband, and only few 7/135(5% 95CI= 1% to 8%) and 8/88(9% 95%CI=3% to 15%) (p=0.24) sought assistance from an elderly woman *(bibi).*

6.5 Discussion

Our findings demonstrate that the match between local and biomedical understandings of convulsions was already high in 2004/06 (Dillip et al., 2009) and we noticed significant changes in the second round of interviews (2007/08) specifically on; 1) increase in percentage for those who reported mosquito nets as measure to prevent convulsion, from 46/135 (34% 95%CI=26% to 41%) in 2004/06 to 70/88 (80% 95%CI=71% to 88%) ($p<0.001$) in 2007/08, 2) environmental measures from 40/135 (30% 95%CI=22% to 37%) in 2004/06 to 53/88 (60% 95%CI=49% to 70%) ($p<0.001$) in 2007/082), 3) decrease in percentage of caregivers who associated "evil eye and sorcery" *(macho mabaya na uchawi)* and convulsion from 45/135 (33% 95%CI=25% to 40%) to 18/88 (20% 95%CI=11% to 28%) ($p=0.03$), 4) a 14 percentage point increase in prompt use of a health facility for children with convulsion, 75/88 (85% 95%CI=77% to 92%) compared to 96/135 (71% 95%CI=63% to 78%) ($p=0.02$) in 2004/06 and 5) a 16 percentage point decrease for those who did not use health facility at all, from 28/135 (21% 95%CI=14% to 27%) in 2004/06 to 4/88 (5% 95%CI= <0.1% to 9%) ($p<0.001$) in 2007/08.

Clearly, a change in the social acceptability of malaria prevention and biomedical treatment of convulsions has occurred since the late 1990s, when medical anthropologists carried out the first studies in this same research area (Hausmann-Muela, 2010; Minja et al., 2005). At that time, the health facility was a second or third choice after convulsions were calmed down by locally known practices and/or after such treatment failed and the child's condition worsened. This change can to a large extent be attributed to the three initiatives which explicitly aimed at increasing the match between local and biomedical understanding and treatment of malaria: the KINET project (1996-2000), IMCI implementation (since 2002) and the ACCESS project (since 2004). All three initiatives took malaria-related values and understandings that existed in the society into account, and this is a major step towards improving the match between local and external knowledge (Minja et al., 2005). Even though a proper case control study was not carried out, it seems reasonable to associate the increased social acceptability which manifests itself in improved practices to such interventions. Higher percentages of caregivers' positive behaviour towards the understanding and treatment of convulsion that is already noticed in our first study (Dillip et al., 2009) is more likely to be the effect of the KINET and IMCI interventions as no other studies (apart from the ACCESS study

(Dillip et al., 2009)) were conducted in the area to explore changes in community understanding and treatment practices for convulsions after the two interventions were ended. Other studies provide additional evidence for the positive impact of social marketing and other communication campaigns on the social acceptability of malaria prevention and treatment in Tanzania and Africa, for instance with regard to IPTi interventions (Mushi et al., 2008) and home-based management of malaria (Elmardi et al., 2009; Nsungwa-Sabiiti 2007). Despite ADDOs being closer to their homes than health facilities, caregivers by-passed these outlets and sought treatment at health facilities. This finding is contrary to what has been reported from eastern Uganda where caregivers living within long distances to providers were more likely to delay seeking treatment (Rutebemberwa 2009). It should be noted that ADDO dispensers had received training on IMCI. In cases of severe malaria with convulsion, immediate referral to health facility is recommended. It is also likely that caregivers had received information on where to treat a seriously ill child through their prior experiences with ADDOs.

The increased social acceptability of biomedical malaria prevention and treatment may even have contributed to the decline of *degedege* incidences which was noted in the two interview rounds within the ACCESS program (from 131 in 2004/06 to 88 in 2007/08) and which has also been reported in the study area (Alba et al., 2011). This is consistent with other studies in the same area which have documented a sharp decrease in malaria transmission (Russell et al., 2010; Killeen et al., 2007). Interestingly, the findings presented here also indicate perceived efficacy of modern treatment for convulsion among caregivers.

While a number of studies in Africa have indicated consultations of respectable community members including old women for advice in cases of convulsion (Munthali, 2003; Beiersman et al., 2007), our study attested caregivers' independence in recognizing convulsion symptoms and seeking appropriate care. This is more surprising since the majority of caregivers in our samples were women whose autonomy in health decision making is commonly limited in African societies (Mwenesi et al., 1995a; Tanner et al., 1998; Comoro et al., 2003). Our findings may reflect the fact that biomedical malaria prevention and treatment has become socially acceptable, also for severe fever cases with convulsions, so that mothers do not need to ask for consultation or permission any more.

Most of the literature on malaria and convulsions in Tanzania and the studies reviewed by William and Jones (2004) did not explicit refer to the concept of acceptability. Our study suggests that the concept of social acceptability can help to link studies on local vs. biomedical understandings of illness with broader debates on access to prevention and treatment technologies and associated services. Further studies on social acceptability should also look at health practitioners and health policies and investigate whether they take local illness understandings into account. They should also explore further meanings of the concept of social acceptability, for instance questions concerning the match of ethics and morality in interactions between health workers and caregivers.

6.6 Conclusions

'Social acceptability' as an important access dimension to health care seems more relevant in studying illnesses that are perceived by communities as not belonging to the biomedical field i.e. convulsion, with this regard, the match between local and biomedical understandings of health problems is central in understanding the concept of acceptability and especially in trans-cultural societies. Study results indicate some positive changes in community understanding and treatment practices for childhood convulsion from the baseline study; however our findings can not be generalized because of the small sample size involved and the influence of long-term health intervention activities in the study area. To improve social acceptability of treatment, it is important to take up existing local words and treatment practices into interventions and involve communities at all levels of the interventions. Moreover the quality of care and efficacy of treatment on the supply side is of relevance to ensure community acceptability of health services.

Competing Interests

The Authors declare that they have no competing interest.

Authors' Contributions

AD was involved in the design and implementation of the study, field work, data management, analysis, interpretation and writing of the manuscript. AS, BO, CL, HM conceived the program and its components and provided technical support and supervision. MW was involved in the design and analysis of the EMIC. BO was involved in the conception and design of the study, data analysis, interpretation and writing of this paper. MH and SA were involved in the design and implementation of the studies and IM contributed to data collection and discussion of the findings. CM was responsible for the development and implementation of the interventions.

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7. Malaria treatment in the retail sector: Drug sellers' knowledge and practices in rural Tanzania

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7.1 Abstract

Background

Throughout Africa, the private retail sector has been recognised as an important source of antimalarial treatment, complementing formal health services. However, the quality of advice and treatment at private outlets is a widespread concern, especially with the introduction of artemisinin-based combination therapies (ACTs). As a result, ACTs are often deployed exclusively through public health facilities, potentially leading to poorer access among parts of the population. Documenting the performance of the retail sector is urgently required to improve and broaden delivery channels for life-saving drugs.

Methodology/Principal Findings

Using data from a shop census and an innovative mystery shoppers approach, we assessed knowledge and practice of shop keepers in private retail outlets in two rural Tanzanian districts. Shop keepers in drug store knew more about malaria and its treatment than their peers in general shops. In drug stores, 52% mentioned the correct child-dosage of sulphadoxine-pyrimethamine (SP) compared to only 3% in general shops. In drug stores, mystery shoppers were more likely to receive an appropriate treatment (OR=9.6), but at a higher price. Overall, adults were more often sold an antimalarial than children (OR=11.3). On the other hand, general shop keepers were often ready to refer especially children to a higher level if they felt unable to manage the case.

Conclusions/Significance

The quality of malaria case-management in the retail sector is not satisfactory. Drug stores should be supported and empowered to provide correct malaria-treatment with drugs they are allowed to dispense. At the same time, the role of general shops as first contact points for malaria patients needs to be re-considered. Interventions to improve availability of ACTs in the retail sector are urgently required within the given legal framework.

7.2 Background

Treatment-seeking behavior for malaria in sub-Saharan Africa is complex, often involving several steps and actors, depending on the local health system, society and culture (McCombie, 1996; Obrist et al., 2007). As a result of poor access to and often poor performance of formal health services, presumptive treatment of malaria episodes at home has become a widespread option (McCombie, 2002; Gyapong et al., 2007). The home-management of malaria (HMM) strategy of the WHO is promoting interventions to improve antimalarial drug use outside the formal health services as a complementary option to improve access to prompt and effective treatment at community level (WHO, 2005b).

In most places, the private retail sector has been identified as an important source of drugs close to people's homes (Foster, 1991; Snow, 1992; Goodman et al., 2004). However, patients obtaining drugs from private retailers may not receive an antimalarial drug, even if it would be appropriate (Kachur et al., 2006). If anti-malarials are dispensed, dosages are often inappropriate, especially for more complex dosage regimens (Slutsker et al., 1994; Abuya, et al., 2007). In order to improve community-wide effectiveness of antimalarial treatment, the popularity of home-management and the quality of treatment obtained from commercial shops need to be better addressed. Considerable improvement in case-management has been shown to be possible as a result of training private retailers in general shops (Marsh et al., 2004) and in drug stores (Mbwasi et al., 2005).

The retail sector for drugs in Tanzania includes two types of licensed drug stores as well as general shops. Fully-fledged pharmacies are allowed to sell all prescription medicines and need to be headed by a pharmacist. Yet in 2003, 60% of the 344 existing pharmacies were located in Dar es Salaam and the rest in other larger towns (Battersby et al., 2003). Part II drug stores *(Duka la Dawa Baridi)* need to be headed by a person with basic medical or health-related training and can be found also in larger villages. These shops are allowed to sell all over-the-counter (OTC) drugs (e.g. analgesics/antipyretics). In practice however, they dispense a much wider variety of medicines, including prescription-only antimalarials. In 2003, 5666 registered part II drug stores were operating in Tanzania (Battersby et al., 2003). General shops are not legally

allowed to sell prescription drugs. However, they often sell common OTC medicines, such as painkillers (Figure 17).

Figure 17: Part II drug store (left) and general shop (right) selling antimalarial treatment in rural Tanzania.

The studies presented here applied a mixed methods approach to compare factual knowledge with every-day practices of private drug retailers in treating cases of malaria in two Tanzanian districts. We included retailers in drug stores as well as general shops in order to get a comprehensive picture of the quality of treatment and advice that can be obtained from the private retail sector.

This research provides valuable information in the light of ongoing discussions on the distribution channels for highly efficacious antimalarial drugs, such as artemisinin-based combination therapies (ACT). The work was carried out within the frame of a project to improve access to prompt and effective malaria treatment in rural Tanzania (ACCESS Programme) (Hetzel et al., 2007).

7.3 Methods

Study setting

A systematic shop census and a complementary qualitative study using mystery shoppers were conducted in the districts of Kilombero and Ulanga, Morogoro Region, south-eastern Tanzania. The study area comprised the 25 villages of the local Demographic Surveillance System (DSS) (Armstrong Schellenberg et al., 2002) and the town of Ifakara, 20 km to the east of the DSS. The mid-2004 population of the DSS was 74,200 and Ifakara had a population of 45,726 in the 2001 population census (United Republic of Tanzania, 2003).

Malaria is highly endemic in the area, accounting for roughly half of all outpatient visits in rural health facilities. The study area is described in more detail elsewhere (Hetzel et al., 2007). Previous studies in the same setting found a range of easily accessible commercial outlets frequently selling drugs for fever episodes (Goodman et al., 2004). In 2004, 29 part 2 drug stores and 460 general shops stocking drugs were counted and chloroquine was found to be completely replaced on the market by sulphadoxine-pyrimethamine (SP) and amodiaquine (Hetzel et al., 2006).

At the time of the surveys, SP was the recommended first-line treatment for uncomplicated malaria; amodiaquine and quinine were second-line and third-line treatment, respectively. Quinine was the drug of choice for severe malaria (MOH, 2000). All anti-malarials were prescription-only medicines and could therefore legally be sold only in the one registered pharmacy located in Ifakara town. However, part II drug stores which were found in some villages were generally tolerated to stock and sell antimalarials. General shops were not allowed to stock any prescription drugs, which was reflected in the low availability of antimalarials reported elsewhere (Hetzel et al., 2006).

Shop census

Between May and June 2004, all commercial outlets in the DSS area and Ifakara town were visited in order to investigate the availability of antimalarial drugs in the retail sector. The detailed methodology of this census, as well as the results on drug

availability have been published elsewhere (Hetzel et al., 2006). This paper makes use of additional information on shopkeepers' knowledge of malaria and its treatment, collected during the same survey. During the shop-visits, the shop keepers were asked to mention signs and symptoms of malaria. Then, they were asked what the recommended treatment was for uncomplicated malaria in a two-year-old child and an adult. In addition, the interviewers recorded information on the estimated number of customers per day.

Mystery shoppers

The results of the census were complemented in September and October 2004 by "mystery shoppers", simulated clients who purchased drugs for predefined malaria case-scenarios.

From a preliminary list of outlets stocking drugs in 2004 (n=510), a sample of 111 general shops (approx. 20%) was chosen at random. The sample was drawn per village and weighed by village size. A back-up sample was drawn to compensate for shops that would be closed or could not be visited for other reasons. In addition, all 19 drug stores from the DSS area and 10 from Ifakara town were added to the sample.

Three case scenarios were randomly assigned to each shop:

(A) child aged 2-4 months, with fever/hot body for one day and problems with drinking/breastfeeding

(B) child aged 2-4 years, with recurring fever/hot body for 3 days (especially at night), problems with drinking and eating, diarrhoea and tiredness/not playing as usual

(C) adult, with recurring fever/hot body for 2 days, headache, dizziness and loss of appetite.

Symptoms for all scenarios did explicitly exclude signs of convulsions or unconsciousness. For the child-scenarios, the mystery shoppers would carry their children when visiting the shops, if at all possible.

Local DSS field staff identified suitable mystery shoppers from the villages in which the respective shops were located. On the day of the study, the mystery shoppers were explained the aim of the exercise and instructed by project staff. Mystery shoppers were asked to visit one selected shop and ask for treatment based on the aforementioned case-scenario. Each mystery shopper received 2,000 Tanzanian shilling (TSh) (US $1.80) to buy drugs. After completing their assignment, they were interviewed by project staff about what exactly happened when they visited the shops, what they had told the shop keeper, and what advice and drugs they were given. Interviews were tape-recorded and later transcribed. Drugs and remaining money were collected, types and amount of drugs recorded, and the mystery shoppers were paid a small fee for their collaboration.

Data entry and analysis

Generic and brand names (if possible), as well as amount and price of the drugs obtained by the mystery shoppers were entered in a Microsoft Access database (Microsoft Corp., Seattle, USA). Interviews with the mystery shoppers were entered with word processing software in an RTF file and imported into MAXQDA software VERBI GmbH, Marburg, Germany) for analysis. Statistical analysis was done with Intercooled Stata 9 (StataCorp, College Station, Texas, USA).

Ethics

While mystery shoppers were fully informed and asked for informed consent, the nature of this study did not allow informing the shopkeepers in advance and asking them for consent to participate. To protect shopkeepers' privacy, no names of staff were recorded and names of shops were never mentioned in connection with the study's results. For the shop census, informed consent was obtained from shopkeepers as described in detail in the aforementioned publication.

