Caregivers' Treatment-Seeking Behaviors for Malaria in Children Five and Under: A Field Study in Uganda's Butaleja District

by

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Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

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Abstract

Background: Reducing malaria mortality is a global priority. Uganda has focused its national strategic plan to have by 2010: 85% of children under five receive first-line antimalarials within 24 hours of fever onset and following diagnostic confirmation. In 2004, artemisinin-combination therapies (ACTs) were adopted as first-line treatment for uncomplicated malaria in children older than 4-months.

Method: A three-study series investigated caregivers' malaria related treatment-seeking behaviors for young children to inform future public health initiatives in Uganda's Butaleja District: a literature review, a household survey, and a multiple case study. In this document, these appear as three manuscripts in Chapters 2-4.

Results: While drug delivery improvements have increased ACT usage, these studies concur that initiatives still failed to meet the 2010 national target. Only 21% of children received blood tests, 31.6% received no antimalarials, 31.6% received "appropriate" (only first-line) antimalarials, and 36.8% received subordinate antimalarials. Among subordinates, 5.8% of children were mis-prescribed ACTs and 22.4% received ACTs and subordinate antimalarials. Home management was an important initial treatment source since visits to public facilities were commonly associated with hardships. Caregivers' knowledge and preference about antimalarials varied with prior experiences and beliefs. The survey evaluated 160 behavioral questions in determining four independent predictors of likelihood that a child would receive an "appropriate" antimalarial: obtaining antimalarials from regulated outlets (OR=14.99); keeping ACT in the home for future use (OR=6.36); reporting they would select ACT given the choice (OR=2.31); and child's age older than 4 months (OR=5.67). The study further employed the Health Belief Model to identify 10 scales of "Assets" and "Challenges" to guide more precise insights into caregivers' behaviors. Four "Asset" scales predicted significantly whether a child received an "appropriate" antimalarial: Precursors to Receiving an Appropriate Antimalarial (R^2=21%); Episode Management (R^2=39%); Caregiver Knowledge (R^2=6%); and Professional Assistance with Critical Decision (R^2=9%). Similarly, two "Challenge" scales were significant predictors: Lack of Assistance with Critical Decision (R^2=9%), and Problems Obtaining a Best Antimalarial (R^2=4%).

Conclusions: To conform practice to policy, this research sequence highlighted the importance of engaging the full spectrum of stakeholders in public health initiatives to manage malaria, including licensed and unlicensed providers, caregivers and family members.

Keywords: Malaria; Children five and under; Treatment-seeking behaviors; Uganda; Predictors; Caregivers.

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List of Acronyms

®	The registered trademark symbol has been used in all circumstances when brand name of drugs are used.
ACT	Artemisinin Combination Therapy
AL	Artemisinin-Lumefantrine
AM	Antimalarial
AMFm	Affordable Medicines Facility-Malaria
ANOVA	Analysis of Variance
ART	Artemisinin
AS-AQ	Artesunate-Amodiaquine
AS-MQ	Artesunate-Mefloquine
AS-PYR	Artesunate-Pyronaridine
AS-SP	Artesunate + Sulphadoxine/Pyrimethamine
CAPSS	Consortium for ACT Private Sector Subsidy
CG	Caregiver
CENTRAL	Cochrane Central Register of Controlled Trials
CFV	Common Factor Variance
CHW	Community Health Worker
CQ	Chloroquine
CQ+SP	Chloroquine + Sulphadoxine-Pyrimethamine
CS	Case Study
DDT	Dichlorodiphenyltrichloroethane
DHA-PPQ	Dihydroartemisinin-Piperaquine
EIR	Entomological Inoculation Rate
GDP	Gross Domestic Product
GMAP	Global Malaria Action Plan
Gov't	Government
HBM	Health Belief Model
HBMF	Home Based Management of Fever
HMIS	Health Management Information System
HP	Trained Health Professional
iCCM	Integrated Community Case Management

IRS	Indoor Residual Spraying
ITN	Insecticide Treated Net
LLIN	Long Lasting Insecticidal Net
MeSH	Medical Subject Heading
P. Falciparum	Plasmodium *Falciparum*
P. Malariae	Plasmodium *Malariae*
P. Ovale	Plasmodium *Ovale*
P. Vivax	Plasmodium *Vivax*
PHF	Public Health Facility
PrvHF	Private Health Facility
PMI	President's Malaria Initiative
QAACT	Quality-Assured ACTs
QDA	Quality Data Analysis
RDT	Rapid Diagnostic Tests
RESP	Response
SD	Standard Deviation
SES	Socioeconomic Status
SP	Sulphadoxine-Pyrimethamine
SPSS	Statistical Package for the Social Sciences
SSA	Sub-Saharan Africa
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic and Health Survey
UMIS	Uganda Malaria Indicator Survey
UN	United Nations
UNICEF	United Nations Children's Fund
USD	US Dollar
USh	Ugandan Shilling
WHO	World Health Organization
Y/N	Yes/No

Glossary

ACT Usage	Usage is acknowledged if any of the medicines taken during the febrile illness was an ACT
Affordable Medicines Facility – malaria (AMFm)	The AMFm is a financing mechanism designed to increase the provision of affordable ACTs through the public, private not-for-profit (e.g., NGO) and private for-profit sectors. The AMFm Is being evaluated In a first phase that includes 9 pilots in 8 countries: Cambodia, Ghana, Kenya, Madagascar, Niger, Nigeria, Republic of Tanzania (mainland and Zanzibar) and Uganda.
AMFm Logo	All AMFm co-paid ACT packaging bears a logo (the "ACTm leaf logo") to facilitate communication campaigns and product Identification. The logo Is applied to all quality-assured ACTs purchased through the AMFm
Appropriate Antimalarial	Defined as having received *only* the age-specific first-line malaria treatment for uncomplicated and severe malaria during the course of the febrile illness.
Artemisinin combination therapy (ACT)	An antimalarial that combines artemisinin or one of its derivatives with an antimalarial or antimalarials of a different class.
Artemisinin Monotherapy	An antimalarial medicine that has a single active compound, where this active compound is artemisinin or one of its derivatives.
Caregivers	A caregiver constituted the parent who provided daily care for the child, including supervision, bathing and feeding.
Cerebral Malaria	Is a consequence of severe malaria. The infected blood cells enter the brain, causing blockage of blood vessels, swelling of the brain and brain damage, resulting in neurological complications such as neurological and cognitive deficits, seizures and coma.
Cure	Elimination of the symptoms and asexual blood stages of the malaria parasite that caused the patient or carrier to seek treatment.
Drug Resistance	Reduced susceptibility of the causal agent to a drug. WHO defines resistance to antimalarials as the ability of a parasite strain to survive and/or multiply despite the administration and absorption of a medicine given in doses equal to - or higher than - those usually recommended.

First-Line Treatment	The government recommended treatment for uncomplicated and severe malaria in 2011. For children less than 4 months, this included quinine (oral or injectable) or artesunate (injectable or rectal) therapy. For children 4 months and older, this included ACT and/or artesunate (injectable or rectal) or quinine (injectable).
Licensed outlets	Licensed outlets are guided by a regulated scope of practice that requires them to be staffed by qualified health providers and to sell medicines as outlined within their specific scope.
Non-Artemisinin Therapy	An antimalarial treatment that does not contain artemisinin or any of its derivatives.
Plasmodium (P)	A genus of protozoan vertebrate blood parasites that includes the causal agents of malaria. *P. falciparum, P. malariae, P. ovate* and *P. vivax* cause malaria in humans.
Private Not-for-Profit facilities	Include non-governmental and faith-based organization
Private Outlets	These constitute licensed for-profit outlets such as health facilities, pharmacies, clinics and drug shops, and a variety of unlicensed outlets such as standalone drug shops, general retail shops, kiosks and mobile vendors.
Public Facilities	The Ugandan public health care sector includes public health facilities (government facilities), CHWs, and private not-for-profit health facilities (non-governmental and faith-based organization).
Public Health Facilities	These facilities include: government run hospitals, health centres IV, III, II, and community health worker.
Public Outlets	Refers to outlets within public facility settings.
Recurrence	The recurrence of asexual parasitaemia following treatment. This can be caused by a relapse or a new infection.
Regulated Outlets	Are licensed outlets which include those outlets guided by a regulated scope of practice that requires them to be staffed by qualified health providers and to sell medicines as outlined within their specific scope.
Relapse	Relapse occurs when the blood stage infection has been eliminated but hypnozoites persist in the liver and mature to form hepatic schizonts. After a variable interval of weeks or months the hepatic schizonts burst and liberate merozoites into the bloodstream.
Severe Anaemia	Haemoglobin concentration of <5 g/100 ml.
Sever *P. falciparum* Malaria	Acute *P. falciparum* malaria with signs of severity and/or evidence of vital organ dysfunction.

Transmission Intensity	The intensity of malaria transmission measured by the frequency with which people living in an area are bitten by anopheline mosquitoes carrying sporozoites. This Is often expressed as the annual entomological inoculation rate (EIR), which is the number of inoculations of malaria parasites received by one person in one year.
Treatment/ Dosing Regimen	The timing and number of doses of an antimalarial used to treat malaria. This schedule often varies by patient weight.
Uncomplicated Malaria	Symptomatic infection with malaria parasitaemia without signs of severity and/or evidence of vital organ dysfunction.
Unregulated private drug delivery sector	Includes those outlets that are unlicensed and operated by untrained staff.

Preface

This statement is to certify that the work presented in this thesis was conceived, conducted, written, and disseminated by Rosemin Kassam. All research described in this dissertation was approved by Simon Fraser University Office of Research Ethics; certificate number 2011s0113 and University of British Columbia Office of Research Services H10-02909.

This dissertation includes a collection of three manuscripts, each representing a sub-study of the overall research program. Each of the studies and manuscripts had input from the following co-authors:

Chapter 2: Kassam R, Liow E, Rasool N, Collins JB. Malaria Management in Uganda: Review of Current Context and Caregivers' Treatment-Seeking Behaviors for Young Children.

Chapter 3: Kassam R, Collins JB, Sekiwunga R, Mweru K, Hashasha D, Tembe J. Caregivers' Treatment-Seeking Behaviors and Factors Associated with Young Ugandan Children Receiving an Appropriate Antimalarial: a Rural Cross-Sectional Survey.

Chapter 4: Kassam R, Sekiwunga R, Mweru K, Hashasha D, MacLeod D, Collins JB, Tembe J. Patterns of Treatment-Seeking Behaviors among Caregivers of Febrile Young Children: a Ugandan Multiple Case Study

Chapter 1. Introduction

1.1. Background and Significance

The United Nations Children's Fund (UNICEF) has proclaimed malaria as the leading killer of children under five worldwide, with malaria incidence estimated at 219 million and deaths reported at approximately 660,000 in 2010.[1] Almost 90% of these deaths occur in sub-Saharan Africa (SSA), of which 91% are children under five. Children between three months and five years of age are most susceptible to malaria due to waning of their natural immunity from maternal antibodies and an acquired immunity that has not fully developed.[2] Among those who survive, many are left with persistent anemia, impaired brain function and/or paralysis hampering physiology and cognitive development.

Reducing child mortality from treatable diseases is a global priority.[3] At a 2000 summit in Abuja, Nigeria, African leaders pledged to halve malaria mortality by 2010.[4] One of the proposed declarations was to have at least 60% of those suffering from malaria be able to access and use correct, affordable and “appropriate” treatment within 24 hours of onset of symptoms. Accordingly, two of the United Nation’s Development Goals focus on reducing this unacceptably high level of child mortality rate.[5] Prompt treatment with effective antimalarial is the cornerstone of case management. However, despite several large-scale initiatives to develop and disseminate effective drugs, the Abuja target continues to be elusive in some SSA countries. The literature proposes that a key impediment to achieving this target has been inadequate access to and use of effective interventions at the population level.[6-9] A large proportion of caregivers delay seeking proper treatment for their children, with many children treated presumptively and often with ineffective medicines obtained from the private sector. Country level data for 2010 indicates that 80% of malaria cases in the World Health Organization (WHO) African region occur in just 17 countries, with Uganda being among the six highest

burden countries along with Nigeria, Democratic Republic of the Congo, United Republic of Tanzania, Mozambique, and Cote d'Ivoire.[10] Though a downward trend in malaria for children under five has been observed in select regions of SSA, there is no such evidence for Uganda.[10-12] In fact, recent health system data and studies across Uganda support either an increase in malaria incidence trend or an incidence rate that remains steady among children under five.[13]

The problems are particularly acute in the eastern rural and remote parts of the Republic of Uganda where a majority of the population lives in high transmission areas, and where the social and economic burden of acute malaria and asymptomatic parasitemia on families and governments is staggering.[14] Families commonly incur out of pocket expenses when seeking malarial treatment for their children coupled with loss of income from missed worked days.[15] Malaria accounts for 25 to 40% of annual outpatient visits and half of inpatient childhood deaths, overall resulting in 39,000 annual deaths in children under five.[16,17] In partnership with international organizations, the Uganda Government invests in large scale efforts to strengthen the delivery of effective antimalarial drugs to communities.[6,12,17-19] In 2004, artemisinin-based combination therapy (ACT) became the first-line malaria treatment for children older than 4-months.[6] The Uganda national case management guidelines were revised in 2005 and 2006 to include a new treatment policy, with provisions made to distribute Coartem© (artemether-lumafantrine) free of charge to government and private-not-for-profit health facilities to the community.[6] However, translating policy into practice to ensure universal access to Coartem© remains a challenge especially in rural areas, due to regular stock-outs of antimalarials at public facilities, dispensing of resistant therapies at health facilities, and limited access to public facilities, regulated pharmacies, and trained health professionals.[20] The outcome is an over-reliance by caregivers of young children on self-management practices in rural settings to obtain antimalarial drugs and on private vendors - many of whom are untrained and unregulated.

Several interventions have been deployed to bring diagnostics and treatment with ACTs closer to the communities in Uganda, including national policies and programs to improve access to ACTs from public providers and licensed private outlets, ban of resistant antimalarials, training of public providers, sensitization meetings with

district level leaders, and information, education and communication campaigns.[21] However, a critical factor in children's health is their obvious reliance on caregivers to seek out appropriate care on their behalf. Research in Uganda supports the notion that inadequate caregiver treatment-seeking practices --- in the context of a weak health system --- is a critical element limiting the use of ACT in children under five.[22,23] In spite this knowledge, interventions mostly center on improving the formal health system (public and licensed private). A few initiatives which have focused on caregivers and their families, have primarily aimed at increasing awareness through mass campaigns and sensitization meetings. While these initiatives have generated some improvement in the usage of ACTs for young children, they have not created sufficient behavior change to achieve the Millennium Development Goals: (Goal 4) to reduce child mortality rate to by two-thirds by 2015, and (Goal 6): to halt the prevalence and death rates from malaria by 2015, or to begin to reverse the incidence of malaria.[24] A reason for their limited impact may be attributed to the simplistic view taken by many such initiatives that a direct relationship exists between caregivers' awareness and action, and improving awareness will automatically change behavior.[25,26] While caregiver awareness about malaria and its treatment is vital to make an informed decision, this one-dimensional concept of behavior change neglects a number of other factors that can influence treatment-seeking behavior.[27] Ecological approaches to health behaviors propose that no single factor individually influences people's behaviors but rather a multiplicity of factors at the individual, family, community, and societal levels interact collectively to influence behavior. Critics of earlier explanatory systems advocate a multi-level system-strengthening approach considering all factors likely to influence uptake of new services and programs by caregivers.[25,28]

1.2. Research Framework

This dissertation summarizes three independent but integrated lines of investigation for improving access to recommended antimalarial treatment for children in rural Uganda occurring during June through August 2011. Research efforts began with a two-phase review of current literature on malaria management (chiefly in Uganda) and a more detailed focus on caregivers' treatment-seeking behaviors. A second line of inquiry

comprised an in-depth field survey of caregivers of children five and under who had experienced a recent episode of fever. Third, eight detailed field-based case studies were aggregated and analyzed for both common and differentiating caregiver experiences. Throughout the research program, conceptualization, operationalization, analysis, and interpretation were guided by the notion that health management is always embedded in the larger contexts of perceptions, expectation, and potential outcomes -- and can be modeled.[27] An established framework is the Health Belief Model (HBM), which is a recognized health research tool to inform future public health programs intending to improve health behaviors.[29] The HBM model guides this study's inquiries about community-based interventions to combat the transmission and mortality of malaria.

1.3. Setting and Objectives

The caregiver research activities in these investigations took place in the District of Butaleja in rural eastern Uganda approximately 210 km northeast of the nation's capital at Kampala.[30] The population of Butaleja District based on 2002 census estimated for 2010 is around 206,300, with approximately 44,300 children under five.[31] The district's chief economy is subsistence farming, with more than four-fifths of the population deriving its livelihood from crop production. Poverty is generally a society-wide phenomenon, although women are likely to be poorer than men because they lack independent sources of income and limited access to resources. Malaria in the district was the highest ranked cause of morbidity during 2007-2009, with about eight in every 10 persons experiencing malaria/fever symptoms.[31]

1.3.1. Research questions and study objectives:

The overall research questions include:

1. What does the recent literature reveal about malaria-related treatment-seeking behaviors?
2. What are caregivers' knowledge, beliefs and practices related to malaria; what challenges do they encounter when seeking treatment; and what common sources of advice and information do they accessed to guide with critical decisions?

3. What are caregivers' experiences when managing children's fever related to malaria?

The objectives of this research are to:

1. Describe caregivers' treatment-seeking behaviors for malaria;
2. Determine what fraction of children received an "appropriate" antimalarial during the last fever episode;
3. Identify educational and environmental behaviors that predict the likelihood of receiving an "appropriate" antimalarial treatment;
4. Quantify caregivers' assets and challenges related to managing malaria for their young children;
5. Assess the differences within sub-counties in the district; and
7. Detail the treatment-seeking patterns and experiences of case studies of eight caregivers while managing the fever (presumed malaria) episode in their youngest child of five years and under. The case studies centered on the febrile episodes resulting in outcome of interest for the children encompassing positive, negative with permanent deficits, and negative with death endings of the child.

1.4. Research Organization

This doctoral dissertation follows the manuscript-based format approved by the Special Arrangements Program in Graduate Studies and the Faculty of Health Sciences at Simon Fraser University. This format includes a collection of three manuscripts, each representing a sub-study of the overall research program, and with a discussion chapter that relates the three manuscripts to each other and the field of research. Unlike some traditional dissertation formats, they do not build on one another in any strictly vertical sense. Rather they are related through the central research questions, but each with its unique study objectives.

This dissertation is organized into five chapters – the central three of which are independent manuscripts. Chapter One presents background information on the significance of the research, the study site, the framework for the dissertation, an overview of the research questions and objectives addressed by the three sub-studies collectively. Chapter Two constitutes a two part review of the literature review: Part I – a critical review of the current status of malaria management in Uganda, and Part II – a

systematic review of caregivers' treatment-seeking behavior in Uganda since the introduction of ACT. Chapter Three represents findings from the first of the two field studies. This survey used a cross-sectional household survey design to examine and quantify caregivers' treatment-seeking behaviors. Chapter Four's field study used a case study methodology to explore treatment-seeking behavior across three segments of caregivers – those whose child experienced a positive outcome and recovered from the illness, those whose child experienced a negative outcome suffering an irreversible deficit, and those caregivers whose child experienced a negative outcome in which their child died. The concluding Chapter Five summarizes key findings from the three sub-studies collectively, discusses potential limitations for both field studies, offers recommendation for future interventions, and concludes by highlighting unique contributions of the three-sub-studies to the overall problem of how best to improve caregivers' treatment-seeking strategies for a young febrile child.

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Chapter 2.