The shop survey and mystery shopper study were granted ethical clearance as part of the ACCESS Programme proposal by the institutional review board of the Ifakara Health

Research and Development Centre and the Tanzanian National Medical Research Coordinating Committee (NIMR/HQ/R.8a/Vol.IX/236).

7.4 Results

Shop census

The sample for this analysis included interviews with shopkeepers of 29 Part 2 drug stores *(Duka la Dawa Baridi)* and 460 general shops, all of which stocked drugs the day of the interview. General shopkeepers had on average a lower education than their peers in drug stores (7 vs.10 years, P<0.001). A shop keeper with medical or health-related qualifications was found in 93% of the drug stores and 1.5% of the general shops (P<0.001). Shopkeepers reported the number of customers buying drugs per day to be on average 19 (95% CI 14 to 24) in drug stores and 10 (9 to 11) in general shops (P<0.001).

Knowledge of malaria symptoms and treatment

Shopkeepers of drug stores most frequently mentioned fever, headache and vomiting (86.2% each) as symptoms of malaria (not specified whether in children or adults). In general shops, fever (60.4%), headache (40.2%) and joint pains (38.9%) were most frequently mentioned (Table 13). Generally, shopkeepers of general shops seemed to be significantly less aware of malaria symptoms. They mentioned all of the recorded symptoms less frequently than shopkeepers of drug stores. Out of 15 symptoms associated with malaria, shopkeepers in drug stores mentioned on average 4.8 (95% CI 4.1 to 5.5), while in general shops they mentioned only 2.4 (2.3 to 2.5) (P=0.005). If asked for “severe malaria” *(malaria kali),* a similar picture arose. The symptoms most often mentioned by general shop keepers were high fever (43.7%) and weakness (17.9%), while in drug stores, shop keepers most often mentioned high fever (79.3%) and convulsions *(degedege)* (51.7%) (Table 13).

Table 13: Malaria symptoms mentioned most frequently by shopkeepers (N=489)

symptom	Drug store % (95% CI)	General shop % (95% CI)	P*
N	29	460	
What are symptoms of malaria?			
Fever	86.2 (68.3-96.1)	60.4 (55.8-64.9)	0.006
Headache	86.2 (68.3-96.1)	40.2 (35.7-44.9)	0.000
Joint pains	62.1 (42.3-79.3)	38.9 (34.4-43.5)	0.014
Vomiting	86.2 (68.3-96.1)	32.5 (28.2-37.0)	<0.001
Malaise	31.0 (15.3-50.8	19.6 (16.1-23.5)	0.138
Feeling cold	17.2 (5.8-35.8)	16.3 13.0-20.0)	0.895
Poor appetite	20.7 (8.0-39.7)	9.8 (7.2-12.9)	0.063
Weakness	27.6 (12.7-47.2)	7.2 (5.0-10.0)	<0.001
Diarrhoea	27.6 (12.7-47.2)	5.9 (3.9-8.4)	<0.001
Dizziness	13.8 (3.9-31.7)	3.9 (2.3-6.1)	0.013
Don't know	0.0 (0.1-11.9)	11.5 (8.7-14.8)	0.053
What are symptoms of severe malaria?			
Changed behaviour	24.1 (10.3-43.5)	17.0 (13.7-20.7)	0.326
Unconsciousness / coma	17.2 (5.8-35.8)	7.4 (5.2-10.2)	0.059
Weakness	34.5 (17.9-54.3)	17.9 (14.5-21.7)	0.027
Anaemia	10.3 (2.2-27.4)	0.7 (0.1-1.9)	<0.001
Convulsions (*degedege*)	51.7 (32.5-70.6)	10.0 (7.4-13.1)	<0.001
Splenomegaly (*bandama*)	3.4 (0.1-17.8)	0.2 (0.0-1.2)	0.008
High fever	79.3 (60.3-92.0)	43.7 (39.1-38.4)	<0.001
Don't know	3.4 (0.1-17.8)	27.1 (23.1-31.5)	0.005

* Wilcoxon rank sign test

In drug stores, most shopkeepers knew that an antimalarial drug was the recommended treatment for malaria in a two year-old child (89.7%) and in an adult (93.1%). In general shops, shopkeepers most frequently said that the child should be referred to a health facility (34.3%) while adults should take an antimalarial drug (53.7%). Shopkeepers of drugs stores had significantly better knowledge of malaria treatment, as shown in Table 14. In drug stores, 65.5% mentioned SP as the recommended treatment for a child aged

2 years and 79.3% for an adult. In general shops this percentage was significantly lower. Of those who mentioned SP, 78.9% knew the correct child dose in drug stores and 26.8% in general shops (P<0.001). No shopkeeper mentioned traditional treatment, or that the episode should not be treated at all.

Table 14: Shopkeepers' understanding of the recommended treatment of uncomplicated malaria (N=489)

Treatment‡	Drug store % (95% CI)	General shop % (95% CI)	P*
N	29	460	
Child aged two years with uncomplicated malaria			
Referral to health facility	3.4 (0.1-17.8)	34.3 (30.0-38.9)	0.001
Antipyretic	55.2 (35.7-73.6)	30.9 (26.7-35.3)	0.007
Antimalarial	89.7 (72.6-97.8)	31.7 (27.5-36.2)	<0.001
- SP	65.5 (45.7-82.1)	12.2 (9.3-15.5)	<0.001
- SP + PCM	34.5 (17.9-54.3)	4.6 (2.8-6.9)	<0.001
- SP correct dose	51.7 (32.5-70.6)	3.3 (1.8-5.3)	<0.001
- SP correct dose + PCM	31.0 (15.3-50.8)	0.9 (0.2-2.2)	<0.001
Adult with uncomplicated malaria			
Referral to HF†	0 (0-11.9)	23.7 (19.9-27.9)	0.003
Antipyretic	55.2 (35.7-73.6)	43.9 (39.3-48.6)	0.237
Antimalarial	93.1 (77.2-99.2)	53.7 (49.0-58.3)	<0.001
- SP	79.3 (60.3-92.0)	35.0 (30.6-39.6)	<0.001
- SP + PCM	48.3 (29.4-67.5)	15.7 (12.5-19.3)	<0.001
- SP correct dose	75.9 (56.5-89.7)	28.9 (24.8-33.3)	<0.001
- SP correct dose + PCM	44.8 (26.4-64.3)	14.3 (11.3-17.9)	<0.001

SP = Sulphadoxine-pyrimethamine; PCM = Paracetamol

* Wilcoxon rank sign test

‡ Double-mentioning possible

† one-sided, 97.5% confidence interval

In a multivariate logistic regression analysis adjusted for shop type, number of customers and shop location, higher general education was a significant predictor of knowing SP as recommended treatment for adults (OR=1.15, 95% CI 1.02-1.30;

P=0.020). A health-related qualification was a strong predictor of knowing SP as a child treatment (OR=12.36, 2.45-62.20; P=0.002). Correctly dosed SP for adults – but not for children - was correlated with higher education (OR=1.15, 1.01-1.30; P=0.032) and a health-related qualification (OR=4.80, 1.08-21.34; P=0.039). Generally, there seemed to be better knowledge of the appropriate treatment among shopkeepers in Ulanga DSS villages, compared to Kilombero DSS and Ifakara town.

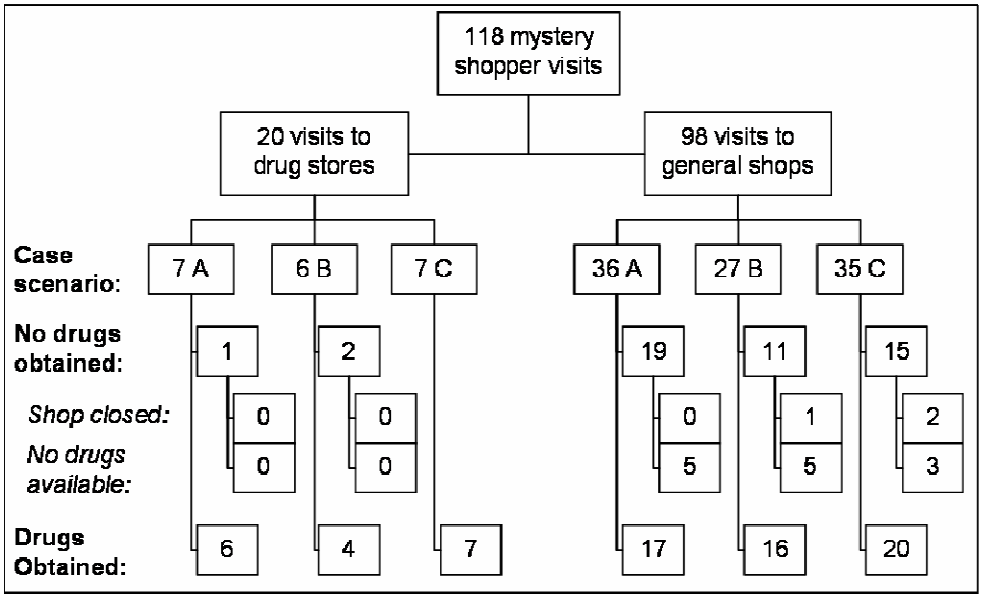
Referral

Shop keepers were asked for situations in which they would refer a customer to another outlet or a health facility. In drug stores, 19 or 65.5% of the shop keepers said they would refer customers if they showed signs of severe malaria, in general shops this was indicated by 259 or 56.3%. Of the general shop keepers, 56 or 12.6% said they would never refer somebody to another outlet or a health facility, while this was never mentioned by shop keepers of drug stores.

Mystery shoppers

A total of 20 Part 2 drug stores and 98 general shops were visited by mystery shoppers. General shops comprised all sorts of outlets, from permanent modern shops to temporary stalls. Case-scenarios were distributed as shown in Figure 18.

Figure 18: Flow-chart of mystery shoppers study. Refer to main text for details.



Case scenarios: A = child, aged 2-4 months; B = child, aged 2-4 years; C = adult.

Drug sale

Mystery shoppers obtained drugs in 53 (54.1%, 95% CI 62.1-96.8) general shops and 17 (85.0%, 43.7-64.2) drug stores (P=0.01) (Table 15).

Table 15: Number of shops that dispensed drugs to mystery shoppers

	Drug store	General shop	Total
Area	n (%)	n (%)	n (%)
Ulanga DSS	2/2 (100)	23/30 (76.7)	25/32 (78.1)
Kilombero DSS	10/10 (100)	20/44 (45.5)	30/54 (55.6)
Ifakara	5/8 (62.5)	10/24 (41.7)	15/32 (46.9)
Total	17/20 (85.0)	53/98 (54.1)	70/118 (59.3)

Out of the 17 **drug stores** that sold drugs, 88.2% (63.6 to 98.5) dispensed an antipyretic and the same percentage of 88.2% (63.6 to 98.5) an antimalarial (Table 15). SP, amodiaquine and quinine were sold six times each. Once, SP and quinine were sold

together. All drug stores sold SP together with paracetamol, as recommended in the national guidelines {MOH, 2000 222 /id}. Quinine was always, and amodiaquine in most cases sold together with paracetamol.

No anti-malarials other than SP, amodiaquine or quinine were dispensed. Two drug stores sold an antibiotic, together with amodiaquine or quinine + paracetamol. In the Kilombero DSS villages, Vitamin B was sometimes dispensed together with antimalarials.

Of the 53 **general shops**, 84.9% (72.4 to 93.3) sold an antipyretic, usually paracetamol and 18.9% (9.4 to 32.0) sold an antimalarial, either SP or amodiaquine. 3 out of 5 times, SP was dispensed together with paracetamol. 2 out of 4 times, amodiaquine and paracetamol were dispensed together. Twice, general shop sold an antibiotic (Table 16).

On average, drug shops sold more products per client than general shops, which often had only paracetamol on offer. Drug stores most frequently sold two products (to 44% of the mystery shoppers) (mean 2.9 products, 95% CI 2.0 to 3.8). General shops most often sold only one product (66% of the mystery shoppers) (mean 1.5 products, 1.2 to 1.8).

Table 16: Types of medicines sold to mystery shoppers

	Drug stores (N=17)	General shops (N=53)
Type of drugs	n (%)	n (%)
Antimalarials		
SP	6 (35.3)	5 (9.4)
Amodiaquine	6 (35.3)	4 (7.6)
Quinine	4 (23.5)	0
Any antimalarial	15 (88.2)	10 (18.9)
Antipyretics		
Paracetamol	14 (82.4)	39 (73.6)
Any antipyretic	15 (88.2)	45 (84.9)

Other drugs		
Antibiotic	2 (11.7)	2 (3.8)
Vitamin B complex	5 (29.4)	0
Combinations		
SP & paracetamol	6 (35.3)	3 (5.7)
Amodiaquine & paracetamol	4 (23.5)	2 (3.8)
Quinine & paracetamol	4 (23.5)	0
SP & quinine	1 (5.9)	0
Antimalarial & antibiotic	2 (11.7)	0

Predictors of drug sale

Univariate and multivariate models were fitted to assess factors related to obtaining an antimalarial and obtaining an antimalarial treatment according to Tanzanian guidelines.

Adjusted for the confounding effect of age group (i.e. case scenarios A, B, C, as described above), visits to a drug store resulted significantly more often in obtaining a drug than visits to a general shop (OR=6.02, 95% CI 1.57 to 23.10) and shopkeepers in the DSS were more likely to sell a drug than their counterparts in Ifakara (OR=2.53, 1.04 to 6.18).

In drug stores, mystery shoppers were significantly more likely to receive an antimalarial (OR=76.47, 13.07 to 447.50) (Table 17). Adults were more likely to be sold an antimalarial compared with infants (OR=9.30, 1.70 to 50.92) and compared with the two child scenarios (OR=11.27, 2.36 to 53.81) (not in table). There was no significant difference in this outcome between shops located in the villages or in Ifakara town.

In order to assess whether the observed difference in antimalarial dispensing was due to a lower availability of drugs in general shops, the same analysis was carried out only with shops that had dispensed any drugs at all. It resulted that drug stores were again more likely to dispense an antimalarial than general shops (OR=70.71, 9.38 to 533.10). If a drug was sold, mystery shoppers were in both types of shops equally likely to receive an antipyretic drug.

Table 17: Univariate and multivariate logistic regression analysis of the relationship between (any) antimalarial drug obtained and selected predictors (all visited shops)

Predictor	n	Univariate model		Multivariate model	
		Odds Ratio (95% CI)	P*	Odds Ratio (95% CI)	P*
Case scenario					
- Child 2-4 months	43	1		1	
- Child 1-4 years	33	0.85 (0.22-3.30)	0.815	0.62 (0.09-4.00)	0.612
- Adult	42	3.43 (1.18-9.98)	0.024	9.30 (1.70-50.92)	0.010
Shop type					
- General shop	98	1		1	
- Drug store	20	26.40 (7.91-88.10)	<0.001	76.47 (13.07-447.50)	<0.001
Location					
- Ifakara	32	1		1	
- DSS	86	0.95 (0.35-2.53)	0.911	1.65 (0.41-6.66)	0.480

* Wald test of significance of effect

Adjusted for the same confounders as listed in Table 17, mystery shoppers visiting a drug store were more likely to receive the recommended first-line antimalarial SP (OR=9.62; 1.53 to 60.53) or even SP together with paracetamol (OR=16.40; 2.28 to 117.99) than those who went to a general shop.

Again, the same analysis was carried out only for those shops that had dispensed an antimalarial. In this case, drug stores did not dispense SP (or SP with paracetamol) more often than general shops.

Price

In drug stores, mystery shoppers paid a median price of TSh 1000 or US $0.90 (interquartile range [IQR] 0.50-1.53) for drugs, while in general shops they spent only TSh 140 or US $0.13 (IQR 0.09-0.29, equality-of-medians test P<0.001).

Table 18: Linear regression model of predictors of higher expenditures for antimalarial drugs

		Univariate model		Multivariate model	
Risk factors	n	Estimated effect (95% CI)	P*	Estimated effect (95% CI)	P*
Case scenario					
- Child 2-4 months	20	1		1	
- Child 1-4 years	22	-0.12 (-0.42 to 0.18)	0.423	-0.16 (-0.37 to 0.05)	0.124
- Adult	26	-0.15 (-0.44 to 0.13)	0.285	-0.25 (-0.45 to -0.06)	0.012
Number of products	68	0.19 (0.11 to 0.27)	<0.001	0.12 (0.05 to 0.19)	0.001
Shop type					
- General shop	50	1		1	
- Drug store	18	0.75 (0.56 to 0.95)	<0.001	0.59 (0.38 to 0.80)	<0.001
Location					
- Ifakara	15	1		1	
- DSS	53	-0.11 (-0.39 to 0.17)	0.434	-0.06 (-0.24 to 0.13)	0.548

*Wald test of significance of effect

In a multivariate linear regression model we assessed the effect of the age group (case scenario A, B, C), the number of products sold, the shop type and the location (Ifakara vs. DSS) on the price charged to the mystery shoppers. Significantly less (-25%) money was spent for adult cases (case scenario C) compared to children aged 2-4 months

(case scenario A) (P=0.012) and 59% more in drug stores than in general shops (P<0.001). Obviously, more money was spent if more drugs were sold (12% more per additional product; P=0.001) (Table 18).

Dosage and advice

The accuracy of the dosages was judged from the amount of drugs the mystery shoppers obtained and from their accounts of the advice they were given by the shopkeepers.

10/11 (90.9%) SP doses were tablets, one was a suspension. 4/10 (40.0%) amodiaquine doses were tablets and 6 were suspensions. Quinine was sold 2/4 (50%) times as tablets, and twice as syrup.

10/11 (90.9%) SP dosages (incl. the suspension) and 4/10 (40%) amodiaquine dosages (2 tablets, 2 suspensions) were correct, considering the amount sold and the advice given. For two amodiaquine doses, no dosage information was available. Quinine tablets and syrup doses were all wrongly dosed. With the low number of samples no relevant comparison could be made between the appropriateness of the dosages and the shop types. Yet it should be noted that in general stores, all SP dosages tablet were correct, while in the drug stores, 1/6 was under-dosed (adult case). On the other hand, all amodiaquine dosages which were sold in drug stores (and for which the dosage information was available) were correct while those sold in general shops were under-dosed.

3 (15.0%) drug stores and 29 (29.6%) general shops did not sell any drugs to the mystery shoppers although they would have had drugs in stock (Figure 17). In all of these drug stores the mystery shoppers were advised to seek treatment or advice from a health facility. In the general shops, 86.2% (25/29) of the shopkeepers referred the mystery shoppers to a higher level: 62.1% (18/29) to a health facility and 31.0% (9/29) to a drug store (some of them to both).

7.5 Discussion

The private retail sector plays a central role in the provision of malaria treatment in Tanzania. In rural areas, 68% of the population live within 5km of a health centre or a dispensary (98% in urban areas) (United Republic of Tanzania, 2005). Yet, poor quality of care, shortage of skilled providers, stock-outs of essential drugs, and long waiting times (Mamdani et al., 2004; Dillip, 2007) are challenges which may drive patients to seek care (or at least buy drugs) from more expensive private or mission facilities, or from drug stores. The private retail sector can complement health facility services where the facilities are unable to deliver (Hetzel et al., 2007).

In the studies presented here, drug stores reported to have significantly more customers for drugs than general shops, reflecting the relative importance of these types of outlets in the provision of antimalarial medicines. In an earlier study, general shops have been described as being important treatment sources for fever/malaria, with 29% of fever cases using this source of treatment. Yet, in terms of drug volumes, general shops accounted for only 6-7% of all antimalarial doses dispensed in the two study districts (Goodman, 2004).

General shops are important first contact points of patients with a network of treatment providers. They are numerous even in small villages and often more easily accessible than drug stores or health facilities (Hetzel et al., 2006). While general shops are not legally allowed to dispense antimalarial drugs, they are recognised in the national policy as one component of the health care delivery structure (MOH, 2000; MOH, 2002). Providers in general shops are generally less knowledgeable about malaria and its appropriate treatment, supporting the ban of antimalarial drugs from these outlets. Surprisingly, only 60% of general shopkeepers mentioned *homa* (fever) as a symptom of malaria. In part, this may be explained by the parallel use of *homa* as a term to describe a less severe febrile illness or general malaise (Winch et al., 1996; Hausmann Muela, 2000). Knowing the correct treatment was clearly a function of the shopkeeper's education, which in general shops was lower than in drug stores. Only 3.3% of the shop keepers in general shops were able to mention the correct SP dosage for children and

28.9% for adults. However, they did not seem to be completely unaware of their limitations, as 34.3% of the general shop keepers mentioned referral to a health facility as the correct action for a 2 year-old child with malaria.

Drug stores on the other hand are the lowest level of providers which is generally tolerated to dispense prescription-only antimalarial drugs. Unfortunately, they often do not reach out into small villages or remote areas (Hetzel et al., 2006). Shop keepers in drug stores were more knowledgeable about malaria-related symptoms and malaria treatment than their counterparts in general shops. Knowledge of antimalarial treatment was strongly correlated with basic medical or health-related training, a prerequisite for shop keepers of licensed part II drug stores (United Republic of Tanzania, 2003). Yet, their performance was still not very satisfactory, with only 51.7% mentioning SP in the correct dosage as recommended treatment for children.

Knowledge vs. practice

In order to get a realistic picture of drug-sellers' performance, we used mystery shoppers; an approach which is innovative and has been used in only few occasions in African private sector settings (Tavrow et al., 2003; Nyazema et al., 2007). The main challenge of applying this methodology in a rural setting, which is to find un-suspicious and capable mystery shoppers within a certain village, was tackled with the help of knowledgeable village-based DSS field staff.

Daily shopkeepers' practices clearly reflected their level of understanding of appropriate treatment, the current drug regulations, as well as the low antimalarial availability in general shops (Hetzel et al., 2006). Antipyretics were frequently sold in drug stores and general shops. Most drug stores (88.2%) also sold antimalarials to the mystery shoppers, usually in combination with paracetamol. In contrast, during a study conducted elsewhere in Tanzania in which shop keepers were under observation, only 17.1% of febrile patients had received an antimalarial (Kachur, 2006). In general shops, 18.9% of the mystery shoppers were sold an antimalarial. This was slightly more than would have been expected based on the shop census in which 8% of all general shops that had drugs in stock also stocked an antimalarial (Hetzel et al., 2006).

While many shop keepers in drug stores knew that SP was the recommended treatment for children and adults, in practise, amodiaquine and quinine were sold as often as SP. This may to some extent reflect that amodiaquine was slightly more readily available in drug stores and, according to anecdotal evidence, quinine was popular as it was often regarded a strong and powerful medicine (Hetzel et al., 2006). Overall, it was more likely that a mystery shopper received an antimalarial or even SP in a drug store. However, drug stores did not adhere better to the guidelines than general shops. This may in part be attributed to the fact that in general shops there were fewer different antimalarial products available and therefore less opportunity to diverge from the first-line regimen. Mere non-availability may also be a reason why no other antimalarials than SP, amodiaquine and quinine were sold, along with the fact that with the cash provided by the researchers, the mystery shoppers would not have been able to purchase expensive drugs such as artemisinin mono therapies or ACT (Kachur, 2006).

Altogether, adults would more readily be dispensed an antimalarial than children. This is interesting in the light of findings from a cross-sectional community-survey in which adults would be treated more frequently with shop bought drugs while children were more often brought to a health facility (Hetzel et al., 2007). This may give some indications of provider-side influences on treatment-seeking behaviour.

Treatments for adults were 25% cheaper than treatments obtained for very young children and drug stores were more expensive than general shops. The latter was also found in another study in the same area, where more expensive treatments were obtained from non-governmental organisation (NGO) facilities and drug stores, usually by people from the better-off socio-economic stratum (Njau et al., 2006).

Private retailers may commonly be perceived as being mainly business-driven in their behaviour. In this study we found that in theory, more than half of all shop keepers said they would refer severely ill patients and general shopkeepers commonly regarded referral as best option for young children. In practice, 15% (3/20) of drug stores and 30.5% (25/82) of general shops did not sell any medicines but referred the simulated patients to a higher level of care – although they would have had drugs in their shops. The awareness of shopkeepers that certain cases need to be dealt with at a higher level may be a good entry point for interventions targeted at the retailer level. Several projects targeting private drug retailers, have already counted on the ability and willingness of

shopkeepers to refer severe or complicated cases to an appropriate facility (Mbwasi et al., 2005; Marsh et al., 1999).

Implications for policy and interventions

The importance of the retail sector as a source of malaria treatment and care complementary to health facility has been recognised internationally (TDR/WHO, 2006) and within Tanzania (MOH, 2002). However, the major concern regarding the private sector has been inadequacy of the treatments offered by often untrained (or not sufficiently trained) shopkeepers (Marsh et al., 1999; McCombie, 2002; Brugha et al., 1999). This issue has re-emerged in the discussions about appropriate delivery channels for ACTs. Defining the role of each type of retailer present in a health system within the frame of their capabilities and the given legal context is an important first step in improving quality and access.

Fully-fledged pharmacies only reach 17% of the Tanzanian population and are hence not sufficient to meet the demand for essential drugs (Ndomondo-Sigonda at al., 2005). Part II drug stores which are the largest network of licensed drug-retailers in Tanzania (Battersby et al., 2003) are licensed to sell only OTC drugs, to which none of the recommended antimalarials belongs. Kachur et al. (2006) showed that patients at drug stores are as likely to be infected with malaria as patients seeking care at health facilities. Considering this demand for antimalarial treatments, there is a need to make efficacious antimalarial drugs available in drug stores. In reality this is usually tolerated by the authorities who recognise the lack of alternatives. In order to improve the quality of services in drug stores, specialised training for drug vendors may be a valid option for improving management of malaria-cases, as has been shown in other areas (Marsh et al., 2004). The mere definition of educational prerequisites as currently the case for Part II shops may only lure health workers away from health facilities to a more profitable business in the retail sector. Yet, training alone is unlikely to improve performance if not coupled with appropriate means of rewarding the shopkeepers for good practices (Brugha et al., 1998; Brugha et al., 1999). These approaches are combined in a project that upgrades Part II shops to Accredited Drug Dispensing Outlets (ADDO) and that is currently being implemented in selected districts in Tanzania (Ndomondo-Sigonda et al, 2005; Mbwasi, 2005).

The role of general shops should not be the dispensing of prescription medicines. Yet, due to their importance as easily accessible first contact point for malaria patients, they should not be completely left aside when targeting the private sector. There are several options to strengthen their role in the health sector. Firstly, they could be upgraded to drug retailers (e.g. ADDOs) if appropriately trained, thereby increasing the population coverage with antimalarial providers. Secondly, general shop keepers could be trained on the appropriate first aid for malaria cases with OTC medicines and subsequent referral to a higher level. Considering that general shops may manage malaria cases only with antipyretics, particularly in places where they are the nearest provider, targeted information or training may decrease the number of inappropriately managed cases at the lowest level. The social pressure exerted on shopkeepers by communities' expectations on their performance should not be under-estimated. In our study, a considerable number of shopkeepers did without business in favour of referring the patient to a drug store or a health facility.

Including all levels of formal and informal health care providers is feasible within the existing legal framework and guided by the national malaria control policy. Alternative approaches including lowest level shops may be a step forward in improving access for people living in remote areas or deprived villages which so far lack any provider of antimalarial medicines (Hetzel et al., 2006).

7.6 Conclusion

Private retailers play an important role in the provision of prompt and effective malaria treatment, complementing the services of formal health facilities. Yet, the quality of case-management in the retail sector leaves much room for improvement. Drug stores should be empowered and encouraged to provide correct malaria-treatment with drugs they are legally allowed to dispense. At the same time, the role of general shops as important first contact points for malaria patients needs to be re-considered within the given legal framework.

Interventions on shop-level should consider all types of private retailers. While antimalarial medicines, such as ACTs ought to be dispensed only by qualified personnel,

general shop keepers may acquire sufficient knowledge to properly recognise malaria cases and refer them to a trained provider.

Authors' contributions

MWH was responsible for all aspects of the shop census, contributed to the development of the mystery shoppers study, selected the sample, analysed the data together with AD and wrote the manuscript in collaboration with the other authors. JJM prepared the mystery shoppers research plan and data collection activities, and supervised the field-work. CL and BO conceived the research questions and contributed to the design of both studies and the discussion of the manuscript. AM and CM provided support during field-work and contributed to the discussion of the findings. AS and HM contributed to the research questions and the study design. All authors read and approved the final manuscript.

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Competing Interests

We declare that we have no competing interests.

8. Mystery shopping in community drug shops: Research as development in rural Tanzania

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8.1 Abstract

Background

Throughout Africa, the private sector plays an important role in malaria treatment complementing formal health services. However this sector is faced by a number of challenges including poor dispensing practices by unqualified staff. The Accredited Drug Dispensing Outlet (ADDO) program was introduced in Tanzania in 2002 to improve the quality of retail services and especially of dispensing practices. Using mystery shopping methodology, this study compares dispensers' practices before and after ADDO interventions. The aim is to assess changes in malaria case management in drug outlets.

Methods

Mystery shoppers were identified in the villages with the assistance of HDSS field staff. A total of 865 visits were made to general shops and drug shops between 2004 and 2009. Three case scenarios were developed to assess the quality of treatment; a) child aged 2-4 months, with fever/hot body for one day and problems with drinking/breastfeeding, b) child aged 2-4 years, with recurring fever/hot body for 3 days problems with drinking, eating, diarrhoea and tiredness/not playing as usual and c) adult, with recurring fever/hot body for 2 days, headache, dizziness and loss of appetite

Results

Study findings indicate improvements in dispensers' knowledge and practices in management of fever, especially after the roll out of ADDO program in the study area. A 30 percent increase was noted after ADDO interventions on four assessed indicators developed based on the national malaria control guideline on malaria case management. On the other hand advice on the use of Insecticide Treated Nets (ITNs) as a measure to prevent malaria was not consistent over years even after ADDO interventions. Children aged two to four years and adults were more likely to be provided with anti-malarials than children between two to four months. Despite challenges posed

against the methodology, findings reveals how useful the mystery shopping technique can be for community assessments of ADDO interventions in retail outlets.