Malaria Management in Uganda: Review of Current Context and Caregivers' Treatment-Seeking Behaviors for Young Children

2.1. Introduction

The World Health Organization (WHO) proposes that the best strategy to manage uncomplicated malaria in young children is to initiate prompt and effective antimalarial treatment within 24 hours of the onset of fever and, where accessible, after confirmation by microscopy or rapid diagnostic tests (RDTs).[1] Presently, artemisinin combination therapies (ACTs) are the recommended treatments for uncomplicated *Plasmodium falciparum* (*P. falciparum*) malaria.[1] Household survey data from ACTWatch 2009-2012 reports the usage of ACT in children under five with fever to have increased from 3-21% in 2009 to 8-44% in 2012 in six African countries Uganda, Nigeria, Zambia, Democratic Republic of the Congo, Benin, and Madagascar.[2] Similarly, the percentage of children who received a prompt ACT also increased from 3.0-19.5% in 2009 to 7.0-35.6% in 2012. While a larger proportion (44.2%) of children in Uganda received an ACT in 2012 than in the other five African countries, less than a fifth (17.8%) received a confirmatory diagnosis for malaria.[2] Furthermore, since not all caregivers seek treatment for their febrile children at public or private outlets, the actual proportion of all children with malaria who receive an ACT may be lower.[3] Analysis of 26 household surveys conducted in nine African Region countries between 2010 and 2012 using a positive rapid diagnostic tests among febrile children as a proxy for confirmed malaria, reported receipt of ACT to range from 1% to 42% with a mean of 16%.[4] Confounding children's health is an obvious reliance on caregivers to seek out appropriate care -- a decision-making process that is complex and influenced by a host of factors. Seeking care for a child's febrile illness and the type of treatment selected is influenced by: caregivers'

knowledge about the cause of malaria, their ability to recognize and correctly interpret its symptoms; their perception of severity; their cultural and local beliefs about health and ill-health; the decision-making structures and resources within households; their past experiences and current treatment expectations; and community factors, including the characteristics of the health system.[5-13]

In regions where malaria is common, the literature proposes that most caregivers associate it with fever.[5,13] However, some cultures believe that certain malaria symptoms such as convulsions and splenomegaly have supernatural causes and should be treated with traditional remedies, since the use of modern care procedures can be fatal.[5,13,14] Caregivers' experiences with malaria also vary. While caregivers know that children can die from malaria, they have also seen instances in which the infection resolves uneventfully.[5] When they finally make a decision to seek treatment for what they presume to be malaria, what actually happens depends on both the demand side – what people want, and the supply side – what is available to them.[5] In many ways this decision-making process in sub-Saharan Africa (SSA) is more complex than parallel decisions in North America where there would be no question whether a clinic or hospital actually has the drug on hand to treat the disease. In SSA, drug shortages within public health facilities are common occurrences.[5] Additionally, caregivers in SSA need to consider household resources, distance to treatment centers, and time of day and week when illness occurs. Consequently, they often delay decisions while they weigh options, gather funds, and make arrangements. Thus, self-medications, reportedly convenient and cheap, are regularly initiated as the initial first-step in the treatment of malaria. Unfortunately, in the case of children, waiting can have severe and irreversible consequences as death can occur very quickly. It is not uncommon for a child to have mild fever on day one, then to develop serious complications the next day and die.

Successful intervention strategies to optimize malaria care among young children require an understanding of caregivers' treatment-seeking behaviors. Given that such behaviors are influenced by demographic factors as well as socio-cultural, economic, political and environmental realities, explorations are needed to better understand the behaviors of the target population and the communities in which they live.[15] Various reviews have documented treatment-seeking behavior in SSA, but none have focused

exclusively on Uganda.[5,9,13,16-18] While countries within SSA share similar socioeconomic realities and public health infrastructure challenges; they differ with respect to political, religious, tribal and other cultural and local influences. These differences may in turn translate into different predisposing, enabling and reinforcing factors that do not lend to generalizability of study results from one country to another.[15] The aim of this review is therefore to conduct a two-part assessment: (1) a critical review of the literature to present contextual information relevant to malaria management in Uganda, and (2) a systematic review of the literature on caregivers' treatment seeking behaviors in Uganda since the introduction of ACT as first-line antimalarial treatment.

2.2. Methods

The current review comprises two parts: (Part I) the current context of malaria management in Uganda, and (Part II) current understanding of caregivers' treatment-seeking behavior for malaria for children under five in Uganda. The web search engines using Google and Google Scholar and the academic databases: PubMed, ERIC, EMBASE, CINAHL, PubMed, OvidSP (MEDLINE), PSYC Info, and Springer Link, Cochrane Central Register of Controlled Trials (CENTRAL) and Cochrane Database of Systematic Reviews were searched for relevant documents. In addition, references from all documents resulting from the electronic searches were screened and appropriate references retrieved for the review. Key words/phrases used in the web search engines included: "sub-Saharan Africa", "Uganda", "malaria", and terms reflecting "topics of interest". These key words/phrases were used in a variety of combinations, and included synonyms, alternative terminologies, alternative spelling, related terms, and variation in word endings. Boolean operators combined and excluded terms from the search strategy. Example of topics explored included: household, caregiver, treatment-seeking, behavior, knowledge, attitude, practice, adherence, home management, drug use, perception, usage, perception, antimalarial, specific antimalarials, indoor residual spraying, bed net, policy, health system (private and public), community health workers, vector control, case management, pathology, burden, transmission intensity, incidence, mortality, economic, treatment guidelines, Ministry of Health, Global Fund, President's Malaria Initiative, Rollback Malaria, AMFm, and others. Similarly, keywords and MESH

terms identified relevant literature from academic databases, for example ("Africa South of the Sahara"[Mesh] AND Malaria) plus keywords used for web search engines. Three of the authors collated all literature relevant to treatment-seeking for malaria in SSA using RefWorks©, a web-based bibliography database manager. All in-vitro studies were excluded. All records resulting from these searches were screened and all documents which met the inclusion criteria of the review paper were retrieved and evaluated. While the authors strove to identify all pertinent documents, there may be some literature inadvertently omitted, such as documents in the grey literature or not yet published.

A literature review identified the relevant documents for the Current Context (Part I) section of the review. Inclusion criteria for this part included: (1) English-language documents, (2) published primary and secondary literature and technical reports, and (3) most recent publications providing context on the following seven pre-specified topics related to malaria management: global and local priorities, pathology, disease burden, vector control, case management, treatment guidelines, and role of health system. While the review primarily focused on Uganda, it also included relevant literature from SSA. A data extraction form was used by two reviewers to extract and record findings from each paper related to seven topics.

For the Treatment-Seeking Behavior (Part II) section of the review, a systematic literature search determined what was known about caregivers' treatment-seeking behavior patterns for management of uncomplicated malaria in children under five in Uganda. For this study, caregivers primarily constituted the parent who provided daily care for the child, including supervision, bathing and feeding. Inclusion criteria for the Treatment-Seeking Behaviors part included the following: (1) published original studies, (2) English-language studies since 2004 considering the use of ACT, (3) conducted in Uganda, (4) population-based exploratory studies using household surveys and qualitative methodology, (5) population-based intervention studies designed *a-priori* to collect baseline household behavior data prior to delivering an intervention, and (6) regional and national studies. All studies which did not evaluate caregivers' treatment-seeking at the population-level were excluded, such as exit interviews from a select population visiting a public or private outlet. The rationale for selecting 2004 as the start year was because it coincided with the year when the WHO recommended countries

revise their malaria policies to include ACT. In some instances reference to earlier studies elucidated change in behavior over time. The two reviewers used a data extraction form to extract and record findings from each paper related to six pre-specified themes: (1) knowledge about malaria, (2) knowledge about the first-line antimalarial, (3) types of sources accessed for advice or treatment, (4) drug use pattern, (5) perception of efficacy and (6) time to initiating care/treatment.

2.3. Results

Figure 2.1 illustrates the literature search undertaken for this review. From a pool of more than 10,000 searches, a total of 1,403 published literatures relevant to SSA were collated in RefWorks©. This included 1,125 primary and secondary *in-vivo* studies and technical reports conducted in SSA but outside Uganda, and 278 primary and secondary *in-vivo* studies and technical reports specific to Uganda.

In all, 140 individual documents were included in the review paper. Tables 2.1 and 2.2 summarize the total number and percentage of documents cited within each of the two parts of the review. Some documents were cited in both Parts of the review and within multiple sections. A total of 125 references were included in Part 1 of the review - contextual information relevant to malaria management in Uganda. These consisted of 63 primary studies, 19 secondary studies, 33 technical reports, 8 editorials, 1 books, and 1 conference proceedings.

Figure 2.1. Flowchart of Search Strategy Used for Parts I and II of the Study

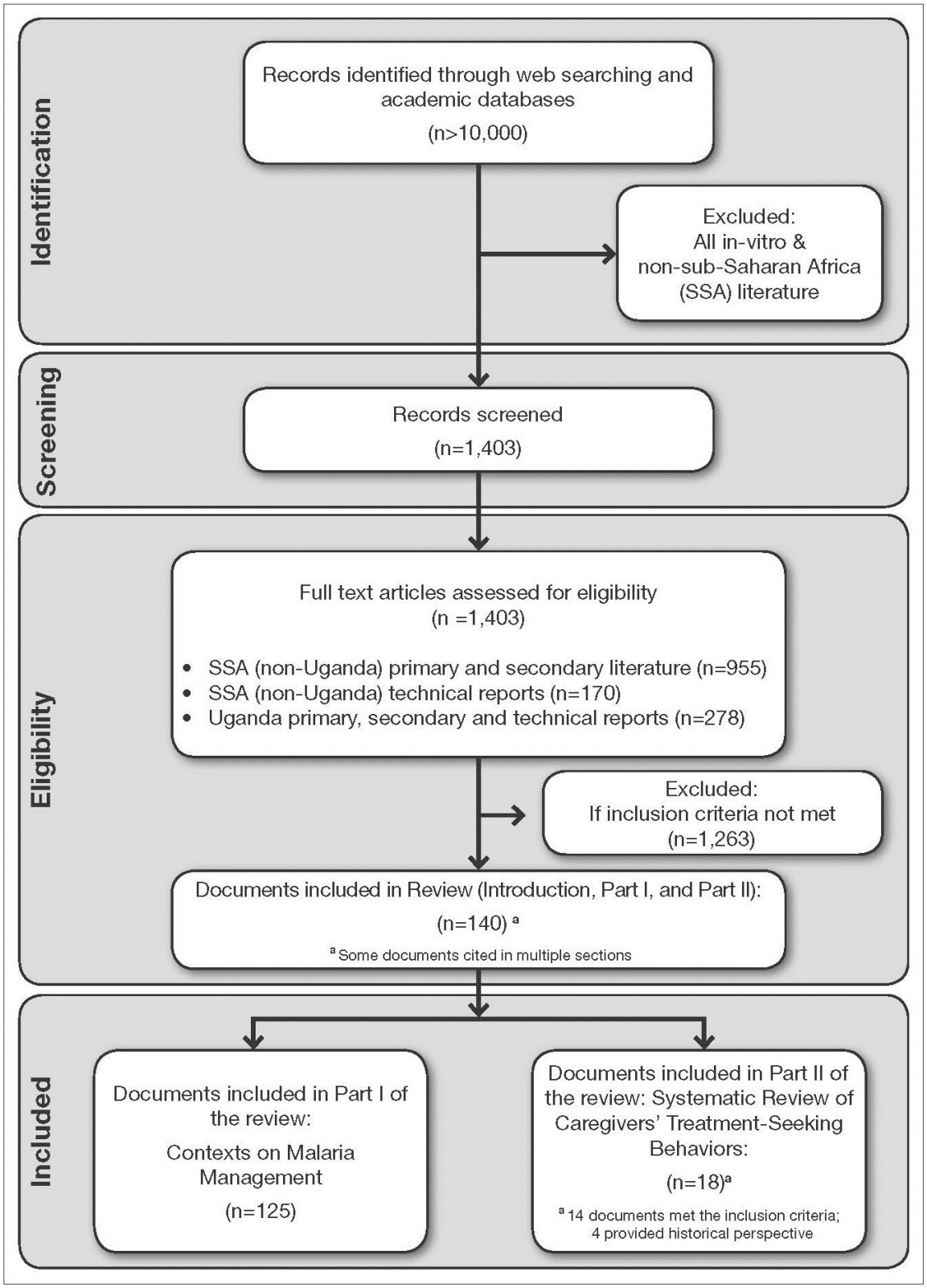

Table 2.1. Categorization of Documents Included in Part I Critical Review: Current Context of Malaria Management in Uganda

Sections	Types of References Used	Number[a]	% of Total[a]
Critical Review (Part I)	**Total Summary**	**125**	**100.0**
	Primary Literature	63	50.4
	Technical Reports	33	26.4
	Secondary Literature	19	15.2
	Editorials	8	6.4
	Books	1	0.8
	Conference Proceedings	1	0.8
Global and Local Priority	**Section Summary**	**11**	**8.8**
	Technical Reports	11	8.8
Malaria Pathology	**Section Summary**	**9**	**7.2**
	Secondary Literature	6	4.8
	Technical Reports	2	1.6
	Primary Literature	1	0.8
Disease Burden	**Section Summary**	**45**	**36.0**
	Primary Literature	20	16.0
	Technical Reports	15	12.0
	Secondary Literature	7	5.6
	Editorials	2	1.6
	Books	1	0.8
Malaria Control	**Section Summary**	**30**	**24.0**
	Primary Literature	12	9.6
	Technical Reports	6	4.8
	Secondary Literature	8	6.4
	Editorials	3	2.4
	Books	1	0.8
Treatment Guidelines for Uncomplicated Malaria	**Section Summary**	**13**	**10.4**
	Primary Literature	5	4.0
	Technical Reports	5	4.0
	Secondary Literature	2	1.6
	Editorials	1	0.8
Role of the Health System in Accessing Antimalarial Medicines	**Section Summary**	**53**	**42.4**
	Primary Literature	37	29.6
	Technical Reports	7	5.6
	Secondary Literature	6	4.8
	Editorials	2	1.6
	Conference Proceedings	1	0.8

[a]Some documents are cited in more than one section.

Table 2.2. Categorization of Documents Included in Part II Systematic Review: Caregivers' Treatment Seeking behaviors in Uganda

Sections	Types of References Used	Number[a]	% of Total[a]
Systematic Review (Part II)	**Total Summary**	**18**	**100.0**
	Historical Literature	4	22.2
	Systematic Review	14	77.8
Introduction	**Section Summary**	**5**	**27.8**
Knowledge about Malaria	**Section Summary**	**8**	**44.4**
Knowledge about Current Antimalarial Drug Policy	**Section Summary**	**6**	**33.3**
Types of Sources Accessed	**Section Summary**	**11**	**61.1**
Introduction	Primary Literature	8	44.4
Initial source of care: home vs public outlets vs private outlets	Primary Literature	9	50.0
Sources of care used over the course of a child's illness	Primary Literature	7	38.9
Source of antimalarials and ACT	Primary Literature	3	16.7
Drug Use Pattern	**Section Summary**	**10**	**55.6**
Medicines obtained by caregivers for children	Primary Literature	9	50.0
Use of antimalarials and ACTs	Primary Literature	5	27.8
Perception of Treatment Efficacy	**Section Summary**	**4**	**22.2**
Introduction	Primary Literature	2	11.1
Traditional herbs vs medicines	Primary Literature	2	11.1
Medicines for malaria	Primary Literature	3	16.7
Time to Initiating Care/Treatment	**Section Summary**	**5**	**27.8**

[a]Some documents are cited in more than one section.

For Part II of the review – caregivers' treatment-seeking behaviors, a total of 18 relevant primary studies were selected. Table 2.3 provides an overview of the 18 studies retrieved to evaluate the six themes related to caregivers' treatment-seeking behaviors in Part II of the review. While only 14 of the selected studies met the inclusion criteria for Part II, an additional four studies which did not meet the inclusion criteria were also included because they provided a valuable historical perspective. For example, the study by Kemble et al (Table 2.3) did not evaluate caregiver behavior with respect to ACT. However, since this study was conducted at the cusp of the transition from chloroquine+sulfadoxine/pyrimethamine (CQ+SP) to ACT, it provided a valuable baseline to gauge how treatment-seeking evolved. Of the 18 studies included, six were national studies and 12 provided regional perspectives covering the time period from 1993 to 2012. Collectively, four of the six national studies published in the grey literature

provided findings from 2009 through 2012 (ACTWatch surveys collected data in 2009 and 2012 and the Uganda Bureau of Statistics (UBOS) collect data in 2009 and 2011), allowing longitudinal assessment of caregiver's treatment-seeking behaviors at the national level. The two national studies by Littrell et al and Nabyonga-Orem et al constituted sub-analysis of data collected from ACTWatch 2009 and UBOS 2011 surveys, respectively. Given the considerable differences in design, methodology, and definitions existing across the 14 studies that met the inclusion criteria for Part II, the review does not represent a Cochrane-like meta-analysis.

Table 2.3. Summary of Studies Included in the Systematic Review Evaluating Caregivers' Treatment-Seeking Behaviors

Author & Publication Year	Study Year	Ntl/ Rgnl[a]	Methodology (Qlt or Quan)[a]	Outcomes Extracted for Following Six Themes					
				Knowledge: Malaria	Knowledge: AM Policy[a]	Sources Accessed	Drug Use Pattern	Perception of Efficacy	Time to Care/Tx[a]
Lubanga et al 1997[138]	1992	Rgnl	Quan	X					
Kengeya-Kayando et al 1994[137]	1993	Rgnl	Qlt	X					
Nuwaha 2002[14]	1999	Rgnl	Qlt & Quan	X					
Kemble et al 2006[72]	2004-2005	Rgnl	Quan		X	X	X		X
Hildenwall et al 2007[139]	2005	Rgnl	Qlt	X			X		
Rutebemberwa et al 2009[140]	2006	Rgnl	Quan			X			
Tabuti 2008[62]	2006	Rgnl	Qlt & Quan	X			X	X	
Rutebemberwa et al 2009[98]	2007	Rgnl	Quan			X			
Rutebemberwa et al 2009[12]	2008	Rgnl	Qlt		X	X	X	X	
ACTWatch 2009[136]	2009	Ntl	Quan	X	X	X	X	X	X
Littrell et al 2011[110]	2009[b]	Ntl	Quan		X	X	X		
Nabyonga-Orem et al 2013[71]	2009	Ntl	Quan			X			
UBOS 2010[91]	2009	Ntl	Quan	X	X	X	X		X
Rutebemberwa et al 2012[119]	2010	Rgnl	Quan			X			
Awor et al 2012[130]	2011	Rgnl	Qlt & Quan			X			
Fink et al 2014[134]	2011[c]	Rgnl	Quan				X		
UBOS 2012[81]	2011	Ntl	Quan				X		X
ACTWatch 2013[92]	2012	Ntl	Quan	X	X	X	X	X	X

[a]Abbreviation: Antimalarial (AM); National (Ntl); Qualitative (Qlt); Quantitative (Quan); Regional (Rgnl); Treatment (Tx).

[b]The data from Uganda was collected in 2009.

[c]Considered baseline data extracted in 2011.

2.4. Discussion - Part I: Contextual Information to Understand Malaria Management

This section presents an overview on: (1) global and local priorities for the management of malaria, (2) malaria pathology, (3) disease burden, (4) malaria control strategies, (5) treatment guidelines, and (6) the role of the health system in accessing antimalarials.