Conclusion

Study findings signify the importance of ADDO interventions in improving malaria case management in drug retail outlets. If ADDOs are closely monitored and strengthened to provide appropriate malaria treatment and the program is rolled throughout the country, a reduction in malaria morbidity and mortality is possible in the country. Innovative community based participatory research approaches and more systematic mystery shopping techniques would allow for comparative community-based assessments of ADDO interventions across regions.

8.2 Background

The private sector has been widely recognized as an important source of malaria treatment in Africa, complementing formal health services (McCombie, 1996; Gyapong et al., 2007; Williams et al., 2004). In rural Tanzania 68% of the population live within 5km of a health centre or dispensary (United Republic of Tanzania, 2005). However poor quality of care, shortage of skilled labor, longer distances to formal care, stock outs of drugs and long waiting times are challenges which drive patients to seek care or purchase drugs from expensive private facilities or from drug shops (Hetzel et al., 2008b; Goodman et al., 2007a; Williams et al., 2004). A survey conducted in African countries revealed that despite an increase in malaria treatments offered through the formal health facilities, only 15% of children with fever were treated with artemisinin combination therapy (ACT) (WHO, 2009). To improve access to malaria treatment, the Home Management of Malaria strategy of the WHO advocates for private sector interventions to increase community access to malaria drugs and complement stock outs at public health facilities.

While the contribution of private sector is without doubt recognized as an important source of malaria treatment close to people's home (Hetzel et al., 2008b), retails outlets are faced by a number of challenges including poor dispensing practices by unqualified staff, inappropriate dosage offered to customers, stocking of unregistered and sub-standard drugs, inadequate drug storage and poor dosage information (Hongoro et al., 2000; Abuya et al., 2007; Goodman et al., 2007a; Goodman et al., 2007b; Roberts et al., 2011). In Tanzania, an assessment conducted under the Strategies to Improve Access to Medicine (SEAM) program revealed gaps in performance of drug retails outlets (Rutta et al., 2009). To improve the performance of drug stores, the Ministry of Health and Social Welfare (MOHSW) through the Tanzanian Food and Drug Authority (TFDA) and Management Sciences for Health (MSH) introduced the Accredited Drug Dispensing Outlet (ADDO) program in 2002, after a successful piloting in Ruvuma region. A main aim of the ADDO program was improving the quality of dispensing practices from technical and from consumer perspectives (Rutta et al., 2009). The modality of ADDO operation included transforming the existing Part II drug stores (allowed to sell non-prescription medicines only) to Accredited Drug Dispensing Outlets where drugs are to be dispensed by trained dispensers in premises that comply with defined standards

(Rutta et al., 2009). Dispensers were trained to listen carefully to the client's description of the signs and symptoms and advise him/her thoroughly, recommend and provide appropriate medicines, advise on the use of preventive tools like treated bed nets and seeking hospital care if no improvements were observed (Rutta et al., 2009). It was expected that by the year 2010 the program would be rolled out throughout the country (Alba et al., 2010a), a target which has not yet been reached.

Close supervision and monitoring of ADDO is of relevance to ensure that dispensers' ethics and established services are maintained after accreditation (Rutta et al., 2009). Due to limited capacity of TFDA and MSH to carry out supervision activities, the program opted for a decentralized approach where local government have been held responsible for routine inspections and report their findings to a District Drug Technical Advisory Committee and later to TFDA (Rutta et al., 2009; Roberts et al., 2011). However routine inspection through the ADDO Program was so far limited to inspection of shops activities including searching for unauthorized medicines, checking if referral books are filled and whether dispensers abide to work ethics. Various studies in neighboring countries have applied the mystery shopping methodology to learn about the actual dispensing practices of dispensers (Tavrow et al., 2003; Marsh et al., 2004; Nyazema et al., 2007). In Europe, the methodology has also been used to assess performance in community pharmacies. After a debate in the United Kingdom regarding the ethics of using mystery shopping methodology, standards were developed (Jesson, 2005) which should also be applied and possibly adapted if the method is to be used in Africa.

In Morogoro region, the ADDO program was introduced in 2006. Through the ACESS program, a mystery shopping study was conducted to assess the impact of ADDO training on dispensers' practices. ACCESS is a malaria intervention program that has been working in the two districts of Morogoro (Ulanga and Kilombero) with the aim of improving access to prompt and effective malaria treatment. Among the major interventions of the ACCESS program is to improve the performance of drug selling shops. Following this intention, a mystery shopping study was conducted in 2004 and 2005 to obtain a general understanding of shopkeepers' knowledge and dispensing practices (Hetzel et al., 2008b). When ACCESS learnt about the ADDO program, it advocated for launching the program in Morogoro region in 2006. It also promoted ADDOs through its social marketing program and agreed to assess the outcome of ADDO interventions through continued mystery shopping studies. The present study

therefore compares dispensers' practices before and after ADDO program as a means to assess the outcome ADDO interventions in terms of improving the performance of drug retail outlets in the two districts.

8.3 Methods

Study area

The study was conducted in two districts of southeastern Tanzania, namely Kilombero and Ulanga. The study districts form part of a large Health Demographic Surveillance System (HDSS). The main administrative and commercial centre is Ifakara, a bustling town with a population of about 59,497 in 2010 (pers. comm. Kilombero District planning officer). The area comprises of 13 public and private health facilities (11 dispensaries and 2 health centres) with 55 and 135 Accredited Drug Dispensing Outlets (ADDOs) in Ulanga and Kilombero districts respectively (Alba et al., 2010a).

Study design

The study was conducted within the framework of the ACCESS Program, a malaria intervention program aiming at improving access to prompt and effective malaria treatment in Kilombero and Ulanga districts. The program has three main areas of interventions (*community, health facility and drug outlet*). The monitoring and evaluation component carries out before-after design studies to assess the impact of the said interventions. A thorough description of the ACCESS program is found elsewhere (Hetzel et al., 2007).

A total of 865 general and drug shops were visited between 2004 an 2009. Because there are more general shops than drug shops, all drug shops in the area were purposively included in the study for each year. The choice of general shops included a 20 percent random sample of all shops every year depending on the size of the village.

Based on the list of common signs and symptoms for mild malaria from the National Malaria Control Program (MOH, 2003), three case scenarios were developed, each for one shop

Child aged 2-4 months, with fever/hot body for one day and problems with drinking/breastfeeding

Child aged 2-4 years, with recurring fever/hot body for 3 days (especially at night), problems with drinking, eating, diarrhoea and tiredness/not playing as usual

Adult, with recurring fever/hot body for 2 days, headache, dizziness and loss of appetite

Symptoms for all scenarios did explicitly exclude signs of convulsions or unconsciousness.

To ensure that mystery shoppers were not easily identified by dispensers, the HDSS field workers helped to identify and recruit local villagers. The ACCESS staff trained the villagers on what symptoms to report and asked them to purchase drugs if advised by the dispenser. For children cases, mystery shoppers were asked to carry their children with them to identified outlets. The average time used by mystery shoppers in each shop ranged between eight to fifteen minutes depending on the case scenario. Mystery shoppers then reported their experience with the dispensers to the ACCESS staff, using the list of questions that the program aimed at exploring. The reports were tape recorded for further analysis. Each mystery shopper received Tsh 2000 (US 1.60) as allowance for participating in the study.

Data Analysis

Recorded data were transcribed and entered in Microsoft Word software as Rich Text Format and imported in MAXQDA for data coding. Different themes were formed in MAXQDA with reference to the questions for analysis. Data were analysed on general basis and not linked to any specific shops.

Ethics

The nature of the study did not allow informing the drug dispensers and therefore no informed consent was obtained; oral informed consent was on the other hand obtained from the mystery shoppers. To protect the privacy of the dispensers, no dispenser's name was recorded, and results were not linked to any specific shops visited. Ethical Clearance of the ACCESS Program proposal was granted by the National Institute for Medical Research of the United Republic of Tanzania (NIMR/HQ/R.8a/Vol.IX/236, September 16, 2003)

8.4 Results

A total of 865 visits were made to both drug and general shops between 2004 and 2009. We purposively excluded general shops in our analysis, because 1) these shops are theoretically not allowed to sell anti-malarials and 2) only insignificant percentage of mystery clients obtained anti-malarials from general shops. Our analysis was therefore restricted to 264 outlets, these included part II drug shops, ADDOs and pharmacies.

No practical problems with regard to the identification of mystery shoppers were encountered during the visits perhaps because mystery shoppers were local villagers whom dispensers have daily contacts with. If a shop was found closed, a follow up was made for three days to confirm whether it was permanently closed or the owner/dispenser had other social problems leading to temporarily closure of the shop. The description of case scenarios is presented in Table 19.

Table 19 Drug shops visited between 2004 and 2009

	2004	2005	2006	2007	2008	2009
Shop visited	20	32	44	55	52	61
Case scenarios	7a[1] 6b[2] 7c[3]	8a 11b 13c	15a 14b 15c	17a 19b 19b	16a 17b 19c	19a 22b 20c
Shops provided anti-malarials	17 (85%)	19(59%)	32(73%)	41(75%)	42(81%)	57(93%)
Shops provided appropriate anti-malarial*	14(82%)	15(80%)	25(78%)	12(29%)	13(31%)	32(56%)
Dispensers recommended use of ITN	4(20%)	6 (19%)	10 (23%)	10 (18%)	6 (11.5%)	8 (13%)

[1] Child aged 2-4 months, with fever/hot body for one day and problems with drinking/breastfeeding.
[2] Child aged 2-4 years, with recurring fever/hot body for 3 days (especially at night), problems with drinking, eating, diarrhoea and tiredness/not playing as usual.
[3] Adult, with recurring fever/hot body for 2 days, headache, dizziness and loss of appetite
* Defined according to the country's guideline for treatment of mild malaria

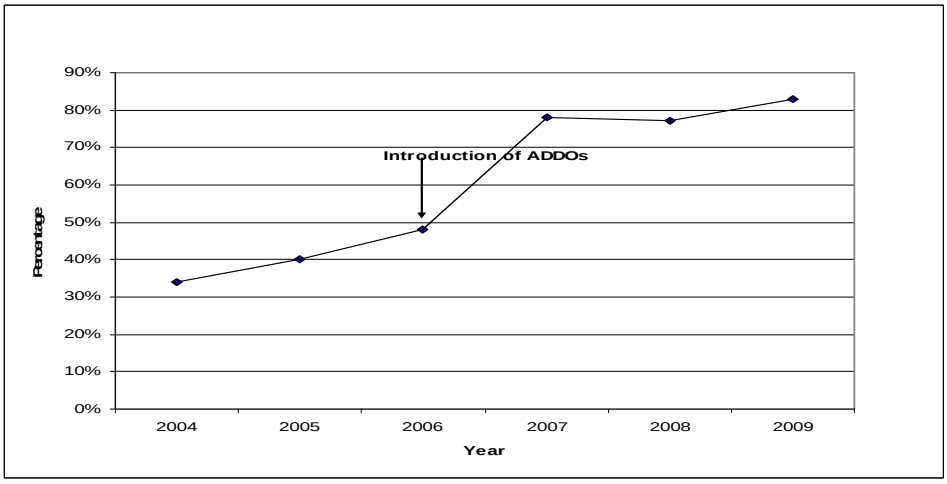
More than 50% of mystery shoppers received anti-malarials in drug shops each year (Table 19). However, at the end of 2006, after the switch of the first line anti-malarial from sulphadoxine-pyrimethamine (SP) to artemether-lumefantrine (ALu), there was a huge decrease in percentage of mystery customers who were provided with appropriate anti-malarials. This situation improved only slowly from 2007 to 2009 (Table 19). Of all three case scenarios, children aged two to four years and adults were more likely to be provided with anti-malarials than children between two to four months. For the latter, mothers were mostly advised to seek treatment at a health facility. Advice on the use of Insecticide Treated Nets (ITNs) was not consistent over years, and after the launch of ADDO in 2006, no huge changes were noted regarding the emphasis on the use of ITN as a measure to prevent malaria

Outcome of ADDO interventions

A central interest of the study was to compare the quality of dispensing practices by drug dispensers over the years and especially after the introduction of ADDOs in the study

area. Based on National Malaria Control guidelines and ADDO dispenser's training on Integrated Management of Childhood Illnesses (IMCI), four indicators were developed and used to measure the quality of dispensing and advice offered, these included i) if the shop attendant explains the side effects of the drug dispensed ii) explains the importance of consulting a medical doctor if symptoms persist iii) asks how much the child weighs before dispensing a drug and iv) asks if any anti-malarials was taken before visiting the shop.

Figure 19: Quality of treatment practices in drug selling shops



Since ADDOs are commonly the first stop for people with illness, IMCI guideline in ADDOs suggest that, dispensers need sufficient background knowledge to decide a rational course of action, determine whether it is within their capability and patient interest to treat the condition and recommend referral to healthy facility. The four indicators assessed contribute to effective management of fever at retail sector level. Figure 19 indicates that the percentage of customers who got correct advice and treatment based on the four indicators increased by 30% from 2006 to 2007 and remained high after the introduction of ADDOs in the study area.

8.5 Discussion

Our findings reveal improvements in dispensers' knowledge and practices in the management of fever, especially after the roll out of ADDO program in the study area. Moreover, the study indicates how useful the mystery shopping technique can be for a community-based assessment of ADDO interventions in retails outlets. Our findings correspond to those of other studies (Tavrow et al 2003, Marsh et al, 2004) which used the same technique to explore the quality of treatment practices in drug selling shops before and after specific interventions.

The decrease in percentage of mystery customers who received appropriate anti-malarials between 2007 and 2009 was attributed to the change of treatment policy from SP to ALu which led to severe ALu stock-outs in drug shops. Our findings correspond with the shop survey conducted in the same area which revealed stock outs of ALu in drug selling shops between 2006 to 2008 (Alba et al., 2010a). As a result of ALu stock-outs, shop keepers resorted to dispense SP and other monotherapies. The low availability of ALu in these shops was related to the perceived low profit margin of the drug by dispensers and the fact that ALu could only be found at the wholesalers with a distance of approximately 200 km from the study area (Alba et al., 2010a)

Studies reviewed by Goodman et al (2007a) in Africa indicate that drug dispensers were less likely to enquire illness information from customers and provided unclear information regarding treatment and use of drugs provided. However private practitioners' interventions were found to have a positive impact on specific dispensing practices. Based on the four indicators assessed in this study, the positive outcome of ADDO interventions is revealed by the huge increase in the percentage of mystery clients provided with relevant information on diagnosis and treatment of fever. Explaining the side effects of the drug dispensed for example ensures that a patient adheres to the recommended treatment. It is not enough that the dispenser only dispenses drugs but also explains the importance of visiting health facility when symptoms persist since illness progression might be a result of among other things resistant to drugs prescribed. The first line treatment for mild malaria (ALu) requires careful dosage management depending on the age and weight of the patient and especially children, it is therefore crucial for the dispenser to provide treatment based on the weight of the child in order to avoid over/under dosage.

Studies using mystery shopping technique have shown that drug shop interventions do have an impact in improved dispensing practices (Tavrow et al. 2003; Marsh et al. 2004; Tawfik et al., 2006). In Uganda negotiation sessions with private practitioners had a significant impact in management of childhood illness, with regard to malaria; there was an increase in percentage from 2 to 73 before and after intervention respectively among clients who were given correct anti-malarials (Tawfik et al., 2006). ADDO evaluation conducted in Ruvuma also indicated a 20 percent increase among simulated fever patients who were referred to health facility without being provided with anti-malarials at ADDO (Roberts et al., 2011), a point which was strongly emphasized during dispensers' training in order to cope with the problem of drug resistance.

As part of their training, dispensers were educated on the importance of advising clients on the use of preventive measure i.e. the use of ITNs (Rutta et al., 2009). However, no remarkable changes were noted after the introduction of ADDO regarding advice given by dispensers on the use of ITNs as malaria preventive measure. This corresponds to a study in Uganda where, despite practitioners' intervention; some practices related to advising customers about prevention measures were resistant to change (Tawfik et al., 2006). Such findings indicate the rationale for continued refresher training and supportive supervision to explore challenges facing drug dispensers.

Reflecting on the methodology and information obtained in our case study, it is clear that through mystery shopping, rich information about dispensers' practices were collected (also on indicators not reported here). Mystery shopping allowed gathering relevant information which could otherwise not have been obtained, for example by exit interviews. An advantage of the mystery shopping approach is that customers are aware of what they need to observe or assess. Also in our study, village mystery shoppers have received prior training regarding the nature of study and therefore were more likely to understand and judge whatever treatment experiences they encountered with dispensers.

Since it involves pretense or even deception, mystery shopping has been contested on ethical grounds. Nevertheless, there are different guidelines by different interest groups with regard to ethics in conducting mystery shopping studies (Jesson, 2005). From the Market Research Society's point of view, mystery shopping is an ethical research technique provided that those shopped are informed in advance about the activity

(Jesson, 2005). From an ethnographic perspective, 'covert research is a contestable method' (Jesson, 2005) and involves a reciprocal connection with the study participants. Sociologists agree that covert methods may be justified in certain circumstances, but they warn that covert methods violate the principles of informed consent and may invade the privacy of those being studied.[7]

As indicated earlier, the nature of the study could not allow informing dispensers about the whole activity and therefore no informed consent were obtained from the dispensers, however, confidentiality was highly maintained and all data obtained were used for the purpose of assessing the quality of malaria case management before and after the introduction of ADDO. Study findings were also not linked to any specific shops.

Our study minimized potential ethical objections by giving a thorough training to mystery clients about the presentation of case scenarios and making sure that mystery visit took a short time and not interfering with dispensers' daily routine of attending real customers. Moreover, mystery shoppers were careful trained that the study aim is to assess the practices of dispensers and therefore they should ask tricky questions when advised to receive any treatment, i.e. injection/swallowing drugs at the shops.

Our evaluation of ADDO interventions can of course not provide an in-depth understanding of routine dispensers' practices, a point raised by Jesson (2005). The visits were of short duration and the reported results determined by shoppers' experiences and perceptions of the visits. Inter-shopper variability was minimized by training them to focus on specific issues to be explored and by using an interview guide with standardized questions to elicit shoppers' experiences after their interaction with the dispensers.

Our methodology could further be improved. As proposed by Murphy and Dingwall (2007), informed consent could be negotiated and re-negotiated over time, provided that as part of their professional ethics, health providers are open to be evaluated or inspected on their conducts and should be responsible to participate in any activities that

[7]Statement of Ethical Practice for the British Sociological Association (March 2002), available at: http://www.britsoc.co.uk/about/equality/statement-of-ethical-practice.aspx

contribute to improvement in health care delivery (Levine, 2008). In a study of sexual health service delivery for example, health professional were willing that mystery shopping should be used to assess user satisfaction on the ground that one can improve service delivery after understanding how such service is perceived from an outsider's perspective (Baraister et al., 2007). Moreover, evidence reveals that health providers are willing to have covert observers during their professional practices over a specific period of time provided that they (professionals) are informed in advance of the likelihood of the activity and are provided with feedback (Kinnersley and Pill, 1993). A study by Goodman et al (2007a) also revealed how willing and cooperative drug dispensers were in participating in studies/interventions that aims at improving quality and access to malaria treatment

With experience of conducting a mystery shopping study in drug outlets, and challenges posed against the methodology itself, our study supports the idea stipulated in ESOMAR (2005) that for the purpose of assessing a specific intervention, mystery shopping might be useful tool to be applied provided that those shopped are aware of the possibility of a visit as what is required in market kind of researches. The importance of prior information to the study subjects about the possibility of a mystery visit should therefore be emphasized. Such information should clearly be explained either during training/intervention or several months before the intended activity without indication of specific date or month of the intended activity.

An additional affect not yet mentioned in the literature is that the training also has empowering effects on the mystery shopping villagers. We noted how willing and cooperative communities/mystery shopping villagers were towards assessing their providers' practices. They seemed positive about all the activity, were eager to participate and proud be part of bringing about development in their own society. There is a need for new approaches which involve people as participants in in-depth studies, not just rapid assessments, as shown for instance by community-based participatory research propagated in the United States (Horowitz et al., 2009).

Study findings indicate that if ADDO program is scaled up country-wide and supportive supervision is in place, quality of malaria case management in the private sector could improve and therefore reduction in malaria morbidity and mortality. Studies reviewed by Goodman et al. (2007a) also demonstrate that targeting the private sector can have an

impact in improving the quality of malaria treatment, considering also that drug shops are commonly the first stop for people with ill health. Despite the challenges posed against the methodology, mystery shopping remains the only method providing data on the actual behavior of the dispensers (Nyazema et al., 2007).

8.6 Conclusion

Study findings indicate improvements in dispensing practices after ADDO intervention in the two study districts. Such findings alert promising news for reduction of malaria morbidity and mortality if the private sector is strengthened and supervised to provide appropriate malaria treatment. Despite challenges of applying the technique, mystery shopping provides a good assessment tool, specifically as a means of evaluating performances of particular interventions. The sudden improvements in dispensing practices after ADDO intervention for example could easily be revealed after mystery shoppers were used to explore the actual experience of service provision in drug shops. Provided that those 'shopped' are aware of the possibility of being 'mystery visited' mystery shopping is a useful tool in ensuring that valid and rich information is obtained. Innovative community based participatory research approaches and more systematic mystery shopping techniques would allow for comparative community-based assessments of ADDO interventions across regions.

Competing Interests

The Authors declare that they have no competing interest.

Authors' Contributions

AD was involved in the design and implementation of the study, field work, data management, analysis, interpretation and writing of the manuscript. AS, BO, CL, HM conceived the program and its components and provided technical support and supervision. MH coordinated field work activities in 2004 and 2005 and contributed to the manuscript. SA was involved in the design, implementation of the study and coordinated the field work between 2007 and 2009. JL coordinated the implementation of the ADDO

program and contributed to the manuscript. BO was involved in the conception and design of the study, data analysis, interpretation and writing of this paper. IM and CM contributed to data collection and discussion of the findings. The final manuscript was approved by all authors.

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9. Overall discussion and conclusions

9.1 The broader context

This thesis examined treatment seeking for childhood malaria in a context of unprecedented global efforts in malaria control. In the past decade, global commitment to malaria control has translated into policy changes, the introduction of new technologies like ACT and RDT and the scaling up of prevention and treatment interventions. In Sub-Saharan Africa, and more specifically in Tanzania, the renewed efforts in malaria control have contributed to impressive gains in child survival.

In Tanzania, the mortality of children younger than 5 years dropped from 25 percent from 1990 to 2003 (Masanja et al., 2008) and again 28 percent from 2005 to 2010 (PMI, 2011b). Over the same period (2005-2010), the ITN use among children under five and pregnant women increased from 16 percent (in both groups) to 64 and 57 percent, respectively. On the mainland, the frequency of severe anaemia in children six months to five years of age, shown to be strongly associated with malaria dropped by 50 percent (PMI, 2011b). In 2010, 65 percent of children under age five who had a fever during the two weeks preceding the Demographic Health Survey were taken to a health facility. However, the proportion of children who were treated with anti-malarial drugs did not change much for mainland Tanzania from 2004-05 to 2010 (NBS and ICF Makro, 2011). The proportion of children who were treated on the same or next day has even decreased significantly, from 51 percent in 2004-05 to 41 percent in 2010 (NBS and IFC Makro, 2011).

There are significant variations by region, even within mainland Tanzania. In Morogoro Region, where this study was carried out, the prevalence of malaria (main P. falciparum) was in the middle range: 15.7 percent, compared with 0.4 percent in Arusha and 41 percent in Kagera (see Figure 2). In Morogoro Region, 96 percent of children who had a fever were taken to a health facility or provider (NBS and IFC Makro, 2011). Similar data for children with convulsions are not available.

What earlier studies, not only in Tanzania, but in East Africa, West Africa and Southern Africa have shown is that many communities have separate, named categories for mild and high fevers and associated symptoms and clearly distinguish them from the more dramatic condition characterized by convulsions or seizures (Williams and Jones, 2004). Studies on illness concepts in Tanzania found the terms *homa* and *maleria* for febrile illnesses and *degedege* for seizures or convulsions in small children (see Winch et al., 1996; Tarimo et al., 1998; Mayombana 2004; Warmsame et al., 2007). Further research found that the appearance of convulsions frequently led to the perception that some form of 'supernatural' or 'spiritual' force was, or has become, involved in the illness process and any cure necessitates the involvement of a traditional healer. This was a widespread perception and has been well documented for malaria in East Africa, West Africa and Southern Africa (Williams and Jones, 2004).

Especially with regard to treatment seeking, there is clearly a need for a deeper understanding of what is happening on the ground. Do the global and national efforts and new policies translate into interventions which actually reach down to the household level? And do young children actually gain prompt access to effective malaria treatment, or are those with signs of a possibly a life-threatening condition, namely convulsions, first brought to traditional healers?

This thesis used a health social science approach to examine these questions in an area of Morogoro Region which has long been a centre of malaria research and interventions: Ifakara and the two districts Kilombero and Ulanga. The PhD project was carried out within the ACCESS program which contributed to bringing the international and national efforts down to district, community and household levels. From 2004 to 2008, the ACCESS program applied a social marketing approach to improve awareness and promote prompt and effective treatment of mild and severe forms of malaria in the communities. The program supported the CHMT in improving quality of care in the health facilities and advocated for the introduction and use of community pharmacies (ADDO). In addition to the intervention, the ACCESS program had a strong monitoring and evaluation component.

The overall aims of the thesis were twofold: On one hand, it intended to contribute to the evidence base to assess effectiveness of the ACCESS interventions implemented between 2004 and 2008. On the other hand, it aimed at increasing scientific

understanding of whether, why and how young children “gain access” to prompt and appropriate malaria treatment.

The thesis identified two gaps in scientific knowledge: 1) a lack of case study data on access to treatment for children with mild malaria and especially severe malaria (convulsions) and 2) the need for a more accurate understanding of the malaria knowledge and treatment practice of drug sellers. These knowledge gaps informed the formulation of the specific objectives of this thesis. These objectives were:

1. To investigate whether malaria treatment seeking for children with fever and convulsion has changed during the first phase of the ACCESS program (Chapters 4-5).

2. To examine whether ‘acceptability’ is an important access dimension in treatment seeking for childhood convulsions (Chapter 6).

3. To assess the usefulness of mystery shopping methodology for assessing changes in the performance of drug sellers in community pharmacies (Chapters 7-8).

The following paragraphs highlight and discuss the main findings for each of these objectives; critically examine the limitations of the methods used and emphasize the need for more contextualized health social science research on malaria.

9.2 Changes in malaria treatment seeking for children with fever and convulsion during the first phase of the ACCESS program

This thesis provides the first systematic community based study of actual treatment seeking for children with convulsions in Tanzania and, to our best knowledge, also in Africa. The studies on treatment seeking (Chapters 4-6) investigated whether malaria treatment seeking for children with fever and convulsion has changed during the first phase of the ACCESS program (2004-2008).

Socio-cultural factors explaining timely and appropriate treatment

In a first step, the thesis recorded treatment seeking for actual illness episodes in three sub-studies from 2004 to 2006 in Kilombero and Ulanga districts. It analyzed socio-cultural factors (Chapter 4), especially the explanatory models developed by caretakers of under five year old children in actual cases of convulsions (n=135) and compared them with explanatory models for under-fives with self-reported malaria (n=72) and fever (n=28). The majority of the interviewed caretakers (n=235) were women (82.6%). In this rural area, most respondents were farmers (94.9%) and many did not have a regular or dependable income (41.3%). Over all, two-thirds of the children (60.9%) were brought to a health facility within 48 hours and received an anti-malarial (57%). The other children (23%) in our sample were also treated with anti-malarials but not at a health facility.

The most surprising finding was that more children with *degedege* were taken to a health facility within the required time frame (71.1%), than children with *homa* or malaria (45.6%). Moreover, the caretakers of children with convulsions also mentioned malaria (p=0.04) and *homa* (p=0.03) when talking about the symptoms, indicating that caretakers made a link between convulsions and *homa* or malaria.

The data further showed that symptoms rather than causes were now the drivers of health seeking behaviour. Perceived causes of *degedege* reported in earlier studies still played a role: Spirits, the insect '*degedege*', and non-abstinence from sex were associated with less timely use of health facility and receipt of anti-malarial. However, these ideas were not so influential as to keep the majority of children with *degedege* from accessing health facilities and receiving anti-malarial medication. More importantly, a "dirty environment" (bushes, grasses, stagnant water) was now considered as a contributing cause as they served as breeding sites for mosquitoes which were recognized as the cause of *degedege* and accelerated the need for prompt treatment. Another study in the same program found that mosquito bites were the most cited perceived cause for fever and *degedege* cases (Hetzel et al., 2008).

Even for children with *degedege* who were not brought to a health facility at all, caretakers' explanations had more to do with poor services in the respective facility, and/or lack of money to pay for consultation and/or treatment, than with the belief that *degedege* is better managed by traditional healers. The main reasons why services

were considered as inadequate were a lack of drugs, competence and/or equipment to make accurate diagnosis.

All in all, the findings from our study differ from those of many other studies on malaria and convulsions which emphasize traditional healing practices as preferred treatment (Mwenesi et al., 1995; Makemba et al., 1996; Winch et al., 1996; Ahorlu et al., 1997; Snow et al., 1998; Minja et al., 2001; Comoro et al., 2003; Hill et al., 2003; Mayombana, 2004; Adongo et al., 2005; Beiersman et al., 2007; Warsame et al., 2007). On the other hand, our study supports the findings of studies which identified modern care as the first choice of treatment for 78% of fatal malaria cases (De Savigny et al., 2004) and report that 90% of respondents identified convulsions as severe condition and recognized the need to seek modern treatment (Ahorlu et al., 2005).