2.4.1. Global and local priority

There has been substantial worldwide interest to reduce the burden of malaria.[19] In 1992 at a Ministers of Health Conference in Amsterdam, the international community established malaria as a global health priority by adopting the Global Malaria Control Strategy.[20] In October 1998, the United Nations Children's Fund and the WHO, in partnership with the President of the World Bank and the Administrator of the United Nations Development Programme, launched the "Roll Back Malaria Partnership" initiative to coordinate global efforts to tackle malaria.[21] Partners in the "Roll Back Malaria" effort included governments of malaria-endemic countries, donor governments, and international non-governmental organizations, the private sector, community-based organizations, foundations, research and academic institutions and civil society bodies. This effort was further accentuated by three important events: (1) the pledge by African leaders in 2000 at a conference in Abuja, Nigeria of their commitment to halve malaria mortality by 2010 (this would later come to be known as the Abuja Declaration); (2) the introduction of the Millennium Development Goal number 6 in 2000 calling for halting and reversing the incidence of malaria by 2015; and (3) the declaration in 2001 by the United Nations that 2001–2010 would be the decade to roll back malaria in developing countries.[22-26] A key strategy proposed by the Abuja declaration was to ensure that by 2005 at least 60% of those suffering from malaria would be able to initiate effective treatment within 24 hours of the onset of symptoms.

In 2008 at the Millennium Development Goals Malaria Summit, the "Roll Back Malaria" partners endorsed the Global Malaria Action Plan (GMAP) to the agenda of malaria control and elimination forward. Of the several targets established by the GMAP,

three included: (1) achieving universal coverage of malaria prevention tools and treatment by 2010; (2) reducing global malaria cases from 2000 levels by 50% in 2010 and by 75% by 2015; and (3) reducing global malaria deaths from 2000 levels by 50% in 2010 and to near zero preventable deaths by 2015.[27] In accordance with Roll Back Malaria, the Uganda National Malarial Control Strategic Plan established the following targets to be achieved by 2010:[28]

- Increase the number of Ugandan households owning at least one insecticide treated net (ITN) to 85% and those owning two ITNs to 60%; increase the number of children sleeping under an ITN to 85%;
- Increase the number of Ugandan districts covered by insecticide residual spraying (IRS) to 15;
- Increase the proportion of children under five to receive antimalarial treatment as per guidelines to 85%;
- Increase the proportion of pregnant women attending antenatal clinics to receive intermittent preventive treatment to 85%; and
- Decrease case fatality from malaria in under five years of age to 2%.

The President's Malaria Initiative (PMI) along with the Global Fund are the main financial contributors to malaria control in Uganda.[3] The PMI, a key component of the U.S. Government's larger Global Health Initiative, was established in 2005 as a US $1.2 billion interagency initiative to reduce the burden of malaria in 15 African countries. In 2006, Uganda was chosen as one of three high burden countries for the initiative. While today there is an increased awareness of malaria and its devastating impact, and there are effective strategies to make it possible to prevent and treat malaria, Uganda is still far from achieving the established targets.[19] Thus, there still remains much work to be done to achieve the stated goals.

2.4.2. Malaria pathology

Malaria is caused by the *Plasmodium (P)* parasite, of which there are four species that routinely infect humans: *P. falciparum*, *P. vivax*, *P. ovale* and *P. malariae.*[29,30] *P. falciparum*, the most predominant and virulent specie in SSA, is responsible for 95% of malaria deaths and is the only specie that can attack the brain.[29,30] The life cycle of *P. falciparum* is complex and undergoes several development

and maturation phases before causing disease in humans.[31] Malaria begins when the mosquito vector, a female anopheline mosquito, injects plasmodial sporozoites into the human blood from its salivary gland during a bite. Within minutes the sporozoites leave the blood stream to invade the liver cells, where they remain and mature over 10-14 days before they are released back into the bloodstream. The sporozoites then enter red blood cells to undergo further maturation, consisting of an irregular cycle of approximately 24-32 hours, before invading various organs in the body.

Disease caused by *P. falciparum* usually proceeds in two forms: uncomplicated malaria - which can be easily treated with full rapid recovery and severe malaria – which ensues when treatment is delayed and vital organs are infected. The initial signs and symptoms are usually nonspecific, mimicking flu-like symptoms. Acute mild to high paroxysmal fever fluctuating with chills and sweating is the most common initial feature, associated with the maturation of sporozoites within the red blood cells followed by rupture of the infected red blood cells.[18] Other symptoms of uncomplicated malaria include headache, fatigue, myalgia, nausea, vomiting, and diarrhea. As the burden of the parasite increases severe malaria follows within hours, manifesting as anemia due to destruction of red blood cells, hypoglycemia with lactic acidosis, respiratory distress, cerebral malaria characterized by abnormal behavior, seizures and coma, and ultimately death.[29,30] Survivors of severe malaria carry a risk of long-term debilitating sequelae such as epilepsy, spasticity, blindness, and behavioral and cognitive impairments.[18] Additionally, those who receive blood transfusions are potentially exposed to HIV infections from tainted blood supply or contaminated syringes and needles.[32]

The severity of malaria is not always correlated with high parasitemia, but is rather often related to an individual's immune status.[33] Given that immunity acquired from the mother wanes after 3–6 months of age and most children under five have not developed sufficient acquired natural immunity to the parasite, young children are most vulnerable with over 75% of morbidity and mortality affecting this age group.[34,35] The lack of natural immunity is further exacerbated by poverty, increased exposure to mosquitoes through inadequate water and sanitation and reduced immunity due to malnutrition, conditions which are prevalent in many rural and remote areas of Uganda.[36]

2.4.3. Disease burden

Malaria transmission intensity

The Metselaar and Van Theil malaria distribution model is commonly used to classify malaria transmission intensity into four categories: (1) *hypo-endemic*: referring to regions where prevalence is less than 10%; (2) *meso-endemic:* referring to regions with significant annual transmission (be it seasonal or perennial) and a prevalence between 11-50%; (3) *hyper-endemic:* referring to regions where prevalence is between 51-75%; and (4) *holo-endemic:* referring to regions with more than 75% prevalence rate.[37] Epidemic areas are defined as those regions prone to distinct inter-annual variation, and in some years no transmission taking place at all. While there is a lack of consensus among experts concerning the best approach to measure malaria transmission, the entomological inoculation rate (EIR) - which estimates the number of bites by infectious mosquitoes per person per unit time (usually per year), remains the best direct measure of transmission intensity than indirect measures such a incidence, prevalence or other traditional epidemiological estimates.[38] Furthermore, the incidence of clinical malaria and mortality in children has been shown to increase with increase in EIR.[39,40]

Uganda is cited as one of the top four countries accounting for the majority of the world's malaria infections after Nigeria, India, and Democratic Republic of the Congo, with malaria contributing to the major share of the disease burden.[4,19] Malaria is highly endemic in 95% of the country, with the temperature and rainfall pattern promoting a consistent, high level, year-round perennial transmission and relatively little seasonal variability.[41] The peak incidence of clinical malaria within these areas usually follows the peak of the rains after a delay of 4-6 weeks. Most cases are seen from December to February and May to July, except for the north where the malaria season is between May and November. The few regions that fall into the hypo-endemic category include Kampala, the major city, and the highland areas of Eastern and Western Uganda, which are prone to epidemics.[42-45] One such affected area is Kabale district, which had been declared in the 1950s to be malaria free by the WHO but in 1999 the incidence of malaria had returned to epidemic values.[46] With approximately 90% of the population living in areas of moderate to very high transmission levels, malaria infection is a very common occurrence throughout Uganda, with almost everyone developing a new

infection every year and everyone experiencing a disease event at some stage in their lives.[18] People in central Uganda, particularly in areas around Lake Kyoga and the Nile river have high EIR, some areas approximating 1,586 infectious bites per year (Apac District) and 562 bites per year (Tororo district).[41]

Incidence and mortality

Well into the 20th century, malaria was a major global health problem.[5] Since then it has been eliminated from Europe, North America and parts of other continents through deliberate vector control programs, treatment with effective drugs, and improved social and living conditions.[5] Today, malaria remains a problem of low and middle income countries in select continents, and in many parts of Africa it is a leading cause of morbidity and mortality.[47-52] Specifically, malaria is strongly associated with poverty, and most prevalent among those living in rural areas and in conflict zones, due to poor quality housing that offers few barriers against mosquitoes and provides limited access to preventive interventions and effective treatment.[53]

The 2011 World Malaria Report estimates a 17% decrease in the overall global incidence of malaria from 2004 to 2010, with a reduction in cases from 235 million in 2004 to 216 million in 2010.[54] While reported cases of malaria in Africa have declined from 190 million in 2004 to 174 million in 2010, a larger percentage of the global decrease has been due to reduction of malaria incidents outside Africa.[54] However, decrease in malaria incidence is not a universal finding across Africa, and significant improvements are thought to occur predominantly in regions with low transmission intensity (for example: South Africa, Rwanda, and Ethiopia), island communities (for example: Zanzibar and Bioko Island), areas with better public health infrastructure than most of Africa (South Africa), and regions with unusually strong local infrastructure for malaria research and monitoring (for example: parts of Kenya, Gambia, and Zambia).[45,55-57]

Malaria mortality trends from 2004 to 2010 also show a significant decline over time.[54,58] The study by Murray et al reported a 32% reduction in global malaria (all ages) mortality, a decrease from a peak of 1,817,000 in 2004 to 1,238,000 in 2010. [58] For children five years and under, malaria mortality rate declined from 1,047,000 in 2004 to

699,000 in 2010, with most deaths occurring in western, eastern and central Africa.[58] Although Murray et al reported 1.3 times more deaths for children under five in Africa than did the 2011 Word Malaria Report, the trends are parallel.[54,58]

For Uganda however, the evidence for a decrease in malaria burden is absent.[45] Malaria continues to be the most commonly reported illness by both public and private health facilities, with annual child deaths estimated at 70,000 to 110,000 in some reports and 39,000 in others.[28,51] The Uganda Health Management Information Systems (HMIS) data - the primary source of disease incidence and mortality for the country -- supports a rising trend in malaria burden in Uganda.[59] Clinically-diagnosed malaria accounts for 25-40% of outpatient visits at health facilities, 15-20% of all hospital admissions, 9-14% of all hospital deaths.[3] Almost half of all hospital deaths among children five and under are due to malaria, with another substantial proportion occurring at home and not accounted for.[3] While the HMIS data source has been criticized for over-reporting malaria diagnosis without diagnostic confirmation, this source may actually under-represent the true burden of incidence, morbidity and mortality of malaria in Uganda as it only considers cases treated at health facilities.[53,60] Given that 60-80% of fever cases are treated outside the public health system, estimates of both private and public settings are necessary to fully quantify the burden.[45,53,60] Other indicators have also suggested a high incidence rate of malaria in Uganda. One such measure is the slide positivity rate, a measure of the percentage of individuals presenting to health facilities with suspected malaria who have a positive diagnostic confirmation which has remained steady in high transmission areas for children under five.[45,61]

High incidence rates have also been confirmed by various studies. A survey of adult household members from a high transmission area of eastern Uganda in 2006 reported between 1 and 30 malaria episodes per year.[62] Another study conducted in eastern Uganda observed a new infection within three month of children receiving an ACT – despite its advertised cure rate of 100%.[63] Two additional studies evaluating the incidence rate in Uganda offer further insights. The first is a retrospective study involving five high pediatric burden hospitals reflecting the diversity of malaria transmission across the country and among children aged 0-14 years. This study reported increases in malaria admissions from 1999 to 2009 to range from 47% to 350% depending on the

hospital site.[59] While researchers adjusted for factors which might influence increased admission rates such as population growth, yearly seasonal variation in rain fall patterns and admissions not diagnosed as malaria, data was not adjusted for inadequacies in local hospital information systems and for the proportion of true malaria diagnosis or changing diagnostic patterns. However, such systematic biases also existed in retrospective studies reporting declining incidence of malaria.[59] The second study used prospective surveillance data involving a convenience sample of 100 children with a median age 5.5 months living in an area of high transmission intensity in eastern Uganda (Tororo). This study also observed the relative risk of malaria increased by 52% from 2008 to 2011, with malaria incidence peaking at 6.5 episodes per child per year at 25 months of age and an average of 4 episodes per year.[55] What was most striking about these results was that these children had near universal access to long lasting insecticide nets (LLINs) and they were followed monthly to ensure adherence to the use of LLINs. noteworthy however is that no child developed severe malaria in this study, suggesting that malaria morbidity can be limited with prompt access to appropriate diagnosis and effective treatment.[59] Albeit limited, current data from Uganda does not yet support the notion that important reduction in malaria incidence has occurred in Uganda.[45]

As has been the case with incidence data, confirming mortality trends for Uganda has been equally problematic due to lack of good quality data on the determinants of death and because many deaths occur outside the hospital setting.[45,64] Nonetheless, the current data does confirm that Uganda continues to experience a high malaria-related mortality rate. The study by Murray et al estimated 23,126 children under five die of malaria each year in Uganda.[58] The 2008 World Malaria Report estimated a higher number -- 39,000 -- ranking Uganda third in the world behind Nigeria and the Democratic Republic of the Congo.[51] A 2005 report from the Uganda Ministry of Health reported malaria to be responsible for 9-14% of hospital deaths, this percentage represented nearly half of children under five.[45] Current estimates from government sources suggest that the number of deaths per 1,000 population has declined from about 6.5 in 2002 to 4.5 in 2010, although the accuracy of this data has yet to be confirmed.[45] Given the weakness of existing health information systems in Uganda, it is likely that these proposed statistics underestimate the true mortality rate.[21,45]

Economic burden

The WHO Africa Malaria Report 2006 estimated malaria to be a significant economic burden, consuming up to 40% of Africa's health budget and resulting in 1.3% reduction in growth and a staggering US $12 billion loss.[65,66] In monetary terms, the economic burden represents the impact of an illness on health and social well-being, and commonly considers direct, indirect and intangible costs.[67] "Health" includes life-years lost to premature death and morbidity caused by the illness, and "social" includes coping strategies and hindrances to usual social participation because of the illness.[67] Examples of direct costs include those incurred by government, donors, communities, households and/or individuals when providing or seeking treatment or preventive interventions; indirect costs include loss of productivity due to absenteeism, debility or premature death, where absenteeism can be due to debility from the illness or time lost to care for a sick family member; and intangible costs refer to the anxiety, pain and suffering resulting from the illness.

For malaria endemic countries of Africa -- including Uganda -- malaria is a major limiting factor to economic and social development, translating in considerable gross domestic product (GDP) loss.[52] At the household level these losses can take a variety of forms such as: decreased school attendance, reduced ability to save and invest, and on-going amendment of economic decisions to pay for expenditures incurred from treatment of malaria. At the country level, there are increased government expenditures on control and treatment of malaria and reduced economic development through decreased industrial and agricultural productivity from loss of man-hours, decreased worker productivity and labor turnover. Although the exact burden of malaria in Uganda is difficult to quantify, the Ministry reports that an estimated 10 to 12 million clinical cases are treated in the public health system alone, accounting for 30-50% of outpatient visits and 35% of hospital admissions.[28,68] The GDP loss from malaria was estimated to be US $11 million in 2003 or 5% of total health expenditures in Uganda.[69] A retrospective malaria morbidity economic impact study using time series data from 1999-2003 concluded a far worse outcome, with the GDP loss estimated to be US $49.8 million or US $1.93 per capita.[67] However, both sources confirm a significant impact leading to decreased long term growth and social development of the country.

With approximately 60-80% of fever cases treated outside the Ugandan public facilities, malaria is also a significant economic burden for families who must pay out of pocket. At the household level, expenditures include spending on preventive measures such as purchasing nets, aerosol sprays, mosquito coils, purchase of antimalarial medicines from informal and private sectors, transportation to public facilities, loss of wages from absenteeism, cost of supporting a child that has suffered irreversible morbidity from malaria and even funeral expenses.[67,70] A recent study aimed at quantifying out-of-pocket expense associated with care seeking outside the home for children under five estimated households to spend per fever episode US $7.26 in urban areas and US $3.39 in rural areas.[71] While those living in urban areas spent twice as much on consultation and on medicines than did those in rural settings (consultation: urban US $ 4.85, rural US $ 2.85; medicines: urban US $ 4.35, rural US $2.06), the overall burden of expense was proposed to be greater among those living in rural areas, since those living in rural areas sought care more frequently (urban: 68.5% vs rural: 83.9%) and incurred greater transportation cost per care episode sought (urban: US $ 1.65 vs rural: US $ 2.35). Furthermore, caregivers in rural areas are disproportionately less educated and of lower socioeconomic status relying primarily on subsistence farming, resulting in less disposable income and therefore lower capacity to pay.

Lost wages incurred from missed work is another factor contributing to economic cost. Kemble et al found the median duration of illness in children to be 4-7 days, with caregivers spending a median of 2 days (range: 0-21 days) caring for their child rather than performing their usual activities.[72] It is estimated that a single episode costs a family an average of almost US $9 in lost productivity because of the inability to work. With a GDP per capita of just US $300, this constitutes a loss of 3% of annual income with every malaria episode for a household of median income.[69] The rural farming communities such as Butaleja, the loss in annual income is likely to be higher. Approximately 77% of the population survives on $2 a day or less; it is, therefore, not uncommon for households to spend 25% of their yearly income on malaria or to take loans to pay for treatment costs.[62,73,74]

In addition to loss of income from absenteeism by family members caring for young children suffering from malaria, there is the loss of future economic opportunities

for children suffering from malaria.[67] It is estimated that in endemic areas, malaria can impair up to 60% of a child's ability to learn because of absenteeism from school and/or the inability to learn due to morbidity following a severe episode of malaria or from fatigue experienced from chronic anemia.[46,70] High infant and child mortality rates have also been linked to high fertility rates to ensure a sufficient high number of children surviving to adulthood; which in turn reduces the family's investment in education per child, especially for girls. All these aspects translate into limited employability, reduced future educated human capital, increased employment costs, reduced incentive from foreign investments and reduced GDP.[67,70]

2.4.4. Malaria control

Malaria control is defined as efforts to reduce malaria morbidity and mortality to a locally acceptable level through the use of preventive and curative measures.[19] While it is widely accepted that the development of a safe, efficacious, and affordable vaccine will be the single most important contribution to reducing global malaria mortality; it is unlikely that such a vaccine will be available for widespread use in the immediate future.[18,75] In the meantime, the strategy for sustained malaria control in endemic countries remains through vector control interventions, such as indoor residual (house) spraying (IRS) and insecticide treated nets/curtains (ITNs), and prompt case management with antimalarial drugs.[18,76]

Strategies for vector control

The intent of malaria vector control is to protect individuals against infective mosquito bites, thereby reducing the intensity of transmission at the community level. Both ITNs and IRS have been shown to be effective.[19,30,77,78]

Insecticide-treated bed nets and curtains are the main vector control strategy used in Uganda.[19,30] ITNs work by both repelling and killing mosquitoes. The recently developed long lasting insecticide treated nets (LLINs), which remain effective for up to three years without retreatment, have been shown to reduce mortality in children under five in malaria-endemic areas of SSA by about a fifth.[30,53,75,79] The Uganda National Malaria Control Program target for 2010 was to have 85% of household own one or

more ITN and to have more than 85% of children under five sleep under an ITN the previous night.[28] In collaboration with the President's Malaria Initiative, the Global Fund for AIDs, Tuberculosis and Malaria and community-based organizations, several large-scale programs have been implemented in Uganda over the last few years to promote the use of ITNs through mass campaigns, free distribution to infants and pregnant women through antenatal clinics, provision of subsidized ITNs through the private sector, and sale of ITNs at full cost through the commercial sector.[19,45] Between 2006 and 2011, the Uganda Demographic and Health Survey (UDHS) demonstrated notable increases in the number of households that owned at least one ITN (from 16% to 60%), and the number of children under five who reported sleeping under the net the previous night (from 10% to 43%). While the ownership of ITN was reported to be higher in rural areas than urban areas (60% vs 58%), usage for children under five was lower in the rural (49% in urban vs 42% in rural). Current data suggests that ownership does not necessarily assure usage.[80,81] Despite remarkable increase in ownership and report usage of ITNs, the 85% targets for 2010 have yet to be reached.