9.3 Acceptability as an important access dimension in treatment seeking for childhood convulsions

In a second step, two of the sub-studies conducted in 2004-2006, namely the fever survey (Chapter 5) and the *degedege* study (Chapter 6) were repeated in 2007-2008 to examine potential changes in treatment seeking. With regard to mild malaria, the main improvements were in the understanding of causes (2004: 62%; 2008: 84%), an increase in health facility attendance as first option for under five year old children (2004: 27%; 2008: 52%), a higher treatment coverage with anti-malarials (2004: 86%; 2008: 96%) and more timely use of anti-malarials (2004: 80%, 2008: 93-97%). However, there was a drop in the proportion of young children who received the recommended treatment (2004: 80%; 2008:53%), and this was mainly due to the low availability of ALu in drug shops of the private sector.

Improvements in treatment seeking have also been recorded for children less than five years of age who suffered convulsions. Even a higher percentage of these children were brought to a health facility within 24 hours (2004:71%, 2008: 85%) and received an anti-malarial (2004:67%; 2008:77%). The proportion of the small minority who was first treated at a drug store remained the same (2004:3%; 2008:4%), even though ADDOs

now provided anti-convulsive medicine. Care takers who did not bring the child to a health facility for convulsion treatment were less driven by a preference for traditional healing: there was a 14% point decrease among caregivers who associated convulsion with “evil eye and sorcery”.

The contrast of these findings with findings from previous studies can be explained a) by differences in accuracy of data collection, b) new explanatory models integrating local and biomedical understanding, and c) changes in explanatory models due to long and high exposure to biomedical research and interventions, also through the ACCESS program. The last two explanations point to an increase in social acceptability of malaria interventions in the local community.

Guided by perspectives developed in medical anthropology, we use the term social acceptability to emphasize that individual perceptions are influenced by social representations and modified in social interactions. As indicated in Penchansky and Thomas (1981), we suggest that a ‘fit’ or match between providers and clients with regard to their understandings of disease is of particular relevance. The usefulness of such an approach is most obvious if striking differences exist in providers’ and clients’ views about the causes and treatment of health problems, as has been reported, for instance, for high fever and convulsions in Africa and Asia (Williams and Jones, 2004; Nsungwa-Sabiiti et al., 2004). Improving the match between local and biomedical understanding of disease is fundamental to ensuring acceptability of health care services and successful control and management of health problems. The study findings indicate that explanatory models can be modified with communication campaigns, provided that this change resonates with the beneficiaries.

Differences in the accuracy of data collection may also help to explain the difference between the findings of our studies and those of earlier research. The methodology developed in this study allowed for a systematic analysis of actual convulsion cases. This posed a major problem in previous studies because convulsions are comparatively rare. The present study used the Health and Demographic Surveillance System (HDSS) database as a sampling frame for the community-based studies on treatment seeking (Hetzel, 2007). In the absence of vital registrations, trained field workers visit every household in every HDSS village every four months and record births, deaths, in- and out-migrations and socio-economic indicators.

The HDSS fieldworkers and ACCESS program fieldworkers collaborated in data collection of the treatment surveys. The HDSS fieldworkers included a fever question into their routine household visits every for months. They thus identified children with an episode of fever or of *degedege* in the past 14 days. For fever cases, the HDSS fieldworkers, or ACCESS fieldworkers who accompanied them, immediately conducted the interview with the caretakers of the child, in most cases with the mother (86%) or the father (10%). For degedege cases, the fieldworkers returned two to four weeks after the HDSS visit to conduct the interview. This design made it possible to randomly select cases of mild fever and to systematically identify and follow up degedege case.

Moreover, the main instrument used in the treatment-seeking surveys was the Explanatory Model Interview Catalogue, or EMIC (Weiss 1997). The EMIC provided a framework for the development of a semi-structured interview with open-ended questions and screening queries on pre-defined answer categories (see Appendix B). The answer categories had been elicited in prior qualitative studies on local terms used for symptoms and causes as well as on available treatment options. The semi-structured interview schedule then allowed for a systematic in-depth assessment of the explanatory models constructed by the caretakers in these concrete illness episodes.

The EMIC framework aims at studying the distribution of explanatory models within communities. It thus helps to overcome 1) the disadvantages of small-scale ethnographic studies and 2) the application of a purely biomedical illness definition which is not necessarily shared by the community (Hetzel, 2007). The EMIC thus made it possible to come up with a quantitative estimation of the distribution of signs and symptoms as well as perceived causes of fever cases.

However, the application of the EMIC under the given circumstances also had its drawbacks. It is a sophisticated and long interview. To fill in the form correctly was challenging for the HDSS fieldworkers who were working alone and had only a few fever cases to interview. On the basis of the EMIC interview, a new instrument with less answer categories on symptoms and causes and more refined sections on help-seeking actions should be developed and validated in further empirical and comparative research.

Limitations of the treatment studies

The location and the design set certain frames for this PhD research. Since the inhabitants of the Kilombero Valley have long been exposed to malaria research and interventions and also participated in the ACCESS interventions and studies, their malaria related knowledge and practice can be expected to be more aligned with biomedical and public health perspectives than those of Tanzanians in other parts of the country. However, since this research was confined to Kilombero Valley, this assumption can neither be falsified nor verified. A comparison with data from other studies is difficult in this rapidly changing context if they were collected several years ago and with different methods. Even within the Kilombero Valley, a comparison is difficult for the same reasons.

The fact that myself as well as my fieldwork assistants were part of the ACCESS team may have introduced a researcher bias. This bias may have been reinforced by the fact that the research was conducted in the HDSS Ifakara, not just because of many other researchers have been active in the area but also due to the HDSS set up. From a public health perspective, the HDSS provided an excellent epidemiological framework for this study, but from a social science perspective, the HDSS may have its drawbacks.

Social science differs from the natural sciences in that the researchers are part of the phenomena which they study. The answers of the caretakers may have been influenced by their relationship with the HDSS/ADDESS fieldworkers. They may have “edited” the real illness story to match what they assumed the fieldworkers wanted to hear. Or, due to research fatigue, they may have left out important details. The relationships between HDSS fieldworkers and caretakers may also have had a positive influence because the fieldworkers came from the same community and knew the caretakers personally and “speak their language”. This may, on the other hand, also have led to story editing on the side of the fieldworkers. Experience in anthropological field research and anecdotal evidence from this and other HDSS sites raises concerns about the influence of routine data collection on the quality of interview data. A systematic and in-depth cross-checking of data collected with different methods would help to clarify these concerns about data quality.

The main limitation of this study is the selection of cases on the basis of reported fever only, since not every fever case is due to malaria (Alba, 2010). Considering every fever as a potential malaria case is consistent with the Integrated Management of Childhood Illness guidelines for treatment in areas of stable malaria (Gove et al., 1997). When the study was designed in 2003 and the area had very high levels of malaria transmission, this approach was warranted. However, this is not longer justified (Alba, 2010). Recent data suggest a drastic change in the epidemiology of malaria in the study area, and recent study piloting the use of Rapid Diagnostic Tests for malaria in local health facilities found that only 40% of fever cases were actually due to malaria (D'Acrémont et al., unpublished data). It is difficult to assess how much the presence of RDTs at the time of our surveys would have changed our findings. Future studies should take these concerns into account and adjust their designs accordingly.

With regard to the data on degedege cases, another bias was introduced by selecting only cases which had recovered the day before the interviewers' visit. Although this rule was correct for ethical reasons, the study missed out on potentially more severe cases who were still / again sick or had even died. It was originally planned to also analyse verbal autopsies but due to practical problems this idea was given up. ,

9.4 The usefulness of mystery shopping methodology for assessing changes in the performance of drug sellers in community pharmacies

In a third step, mystery shopping methodology was applied to explore dispensers' knowledge on management of malaria in drug retail outlets. Drug shops have been recognized as an important source of malaria treatment complementing formal health service; however they are faced by a number of challenges including poor dispensing practices by unqualified staff. The ADDO program was introduced in Tanzania in 2002 after a successful piloting in Ruvuma region. The main aim of the ADDO program was improving the quality of dispensing practices from technical and from consumer perspectives (Rutta et al., 2009). The program was implemented by the Ministry of Health and Social Welfare (MoHSW) through the Tanzanian Food and Drug Authority

(TFDA) and Management Sciences for Health. Within the ACCESS program, mystery shopping studies were conducted between 2004 and 2009.

The first study (Chapter 7) was carried out in 2004 to explored drug seller's knowledge and practice with the aim of documenting their performance Findings indicated that the quality of malaria case-management in the retail sector was not satisfactory. To improve the situation, the ACCESS program in 2005 introduced a training component. Drug dispensers were trained on the management of malaria, administration and dosage of SP (the first line drug for malaria until 2005). When ACCESS program learnt about the coming of ADDO program in the study area in 2006, the plan changed, since 2006 the program has been working closely with the ADDO program to improve the quality of care in drug outlets.

Studies presented in Chapter 8 used mystery shoppers to assess the impact of the ADDO program by comparing dispensers' practices before and after the implementation program in the study area. Mystery shopping has been applied in various studies in and out of Africa to learn about the actual dispensing practices of dispensers. Since monitoring of ADDO by TFDA and MSH was limited to inspection activities, it was a break for the ACCESS program, using mystery shopping to compare the actual dispensing practices before and after ADDO implementation. Based on the list of common signs and symptoms for mild malaria from the National Malaria Control Program, four indicators were developed and used to measure the quality of dispensing and advice offered i) if the shop attendant explains the side effects of the drug dispensed ii) explains the importance of consulting a medical doctor if symptoms persist iii) asks how much the child weighs before dispensing a drug and iv) asks if any anti-malarials was taken before visiting the shop. Findings indicated a 30% increase on the four assessed indicators after the implementation of ADDO program in the study area. Findings revealed the value of ADDO interventions in improving malaria case management in drug retail outlets. It gives an implication that, if ADDOs are closely monitored and strengthened to provide appropriate malaria treatment and the program is rolled throughout the country, a reduction in malaria morbidity and mortality is possible in the country.

Limitations of mystery shopping methodology

Since it involves deception, mystery shopping had been accused on ethical grounds. However different interest groups have provided guidelines for an ethical conduct of mystery shopping studies (Jesson, 2005). From the Market Research Society's point of view, mystery shopping is an ethical research technique provided that those shopped are informed in advance about the activity (Jesson, 2005). From an ethnographic perspective, 'covert research is a contestable method' (Jesson, 2005) and involves a reciprocal connection with the study participants. Sociologists emphasize the importance of informed consent but acknowledge that sometimes covert research is necessary.

No informed consent was obtained in our studies. This is because the nature of the study could not allow informing dispensers in advance about the whole activity. On the other hand confidentiality was highly maintained and all data obtained were used for the purpose of research only. Study findings were also not linked to any specific shops.

Mystery shopping has also been charged of not providing contextual data on routine dispensers' practices (Jesson, 2005). This is because the visits normally take short duration of time. We attest that our assessment of ADDO interventions can of course not provide an in-depth understanding of routine dispensers' practices. Another critique of the methodology is related to the fact that results are determined by shoppers' experiences and perceptions of the visits (Jesson, 2005). Our study minimized inter-shopper variability by training mystery shoppers to focus on specific issues to be explored and by using an interview guide with standardized questions to elicit shoppers' experiences after their interaction with the dispensers.

Despite challenges posed by mystery shopping, study findings indicated how mystery shopping technique could be usefully employed to assess the impact of ADDO intervention in drug shops. Innovative community-based participatory research approaches and more systematic mystery shopping techniques would allow for comparative community-based assessments of drug shop interventions across regions and countries. To improve the methodology, our study recommends what has already been proposed by Murphy and Dingwall (2007): informed consent should be negotiated and re-negotiated over time, provided that as part of their professional ethics, health providers are open to be evaluated or inspected on their conducts and should be

responsible to participate in any activities that contribute to the improvement in health care delivery (Levine, 2008). Further studies should also take these challenges into account when implementing mystery shopping programs.

9.5. Examining malaria in social, political and economic contexts

As indicated in the ACCESS livelihood framework (Obrist et al., 2007) decisions to seek treatment is influenced by a number of factors including existing policies in place, availability of care and livelihood resources that people need to mobilize when they fall ill. Some studies have started to realize the influence of political, structural and environmental factors in treatment seeking. When an individual falls ill, the next step is always to seek treatment within the constriction imposed by their environment (Williams et al., 2004). It is therefore critical for treatment seeking studies to examine the impact of broader social, political and economic contexts in treatment decision making.

There is clearly a need to for more embedded studies of fever concepts and associated prevention and treatment seeking, not only examining connections with broader understandings of health and illness, but also conducting a social analysis of decision making, gender and the position of caretakers within households and communities. Studies in Kilifi, Kenya (Mwenesi, 1993) and in Tanga, Tanzania (Oberlander and Elverdan, 2000; Montgomery. 2006) have shown that even if women bring the child to a healthcare facility, decisions regarding the timing and type of treatment may be made by a male family member, usually the child's father, uncle or grandfather. Another study in peri-urban Dar es Salaam, however, found that mothers made "strategic" decisions, only in serious cases others came in (Kamat 2006). In contexts of livelihood insecurity, treatment seeking is deeply embedded in the daily struggle for making ends meet, especially in urban areas (Kamat 2006), but also in rural areas, the search for resources to reach a health facility and to pay for services and drugs (in spite of exemptions) influence access to prompt and effective treatment (Hausmann Muela 2000). In Kilombero valley, despite difficult situations, caregivers made greater efforts to take their serious ill children to health facility (Obrist et al., 2010). They covered long distances either by foot or using bicycles. A study in the similar geographical area revealed how

communities access treatment during farming season, when they move to stay in the remote fields far from health facilities (Hetzel et al., 2008). Despite long distances to health facilities, more that 50% of fever cases were treated at health facility and the use of mosquito net was as high as 98%.

As Muela Ribera and Hausmann (2011) have convincingly argued, based on their ethnographic studies in Ifakara, southeastern Tanzania, social science research on access to malaria care should put more emphasis on the analysis of cumulative processes of vulnerability. They suggest examining the underpinnings of the cumulative dimension of vulnerability at three levels: (1) structural: elements that determine access to material and social resources; (2) agent driven: the consequences of coping strategies that enhance vulnerability; and (3) conjunctural: periods characterized by the confluence of adverse circumstances. Such a social science analysis of cumulative processes of vulnerability would paint a more comprehensive picture of people's struggle for health. It would further open up a more systemic and dynamic perspective on access to malaria care for disadvantaged populations.

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Appendix A: Village descriptions

Village	Livelihood	Estimated Number of households	Ethnic groups	Religion	Transport	Mobile phone
Kilombero District (Ifakara township)						
Ifakara	Agriculture Business	2,235	-Mbunga -Pogoro -Ndamba	Christian 60% Muslim 40%	Road and railway-	All phones-Tigo, Celtel, Zantel, Vodacom
Lipangalala	Agriculture Business	2,115	-Mbunga -Pogoro -Ndamba	Christian 60% Muslim 40%	Road and railway-	All phones-Tigo, Celtel, Zantel, Vodacom
Mlabani	Agriculture Business	1,184	-Mbunga -Pogoro -Ndamba	Christian 60% Muslim 40%	Road and railway	All phones-Tigo, Celtel, Vodacom, Zantel
Viwanja Sitini	Agriculture Business	3,244	-Mbunga -Pogoro -Ndamba	Christian 60% Muslim 40%	Road and railway	All phones-Tigo, Celtel, Vodacom, Zantel
Katindiuka	Agriculture Business	941	-Mbunga -Pogoro -Ndamba	Christian 60% Muslim 40%	Road and Railway	All phones-Tigo, Celtel, Zantel, Vodacom
Kilombero District (rural)						
Idete	Agriculture Small business Fishing Charcoal burning Forest activities	2400	-Ngoni -Ndamba -Pogoro,hehe -Ngindo -Sukuma -Chagaa -Nyakyusa -Nyiramba -Haya	Christian 70% Muslim 30%	Road and railway	No phone networks
Miwangani	Agriculture Small business Fishing	400	-Matumbi -Ndegereko and idete's tribes (above)	Christian 65% Muslim 35%	Road and railway	Commonly celtel and Vodacom at few places

Namawala	Agriculture Livestock keeping Fishing Small S. Business	1200	-Sukuma -Pogoro -Ngindo -Ndamba -Pare -Makonde	Christian 75% Muslim 25%	Road and Railway	Commonly Celtel at few places
Kisegese (not found on map) (New, settlers from Namawala village)	Agriculture Small S. Business	450	-Hehe -Bena -Ndamba -Nyakyusa	Christian 99% Muslim 1%	Road and railway	No phone networks
Mofu (no info in table)						
Mbingu	Agriculture Small S. Business	1500	-Ndamba -Nyakyusa -Hehe -Bena -Ngoni -Chagga -Kerewe -Sukuma -Waha -Pogoro -Mbunga	Christian 80% Muslim 20%	Road and railway	No phone networks
Mpofu (new, settlers from Mbingu village)	Agriculture	500	-Hehe -Ndali -Nyakyusa	Christian 98% Muslim 2%	Bad road	No phone networks
Igima (new, settlers from Mbingu village)	Agriculture Livestock keeping	1100	-Hehe -Bena -Nyakyusa -Sukuma -Maasai	Christian 85% Muslim 15%	Road and railway	No phones network

Mchombe	Agriculture Small business Livestock keeping	1250	-Nyakusa -Hehe -Ndamba -Matumbi -Ngindo -Ndengereko	Christian 70% Muslim 30%	Road and railway	-No phone networks
Mngeta	-Agriculture -Livestock keeping	950	-Hehe -Ndamba -Nyakyusa -Pogoro	Christian 85% Muslim 15%	Road and railway	No phone networks
Lukolongo (New, settlers from Mchombe)	Agriculture Small business Fishing Livestock Keeping	1000	-Ndamba -Nyakyusa -Hehe -Pogoro	Christian 90% Muslim 10%	Road	No phone networks
Mkangawalo	Agriculture Small business Fishing Livestock keeping	1100	-Ndamba -Hehe -Nyakyusa -Maasai -Sukuma -Pogoro	Christian 95% Muslim 5%	Road and railway	No phone networks
Ikule (New, settlers from Mkangawalo)	Agriculture Small business Livestock keeping	1100	-Hehe -Nyakyusa -Bena -Sukuma	Christian 98% Muslim 2%	Road and railway	No phone networks
Njage (not found on map)	Agriculture Small S. Business	520	-Nyakyusa -Hehe -Bena -Matumbi	Christian 90% Muslim 10%	Road and railway	No phone networks
Ulanga District						
Kivukoni	Agriculture Small business Fishing	1295	-Ndamba -Pogoro -Ngindo -Hehe -Ngoni -Masai	Christian 80% Muslim 20%	Road	All phone networks, tigo, vodacom, celtel

			-Gogo -Sukuma -Mang'ati			
Minepa	Agriculture Fishing-smallscale Small S. Business	650	-Pogoro -Ndamba -Nyakyusa -Mawanda -Ngoni -Sukuma	Christian 40% Muslim 60%	Road	All phone networks Celtel, Tigo, Vodacom
Mavimba	Agriculture Small S. Business	650	-Ngindo -Pogoro -Mawanda	Christian 40% Muslim 60%	Road	Commonly Celtel
Milola	Agriculture Small S. Business	350	-Ngindo -Pogoro -Ndamba -Ndwewe -Sukuma	Christian 25% Muslim 75%	Road	Commonly Celtel
Igumbiro (many people believe in witchcraft)	Agriculture Laborers-MITIKI	500	-Ngindo -Pogoro -Sukuma	Christian 25% Muslim 75%	Road	Commonly Celtel
Lupiro	Agriculture Small S. Business	950	-Ngindo -Pogoro -Ndamba -Ndwewe -Ngoni	Christian 40% Muslim 60%	Road	Commonly Celtel and Tigo at few places
Igota	Agriculture Small S. Business Honey collection	350	-Pogoro -Ndamba -Ngindo	Christian 70% Muslim 30%	Road	Celtel at few places
Kichangani	Agriculture Small S. Business	750	-Pogoro -Ndamba -Hehe -Ndwewe -Kurya	Christian 65% Muslim 35%	-Road	Celtel at few places
Idunda	Agriculture Small business	400	-Pogoro -Ndamba	Christian 80% Muslim 20%	Road	Commonly Celtel

			-Hehe			
Nakafulu	Agriculture Labourers-MITIKI	250	-Pogoro -Ngindo -Ndamba	Christian 55% Muslim 45%	Road	Commonly Celtel
Kidugalo	Agriculture Labourers-MITIKI	971	-Pogoro -Ngindo -Sukuma -Waha	Christian 80% Muslim 20%	Road	No phone networks
Iragua	Agriculture Small business Fishing- Labourers-MITIKI	1082	-Pogoro -Ngindo -Sukuma	Christian 80% Muslim 20%	Road	No phone networks

Appendix B: Semi-structured interview for caretakers (EMIC)

Malaria-Related Illness in Under Five Children

Semi-Structured Interview for Caretakers

EMIC for Children

With or without *degedege*

Master Copy

2004

PROMPT & EFFECTIVE IRC ACCESS MALARIA TREATMENT

4.3.8 INDEPTH FOLLOW-UP OF HOUSEHOLDS 2004
EMIC CATALOGUE
EMIC for Children IC DSS & IFK.doc

MALARIA-RELATED ILLNESS – INTERVIEW

1. **Respondent Study No:** _____ **Date:** Day _____ Month _____ Year _____

2. **Village Name:** _____

3. **Respondent Name:** First _____ Last _____ **Age:** _____ **Sex:** M ☐ F ☐

4. **Name of child** *(patient)*: First _____ Last _____ **Child's permanent ID:** _____

5. **"What is the age and sex of the child/patient?"**

Age: *Months* _____ **Sex:** M ☐ F ☐

6. **'What is your relationship to this child?'**

(Narrative) _____

Tick √ accordingly

Mother 1	Father 2	Grandmother 3	Other specify 4

RESPONDENT'S SOCIAL AND DEMOGRAPHIC INFORMATION

7. **House Number:** ☐☐☐☐☐ *As used in DSS HRS Books*

8. **Religion:** *Tick one only*

Traditional Religion 1	Muslim 2	Christian 3	Other (specify) 6_____

9. **Marital Status:** *Tick one only*

Never married 1	Married 2	Sep / Div 3	Remarried 4#____	Widowed 5

10. **Relationship with Household Head**

Self 1	Spouse 2	Parent 3	Child 4	Other *(specify)* 5	**Sex:**	M	F

11. **Children & Elders** *(of the household head):*

Sons					Daughters					Elders
<5 Yrs		≥5 Yrs			<5 Yrs		≥5 Yrs			≥18 yrs
Alive	Dead	Alive	Dead		Alive	Dead	Alive	Dead		

11.1. Apart from your children, how many other dependents live in your household at the moment (today)? *Put total in the boxes*

Under 5 Yrs [ ] **Elders (5 Yrs and older)** [ ]

12. Education: **Years** [ ] *If no school:* **Functional Literacy?**

No 0	Yes 1

Occupation

13. "What is your main source of income and livelihood?"
If married, **"What about your husband/wife, what is her/his occupation?"**

1	Nil	6	Trade / Business	11	Retired
2	Student	7	Service	12	Teacher
3	Housewife	8	Farmer	13	Deceased
4	Unskilled labour	9	Fisherman	14	Other (specify)_____
5	Skilled labour	10	Farmer-Fisherman (both)		

Specify codes: **Personal Occupation:** [ ] **Spouse's Occupation:** [ ]

14. "Is your household income usually regular and dependable?"

Tick one only

Yes 3	Possibly 2	Uncertain 1	No 0

(Narrative) _____

PATTERNS OF DISTRESS

Inclusion criteria: Caretaker noticed child was ill at most 14 days before interview, and child has been free of all symptoms for at least 24 hours at time of interview.

SPONTANEOUS ACCOUNT OF PROBLEM:
'I appreciate your agreeing to talk to me about this child's problem. It is a problem that also affects many other people in this district. I want to understand how you think about this problem. Keep in mind that it is your ideas that I am interested in, so please do not feel there is a right or wrong answer to the questions."

15. "What was the problem that the child was suffering from? Please tell me all that you know about it." *Record account of problem, as described in respondent's own words:*
(Narrative) _____

_____

_____

16. "Where were you when you first noticed the child was not well?"

Home	Shamba
1	2

17. "How did you first know that something was wrong with the child?"

(Narrative) _____

_____

_____

Tick spontaneously reported symptoms under the columns for "spontaneously" and "early". Ask about the others: Have they been noticed? If yes tick "probe". Have they been noticed early on? If yes, tick also the block under the column "early".

Patterns of Distress	Spon	Probe	Early	Patterns of Distress	Spon	Probe	Early
1. No interest to play *(hataki kucheza)*				14. Diarrhoea *(kuharisha)*			
2. Not happy *(hana raha)*				15. Vomiting *(kutapika)*			
3. Sleeps *(analala)*				16. Shivering *(anatetemeka)*			
4. Loss of appetite *(hapendi kula)*				17. Twitching *(anastuka)*			
5. Crying all the time *(analialia)*				18. Body becomes stiff *(mwili unakauka; anakakama)*			
6. No strength *(hana nguvu)*				19. Delirium *(anaweweseka)*			
7. Hot body *(mwili wa moto, joto kali sana)*				20. Eyes turn white *(macho yanakuwa meupe)*			
8. Hot head *(kichwa cha moto)*				21. Kicking of leg and arm *(anarusha mkono na mguu)*			
9. Hot abdomen *(tumbo la moto)*				22. Froth in the mouth *(anatoa mate mdomoni)*			
10. Periodic fevers *(homa za vipindi)*				23. Mouth twisted sideways *(mdomo ulienda pembeni)*			
11. Cough *(anakohoa)*				24. Falling down *(anaanguka)*			
12. Difficult breathing *(anahema kwa shida)*				25. Easily startled/frightened			
13. Yellow eyes *(macho ya njano)*				26. Other physical symptoms			

18. "Among all these symptoms, which one do you think is the single most dangerous?"
Code single most dangerous symptom from the above numbered list of patterns of distress ☐

18.1. What is it about this symptom that makes it the most dangerous?

(Narrative) _____

_____

_____

19. "How do you call this illness in your language?" *Specify name, summary term, or short description in the patient's words.*
(Narrative)

_____

Specify exact term used: _____

	Yes	No
Identified as homa?	1	0
Identified as malaria?	1	0
Identified as degedege?	1	0

20. Did some particular features make you think it is the illness you identified *(refer to the term mentioned above)*?

(Narrative) _____

_____

21. Did you know that yourself or did someone tell you? If so, who told you?

Tick all that apply

Resource Persons	Spon	Probe
1. I knew it myself		
2. Female elder		
3. Male elder		
4. Aunt (of the child)		
5. Father/ uncle (of child)		
6. Neighbour		
7. Government health facility staff		
8. Private health facility staff		
9. Shopkeeper (general store)		
10. Shopkeeper (drug store)		
11. Shopkeeper (Pharmacy)		
12. Community health worker		
13. Local healer		
14. Other *(mention):*		

21.1. What made you ask this person *(the first person consulted)*?

Tick all that apply

	Spon	Probe
1. I knew it myself		
2. It is someone I can talk to		
3. He/she is experienced/ knowledgeable		
4. He/she is a medical professional		
5. I am expected to consult him/her (customs)		
6. Other (mention):		

22. "Do you think that the illness that the child had was serious? In your opinion, how serious was the child's condition? Might it be fatal?"'

Tick only one

Usually fatal 4	Sometimes fatal 3	Serious but not fatal 2	Not serious 1	Cannot say 0

22.1. What makes this condition serious?

(Narrative) _____

_____

_____

PERCEIVED CAUSES

23. "I would like to know what you think may have caused this child's problem?"
Summarize respondent's ideas about causes in the respondent's own words (first-person account).

(Narrative) _____

_____

Tick the block for each of the reported causes under the column for "spontaneously". Ask about the others, and for those affirmed tick the block under the column "probe".

Perceived Cause	Spo	Pro
Ingestion		
1. Impure water		
2. Eating leftover food		
3. Unbalanced diet		
4. Starchy food		
5. Breast feeding		
Insects / Worms		
6. Mosquito bite		
7. Other insect bite		
8. Houseflies		
9. Worms		
10. Other		
Fatigue/Work/Constitution/blood strength		
11. Physical hard work (parent)		
12. Stage of child growth		
13. Constitution/ blood weakness		
14. Hereditary		

Perceived Cause	Spo	Pro
Environmental		
15. Sanitation/ Dirty environment		
16. Personal hygiene/not keeping clean		
17. Plant		
18. Contamination - contact		
19. Wind		
20. Heat (sun or fire)		
21. Cold weather		
22. Other		
Supernatural		
23. Spirits *(upepo, majini, shetani)*		
24. Evil eyes or sorcery (uchawi)		
25. God		
26 Failure to abstain from sex (parent)		
27. Bird/ insect called *degedege*		
28. Cannot tell		
29. Other *mention:*		

MOST IMPORTANT PERCEIVED CAUSE

24. "Which of the causes that you have mentioned (or perhaps something else) do you consider the single most important cause of the problem in the child?

(Narrative) _____

_____

Code single most important cause from the above list ☐

25. Did you know that yourself or did someone tell you? If so, who told you?

Tick all that apply

Resource Persons	Spon	Probe
1. I knew it myself		
2. Female elder		
3. Male elder		
4. Aunt (of the child)		
5. Father/ uncle (of child)		
6. Neighbour		
7. Government health facility staff		
8. Private health facility staff		
9. Shopkeeper (general store)		
10. Shopkeeper (drug store)		
11. Community health worker		
12. Local healer		
13. Other *(mention):*		

25.1. What made you consult this person *(the first person consulted)*?

(Narrative) _____

_____

_____

Tick all that apply

	Spon	Probe
1. I knew it myself		
2. It is someone I can talk to		
3. He/she is experienced/ knowledgeable		
4. He/she is a medical professional		
5. I am expected to consult him/her (customs)		
6. Other (mention):		

HELP SEEKING

26. What did you do for your child immediately after recognizing he/she was ill?

(Narrative) _____

_____

(FOR THE ***WHEN*** PART: *Use 1= same day, 2= next day, 3= more than 2 days or 0 for none)*

Tick all that apply

	Spon	Probe	When
1. Give antipyretics (e.g. Panadol)			
2. Give an antibiotic			
3. Give an antimalarial			
4. Give herbal medicine (home care)			
5. Sponging			
6. Ask for advice			
7. Divination			
8. Took child to a health facility			
9. Urinated on the child			
10. Give herbal medicine (from healer)			
11. Other *(mention):*			

27. Why did you take that action first *(specified above)*?

(Narrative) _____

_____

_____

28. Where did you go for advice (who did you see for advice)?

(Narrative) _____

_____

For each of the following sources of help, mark whether respondent reported use either spontaneously in response to the open-ended query, or in response to probe. Note whether person lives in same household.