IRS is another vector control strategy that was reinstated in Uganda in 2006, after an almost 35 year hiatus. In the 1950s there was an all-out-effort to eliminate malaria by exterminating the parasite with massive spraying campaigns using dichlorodiphenyltrichloroethane (DDT). While this effort successfully eradicated malaria in the developed nations, it was not successful in many low to medium income countries.[19,78] In SSA this initiative was abandoned in 1969 before malaria eradication ever started, due to decrease in foreign aid, political instability, wars and population displacement. The vector control strategy was further hampered in 1972 when the use of DDT was banned because of its indiscriminate use and threat to the environment and human health. This resulted in an exponential rise in the incidence of malaria in developing countries that had not yet fully eradicated the disease. Given the devastating humanitarian and economic costs of malaria and the absence of equally effective and efficient alternatives, the WHO recently announced a major policy change to allow IRS on the inside walls of houses and huts by trained and supervised personnel once or twice a year in malaria infested countries.[82] Of the 12 insecticides currently recommended for indoor spraying, DDT (with its longest residual efficacy when sprayed on walls and ceilings) continues to have a major role in vector control. To-date,

environmental assessment and impact of DDT on personnel trained in IRS operation in Uganda have shown DDT to have no deleterious effect. The 2011 Uganda Demographic and Health Survey (UDHS) indicated that only 7 % of the households had received IRS in the 12 months preceding the survey.[81]

Despite the renewed emphasis on vector control in Uganda, disseminating and ensuring appropriate use of such strategies has been an enormous task in the context of limited governmental resources and socioeconomic development. Studies investigating caregivers' knowledge about preventive strategies have found that misconceptions regarding the factors responsible for causing malaria and strategies to prevent against mosquito bites continue to exist.[62,83] A 2006 study in eastern Uganda reported that not all of their study participants were able to name the WHO recommended preventive strategies; for example, 77% knew of bed nets, 76% of clearing bushes, 61% of closing windows and doors in the evening; but only 5% knew of IRS.[62] Still, others have found that knowledge did not translate into use, with fewer households owning ITNs and using insecticides, and even fewer ensuring their children slept regularly under ITNs.[72,84] These challenges have kept coverage levels far below targets set by the Uganda National Malaria Control Strategic Plan, with significant differences in coverage existing between districts.[19,56] The modest scale-up efforts have unfortunately failed to translate into reduced malaria morbidity and mortality, making effective case management an essential component of malaria control strategies in Uganda.[45,55-57]

Strategies for case management of uncomplicated malaria

Malaria control through prompt treatment with effective antimalarial drugs continues to be the mainstay for managing acute cases.[30,54,75,79] For uncomplicated malaria, the objective of treatment is to cure the infection as rapidly as possible, where "cure" is defined as the elimination of the parasite from the body.[1] The first antimalarial drug quinine was discovered in Peru and Ecuador in 1632.[85] Quinine, a component of the bark of the cinchona tree, remained the mainstay of malaria treatment for centuries until more effective synthetic antimalarials such as chloroquine became available in the 1940s.[85] Chloroquine was the treatment of choice for decades, and its introduction raised hopes of malaria eradication until resistance to this drug spread over most of Africa in the 1970s and 1980s.[78] Several other synthetic antimalarials were developed

during and post-World War II, many to protect combat troops from malaria. As *P. falciparum* became increasingly resistant to chloroquine, newer generations of antimalarial drugs were introduced onto the market such as amodiaquine, sulfadoxine/pyrimethamine (SP), primaquine, mefloquine, atovaquone-proguanil, and most recently artemisinin derivatives.[86]

However, with increasing resistance to the new agents, there has been a resurgence of quinine use. Many SSA countries (including Uganda) now recommend it as monotherapy for second line treatment of uncomplicated malaria (first line in children under 4-months) and as first line injectable therapy in severe malaria.[85] Quinine has a narrow therapeutic window with considerable side effects -- both mild and severe -- even at therapeutic doses. Examples of mild side effects include tinnitus, reversible impairment of hearing, headache and nausea, and severe manifestations of vertigo, vomiting, abdominal pain, diarrhea, marked auditory loss and loss of vision.[85] Intravenous injection is associated with venous thrombosis and hypotension can occur when the drug is given too rapidly.[85] Intramuscular injection is painful and known to cause abscesses.[85] Studies assessing the effectiveness and efficacy of quinine given every eight hours for 7-days in combination with another antimalarial demonstrate optimal cure rates compared to shorter day regimens with and without another antimalarial.[85] However, the prolonged treatment course with tolerability problems makes this regimen difficult to adhere to, resulting in higher than acceptable failure rates. Earlier studies from Southeast Asia and South America demonstrated cure rates ranging from 76% to 98%, lower cure rates associated with 3-day mono and combination therapy and higher cure rates with 7-day regimens that were combined with another antimalarial.[85] African studies have found higher recurrent rates with 3-day regimens ranging from 30% to 50%.[85] A recent Ugandan randomized, open label effectiveness study designed to distinguish between recurrence and re-infection reported 64% cure rates in children younger than five taking quinine (23.1% of failures were due to recurrence) compared to 96% cure rates with ACT (no recurrence).[87] Though adherence was comparable for both groups on day-3 (quinine 13%, ACT 12%), non-adherence to quinine increased notably with increasing days on the therapy (19% on day-5, to 31% on day-6 and to 44% on the day-7); with overall non-adherence being higher in the quinine than ACT group (55% vs 17%). Reasons for non-adherence included forgetting to give the medicine (50%),

vomiting (22%), not able to take the drug because of illness (4%) and not understanding instructions. Significantly more caregivers in the quinine group reported difficulty with taking the drug regularly and not adhering compared to those in the ACT group. While non-adherence resulting in a shortened treatment course and/or less frequent administration is one plausible explanation for the poor cure rates observed in this study, the added influence of other factors such as poor drug quality, resistance to *P. falciparum* and pharmacokinetics cannot be ruled out. Reducing the daily dose of a 7-day regimen from 10 mg/kg every 8 hours to one given twice daily has not been shown to be a viable option, with failure rates due to recurrent infections increasing from 6.3% to 16.3% when the dose is decreased to twice a day.[85]

A major advance in the search for effective treatments for drug-resistant malaria came in the mid-1970s with the isolation of artemisinin (ART) from the Chinese wormwood *Artemisia annua.*[65,78,88] Because of the complex process involved with cultivating and harvesting the plant before the drug can be extracted, processed and modified to its optimized pharmacological properties, artemisinin has been more expensive to produce compared to synthetic chloroquine. Currently three artemisinin derivatives are available on the market: artemether, artesunate, and dihydroartemisinin. All three derivatives have exceptionally high potency against combination chloroquine + sulfadoxine/pyrimethamine (CQ+SP) resistant *P. falciparum*, producing faster parasite clearance and fever resolution than any other licensed antimalarial drugs.[78] Their main limitation as monotherapy has been their poor pharmacokinetic properties, including short half-lives, resulting in substantial treatment failures.[18,78] Artemisinin and its derivatives have, therefore, been marketed as combination therapies with longer-lasting partner drugs to assure sustained antimalarial pressure after the plasma concentrations of the artemisinin derivatives have fallen below therapeutic levels. This combination allows artemisinin derivatives to work rapidly to reduce the pool of parasites by 90%, followed by the partner drug clearing the remaining 10% of the parasites with its different mechanism of action. These combinations offer the dual benefit of increased antimalarial efficacy and reduced likelihood that a resistant parasite will propagate and spread.[5] However, in high malaria transmission areas, the post-treatment prophylactic effect of ACTs is short-lived, necessitating on-going vigilance and management of new infections.[63] ACTs need to be given for 3 consecutive days for optimal efficacy, the short

treatment and simplicity of dosing makes it a better option than quinine.[1,78] Current ACTs include: artemether-lumefantrine (AL: Coartem©); artesunate-amodiaquine (AS-AQ); dihydroartemisinin-piperaquine (DHA-PPQ); artesunate-mefloquine (AS-MQ); artesunate + sulfadoxine/pyrimethamine (AS-SP) and artesunate-pyronaridine (AS-PYR). Of these six combinations, only the first three are available in Uganda.[1,78]

There are important differences between very young children and older children/adults in the pharmacokinetics of many medicines, such as absorption, distribution, metabolism and elimination.[1] However, despite the need for such information, few ACT studies have focused on this age group, partly because of ethical considerations relating to the recruitment of very young children to clinical trials and partly because of the difficulty of repeated blood sampling in this age group.[1] Those that have included a range of children have often not done subgroup analysis to distinguish between the different age groups. In spite of the limited literature, there is a general notion that the minor differences in oral absorption and bioavailability that may exist between the different artemisinin derivatives are not clinically significant.[1] It is rather the pharmacokinetic properties of the partner drug that determine the choice of ACT combination in children. Accordingly, based on information of the partner drug, the only combination not recommended in children is the artesunate-mefloquine. Earlier trials with mefloquine monotherapy (25mg/kg) had raised concerns of tolerability in African children and there currently remains insufficient safety data on this combination.

Factors that influence efficacy (such as dose, dosing interval, duration of treatment and administration methods) and determine whether or not a young child will retain their treatment (such as taste, volume, consistency and gastrointestinal tolerability) also need to be considered.[18,65,78] As with most medicines, dosing of ACTs in children is based on weight. However, limited availability of infant formulations often necessitates splitting of adult tablets, making it difficult to ensure accurate and reliable dosing in children.[1,65] Tablets also need to be frequently crushed and mixed with food or water to ease administration in children. In such situations, the bitter taste from the crushed tables can be hard to mask, often resulting in the child either refusing to take the medication or spitting out the tablets. Since young children are more likely to vomit an antimalarial drug, mothers need to be given advice on administration techniques and

on the importance of re-administering the drug if it is immediately vomited. Only recently, a new dispersible formulation for artemether-lumefantrine has been introduced in the market, one that rapidly disperses in a small amount of water to produce a sweet-tasting formulation. However, since the absorption of lumefantrine in artemether -lumefantrine is fat dependent, it needs to be co-administered with milk or other fat-containing food to achieve adequate blood levels. In circumstances where appropriate administration instructions are not provided to the caregiver, sub-therapeutic dosing is a frequent outcome.

2.4.5. Treatment guidelines for uncomplicated malaria

Development of resistance to antimalarial drugs has been a substantial problem, requiring governments to regularly modify their antimalarials drug policies to ensure optimal efficacy. The causes for drug resistance were several: spontaneous mutations in the parasite; logistical hurdles and lack of sustained funding to implement control strategies; wars and population displacements; prevalence of counterfeit or clinically substandard medicines that contain small quantities of the active ingredient to subvert efficacy; and failures to follow a full course of treatment because of cost, inconvenience, and undesirable effects of the drugs. A change in antimalarial policy is recommended when treatment failure with existing drugs exceeds 10%.[1]

In 2004, the WHO recommended that all countries revising their malarial treatment policies opt for a three day regimen of ACTs as the first-line agents for uncomplicated malaria caused by *P. falciparum*, and artesunate or quinine in combination with tetracycline or doxycycline or clindamycin as the second line treatment given over seven days.[1] This was followed by a request to national health authorities of all countries with *P. falciparum* malaria to withdraw the marketing of non-ACT therapies for uncomplicated malaria. In high transmission areas parasitological confirmation (microscopy or rapid diagnostic testing) is recommended to prevent resistance and indiscriminate use of ACTs, however, for those under five years of age in whom malaria can rapidly become fatal, treatment remains empirical based on clinical diagnosis where parasitological diagnosis is not accessible.[1] Given that malaria is the most common cause of fever in children under five in SSA, antimalarial treatment is recommended to

be initiated if there is a history of fever (>37.5^{o} C) in the previous 24 hours with no other obvious cause and/or presence of anemia as evident by pallor of the palm.

Uganda's antimalarial drug policy has been revised twice in the past two decades: first in 2001, when the first line treatment for uncomplicated malaria was changed from chloroquine monotherapy to combination chloroquine (CQ) + sulfadoxine/pyrimethamine (SP); then again in 2004, when the combination CQ+SP was abandon in favor of ACTs.[28] Artemether -lumefantrine given twice a day for three days was recommended as the first agent of choice, with an amendment to use artesunate-amodiaquine once daily for three days as an alternative treatment when artemether -lumefantrine is not available.[89] Contrary to the WHO recommendations, quinine 10 mg/kg given every eight hours for seven days as monotherapy was recommended as the second-line treatment.[89] More recently, dihydroartemisinin-piperaquine was introduced as an alternative to quinine.[90] The recommendation of quinine as a second line agent remains a concern given the challenge of adherence due to its prolonged and complex regimen and associated side effects.[85] However, quinine which is relatively cheap and often the only available antimalarial option renders its removal from the guidelines a risky proposition.

While Uganda adopted the WHO policy to replace all antimalarial therapies with ACTs, the policy has not been easy to implement, with the 2009 Uganda Malaria Indicator Survey (UMIS) data indicating only 23% of febrile children received an ACT.[91] The lack of adequate resources, funding and effective regulation has resulted in the failure to implement this policy among all dispensers of antimalarial drugs.[78] Deployment of ACTs under the brand name of Coartem© in the public sector has increased exponentially since the policy, but periodic drug shortages continue which are further confounded by the ongoing availability of a wide range of subordinate antimalarial drugs.[3] In the private sector, artemisinin derivatives continue to be available as monotherapies due to the high market price of ACTs despite their ban in 2005.[12,92] The use of artemisinin derivatives as monotherapy is particularly troubling due to the risk of developing resistance that can compromise the effectiveness of ACTs.[93] With evidence of progressive reduction of in-vitro susceptibility to artemisinin of *P. falciparum* in China and Vietnam, where artemisinin monotherapies have been deployed for years; there is

fear of the resistance spreading to Africa. Concerns are heightened given that both chloroquine and combination CQ+SP resistance emerged first in Southeast Asia and subsequently migrated to Africa. If *P. falciparum* malaria develops resistance to the artemisinin derivatives, there are currently no alternative compounds available to treat malaria for the next several years.[94,95]

2.4.6. Role of the health system in accessing antimalarial medicines

A key requirement for ensuring adequate treatment of malaria and in achieving the Millennium Development Goals is strengthening of health systems in SSA.[19] A health system is defined by the WHO as the sum of all organizations, institutions, people and resources whose primary purpose is to improve health.[96,97] In Uganda, both public facilities and private (licensed and unlicensed) outlets are accessed for antimalarial drugs. Licensed outlets are guided by a regulated scope of practice that requires them to be staffed by qualified health providers and to sell medicines as outlined within their specific scope.[12,72,98] Traditional healers continue to play an active role, but their importance in the management of malaria varies and tends to be limited to the management of complications such as convulsions and splenomegaly.[12] Prior to the wide use of ACT, across both public and private outlets, only a quarter of the antimalarial drugs dispensed were considered adequate according to the antimalarial policy, and even fewer are administered in the correct dose and within 24 hours of experiencing fever.[72]

Public facilities

The Ugandan public health care sector includes public health facilities (government facilities) and private not-for-profit health facilities (non-governmental and faith-based organization). Public health facilities are stratified into five categories: Hospitals at the district, regional and national levels; Health Centers IV at the health sub-district level; Health Centers III at the sub-county level; and Health Centers II at the parish level.[3] Although not a physical structure, Health Centers I are recognized as operating at the community level where volunteers provide health services as part of a team of community health workers (CHWs).[3] Because of Uganda's decentralized

system, districts are directly responsible for the delivery of health services and the implementation of health programs. In each district, the District Health Officer oversees all facilities in the district, including those operated by not-for-profit organizations (mainly faith-based organizations) and the private sector. The district develops its own health plans and budgets and receives financial support through a variety of mechanisms directly from the Ministry of Finance, Planning and Economic Development. The role of the Ministry of Health is in policy development, strategic planning and orientation, technical support, guidance and supervision, monitoring, evaluation, quality assurance and interventions in cases of epidemics. Much of the Ministry's efforts have been directed towards public health facilities, with the aim to improve the quality of dispensing through training of frontline health workers and to reduce cost of care through the removal of user fees in 2001.[99] Although the removal of user fees initially resulted in increased utilization of public health facilities, reports indicate that this has since decreased. A proposed explanation for this decrease has been the weakness and gaps in the current system and the indirect and direct costs incurred by households associated with travel, time away from work and unofficial treatment costs.[98,100,101]

Despite government investment in the public sector, access to formal health care remains low in Uganda. In the 2008 National Service Delivery Survey, the average distance to a public health facility was 6 km in rural settings.[102] Among those who do access these facilities, they often do so when home or private sector treatments fail or when complications occur.[12] Reasons for seeking care outside public facilities are several: geographical barriers such as distance; financial constraints; demands of domestic life which makes timely access difficult; and general dissatisfaction with public facilities which include inconvenient hours, long wait times, inadequate staffing, poor quality of service, failure to consistently and adequately stock drugs, charging of unofficial fees in spite of user fee removal, and poor attitudes among health workers who reportedly become readily impatient when asked for clarifications.[6,14,18,32,72,98,103-109] Of those who do access care from public facilities, care is often substandard despite implementation of national malaria control policies in the public sector.[110] Children frequently are prescribed suboptimal antimalarial drugs and incorrect doses. Further, more than 80% do not undergo diagnostic testing due to lack of laboratory diagnostic capacity in terms of availability and training.[83,91,111,112] Even when ACT is present, a

survey by Zurovac et al suggests health workers will prescribe quinine and other non-approved antimalarial therapies.[89] At the community level, such challenges have created over-reliance on drug vendors for antimalarials resulting in a proliferating private drug delivery sector, which in rural settings are often not trained or licensed.[113]

In an effort to bring diagnostics and treatment for malaria, pneumonia and diarrhea closer to the community so young children may receive appropriate treatment within 24 hours of onset of symptoms, Uganda has been gradually rolling out the integrated community case management (iCCM) program in various regions. The iCCM builds on the home-based management model implemented in 2001, using CHWs as the major strategy to deliver care.[114] This program is proposed as a first-line entry point for families with sick children who are not able to access case management at health facilities, it is not intended as a cheap alternative or a panacea for the current weak health system.[115] The delivery of iCCM is recognized to be complex, requiring both health care providers and recipients of care to be fully engaged for desired outcomes to be achieved. From the health system perspective, this requires CHWs to follow several pre-specified steps sequentially and completely and for referral health centers to respond adequately and in timely fashion.[116] From caregivers' end, it requires effectively recognizing signs of illness, quickly seeking appropriate care, and promptly implementing recommended treatment and/or referral.[117,118] Deviation from this expectation by either stakeholder can result in adverse outcomes and development of drug resistance, as well as loss of confidence from the community in CHWs' ability to effectively treat their children.[116]

A short-term multi-country study by Ajayi et al demonstrated that trained CHWs under research setting are able follow iCCM protocols.[114] In this study, just over half of children with fever (57%) in the Iganga and Bugiri Districts of Uganda were treated by a CHW with an ACT, with 49% of fever episodes treated within 24 hours.[114] While these results are encouraging, the use of CHWs was not universal despite community wide education and communication campaigns, leaving several questions unanswered. These include 1) understanding why almost half of caregivers in this community opted to not access care from CHWs, 2) among those who sought care from a CHW why did nearly half wait more than 24 hours after onset of fever, and 3) why did a quarter of CHWs not

communicate danger signs, risks of side effects and follow-up opportunities despite the training and supervision received.[114] A subsequent study approximately two years later in a similar region (Iganga-Mayuge Demographic Surveillance Site) found the use of CHWs for treatment of fever in children under five to be lower (11%) despite previous efforts promoting its use.[119] Rutebemberwa et al found those caregivers who used traditional remedies as part of their initial care were less likely to use CHWs. [119]