Help seeking Resource Persons	Spon.	Probe	Household	
			Same	Other
1. I knew it myself				
2. Female elder				
3. Male elder				
4. Father/ uncle (of child)				
5. Aunt (of the child)				
6. Neighbour				
7. Health facility staff (public or private)				
8. Shopkeeper (general store)				
9. Shopkeeper (drug store)				
10. Community health worker				
11. Local healer				
12. Other *(mention):*				

29. Who of the people who gave advice you think gave you "most useful" and who gave "least useful" advice?

Most useful advice	
Least useful advice	

Anti-malarial drugs

30. Did you give any anti-malarial drug? If yes, which ones?

Yes	No

31. If the child was not given any antimalarial drug, *go to Question 38.*

Drug type		Order of giving		
		1	2	3
SP (and brands: Orodar etc)	go to Q 32			
Chloroquine	go to Q 33			
Amodiaquine	go to Q 34			
Quinine	go to Q 35			
Others *(specify)*	go to Q 36			
Others *(specify)*	go to Q 37			

32. SP

32.1. How long after onset of symptoms did you give SP to your child?

Same Day 3	Next Day 2	> 2 days 1

32.2. In what form was the drug that you gave the child?

1= Tablets
2= Syrup
3= Injection
4= Drip
5= Other (mention):_____

32.3. How much SP did you give? *(Insert code in appropriate box – if syrup, estimates in teaspoon full) Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others*

(Narrative) _____

Morning	Midday	Evening

32.4. Where did you get SP that you gave the child? *For each of the following sources, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*
Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
1. I had them at home			
2. Female elder			
3. Male elder			
4. Aunt (of the child)			
5. Father/ uncle (of child)			
6. Neighbour			
7. Government health facility staff			
8. Private health facility staff			
9. Shopkeeper (general store)			
10. Shopkeeper (drug store)			
11. Community health worker			
12. Local healer			
13. Other *(mention):*			

32.5. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

32.6. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?
(Based on the chart in Question 28 above)

32.7. And what did he/she say?

Narrative _____

33. Chloroquine

33.1. How long after onset of symptoms did you give Chloroquine to your child?

Same Day 3	Next Day 2	> 2 days 1

33.2. How many tablets of Chloroquine did you give? *(Insert code in appropriate box)*

Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others

Morning	Midday	Evening

33.3. Where did you get Chloroquine from? *For each of the following sources of help, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*

Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
14. I had them at home			
15. Female elder			
16. Male elder			
17. Aunt (of the child)			
18. Father/ uncle (of child)			
19. Neighbour			
20. Government health facility staff			
21. Private health facility staff			
22. Shopkeeper (general store)			
23. Shopkeeper (drug store)			
24. Community health worker			
25. Local healer			
26. Other *(mention):*			

33.4. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

33.5. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?

(Based on the chart in Question 28 above)

33.6. And what did he/she say?

Narrative _____

_____

34. Amodiaquine

34.1. How long after onset of symptoms did you give Amodiaquine to your child?

Same Day 3	Next Day 2	> 2 days 1

34.2. How many tablets of Amodiaquine did you give? *(Insert code in appropriate box)*

Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others

Morning	Midday	Evening

34.3. Where did you get Amodiaquine from? *For each of the following sources of help, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*

Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
27. I had them at home			
28. Female elder			
29. Male elder			
30. Aunt (of the child)			
31. Father/ uncle (of child)			
32. Neighbour			
33. Government health facility staff			
34. Private health facility staff			
35. Shopkeeper (general store)			
36. Shopkeeper (drug store)			
37. Community health worker			
38. Local healer			
39. Other *(mention):*			

34.4. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

34.5. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?
(Based on the chart in Question 28 above)

34.6. And what did he/she say?

Narrative _____

_____

35. Quinine

35.1. How long after onset of symptoms did you give Quinine to your child?

Same Day 3	Next Day 2	> 2 days 1

35.2. How many tablets of Quinine did you give? *(Insert code in appropriate box)*

Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others

Morning	Midday	Evening

35.3. Where did you get Quinine from? *For each of the following sources of help, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*

Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
40. I had them at home			
41. Female elder			
42. Male elder			
43. Aunt (of the child)			
44. Father/ uncle (of child)			
45. Neighbour			
46. Government health facility staff			
47. Private health facility staff			
48. Shopkeeper (general store)			
49. Shopkeeper (drug store)			
50. Community health worker			
51. Local healer			
52. Other *(mention):*			

35.4. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

35.5. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?

(Based on the chart in Question 28 above)

35.6. And what did he/she say?

Narrative _____

_____

36. **Others** *(specify)* _____

36.1. How long after onset of symptoms did you give the drug to your child?

Same Day 3	Next Day 2	> 2 days 1

36.2. How many tablets of the drug did you give? *(Insert code in appropriate box)*

Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others

Morning	Midday	Evening

36.3. Where did you get the drug from? *For each of the following sources of help, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*

Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
53. I had them at home			
54. Female elder			
55. Male elder			
56. Aunt (of the child)			
57. Father/ uncle (of child)			
58. Neighbour			
59. Government health facility staff			
60. Private health facility staff			
61. Shopkeeper (general store)			
62. Shopkeeper (drug store)			
63. Community health worker			
64. Local healer			
65. Other *(mention):*			

36.4. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

36.5. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?
(Based on the chart in Question 28 above)

36.6. And what did he/she say?

Narrative _____

_____

37. **Others** *(specify)* _____

37.1. How long after onset of symptoms did you give the drug to your child?

Same Day 3	Next Day 2	> 2 days 1

37.2. How many tablets of the drug did you give? *(Insert code in appropriate box)*

Codes: 1= Robo, 2=Nusu, 3=Kimoja, 4=Kimoja na nusu, 5=Viwili, 6=Vitatu, 7=Others

Morning	Midday	Evening

37.3. Where did you get the drug from? *For each of the following sources of help, mark whether respondent reported use spontaneously or in response to probe. Note why they went there.*

Codes: 1= Distance/time, 2=Timing, 3=Convenience, 4=Cost, 5=Good quality service, 6=Others

Help Seeking	Spon.	Probe	Why *(note code)*
66. I had them at home			
67. Female elder			
68. Male elder			
69. Aunt (of the child)			
70. Father/ uncle (of child)			
71. Neighbour			
72. Government health facility staff			
73. Private health facility staff			
74. Shopkeeper (general store)			
75. Shopkeeper (drug store)			
76. Community health worker			
77. Local healer			
78. Other *(mention):*			

37.4. How much did it cost?

1. Consultation	*Tsh.*
2. Drugs	*Tsh.*

37.5. Did you know yourself what drug to give the child or did someone tell you? If so, who told you?
(Based on the chart in Question 28 above)

37.6. And what did he/she say?

Narrative _____

_____

38. *Skip this question if SP has been used, otherwise ask*: **Why didn't you give the child SP (or other first line drug) tablets?**

(Narrative) _____

_____

_____

Tick all that apply

	Spon	Probe
1. Fear of side effects		
2. Too strong for the child		
3. Family members said not to		
4. Friend/family said not to		
5. Told by health facility staff		
6. Told by shopkeeper		
7. Does not know		
8. Other *(mention):*		

39. In addition to (or apart from) giving anti-malarials, did you do anything else to treat the child?

Tick all that apply

	Spon	Prob
1. Give antipyretics (e.g. Panadol)		
2. Give an antibiotic		
3. Give herbal medicine (home care)		
4. Sponging		
5. Ask for advice		
6. Divination		
7. Urinated on the child		
8. Give herbal medicine (from healer)		
9. Give SP		
10. Give Amodiaquine		
11. Give Quinine		
12. Give other antimalarials (1) *specify*		
13. Give other antimalarials (2) *specify*		
14. Do something else		

40. "Which of the treatment options mentioned (or something else) do you consider the most effective way of treating this problem?" *(Regardless of whether it has been used or not in this particular disease episode)*

(Narrative) _____

_____

_____

(Based on the chart in Question 40) ☐

PREVENTION AND CONTROL

41. "Could this child's problem or condition have been prevented? Anything in particular that you think could have prevented it?'

Tick one only

Yes 3	Possibly 2	Uncertain 1	No 0

(Narrative) _____

Tick accordingly for mentioned preventive measures, both for that particular child

	Prevention and control	Particular child	
		Spon.	Probe
1.	Use of mosquito net (untreated)		
2.	Use of a treated mosquito net		
3.	Taking medicines regularly (herbal or biomedical)		
4.	Parent to abstain from sex		
5.	Reduction in strenuous/hard work		
6.	Fumigation/ fogging		
7.	De-worming regularly		
8..	Avoid certain insect bites		
9.	Clean the environment		
10.	Keep personal hygiene		
11.	Drinking clean water		
12.	Attend to ancestral spirits and family gods		
13.	Avoid offending evil spirits, especially the witches		
14.	Mothers with malaria should not breast feed		
15.	Don't know/cannot tell		
16.	Cannot be prevented		
17.	Other *(mention)*:		

General Question on DEGEDEGE

42. "When was the last time you saw a child with convulsion or who was just recovering from convulsion?"

(Narrative) _____

'Record number of days, weeks, months and years in appropriate box'

Days	Weeks	Months	Years

Tick for 'never seen a child with degedege'

Never seen a child with degedege

43. What is that child's relationship to you

Own child 1	Neighbour's child 2	Extended family relation 3	Other specify 4

CONCLUDING ADVICE FROM RESPONDENT

44. "Is there anything else you can tell me about this condition from your experience? Any further comments, advice or suggestions will be appreciated?"

(Narrative) _____

_____

_____

Interviewer: _____ **Supervisor:** _____

Interviewer Signature: _____ **Supervisors Signature:** _____

Interview Date: _____ _____ _____ **Day/Month/Year**

ADDITIONAL COMMENTS

Notes concerning subject's interest and the quality of the interview, and any other noteworthy features and details of this interview

Appendix C: Mystery shopper interview guide

Lead questions for interview with mystery shoppers

Please tell me how things went after you arrived at the shop?

1. What did you say to the shopkeeper?
2. What did he/she say?
3. What illness did he/she think that caused the symptoms of the child?
4. What drugs/ medications did he suggest or give you? *(collect drugs and label them! Record price!!)*
5. Did he/she say why she is suggesting that/those particular drugs?
6. Did he/she instruct you how to use the drugs? How?
7. Did he/she tell of any possible discomfort or reaction from the drugs that he/she has suggested to you e.g. dizziness?
8. Did he instruct you to return if condition does not improve after a certain period of time?
9. Did he/she ask you any questions on the child or the symptoms?
10. Did he/she ask about the child's weight?
11. Did he/she ask if you have used or given the child any type of medications before going or taking her/him to the shop?
12. Did he/she ask as to when illness symptoms started?
13. Did he/she advice you on how to prevent catching malaria? E.g. use of ITN's &/ or IPT?
14. Did he/she ask if you or the child has ever reacted badly after using a certain type of drug?
    a. Did he/she ask as to what drug caused bad reaction and type of reaction?
15. Did he/she advice you to see a doctor? Or to get blood tests in order to be certain of the illness?
16. Did he/she give you any other advice?
17. In general, are you happy or unhappy with the service you received?
    a. What aspects of the service pleased you the most?
    b. What aspects of the service did not please you?

Appendix D: Curriculum Vitae

CURRICULUM VITAE
ANGEL DILLIP

P.O.BOX 32892
DAR ES SALAAM **EMAIL – adillip@ihi.or.tz**
TANZANIA

PROFILE

Name: Angel
Surname: Dillip
Nationality: Tanzanian

EDUCATIONAL QUALIFICATION

2007- June 2012: PhD (Sandwich Program), Public Health and Epidemiology, University of Basel, Switzerland

2002-2004: M.A. (Sociology), University of Dar es Salaam

Concentrations: Advanced Sociological Theory, Methods and Techniques in Social Research, Medical Sociology and Anthropology, Gender and Population Studies, Urban Social Studies

B.A. (Sociology) (Hons)-University of Dar es Salaam, 1999-2002

Concentrations: Social Problems of Urbanization, Medical Sociology and Anthropology, Social Psychology and Counseling, Sociology of Religion, Social Science Research Methods, Race, Class and Ethnicity

WORK EXPERIENCE

Social Research Scientist- **June 2006 - Present**
Ifakara Health Institute (IHI), Ifakara-Tanzania
Implement the ACCESS Malaria Program aimed at improving access to prompt and effective treatment and care for all Malaria episodes in children adults and pregnant mothers. Working on monitoring and evaluation component of the project, activities revolves around;

- studies on morbidity and mortality
- Community survey on care seeking behavior
- Assessment of quality of care at health facilities
- Assessment of drug availability and quality of services in drug selling shops
- Data analysis and report writing.

Assistant Program Officer **February05 - May 2006**
Mwalimu Nyerere Foundation, Tanzania.
Responsible in;

- Concept and protocol development
- Implementation of research and projects
- Data analysis and report writing
- Monitoring and evaluation of intervention

Researcher **April 2004 - January 2005**
Global Network of Religions for Children (GNRC AFRICA), Tanzania
Implement the 'Education for peace program'. Activities revolved around;

- Monitor and review community based education for peace initiatives among children in Dar es Salaam and Zanzibar areas.
- Working with communities and NGOs in designated areas regarding issues touching on the children and youth in difficult circumstances determining how these situations impact, in both the long and short term, on the security and peace of the communities, tolerance and peaceful co-existence.

Postgraduate Teaching Assistant **October 2002- March 2004**
University of Dar es Salaam, Department of Sociology, Tanzania
Duties entailed;

- Facilitating seminar classes for undergraduate classes
- Marking tests, presentations and assignments
- preparing students coursework prior University exams

PUBLICATIONS

- 1. **Dillip. A,** Alba S, Mshana C, Hetzel M., Lengeler C,, I. Mayumana I, Schulze A, Mshinda H, Weiss M.G, Obrist B: Acceptability – A Neglected Dimension of Access to Health Care: Findings from a study on childhood convulsions in rural Tanzania. *BMC Health Services Research* 2012, **12**:113

2. Alba S, M.W.Hetzel, Goodman C, **Dillip A**, Liana J, Mshinda H and Lengeler C: Improvements in Access to malaria Treatment after switch to Artemisinin combination therapy and the introduction of accredited drug dispensing outlets- a provider perspective. *Malaria Journal 2010,* **9***:164*

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