An earlier study evaluating Home-Based Management of Fever (HBMF) using CHWs found the most common reasons for not using services provided by CHWs included previous experience of treatment failure, lack of confidence in a non-medical person, occurrence of stock-outs, and long distances to point-of-treatment.[120] To this end, there still remain gaps in understanding of what constitute optimal models to implement and scale-up such programs.[117] Further research is needed to understand the best role of CHWs in the delivery of ACTs, and to determine their capacity to deliver complex tasks required by the iCCM program in the face of inadequate and inconsistent remuneration models and a health system that experiences frequent stock-outs of medicines and supplies. Studies are also needed to understand what inherent and extrinsic CHW characteristics are likely to ensure long-term retention, timely accessibility in the face of limited or no financial incentives, and adherence to treatment protocols even when consumers demand for polypharmacy and treatment in spite of negative diagnostic test results. Furthermore, training programs for CHWs should be validated to ensure they are responsive to varying educational needs of potential CHWs, and appropriate refresher training need to be considered with adequate apprenticeship and on-going supportive supervision and monitoring which does not tax already limited human and health resources.[45,118,121-123]

Private drug outlets

Health providers working within private sector outlets remain the closest providers to most communities in Uganda, with numbers surpassing those of public providers.[124,125] However, while antimalarials are provided free at public facilities, these medicines can only be purchased from private outlets. Private outlets include licensed for-profit outlets such as health facilities, pharmacies, clinics and drug shops, and a variety of unlicensed outlets such as standalone drug shops, general retail shops, kiosks

and mobile vendors. Most licensed outlets are permitted to sell prescription and non-prescription medicines, with the exception of licensed drug shops which are limited to selling only Class C non-prescription drugs - which since 2008 have included ACTs.[125,126] Unlicensed outlets are generally operated illegally by unqualified staff selling a range of prescription and non-prescription drugs. Despite functioning outside the law, these outfits remain popular in rural areas where they fill an important service delivery gap created by staff shortages and regular drug stock-outs at public health facilities.[127,128] A 2010 census of public and private outlets in three rural eastern districts of Uganda accentuated the abundance of unlicensed drug vendors by estimating 77.1% of 445 public and private outlets consists of unlicensed private vendors.[129]

Studies in Uganda confirm that more than half of caregivers (range: 51.7-56.6%) use private outlets to treat childhood fevers.[92,110,119] Reasons for preferring private outlets include proximity, drugs always in stock, low cost, the option to select from a wide range of drugs and quantity with or without prescription, and the opportunity to purchase drugs on credit.[92,98,130,131] Buying on credit is particularly attractive for mothers who often lack control over household resources, allowing them to access treatment which can be paid for later when they secure the funds. Since private drug vendors are first and foremost business people, many readily succumb to selling what customers demand; and in circumstances when a customer lacks the ability to make an appropriate drug decision, this can limit the demand for effective interventions.[132] Furthermore, the limited availability to cost-effective ACTs in the private sector and a greater preference for cheaper less-effective non-ACT antimalarials has been a major concern.[109,131,133] ACTs have generally been priced according to market demands, costing 5-20 times the price of non-ACTs. A 2007 survey conducted in five eastern and four western districts of Uganda reported the price of a full adult equivalent treatment dose of ACT to range from US $5.40-12.00 (USh 9,000-20,000).[109] Prices varied within and between districts as well as between different private outlet types, with ACTs being most expensive at private clinics, followed by pharmacies and drug shops. Comparatively, the private sector price for a full adult dose chloroquine was estimated at US $0.12-0.60 (USh 200-500) and for sulfadoxine/pyrimethamine US $0.12-0.60 (USh 500-1,000).[109]

In an effort to increase access to ACTs, a small scale project (Consortium for ACT Private Sector Subsidy - CAPSS) was introduced between August 2007 and May 2010 in five mostly rural districts of eastern Uganda to test the feasibility of disseminating subsidized ACT nationally.[126] Following the CAPSS project, the nation-wide program Affordable Medicines Facility – malaria (AMFm) hosted by the Global Fund was introduced in April 2011. The AMFm primarily relies on the licensed private sector distribution network for increasing: (1) the availability of quality-assured ACTs (QAACT) at public and private outlets, (2) their affordability, (3) their market share compare to other antimalarials, and (4) their use among vulnerable populations by reducing cost of QAACT to eligible first-line private and public sector buyers by about 95% through a buyer co-payment financing mechanism paid directly to manufacturers.[134,135] QAACT include ACT products which meet pre-specified quality assurance criteria. All AMFm packaging bear a logo to facilitate product identification and come with recommended retail prices to ensure benefits from co-payments are carried down in the supply chain.[125] For Uganda, this recommended price based on 2010 US dollars was $0.47 for an adult equivalent treatment dose and $0.12 for a child equivalent treatment dose.[125] With the advent of AMFm, a range of ACTs are now available on the market: (1) AMFm subsidized QAACTs – which include nationally approved first-line ACTs whose manufacturers are part of the scheme, (2) nationally approved first-line ACTs whose manufacturers are not part of the AMFm scheme, (3) QAACTs which include non-first line ACTs, and (4) non-QAACT.[135]

Evaluation of the CAPSS project at different points of the intervention revealed the program to have increased availability of ACT at private outlets, reduced the median cost of a full ACT treatment, and increased ACT market share in relation to other antimalarials sold in districts.[126,135] At the end of the four year pilot, availability of subsidized ACT at licensed outlets had increased from 0% at baseline to 82% at the end of the study, the market share of subsidized ACT (estimated as the portion of antimalarials purchased) increased from 0% at baseline to 69% at the end of the study, and the median price of an adult and child equivalent treatment dose of subsidized ACT was comparable and in some cases more favorable to that of quinine.[126] The exact cost of various medicines was not provided. At the end of the pilot, children under five living in the intervention districts were 10 times more likely to receive an ACT compared to

children in adjacent districts where the CAPSS project had not been implemented (18% vs 2%).

Studies evaluating the national AMFm program have generally reported higher uptake of ACT and higher prices than the pilot studies.[125] The usage of ACT for children under five with fever has been reported at 44.2%, with 35.6% receiving an ACT within 24 hours of fever.[92] However, across all types of private outlets, only 10.4% reported stocking any ACT and 9.0% stocked a QAACT product, with market share estimated around 58.9% for any ACT and 38.5% for QAACT.[125,135] Within this pool, all pharmacies surveyed reported stocking an ACT but only three-fifths (63.5%) of drug shops stocked an ACT (data was not stratified for licensed and unlicensed), and a negligible percent (0.3%) of unlicensed general retailers stocked an ACT. When the 84.5% of outlets not carrying any antimalarials were excluded from the analysis, the percentage of those who stocked any ACT increased to 75.6% (69.0% of drug shops and 75.6% of general retailers) and for QAACT 63.3% (59.7% drug shops and 73.7% of general retailers).[125,135] The median cost of ACTs for adult and child treatment doses, including AMFm products, was reportedly higher than the recommended AMFm prices (adult US $1.68 and child US $0.67 vs AMFm adult US $0.47 and child US $0.12). Prices were reported to be higher at drug stores than pharmacies and general retailers.[125]

Though the CAPSS project and the national AMFm program has successfully increased the uptake of ACT among children under five, this proportion still falls short of meeting the national goal to have 85% of children with malaria receive prompt and effective treatment within 24 hours. Additionally, Fink et al in their household survey following the implementation of the national AMFm reported that while 47.5% of children under five with multiple episodes of fever received an ACT, only 32.6% of these episodes were treated with an ACT.[134] Thus, the increase in availability and market share of ACTs from baseline in licensed private outlets has not translated into similar increases in usage for children under five with fever. Equally concerning is the higher than recommended retail prices consumers paid nationally for ACTs, households continuing to purchase less than the full recommended dose of ACT despite lower prices, and those more affluent opting for more expensive ACT brands in the belief that the lower priced AMFm products were inferior.[126,134,135] Lastly, it remains unclear how

AMFm will ultimately impact the poorest families who live in rural and remote areas who obtain their medicines from unlicensed sources. Data from national studies demonstrated few unlicensed outlets reported stocking ACTs, consistent with the reality that ACTs are not approved for sale at these outlets.[125,126] A recent study assessing practices of unlicensed drug outlets in a rural eastern district of Uganda in 2011 revealed limited effect on the dissemination of ACTs in communities that rely on such vendors, with only 26.7% of these outlets stocking any form of ACTs, and with prices ranging from US $0.54 - 5.40 (USh 1,500-15,000).[113] Further research is needed to determine the influence of the AMFm on rural setting, which will ultimately impact the nation's progress toward achieving the Millennium Development Goals.

2.5. Discussion - Part II: Caregivers' Treatment-Seeking Behaviors

Since the adoption of ACT as the first-line treatment for uncomplicated malaria in Uganda, caregivers' malaria-related treatment-seeking behaviors have changed in some ways but continue to resist change in others. Treatment-seeking patterns are summarized using six broad themes: (1) knowledge about malaria, (2) knowledge about first-line antimalarial, (3) types of sources accessed for advice or treatment, (4) drug use patterns, (5) perception of efficacy and (6) time to initiating care/treatment.

Various study types were reviewed, both from peer-reviewed journals and the grey literature. Important methodological differences existed between the various studies, making comparisons between studies difficult and challenging to draw meaningful inferences to other regions of Uganda. For example, all national studies represented urban and rural settings, however most used different sampling approaches to select households within these settings. The ACTWatch surveys used a four-stage sampling strategy that involved initial stratification based on two unspecified strata representing low to moderate and high malaria endemicity before randomly sampling for households.[92,136] On the other hand, the Uganda Malaria Indicator Survey (UMIS) and the Uganda Demographic Health Survey (UDHS) used a two-stage sampling strategy that initially stratified based on 10 broad regional clusters informed from the 2002 Population Census before sampling for households.[81,91] Geographical differences were

accompanied by differences in demographic characteristics, socioeconomic status, and access to public and private drug outlets, with households in urban settings generally having higher education attainment, higher socioeconomic status and better access to public facilities and pharmacies than those in rural settings.[72] In addition, studies differed in their data collection strategy - with some employing qualitative methodology and others using cross-sectional surveys or mixed methodology; they differed in their classification of health facilities and drug outlets; few focused on laboratory confirmed cases of malaria; and none provided answers to all behavior questions of interest. Many studies also employed hypothetical scenarios to assess behavior rather than (or in addition) to actual cases, likely resulting in reporting and recall bias. Still, despite these limitations, the studies collectively illuminate generic patterns of behavior among caregivers, shedding light on knowledge, practices and preferences.

2.5.1. Knowledge about Malaria

Studies conducted in Uganda acknowledge that caregivers have always been able to recognize fever in children, although in the early 90s most were not able to associate fever with malaria and many were not aware that mosquitoes are the cause of malaria.[137,138] Table 2.4 summarizes findings from studies reporting on caregiver' knowledge about malaria since 2004. While no recent study has evaluated knowledge about the cause of malaria exclusively in caregivers of children under five, two studies which included such caregivers report this understanding to have increased appreciably over the years. These include the 2009 national Uganda Malaria Indicatory Survey (UMIS) which evaluated women between the ages of 15 and 49, and the 2006 regional study by Tabuti which included both men and women from households with dependents ranging from 1-15 years.[62,91] Collectively, the studies report most respondents (83-96%) living in eastern regions correctly attributed malaria to mosquitoes.[62,91]

Table 2.4. Caregivers' Knowledge about Malaria

Author & Publication Year (Study Year)	Cause of Malaria		Malaria Symptoms	
	Mosquitoes	Misconceptions	Fever	Misconceptions
Hildenwall et al 2007[139] (2005)	-	-	Considered to be a sign of malaria[a]	-
Tabuti 2008[62] (2006)[b]	96%	71%[c]	97%	82%
ACTWatch 2009[136] (2009)	-	-	76.0%[d]	-
UBOS 2010[91] (2009)[e]	87.0%	16.1%[c]	-	-
ACTWatch 2013[92] (2012)	-	-	79.1%[d]	-

[a]Author examined what illnesses were associated with fever.
[b]Sample included men and women from households with dependents ranging from 1-15 years of age.
[c]Respondents provided at least one incorrect answer.
[d]Respondents were asked what the main symptom of malaria was.
[e]Sample not restricted to caregivers, included women ranging from 15- 49 years.

With respect to knowledge about malaria symptoms, fever remains the best known symptom, with about three-quarters of caregivers in two national studies reporting fever as the main symptom (76% in 2009 and 79% in 2012).[62,92,136,139] On the other hand, caregivers' knowledge about other clinically recognized symptoms of malaria and how presence or absence of these symptoms impact treatment-seeking has been less well-examined. Hildenwall et al found most caregivers in eastern Uganda participating in their qualitative study to be less familiar with symptoms other than fever, whereas Tabuti noted knowledge to be high for some symptoms in their general population.[62,139] Over four-fifths of respondents (80-86%) in the Tabuti study correctly associated chills, joint pains, weakness/lethargy, headache, and loss of appetite with malaria.[62] However, few related vomiting (61%), abdominal pain (53%), irritability (6%), chest pain (6%), dehydration (2%), and labored breathing (2%) with malaria, and none mentioned convulsions.[62] It is reasonable to presume that caregivers would establish high temperature as the primary indicator than confirm other symptoms in very young children, as few will voluntarily report such symptoms.

Misconceptions about malaria presentation and its causes have also been reported prevalent among the general population, often co-existing with correct knowledge. In the regional Tabuti study, many respondents who listed a correct symptom also in the same breath mentioned symptoms not clinically associated with

malaria, such as sneezing (82%), all types of cough (77%) and sore throat (58%). Similarly, respondents in both the Tabuti study and the 2009 national Uganda Malaria Indicatory Survey (UMIS) list mosquito bites alongside non-legitimate causes such as drinking dirty water and eating seasonal foods as the cause of malaria.[62,91] These misconceptions were more prevalent in rural areas and among the poorly educated and less wealthy. Further research is needed to establish if misinformation about malaria is more prevalent in certain geographical regions than others, and what impact this has on caregivers' decision making when seeking treatment or prevention options.

Important knowledge gaps regarding severe symptoms of malaria also emerged. In their study, Hildenwall et al found most caregivers did not share the notion that fever was a non-specific sign associated with several childhood illnesses or that a child could suffer from more than one illness at a time.[139] Accordingly, any symptom combination involving fever was routinely interpreted to be malaria and managed as malaria.[139] Additionally, while most caregivers were able to recognize severe life threatening symptoms in their children, few were able to interpret these symptoms and suggest correct actions.[139] For example, Hildenwall et al reported most caregivers recognized difficulty breathing as a serious condition requiring immediate attention, but there was little consensus about its cause or proposed action.[139] Some caregivers associated difficulty breathing with a delay in treatment of malaria, advocating taking the child to a hospital; whereas others attributed its cause to being exposed to the wind or rain and advocated home treatment with herbs and antipyretics. Studies from the 90's report similar finding with convulsions and splenomegaly, with many caregivers holding a strong belief that these symptoms were caused by spirits and, therefore, best treated by traditional medicines.[14]

2.5.2. Knowledge about current antimalarial drug policy

Table 2.5 summarizes findings from studies reporting on caregivers' knowledge about current antimalarial policy. Review of national studies reveals that awareness about ACT has increased substantially since 2009, a period which coincides with mass media campaigns to promote the introduction of the national AMFm program. Whether this awareness has increased across all regions of Uganda still remains to be confirmed.

However, this increased awareness about ACT among caregivers does not always translate into changed behaviors favoring the preferred treatment choice.

Table 2.5. Caregivers' Knowledge about Current Antimalarial Policy

Author & Publication Year (Study Year)	Correctly Identified First Line Therapy (ACT)[a]	Perceived ACT as the Most Effective Antimalarial[a]	Respond to Fever within 24 Hours (Same or Next Day)
Kemble et al 2006[72] (2004-2005)	17%[b]	-	-
Rutebemberwa et al 2009[12] (2008)	Some caregivers mentioned ACT[a]	-	-
Littrell et al 2011[110] (2009)	57%	35.1%	-
ACTWatch 2009[136] (2009)	-	35.1%	99.1%[c]
UBOS 2010[91] (2009)	-	-	83.4%[d]
ACTWatch 2013[92] (2012)	84.2%[e]	63.8%	-

[a]Abbreviation: artemisinin combination therapy (ACT).
[b]Chloroquine+sulfadoxine/pyrimethamine (CQ+SP) was first-line treatment at the time of the study.
[c]Respondents knew to "respond to fever the same or next day".
[d]Sample not restricted to caregivers, included women between 15-19 years. Did not assess knowledge about policy, instead asked when a child "should be taken for treatment".
[e]Did not assess knowledge about policy, instead asked "what medicines can be used to treat malaria".

In 2004 only 17% of caregivers living in urban settings were able to identify the then first-line therapy chloroquine + sulfadoxine/pyrimethamine (CQ+SP) and none reported knowing about the impending change of the first-line treatment to ACT that year.[72] While Rutebemberwa et al in 2008 noted only few caregivers residing in eastern Uganda were able to name ACT as the first-line treatment, a national study conducted in the subsequent year reported that 57% of caregivers possessed this knowledge.[12,110] This variation may be due to regional differences, although findings from the national study were not stratified to substantiate whether regional differences in knowledge about first-line antimalarial accounted for such variability.[110] Furthermore, only 35% of all caregivers in the 2009 national study named ACT as the most effective antimalarial, and only 14% of those who obtained an antimalarial requested ACT by name.[136] This discrepancy between knowledge and practice was also noted in a subsequent national study conducted in 2012.[92] In this study, 84% of caregivers spontaneously named an ACT as the medicine to be used for malaria, but only 64% named ACT as the most

effective antimalarial and 44% of children were reported to have received an ACT.[92] Similarly, less than half of caregivers (45%) who reported having seen or heard of the AMFm ACTs ever reported purchasing an ACT with an AMFm logo.[92]

No study has examined caregivers' knowledge regarding government recommendations for starting a febrile child under five on an antimalarial; however, some studies have explored different notions around timeliness of treatment. Almost all caregivers in the 2009 ACTWatch survey and 83% of women in the 2009 Uganda Malaria Indicatory Survey (UMIS) reported knowing to initiate treatment for fever on the same or next day.[91,136] Although, this knowledge varied across different regions of Uganda (75-89%), those living in east-central regions were least knowledgeable.[91]

2.5.3. Types of sources accessed

Direct comparison between studies was difficult because not all studies offered definitions for terms such as "self-care", "home treatment", "did not seek treatment", and "at home care". Many studies classified health facilities and private outlets differently, a few stratified public and private outlets down to individual purveyors, and traditional and spiritual healers were not explicitly investigated by most of the studies which were reviewed. Furthermore, there were notable differences in prevalence of various sources accessed for initial care between national and regional findings, suggesting national findings may not always reflect regional practices. Presence of such variability substantiates the need to conduct region-specific baseline assessment prior to developing interventions for improving caregivers' treatment-seeking behavior. Despite these differences, care seeking in Uganda is pluralistic, with home management being a common first response and private outlets the most common external source sought by caregivers over the course of a child's febrile illness.[12,72,92,98,110,119,130,136] For this review, the term "home management" is used to refer to all care/treatment initiated from home such as the use of tepid sponging, giving traditional herbs and/or drugs which have been leftover from previous treatments, borrowed from family members or bought from private outlets for future use. "Public outlets" refers to public facilities such as government run public health facilities, CHWs, and private not-for-profit facilities (non-governmental and faith-based organization), which are generally staffed by qualified health providers and

provide free prescription medicines, medical consultations and diagnoses. “Private outlet” includes licensed for profit settings such as hospitals, clinics, pharmacies, drug stores, and a variety of unlicensed outlets such as standalone drug shops, general retail shops, kiosks, mobile vendors and traditional and spiritual healers.

Initial source of care: home vs public outlets vs private outlets

Caregivers’ first sources of care have been examined in national and regional studies, findings from these studies are summarized in Tables 2.6 and 2.7. Included in this review were three national studies and one regional study that evaluated treatment seeking pattern across three sources: home, public outlets and private outlets, and two national studies which estimated treatment seeking at external sources only (data collected by the Uganda Bureau of Statistics).[71,91,92,110,130,136]

Table 2.6. Sources of Initial Care for Febrile Children

Author & Publication Year (Study Year)	Public Health Facility	Public Outlets[a]	Private Outlets[b]	Home Only
Littrell et al 2011[110] (2009)[c]	14.9%	16.4%	41.7%	42.0%
ACTWatch 2009[136] (2009)[c]	14.9%	16.4%	41.7%	42.0%
Awor et al 2012[130] (2011)	16.5%	19.8%	55.8%	24.4%
ACTWatch 2013[92] (2012)[d]	9.4%	13.3%	26.1%	60.6%

Note: cell entry reflects % of all children with fever.
[a]Public outlets include: community health workers; not-for-profit health facilities; public health facilities.
[b]Private outlets include: churches; drug shops; general stores; grocery stores; pharmacies; private clinics; private health facilities; spiritual healers; traditional healers.
[c]Excludes 3.3% of children whose caregiver did not seek treatment for their fever.
[d]Excludes 2.7% of children whose caregiver “reported they did not do anything to treat the fever”.

Table 2.7. External Sources for Initial Care for Febrile Children

Author & Publication Year (Study Year)	Public Outlets[a]	Private Outlets[b]
Nabyonga-Orem et al 2013[71] (2009)	50.3%	48.4%
UBOS 2010[91] (2009)	44.2%	55.6%

Note: cell entry reflects % of children with fever taken to an external source for initial care.
[a]Public outlets include: field workers; mobile clinics; public health facilities.
[b]Private outlets include: field workers; pharmacies; private clinics; private doctors; private hospitals; private mobile clinics; shops; traditional doctors.

When the focus shifts away from home management and onto first external sources only, national data by the Uganda Bureau of Statistics (UBOS) in 2009 suggests visits to private and public outlets to be similar at about 50%.[71,91] However when care across all three sources (home vs private outlets vs public outlets) are compared, national trends suggest an increase in the proportion of caregivers initiating care from their home from 42% in 2009 to 61% in 2012, with a corresponding decrease in private outlet visits from 42% in 2009 to 26% in 2012.[92,136] Visits to public health facilities remained steady, ranging from 9-15%.[92,136]

While the regional study by Awor et al from eastern Uganda reported visits to public health facilities to be comparable to national findings (17%), this study reported a much lower preference for home management (24%) and higher preference for private outlet (56%) in 2011.[130] However, with no previous studies conducted in this eastern region of Uganda, it was difficult to infer how caregivers' treatment seeking practices for initial care had evolved over time. The observed differences between national and regional trends iterate the need for additional regional and national studies to better understand behavior patterns. Nonetheless, regardless of the observed variations, these findings suggest that despite removal of user fees at public facilities caregivers continue to favor private outlets for initial treatment.[92,110,130,136]

While the impact of home treatment on accessing various external sources was not investigated by most studies, Rutebemberwa et al reported children in eastern Uganda who were given herbs as part of initial care were more likely to visit a private outlet than a CHW, and their visit to a public health facility was often delayed.[119] Based

on an earlier study which found the use of traditional herbs to be independent of traditional healers in this region, as many were already familiar with these products, suggests factors other than seeking care from traditional healers likely deterred caregivers from accessing CHW or public health facilities.[12] Several practical reasons have been cited in the literature for using private drug vendors over public outlets, these include: close proximity, dependable and adequate supplies of drugs, access to cheaper drugs, opportunity to purchase drugs on credit, access to a variety of drug/dose/formulation/quantity, and friendly service.[12,98]

Sources of care used over the course of a child's illness

Data was extracted from six studies to examine caregivers' treatment-seeking pattern over the course of a child's febrile illness, three were regional studies and four national studies. Findings from these studies are summarized in Tables 2.8 and 2.9. The three regional studies were conducted in rural eastern districts of Iganga-Mayuge between 2006 and 2010.[98,119,140] One of the four national studies reported on data collected by ACTWatch in 2009, one reported on data collected by the Uganda Bureau of Statistics (UBOS) in 2009, and one reported on data collected by ACTWatch in 2012.[71,92,110]

Table 2.8. Sources of Care over the Course of a Child's Febrile Illness

Author & Publication Year (Study Year)	Public Health Facility	Community Health Worker	Public Outlets[a]	Private Outlets[b]	External Outlets[c]	Home Only
Rutebemberwa et al 2009[140] (2006)	25.7%	0.6%	26.3%	20.9%	47.9%	52.1%
Rutebemberwa et al 2009[98] (2007)	19.9%	1.2%	22.0%	37.7%	60.1%	39.9%
Littrell et al 2011[110] (2009)[d]	20.7%	2.1%	22.7%	53.0%	71.7%	28.3%
Nabyonga-Orem et al 2013[71] (2009)	-	-	-	-	82.3%	17.7%
Rutebemberwa et al 2012[119] (2010)	16.8%	11.4%	28.1%	51.7%	80.5%	19.5%
ACTWatch 2013[92] (2012)[e]	23.8%	4.3%	31.0%	56.6%	87.6%	12.4%

Note: cell entry reflects % of all children with fever.
[a]Public outlets include: community health workers; not-for-profit health facilities; public health facilities.
[b]Private outlets include: drug shops; general stores; grocery stores; pharmacies; private clinics.
[c]Includes public and private outlets.
[d]Excludes 3.3% of children whose caregiver did not seek treatment for their fever.
[e]Excludes 2.7% of children whose caregiver "reported they did not do anything to treat the fever".

Table 2.9. External Sources of Care over the Course of a Child's Febrile Illness

Author & Publication Year (Study Year)	Public Health Facility	Public Outlets[a]	Private Outlets[b]
Littrell et al 2011[110] (2009)	28.7%	31.7%	73.3%
Rutebemberwa et al 2012[119] (2010)	20.8%	35.0%	64.3%

Note: cell entry reflects % of children with fever taken to an external source over the course of their illness.
[a]Public outlets include: community health workers; not-for-profit health facilities; public health facilities.
[b]Private outlets include: drug shops; grocery stores; pharmacies; private clinics; private health facilities.

Findings from Iganga-Mayuge Districts suggest the use of home management alone to have reduced by more than half between 2006 (52%) and 2010 (20%) and use of external sources sometime over the course of the child's illness to have increased from 48% in 2006 to 81% in 2010.[98,119,140] This increase in use of external sources primarily reflects an increase in the use of private outlets (from 21% in 2006 to 52% in 2010), with the use of public outlets remaining stable (26% in 2006 and 28% in 2010).[98,119,140] When only visits to external sources are considered, preference for private remains greater (64%) than for public outlets (35%).[119]

Findings from national studies conducted in 2009 and 2012 also report a greater caregiver preference for visiting an external source (72-88%) compare to just managing their child via home management (12-28%).[71,92,110] As with initial care, visits to private outlets were more common (53%) than to public outlets (23%), with 4% of caregivers visiting both public and private outlets.[110] When home management is discounted and only visits to external sources are considered, preference for private remains greater (73%) than public outlets (32%).[110]

While data from two national surveys reported most (88-93%) caregivers who visited an external source tended to seek treatment from one source as oppose to multiple sources, this finding was not validated by regional studies.[71,110] Generally visits to CHWs remain low across both national and regional studies conducted between 2009 and 2012, with fewer than 12% of caregivers reporting consulting with a CHW over the course of a child's febrile episode (range: 2-11%).[92,110,119] This remained true even in regions with long standing initiatives to improve malaria management.[119]

As with initial care, factors reported to influence sources of care include: distance to public outlets, reputation for quality treatment and availability of inexpensive or free treatment.[92,98,136] Among those who visited a public outlet in the study by Rutebemberwa et al 45% cited short distance as an important factor.[98] Additionally, caregivers who perceived their child to be severely ill (with fever and the presence of vomiting and diarrhea) were more likely to visit a public outlet, because they believed workers at these facilities to be more experienced and qualified to treat serious illnesses.[98] There were no significant differences in age, sex and education of the household head, age and sex of the child, socioeconomic status between those who did or did not use public outlets.[98]

Source of antimalarials and ACT

Tables 2.10 and 2.11 report on sources of antimalarials and ACTs since 2004, respectively. Until 2012 fever management had been reported to be better at public outlets than private outlets. A sub-analysis of data obtained from the 2009 national ACTWatch study reported that a greater proportion of children whose caregivers sought care at public outlets were likely to receive an antimalarial than those whose caregiver only visited private outlets (68% vs 54%, $p<0.001$).[110] Children were also 3.8 times more

likely to receive ACT if their caregiver visited a public outlet than a private outlet (47% vs 12%, p<0.001).[110] However, coinciding with the implementation of AMFm, national trends suggest a shift in practice among licensed private outlets, with greater numbers of ACTs now obtained from private outlets (30% in 2009 vs 42% in 2012), and fewer from public outlets (46% in 2009 vs 36% in 2012).[92,136] Whether this translates into a greater proportion of visits to private outlets resulting in receipt of ACT than public outlets still remains to be evaluated. Home-stock as a source of antimalarial and ACT has remained steady since 2009, with 21-23% of antimalarial given to children sourced from home and 24% of ACTs sourced from home.[92,136]

Table 2.10. Antimalarials Sources among Febrile Children Who Received an Antimalarial

Author & Publication Year (Study Year)	Public Outlets[a]	Private Outlets[b]	Home Only
ACTWatch 2009[136] (2009)[c]	26.4%	52.8%	20.8%
ACTWatch 2013[92] (2012)[d]	33.3%	47.3%	23.3%

Note: cell entry reflects % of children who received an antimalarial.
[a]Public outlets include: community health workers; public health facilities.
[b]Private outlets include: drug shops; general retailers; grocery stores; pharmacies; private health facilities.
[c]Excludes 3.3% of children whose caregiver did not seek treatment for their fever.
[d]Excludes 2.7% of children whose caregivers "reported they did not do anything to treat the fever".

Table 2.11. ACT[a] Sources among Febrile Children Who Received an ACT[a]

Author & Publication Year (Study Year)	Public Outlets[b]	Private Outlets[c]	Home Only
ACTWatch 2009[136] (2009)[d]	46.4%	29.7%	24.0%
ACTWatch 2013[92] (2012)[e]	36.4%	41.6%	24.0%

Note: cell entry reflects % of children who received an ACT.
[a]Abbreviation: artemisinin combination therapy (ACT).
[b]Public outlets include: community health workers; public health facilities.
[c]Private outlets include: drug shops; general retailers; grocery stores; pharmacies; private health facilities.
[d]Excludes 3.3% of children whose caregiver did not seek treatment for their fever.
[e]Excludes 2.7% of children whose caregiver "reported they did not do anything to treat the fever".

2.5.4. Drug use patterns

Medicines obtained by caregivers for children

A number of studies suggest that most medicines obtained by caregivers are less effective than ACT, many offer at best symptomatic relief, and several are not recommended for treatment of uncomplicated malaria.[12,62,72,81,91,92,110,136,139] Only the qualitative study by Rutebenberwa et al in 2009 explored this practice in depth, reporting caregivers drug choices to be diverse and influenced by their perception of illness, past experiences, cost and availability.[12] In their study, Rutebemberwa et al found most caregivers were not able to differentiate between antimalarials and non-antimalarials, as such many frequently used antipyretics/analgesics as first-line treatment for malaria.[12] Caregivers in this study reported using a range of medicines to treat fever in children, such as: antipyretics and analgesics such as Panadol©, diclofenac© and ibuprofen, antimalarials such as chloroquine, Fansidar©, quinine, and Coartem©, anticonvulsants such as diazepam, steroids such as dexamethasone and various antibiotics. Overall, chloroquine, Fansidar© and Panadol© were the three most common medicines used for fever.[12,62]

Use of antimalarials and ACTs

Tables 2.12 and 2.13 summarize the use of antimalarial among children with a febrile illness and the use of ACT among those who received an antimalarial, respectively. While ACT as first-line treatment for uncomplicated malaria has been national policy since 2004, treatment with ACT is far from being universal. In 2009 national surveys reported 52-60% of Ugandan children with fever were treated with an antimalarial and less than a quarter (21-23%) with an ACT.[91,110] There was no association found between receipt of ACT and household economic status.[110] In the ACTWatch 2009 national study about three-fifths (63%) of antimalarials given were non-artemisinin monotherapies, with quinine being the most common (28%) and ACT constituting a relatively small portion at 36%.[110] A six district household survey in eastern Uganda conducted prior to implementation of the national AMFm program also reported ACT usage at 37%.[134] While more recent national studies report the use of antimalarials in 2011 and 2012 to remain at the 2009 level (54-65%), the usage of ACT doubled to 44% with the introduction of AMFm.[81,92] The proportion of antimalarials representing

ACT has also increased over this period, increasing from 36% in 2009 to 69% in 2011 and 83% in 2012.[81,92,110] However, the use of quinine and chloroquine despite its ban in 2007 has persisted, together accounting for one-third of antimalarials in 2011.[81] Future research is needed to better understand what factors might be inhibiting the remaining caregivers from obtaining ACT, as well as to appreciate why quinine with chloroquine continue to make up one-third of antimalarials dispensed.

Table 2.12. Percentage of Febrile Children Who Received an Antimalarial

Author & Publication Year (Study Year)	Antimalarial	ACT[a]
Littrell et al 2011[110] (2009)	52%	21%
UBOS 2010[91] (2009)	59.6%	23.3%
UBOS 2012[81] (2011)	64.5%	44.2%
Fink et al 2014[134] (2011)	-	37.2%
ACTWatch 2013[92] (2012)	53.5%	44.2%

Note: cell entry reflects % of all children with fever.
[a]Abbreviation: artemisinin-based combination therapy (ACT).

Table 2.13. Percentage of ACT[a] Use among Febrile Children Who Received an Antimalarial

Author & Publication Year (Study Year)	ACT[a]	Non-ACT[a]
Littrell et al 2011[110] (2009)	36%	Quinine: 28%
UBOS 2012[81] (2011)	68.6%	Quinine: 24.2%
ACTWatch 2013[92] (2012)	82.6%	Quinine: 21.3%

Note: cell entry reflects % of children who received an antimalarial.
[a]Abbreviation: artemisinin combination therapy (ACT)

2.5.5. Perception of treatment efficacy

Studies evaluating caregivers' perception of efficacy did not define this term for participants. For these studies, it was therefore not clear if views about efficacy were centered on symptom improvement or elimination of the parasite. Still, review of these

studies reveals that caregivers' perspectives about efficacy are diverse and not readily generalizable.[12,62]

Traditional herbs vs medicines

The study by Tabuti in eastern Uganda was the only study to evaluate the use of traditional herbs for the management of malaria.[62] This study indicated the use of herbs to be an important part of home management among those familiar with its use, with a majority of the users reporting herbs to be effective in malaria.[62] Caregivers' perspectives on use of traditional herbs vs western medicines were examined by two studies.[12,62] While most caregivers expressed a preference for western medicines, both studies noted caregivers to have significantly varied views on the topic. Among those who preferred western medicines, two most common reasons included their belief that western medicines were more effective and they lacked the necessary knowledge to use traditional herbs.[12,62] Those who stated a preference for traditional herbs did so because they were free, readily accessible, and in some cases believed them to be more effective than western medicines.[12,62] Caregivers who used herbs did so independently of consulting with traditional healers, as they report to already be familiar with these products.[62] Polypharmacy with concurrent use of herbs was a common occurrence among caregivers.[12,62]

Medicines for malaria

Studies have consistently reported a discrepancy between the proportion of caregivers who report ACT to be the most effective antimalarial and the actual usage of ACT among children with fever. Table 2.14 summarizes findings from two national studies reporting on caregivers' knowledge about ACT and their use of ACT. For example in 2009 a national study reported 35% of caregivers acknowledged ACT to be the most effective but corresponding usage was only 21%.[136] In 2012, 84% of caregivers were aware that ACT could be used to treat malaria, but only 64% reported it to be the most effective antimalarial and even fewer children were reported to have received an ACT (44%).[92] This discrepancy between what caregivers cite as effective and what they practice might be explained by an earlier study by Rutebemberwa et al where they report perceptions about efficacy to be diverse, complex, and influenced by prior experiences and local beliefs.[12] Most caregivers in this study expressed a preference for combination

therapy, believing it to be more effective than single therapy. Most caregivers also held the belief that all medicines had some value – even "weak" medicines had a role and were useful for managing mild malaria. However, caregivers' preference for specific antimalarials varied, with some indicating a preference for starting with a weaker antimalarial like chloroquine, Fansidar®, Panadol®, diclofenac, and Septrin®, and saving stronger antimalarial like quinine as a last resort. There was also the view that some children responded better to certain medicines, with some caregivers believing a positive response in the past to be a strong predictor of future response and others considering this to be a limitation due to the development of resistance. The researchers found little agreement on the implications of drugs' side effects, with some suggesting its presence signifying a medicine was strong and others considered medicines with side effects as being inferior.[12] Similarly, differences in opinion were found about pre-packaged drugs, with some regarding them as inferior to those dispensed directly from stock-bottles.[12]

Table 2.14. Contrasting Knowledge about ACT[a] with Perception and Use of ACT

Author & Publication Year (Study Year)	Knowledge that ACT Can Be Used to Treat Malaria[ab]	ACT Acknowledged as the Most Effective Antimalarial[ab]	ACT Use Among All Children[a]
ACTWatch 2009[136] (2009)	-	35.1%	20.8%
ACTWatch 2013b[92] (2012)	84.2%	63.8%	44.2%

Note: cell entry for knowledge about ACT and perception of ACT efficacy reflects % of caregivers reporting.
[a]Abbreviation: artemisinin combination therapy (ACT).
[b]Cell entry reflects % of caregivers who reported having knowledge about ACT and perceiving ACT to be most effective.

2.5.6. Time to initiating care/treatment

Initiating prompt treatment

Table 2.15 summarizes studies reporting on time to initiating care/treatment. Since the advent of ACT few studies have evaluated time to initiating *any* treatment from the point of noticing the first symptoms, thus limiting researchers' ability to infer how quickly caregivers' initiate care.[72] In 2004, Kemble et al reported two-thirds of caregivers (70%) living in the urban city of Kampala initiated some type of treatment "promptly" (within 24-hours as per malaria guidelines), with 21% of children receiving a western

medicine within the first 24-hours.[72] In contrast, a larger number of studies have evaluated time to initiating an antimalarial or an ACT from point of initial symptoms.[81,91,92,136] Two national studies conducted in 2009 reported 36-44% of children received an antimalarial and 14-18% received an ACT within the same/next day.[91,136] While receipt of an antimalarial within the same/next day for 2011 and 2012 remained within 2009's upper range (43-44%), receipt of ACT almost doubled to 30-36%.[81,92] Despite significant strides, as with ACT usage, the number of children receiving ACT within 24 hours falls significantly short of the national target - which is to have 85% children with malaria start on an ACT within 24 hours. Given that most caregivers eventually act to manage fever but less than two-fifths initiate ACT within the first 24 hours, most caregivers' treatment decisions do not align with the biomedical community. With caregivers continuing to have at their disposal multiple treatment approaches and resources, it is necessary for future studies to shed light on what factors within the local environment influence these decisions.

Table 2.15. Time to Initiating Prompt Treatment in Febrile Children

Author & Publication Year (Study Year)	Initiating any Treatment within 24 Hours	Antimalarial Treatment within 24 Hours	ACT Treatment within 24 Hours[a]
Kemble et al 2006[72] (2004-2005)	70%	15%	-
ACTWatch 2009[136] (2009)	-	44.2%	17.6%
UBOS 2010[91] (2009)	-	35.7%	13.7%
UBOS 2012[81] (2011)	-	42.5%	29.9%
ACTWatch 2013[92] (2012)	-	43.7%	35.6%

Note: cell entry reflects % of all children with fever.
[a]Abbreviation: artemisinin combination therapy (ACT).

2.6. Summary of Key Findings and Recommendations

In addition to an initial overview of recently published developments on malaria and its social burden, the primary focus of this review was to understand caregivers' treatment-seeking behaviors' in Uganda since ACT was approved as first-line therapy for uncomplicated malaria. This review has provided important insights about caregivers'

knowledge, practices, and challenges; however, it is important to recognize some of the limitations within which inferences are drawn.

The limited regional research exploring caregiver behavior and differences in sampling methodology across the national studies make extrapolations of results to different regions of Uganda (or any country) difficult. Studies conducted prior to 2009 primarily reflected regional behavior in select urban and rural districts of eastern Uganda, whereas those conducted since 2009 gave a more national perspective. While national studies represented both urban and rural settings, only a few indicated which districts were represented, and none specified how representative their rural samples were of their respective district's rural population. Geographical differences were also accompanied with differences in demographic characteristics, socioeconomic status, and access to public and private drug outlets, with households in more urban settings generally having higher education attainment, higher socioeconomic status and better access to public facilities and pharmacies than those in rural settings. Studies also differed in their data collection strategies -- with some employing qualitative methodology and others using cross-sectional surveys or mixed methodology -- in how they classified public and private outlets as well as how they stratified their results according to different purveyors, and in how malaria cases were confirmed. None of the studies provide answers to all behavior questions of interest and they differed in how caregiver behaviors were assessed, with some employing hypothetical scenarios, others using actual cases, and few using both. As with any qualitative and survey methodology that uses self-reported data, findings from most of these studies may have been prone to interviewer, reporting and/or recall biases. Only Rutebemberwa et al in 2007 triangulated their quantitative findings with qualitative data, although their sample was purposively selected and, therefore, considered to be "information rich". Still, collectively, the review highlights patterns of caregivers' treatment-seeking behaviors and areas for further research.

This current review identified the following key findings about caregivers' treatment-seeking behaviors:

- While no recent study evaluated knowledge about the cause of malaria exclusively in caregivers of children under five, studies which included caregivers suggest most residing in eastern rural regions of Uganda associate

mosquitoes with malaria. However, these studies also report misconceptions to be a common occurrence, often co-exiting with correct knowledge.

- Fever remains the best known symptom of malaria, with over three-quarters of caregivers recognizing fever as the main symptom of malaria.
- Caregivers' knowledge about ACT has increased substantially over the years, with half of caregivers in a 2009 national survey stating ACT as the first-line treatment, and about four-fifths in a 2012 national survey naming ACT as the antimalarial to use for treatment of malaria. Whether this increase in knowledge holds true across all regions of Uganda still remains to be confirmed.
- No study examined caregivers' knowledge about what the government recommendations on when to start an antimalarial in a febrile child. However, a large majority of caregivers knew to respond to fever within the same/next day.
- Care seeking in Uganda is pluralistic. Home management remains a common first response, with most who seek external care over the course of a child illness favoring private outlets over public outlets. Visits to CHWs was noted to be a rare occurrence, with less than one-eighth of caregivers in any one study reported to have visited a CHW. Traditional healers were not explicitly investigated by most of the studies.
- While the diversity of home management among current caregivers has not been thoroughly investigated, the current review suggests that initial common practices include home management with traditional herbs and medicines purchased from private drug vendors, leftover from previous treatments or borrowed from family. About one-quarter of antimalarials given to children are also reported to be sourced from home. Those who use traditional herbs do so independently of traditional healers.
- Polypharmacy with multiple pharmaceutical products and traditional herbs has also been reported to be common practice among caregivers.
- Until 2012, fever management was reported to be better at public outlets than private outlets. However, more recent national studies suggest a shift in licensed private outlet practices coinciding with the implementation of AMFm, with a greater number of these outlets dispensing ACT than public outlets.
- A large gap persists between caregivers' practices and Uganda's national policy on malaria. The 2012 national survey found that only about half of febrile children received an antimalarial and only two-fifths (44%) an ACT. Almost a quarter of antimalarials acquired by caregivers still include quinine and/or chloroquine.
- This review established that an increase in knowledge about ACT does not always translate into receipt of a first-line antimalarial for proper malaria management. While 64% of caregivers in a recent national survey acknowledged ACT to be the most effective antimalarial and 84% spontaneously named an ACT as the medicine to be used for malaria, ACT

usage among this cohort was only 44%. Reasons for the discrepancy between effectiveness and practice have not been adequately studied.

- As with ACT usage, the fraction of children receiving ACT within 24 hours (18% in 2009, 30% in 2011, and 36% in 2012) falls significantly short of the national 2010 target - which is to have 85% of all children with malaria start on an ACT within 24 hours.

All studies reveal that treatment-seeking practices continue to be inadequate among a disconcerting fraction of caregivers. Given that most caregivers know to act promptly to care for a child when they suspect malaria but less than half initiate ACT within the first 24 hours, and four-fifths of caregivers' know of ACT but less than half ever obtain an ACT, caregivers' treatment behaviors clearly do not align with guidelines of the biomedical community. The current review informs greatly about how treatment-seeking has evolved since 2004, but further research is necessary before it is possible to identify best public health strategies to improve under-usage of ACT for children. Below are four priority research topics: home management, special needs in rural environments, quantification of caregiver behaviors, and quantification of treatment practices:

Evaluating home management practices

Most of the studies reviewed report high rates of home management, particularly as part of initial care. Studies also report close to a quarter of all antimalarials and ACTs given to children are sourced from home-stocks. Given the high prevalence of home management for initial care, a number of important questions remain unanswered. Future research should explore the diversity and adequacy of home management, the role of home management in a child receiving an ACT, and the sequence of care provided from the moment of initial symptom recognition.

Evaluating caregivers' practices in various rural settings

All behavior exploratory studies conducted since the implementation of AMFm in spring of 2011 reflect caregiver practices nationally. Studies that do examine regional caregiver practices since AMFm do so during on-going interventions. While national studies have included both rural and urban settings, this inclusion has been selective and varied across studies, with none specifying representativeness of their rural samples. The current review determined that while there were common patterns of

behavior across regions, national and regional studies conducted within the same year presented different findings. Similarly, within national studies, findings varied across different regions. These differences are not surprising given that geographical differences were accompanied with differences in demographics, socioeconomic status and access to public and private drug outlets. Generally, those living in urban centers or relatively more urban settings within rural districts are often more affluent and have better access to public outlets and licensed private outlets. It is therefore imprudent to generalize national level or regional specific studies beyond their contexts. Region-specific studies conducted over a wider population are needed to understand regional specific assets and challenges in order to inform effective and relevant behavior change interventions.

Quantification of factors influencing caregiver behaviors

The current review establishes that increased knowledge about malaria and its treatment and increasing ACT access from licensed private outlets are not sufficient to improve all caregivers behavior. Studies to date provide a variety of descriptive data on treatment-seeking behavior which has been used to guide policy and system change. But overall understanding is still limited how this descriptive data can collectively guide future programs to influence behavior change at the household level. As a next step, it is necessary to quantify and to examine descriptive data using structured and psychometrically justifiable approaches to determine caregiver specific assets and challenges which can be improved.

Quantifying use of appropriate antimalarial treatment

Because the use of ACT has been considerably inadequate for years in Uganda, “usage” of ACT has been widely adopted as a strategy for both increasing the use of ACT and as an indicator of success. Increased “usage” of ACT is commonly adopted in exploratory and evaluative studies as an indicator of improved malaria management with the first-line treatment. In these studies, “usage” is acknowledged as long as a fever episode is treated with an ACT, irrespective of combination of medicines used or sequencing of treatment. Review of the current literature proposes that polypharmacy is common for the management of malaria and that it is a preferred approach among caregivers. Given that the use of polypharmacy increases the risk of adverse drug

reactions, interactions, non-adherence and unnecessary expenditure, future studies need to investigate the prevalence of using multiple antimalarials to treat an episode of malaria, as well as to quantify whether ACT is the only antimalarial used for the management of uncomplicated malaria.

2.7. Conclusion

Prompt treatment with an effective antimalarial is the cornerstone of malaria control. Current guidelines recommend that ***all*** children over 4 months in Uganda be given ACT within 24 hours of onset of fever, but despite this recommendation, this review suggests only about two-fifths of caregivers obtain ACT for the management of malaria in children under five. The rest of the children are treated presumptively, and often with ineffective medicines obtained from public and private outlets. Results from this review therefore suggest a disconnect between what the biomedical community understands “best practice” to be and what individual community members expect and prefer.

In Uganda, mothers carry the burden of childcare but they are often subject to decisions on healthcare made by men, senior household members or village elders. In such circumstances, any intervention that is implemented to promote “best practices” will need to be informed by factors influencing caregivers. This review supports the notion that demographic and socioeconomic characteristics, personal beliefs, and expectations are important determinants in caregivers’ decisions about medication use. However, there is still a need to determine how much access caregivers have to reliable information, what supports they have during periods of acute illness, and their perceived self-efficacy with decisions about managing malaria in their young children. Such information will help guide the implementation of effective and relevant future public health programs to influence treatment-seeking behaviors.

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Chapter 3.

Caregivers' Treatment-Seeking Behaviors and Factors Associated with Young Ugandan Children Receiving an Appropriate Antimalarial: a Rural Cross-Sectional Survey

3.1. Introduction

Malaria remains an important health challenge world-wide, with an estimated incidence of 219 million infections and approximately 660,000 deaths reported in 2010.[1] Nearly 90% of deaths occurred in sub-Saharan Africa (SSA), of which 91% were in children under five.[1] Children between three months and five years of age are most susceptible to adverse events from malaria due to waning of their natural immunity from maternal antibodies and an acquired immunity that has not fully developed.[2] Among those who survive, many are left with persistent anemia, impaired brain function and/or paralysis hampering physiology and cognitive development.

Country level data for 2010 indicates that 80% of malaria cases in the World Health Organization (WHO) African region occur in just 17 countries, with Uganda being among the six highest burden countries.[3] Though a downward trend in the burden of malaria for children under five has been observed in select regions of SSA, limited regional data does not yet support this trend for Uganda.[3-5] Recent health system data and studies conducted in various regions of Uganda support either a rising trend or one that has remained steady among children five and under. A study using prospective surveillance data in a high transmission intensity area of eastern Uganda (Tororo) reported the incidence of malaria to have risen by 52% from 2008 through 2011, with incidence peaking at 6.5 episodes per child per year at 25 months of age and averaging four episodes per year.[6] While health system data sources have been criticized for

systematic biases such as over representation of the public health facility burden, inadequacies in local hospital information systems and over reporting of malaria diagnosis without adequate diagnostic confirmation; such biases also existed in retrospective studies reporting declining incidence of malaria.[7-9]

In Uganda where a large majority of the population lives in high transmission areas, the social and economic burden of acute malaria and asymptomatic parasitemia on families and governments is equally staggering.[10] Families commonly incur out of pocket expenses while seeking malarial treatment for their children, as well as experiencing loss of income from missed worked days.[11] Direct and indirect effects of malaria also impacts the economy, resulting in reduced economic development and increased government expenditures on malaria treatment and control programs at the country level.[12-15] Malaria accounts for 25 to 40% of annual outpatient visits, nearly half of inpatient childhood deaths, and approximately 39,000 annual deaths in children under five.[16,17] In 2003, the estimated gross domestic product (GDP) loss from malaria in Uganda was estimated to be US $11 million or 5% of health expenditures.[18] Given the tremendous burden of malaria on households and the economy, case management with prompt and effective diagnosis and treatment has remained a national priority over the past decade. The Uganda Government in partnership with international organizations continues to invest in large scale efforts to strengthen the delivery of effective antimalarial drugs to communities.[5,13,17,19,20]

In 2004 artemisinin combination therapy (ACT) became the first-line malaria treatment for children older than 4-months, with artemether-lumafantrine (Coartem©) as the first-line option and artesunate plus amodiaquine as an alternative, and quinine as the second-line treatment.[13] The Uganda national case management guidelines were revised in 2005 and 2006 to include the new treatment policy, and provisions were made to distribute Coartem© to government and private-not-for-profit health facilities for dispensing to communities free of charge.[13] However, translating policy into practice to ensure universal access to Coartem© has been challenging in rural areas due to regular stock-outs of antimalarials at public facilities, dispensing of resistant therapies at health facilities, and limited access to public facilities, regulated pharmacies and trained health professionals.[21] The result has been an over-reliance by caregivers of young children on

self-management practices and on unregulated private outlets with untrained vendors who are unlicensed to sell antimalarial drugs.

In an effort to bring diagnostics and treatment with ACTs closer to the community, a number of interventions have been introduced in Uganda. These have included national policies and programs to improve access to ACTs from public providers and private outlets, ban of resistant antimalarials, training of public providers, sensitization meetings with district level leaders, and Information, Education and Communication campaigns.[22] At the time of this study the Uganda Ministry of Health approved two major national programs: the Integrated Community Case Management Program (iCCM) in mid-2010 and the introduction of the Affordable Medicines Facility – Malaria (AMFm) in Spring of 2011.[23,24] The AMFm is a subsidized ACT program sponsored by international organizations such as the Global Fund to improve access of ACT through licensed private vendors. It is not yet clear how AMFm will impact those in rural communities who mostly rely on unlicensed private outlets not included in the AMFm scheme.[25,26] The iCCM relies on trained community health workers (CHWs) to serve as a first-line entry point into the formal health care system by offering case management at the community level.[27] Though recent short-term studies confirm that trained CHWs can effectively follow iCCM protocols under study conditions, there is still an on-going debate about the long-term effectiveness of this strategy in reducing child morbidity and mortality.[23,27-35] The delivery of iCCM is recognized to be complex, requiring both providers and recipients of care to be fully engaged for desired outcomes to be achieved. From the providers' end, CHWs must follow several pre-specified steps sequentially and completely for effective care to be provided and referral health centers must respond adequately and in a timely fashion.[27] From the caregivers' end, caregivers must effectively recognize signs of illness, promptly seek appropriate care, and accept recommended treatment and/or referral.[23,31] Deviation from this expectation by either the provider or caregiver can result in adverse outcomes for the child as well as increase the development of drug resistance.[23,27] Findings from a recent qualitative study by Nanyonjo et al reported tension between CHWs and community members to be common when community members did not perceive care offered by a CHW to align with their personal expectations.[30] Such tensions have included the refusal of a CHW to dispense antimalarial medicines after a negative malaria test, the refusal to treat children older

than 5 years, and the refusal to dispense more or different medicines than those allowed by treatment protocols.[30] CHWs were also shunned if they were not trusted or perceived to have insufficient knowledge for treating children.

While biological factors clearly predispose children to increased adverse outcomes from malaria, a confounding factor in children's health is their obvious reliance on caregivers to seek out appropriate care on their behalf. Research in Uganda has supported the notion that inadequate caregiver treatment-seeking practices in the context of a weak health system are important elements limiting the use of ACT in children five and under.[36] Despite knowing this, most interventions have been aimed at improving the health system. The few which have focused on caregivers and their families have principally been aimed at increasing awareness through mass campaigns and sensitization meetings. Although these initiatives have generated some improvement in the usage of ACTs for young children, they have not proven to produce sufficient behavior change to achieve the Millennium Development Goals.[37,38] One reason for their limited impact may be due to their simplistic view that a direct relationship exists between awareness and action, and that changing awareness will automatically change behavior.[38,39] While awareness about malaria and its treatment is necessary to making an informed decision, this one-dimensional idea of awareness influencing behavior does not consider the many other factors which might influence treatment-seeking behavior.[40] Ecological frameworks propose that no one factor alone influences people's behavior, but rather a multiplicity of factors co-exist at the individual, family, community, and societal levels, which interact together to influence behavior. Critics of these earlier efforts advocate a multi-level system-strengthening approach considers all factors likely to influence uptake of new services and programs by caregivers.[30,38]

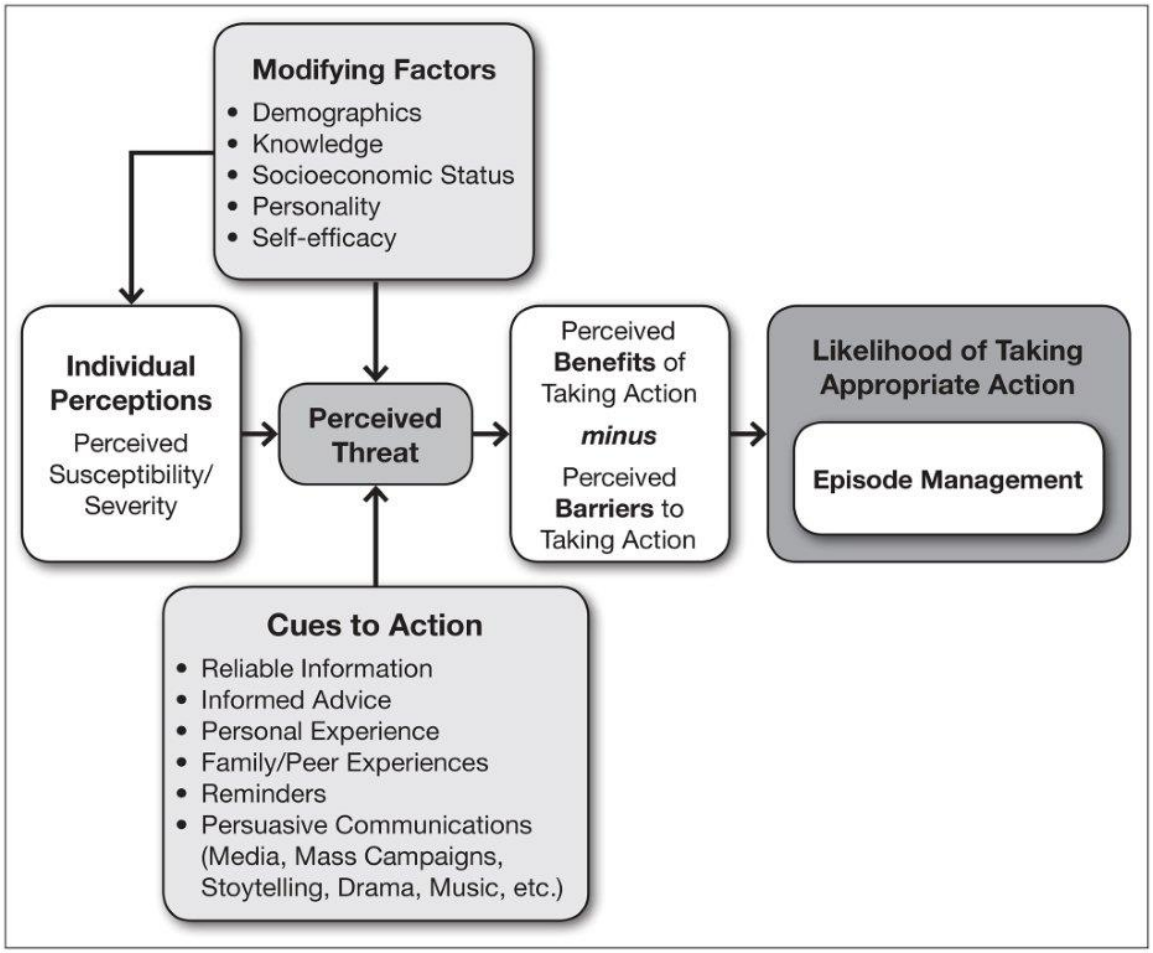
Central to most health promotion planning models is to start with the health issue affecting a target population and to explore what factors might be perpetuating this issue. The intent is to understand how and to what extent these factors might be influencing the problem, to select factors which -- if modified -- will result in alleviating the health issue, to implement program(s) and intervention(s) which can mitigate these factors, and to evaluate the impact of the intervention(s) at alleviating the health

concern.[40] Accordingly, the current study responds to community-based desires to improve malaria care for the very young in the rural Butaleja District of Uganda. As identified by community elders, health providers and district health offices, the chief concern was the under-use of effective antimalarials in young children during acute episodes. As a first step to inform future public health programs in Butaleja, this study undertook exploratory research to examine and evaluate caregivers' treatment-seeking behaviors for managing uncomplicated malaria in children five and under. The specific objectives of the study were: (1) to assess caregivers' treatment-seeking behaviors for malaria, (2) to determine what percentage of children received an "appropriate" antimalarial during their last fever episode, (3) to identify educational and environmental behaviors which maximized the likelihood of receiving an "appropriate" antimalarial treatment, (4) to estimate caregivers' Assets and Challenges related to managing malaria for their young children, and (5) to conduct a sensitivity analysis to ascertain which caregivers attributes (behavior Assets and Challenges and demographic factors) influenced receipt of an "appropriate" antimalarial the most. These objectives were assessed across the district and within different regions of the district.

3.1.1. Theoretical framework

Health behavior theories provide public health researchers with frameworks for understanding specific health behaviors, as well as for guidance in exploring factors which might facilitate or hinder these behaviors.[40] By promoting an understanding of these factors, theories can direct research to identify problem areas amiable to change through intervention programs. There is no shortage of such models, theories, or frameworks; Raingruber reviews about 20 of them under the following seven headings: behavioral change frameworks, intervention models, ecological theories, planning models, communication approaches, innovation/diffusion models, and evaluation models.[41] The current study is anchored on the one of the oldest and most frequently used theories – the Health Belief Model (HBM) to inform future public health programs aimed at improving caregivers' behaviors (Figure 3.1).

Figure 3.1. Theoretical Framework Based on the Health Belief Model



The HBM was first introduced in the 1950s by a group of social psychologists (Godfrey Hochbaum, Irwin Rosenstock, and Stephen Kegels) to help explain simple behaviors which required one-time actions such as why people use or do not use screening tests. Later, they expanded on the work of Albert Bandura to make the model applicable to behaviors requiring long-term change.[42,43] The HBM is a value-expectancy theory which posits that health behaviors are adopted based on assessments about benefits and barriers to action which is articulated in our study by six factors related to caregivers' assets and challenges: (1) perceived susceptibility to the illness, (2) perceived severity of the illness, (3) perceived benefits of the therapeutic intervention, (4) perceived barriers (5) cues to action, and (6) self-efficacy (the belief in being able to successfully execute the action). The first four factors formed the basis of the original

model. Cues to action were added in the 70s recognizing the need for stimuli to motivate individuals to act.[44] To make the model relevant for health promotion interventions requiring long-term change, a sixth component - self-efficacy was added in the late 1980s by Rosenstock, Strecher, and Becker.[43] According to this model, individuals' threat perceptions are influenced by their perceived susceptibility to a disease and its adverse outcomes, which in turn are influenced by cues to action such as internal symptoms or external health communications. Similarly, an individual's perception of the effectiveness of an action is influenced by their perceived benefits of adopting a proposed therapeutic action and perceived barriers (material, psychological and other) to attaining these interventions, where perceived barriers can be accentuated in circumstances where individuals lack self-efficacy. To this end, individuals will most likely adopt a behavior change if they perceive the threat to be high, if they believe the benefits of the action outweigh perceived barriers to undertaking the action, and if they perceive themselves to be competent to take the action. In the context of malaria, caregivers will likely adopt a proposed action (i.e., obtaining an ACT) if (1) they believe their child is susceptible and the infection can have severe consequences, (2) they believe the benefit of adopting the proposed action in preference to their traditional action outweighs perceived barriers they will encounter when seeking an ACT, and (3) they believe they can successfully execute this action. Given that malaria is a recurrent infection, with children under five experiencing on average of four episodes per year, in households averaging 2.3 to 2.8 children the concept of self-efficacy is central and exerts a strong influence on whether a caregiver is able to carry out a desirable behavior with each new infection.[6,45,46] How caregivers view obstacles and take action will eventually determine whether a behavior is implemented. Caregivers with lower self-efficacy are more likely to give up looking for an ACT in the face of difficulties, while those with higher self-efficacy will persevere in the face of deterrents. Thus, the HBM served as a valuable organizing tool for examining studies reported elsewhere in the literature and for framing obvious but unreported issues while developing survey topics. In this study, benefits, appropriate cues and routes to taking actions, and presence of self-efficacy are termed "Assets" while barriers are called "Challenges".

3.2. Methods

3.2.1. Study design

A cross-sectional household survey design was used to examine and quantify caregivers' treatment-seeking behaviours for managing uncomplicated malaria in children five and under in the Butaleja District in Uganda. The study's fieldwork was conducted over a two-month period, between June and July 2011. Ethics approval for the project had been previously obtained from the Child Health and Development Centre Ethical Centre at Makerere University, the Uganda National Council for Science and Technology, the Office of Research Ethics at Simon Fraser University and the University of British Columbia's Behavioral and Research Ethics Board.

3.2.2. Setting

Formerly part of Tororo District, Butaleja was established as an independent district in 2005 and named after its main town of Butaleja where district headquarters are located.[47] Butaleja's administrative structure consists of 10 sub-counties (mostly rural) and two town councils (designated urban centers).[47] At the time of this study, Butaleja had 66 parishes and 397 villages (K. Mweru, MD, written communication, April 2011). The district is situated in eastern Uganda, covers an area of 644 sq. km, and is bordered by Budaka District to the north, Mbale to the east, Tororo to the south east, Bugiri to the south, and Namutumba to the west (Figure 3.2).[47,48] The district is located along the Lake Kyoga catchment where the river Manafwa enters Lake Kyoga, and along the Mpologoma river stretch which is part of the wetlands in eastern Uganda.[49] The ethnic groups in the district include the Banyole tribe representing 66% of the population, followed by the Bagwere tribe at 5%, the Jopadhola tribe at 3%, and the Basoga, the Bagisu, the Iteso, the Baganda, the Banyankole, and the Acholi tribes making less than 2%.[47] The predominant spoken language spoken is Lunyole.[48] The three predominant religious groups include Protestants (53%), Muslims (30%), and Catholics (17%) (K. Mweru, MD, written communication, April 2011). Subsistence farming is the backbone of the district's economy with rice- growing as the mainstay agriculture.[49] The 2002 national census recorded the population of Butaleja District to be approximately 157,475 with an

annual growth rate of 3.3%.[47] Based on this census, it was estimated that by 2010 the population would grow to approximately 206,300, and would constitute about 41,240 households and 44,300 children under five.[47] Of the sub-counties, Mazimasa has the largest population while Himutu and Butaleja sub-counties have the lowest populations; Busolwe Sub County and Busolwe town council have the highest population densities (411 persons per sq km) and Budumba, Butaleja and Busaba have the lowest densities (149-223 per sq km).[47] Life expectancy in 2008 was estimated around 47 years, and mortality rate for children under five in 2006 was 152 per 1000 live births. Malaria was the single-highest ranked cause of morbidity in the period 2007-2009, with about eight in every 10 persons experiencing malaria/ fever.[47]

The people of Butaleja District face a multitude of problems because of their individual socioeconomic circumstances and the district's vulnerability to environmental disasters such as drought, floods and diseases.[49] Almost 40% of the population lives below the poverty line.[49] While poverty is most pronounced in the rural and few of the urban sub-counties such as Nawanjofu, Budumba, Mazimasa and the western part of Kachonga, it is a society-wide phenomenon demonstrated through indicators such as insecurity, low quality of public services, the scarcity of jobs and the lack of physical, technical and health information throughout society.[49] The average literacy rate among persons above 10 years is estimated to be 63%, with males more literate (71.6%) than females (54.0%).[47]

Figure 3.2. Map of Butaleja District

The district normally experiences two major rainfall periods between the months of May to October, although in recent past it has suffered irregular and unpredictable rainfall patterns that resulted in severe flooding of much of the district, creating swamps, submerging gardens, destroying roads and leaving many families homeless.[49] With the emergence of trading centers and towns being setup across the district without adequate physical planning for health and environmental implications, most of the district lacks adequate solid waste disposal systems and latrines, most roadside eating houses operate under unhygienic conditions, and school sanitation is below the expected standard.[49] The weather together with its geographical terrain and unplanned growth makes Butaleja District a hyper-endemic malaria area with high risk of year-round malaria transmission.

3.2.3. Overview of the health care system

The public health infrastructure in Uganda is stratified into four levels by district, sub-county, parish and village.[50] The following information is supplemented with documents from the Regional District Office of Butaleja (K. Mweru, MD, written communication, April 2011). At the highest level, there is one public hospital located in Busolwe town council. The hospital provides curative, preventive, promotive and rehabilitative care through outpatient, inpatient, surgical units and community health services, and serves as a referral site for patients from smaller health centres within the district. At the next lower level are the Health Centre IIIs. At the time of this study, there were 11 such centers located across eight sub-counties; one in most sub-counties, Butaleja sub-county with two and Naweyo sub-county with three. Two of Naweyo's health center IIIs were located close to the borders of Mazimasa and Kachonga, two sub-counties which had no health center III. Center IIIs are regulated to provide a range of care which include inpatient, maternity, outpatient, antenatal, immunization, and outreach services within the sub-counties; to be staffed by one medical clinical officer, laboratory assistant (s), nurse(s), midwife, and a nursing assistant(s); and to administer and dispense: quinine (oral and injection), ACT and sulfadoxine/pyrimethamine. At a still lower level are the Health Centre IIs which operate at the parish level, and at the time of this study there were 11 located in select parishes across seven sub-counties. Four sub-counties had one such center, Nawanjofu, Himutu, Mazimasa and Kachonga sub-

counties each had two such centres, but none existed in Busolwe, Butaleja, and Naweyo sub-counties. Centers II are regulated to provide a more limited range of care on an outpatient basis which include basic medical, antenatal, and immunization services; to be staffed by a nurse(s), and nursing assistant(s); and to administer and dispense: quinine (oral and injection), artemisinin injection, ACT and sulphadoxine-pyrimethamine. At the lowest level, Health Centres I exist as informal structures consisting of volunteers elected by villagers (also known as Village Health teams or CHWs) to provide basic health services at the community level, this includes: distribution of ACT, health education advice and referral to higher level health centers. While it is advocated by the ministry of health that every sub-county have at least one health center III and every parish have one health center II, at the time of this study the district fell short of attaining this goal.

In 2006, the Uganda National Malaria Control Programme introduced a policy to provide cost free ACT at all levels of the health system (levels I to hospitals), supplied as the Coartem® brand.[22] This formulation is composed of a fixed combination of 20 mg of artemether and 120 mg of lumefantrine, supplied in pre-packed weight- and age-specific forms. Other ACT brands can also be purchased for a fee from private outlets. The district however has no pharmacies, thus antimalarials (including ACTs) are sold largely by the few licensed drug shops located mostly in town centers and market areas and by unlicensed private outlets located in villages across the district who do not have formal training in the management of malaria.[51]

3.2.4. Participants

Household surveys were carried out with caregivers who met the following inclusion criteria: they had at least one child five years or younger who had been febrile within the last two weeks, they were the primary care provider for the child including supervision, bathing and feeding, they resided within Butaleja District at the time of the study, they spoke the common district dialect – Lunyole, they agreed to participate, and they willingly signed the consent form using thumbprint or written signature. Survey questions about current practice were asked in reference to the youngest child with fever (refer to as the “Index Child”). All households were excluded whose children had no

fever within the past two weeks or whose fevers were confirmed by a qualified health professional to be associated with an illness other than malaria.

3.2.5. Sample size

The Butaleja District 2009 report estimated approximately 41,240 households in the district.[47] Assuming that every second household had a child of five years and under, the number of household with the target population was 20,620. The Raosoft sample size calculator showed that a representative sample of that number of households at a 5% margin of error with a 95% confidence level required 380 households to be interviewed.[52]

3.2.6. Sampling strategy

Households from all 10 sub-counties and two town-councils were included in the study, but were sampled separately given their different rural/urban characteristics. Since the town-councils were geographically situated centrally within the district and shared similar urban characteristics such greater access to local amenities including licensed drug shops and transportation, they were considered as a unit for sampling purposes. A multi-step sampling process was used to ensure representation of all 10 sub-counties: varying household counts in different villages, different religious denominations, dominant tribes, and proximity to a government health center. For each sub-county, parishes with their respective villages were first stratified according to the number of households in each village (+150, 149-130, 129-110, 109-95, 94-85, 84-70). Each stratum was then grouped according to the three largest religious groups (Protestants, Catholics and Muslims). Two villages from each stratum were then purposively selected across all 10 sub-counties. Similarly, three villages representing each of the three largest religious groups were selected from the two town-councils collectively. Given its predominance, the Banyole had the largest representation. Since some of the religious groups tended to congregate within specific sub-counties, and tribes tended to be scattered across several parishes in some sub-counties and aggregated within specific parishes in others, the remaining 10 villages were purposively selected to increase geographical coverage, representation of the other lesser dominant

tribes (Bagwere and Japadola), inclusion of the 7th Day Adventist groups, those known to favor traditional healers, and samples of villages that were both close to and remote from available health units. In total, 35 different villages were sampled from 27 of Butaleja's 66 parishes.

Sampling at the household level used a simple random process to avoid self-selection. With the help of the local leaders, a central point at each village level was determined and each village was divided into 4 quadrants using natural boundaries. Since no listing of households with children five years and under was available, the first household in each of the quadrants was selected by a dice throw, screened for eligibility and recruited if the inclusion and exclusion criteria were met. Subsequently, every second household was visited and assessed for eligibility. If no caregiver was available or if the household did not meet the inclusion and exclusion criteria, then the immediate next household was visited and assessed for eligibility. The process was repeated quadrant-by-quadrant until 12-13 households within each village were recruited. In total 424 eligible households were recruited.

3.2.7. Research assistant recruitment, training and deployment

Due to language variations in Uganda, the survey was individually administered in the local language of Lunyole by one of seven multi-lingual research assistants recruited from Butaleja District. The research assistants were recent University graduates with some field experience and who were fluent in verbal and written English and in the spoken local dialect. Initially, ten interested candidates were invited to participate in a structured two-week training program which consisted of face-to-face large and small group work, field-based exercises, and formative and summative evaluations. The first week of the training occurred at a hotel in the nearby Urban District of Mbale, followed by field training in the second week. All participants were given a salary, lodging in Mbale and food for the two-week period. During the training, participants were briefed on the study's goal and objectives, the household recruitment process and the survey protocol, and the purpose of each survey question along with its response format were discussed in detail. The survey delivery process (first in English then in Lunyole) was practiced in small groups and rehearsed in the field under the

supervision of the study team, and each participant's ability to elicit the necessary information in an unbiased fashion was assessed using formative and summative assessment. Because Lunyole is not a written language, the questions were translated verbally during the training using group discussions and consensus supported by local members of the research team who were fluent in English and Lunyole. Seven of the ten candidates demonstrating the best understanding of the survey instrument and its delivery process were recruited as research assistants to the study.

3.2.8. Quality control

Quality control measures were introduced throughout the collection phase to ensure integrity of the data. On a day-to-day basis, this process was supported by the local research team consisting of the District Medical Health Officer - who served as the study's site manager, a retired District Health Educator - hired as the field coordinator and a behavioral scientist from Makerere University – who was involved with the study design and oversight. Quality control included reviewing the final survey documents for completeness, conducting spot checks by randomly visiting households and asking caregivers of their experiences with the survey, and reviewing to the audio recorded interview-assisted surveys for accuracy and completeness. Research assistants were provided regular feedback and, when necessary, caregivers were revisited to clarify information. Survey question data were transcribed from completed survey documents onto Excel spreadsheets for cleaning and verification, then subsequently transported into SPSS® v21 files for analysis.

3.2.9. Data collection

Instrument development

Guided by the six Asset and Challenge elements of the HBM, by the literature on caregiver treatment-seeking behavior, and by measurement experts, malaria content experts and key informants from the target population, seven educational and environmental factors were identified *a priori* for developing an inventory of questions to be included in the survey. These factors included: malaria-related knowledge (disease and treatment), episode management, assistance with critical decision, access to

information sources, problems with accessing advice, problems with obtaining the best antimalarial, and perceived ability to initiate/redirect actions. Next, existing survey instruments assessing caregivers' malaria treatment-seeking behaviors were collected, collated, and reviewed for potential fit. Since no one instrument adequately captured all the identified factors, a new instrument was developed and an item pool created by retaining relevant items from existing instruments and introducing new items where necessary. Each item was carefully worded, their order of presentation within the survey was examined, and their response formats were keyed carefully to the intent of each question. The final printed survey encompassed Interviewer Instructions, Research Assistants' Post-Interview Remarks, and 160 questions collecting information on the seven Educational and Environmental Factors, Household Identification, Child's Disease Presentation, Demographics/Socioeconomic status. In order to engage participants on the issue of malaria from the outset, personal and demographic questions were deferred to the end of the survey. Responses were recorded free-form with answer checklists keyed to the questions and a range of word scales - for example: dichotomous scales such as: *yes/no; true/false, and male/female*, and present/absent scales such as: *no problem/yes problem,* to questions about various problems or ease of accomplishing various tasks and *very easy/so-so/ very difficult* for questions asking about access to a public health facility. Caregivers identified various medications the index child had received through photographs printed on laminated posters of all anti-malaria medicines, antibiotics, antihelmetics, analgesics and antipyretics available within the district to report their use of specific medicines.

Instrument validation

A three-step sequential face and content validation process was undertaken, first with malaria content experts residing in the West, next with malaria content experts residing in sub-Saharan Africa, and last with Ugandan key informants who included members of the district health team, district political and opinion leaders, and sample of the target population. Comments from each group were considered and incorporated before moving to the next step. In total, 22 content experts were invited to participate in the survey instrument's face and content validity phase. All content experts were emailed a letter outlining the study's goals and objectives, the survey and a two-page questionnaire inquiring on: the appropriateness of the item pool generated (if they

adequately represented the *a-priori* factors and if were reflective of malaria related issues in rural SSA), the clarity of the items (understandable and unambiguous), the logic and flow of the items, and the ease of administration procedure instructions. Experts were also asked to suggest additional factors and items that were important but missed, and make any suggestions to improve the survey. A structured interview process was used to obtain key informants' perspectives, with discussions occurring in English or Lunyole based on the individual's fluency. In addition to confirming appropriateness of factors and items, key informants provided valuable insight regarding regional use of culturally appropriate terminology. For example, *malaria* and *omusuja* are terms frequently used interchangeably in the district to either mean fever, as a stand-alone symptom referring to a hot body, or to refer to a variety of illnesses with fever as a common symptom. Similarly, *doctor* and *health professional* are expressions commonly used to refer to anyone who provides treatment. Thus, at the recommendation of key informants, the combined term of *omusuja gwesena* was used to ensure information collected would be about fever brought by mosquitos, and for questions relating to health professional descriptions of premises where they worked as well as their dress codes were also collected to separate roles of providers.

3.2.10. Outcome measures and analysis

To quantify caregivers' treatment-seeking behaviors for managing uncomplicated malaria in children five and under, we assessed five outcomes: (1) caregivers' overall treatment seeking behaviors, (2) proportions of children who receive an "appropriate" antimalarial treatment across the district and within the district's 10 sub-counties and two town-councils; (3) educational and environmental behavior survey information which predict the likelihood of receiving an "appropriate" antimalarial; (4) caregivers' educational and environmental Assets and Challenges to managing malaria; and (5) sensitivity of educational and environmental Asset and Challenge factors in detecting differences between caregivers' who obtained an "appropriate" antimalarial versus those who did not, and in detecting regional differences. Throughout, statistical analyses were conducted using SPSS 21.0 for Windows.

3.2.11. Educational/environmental insights into caregivers' treatment-seeking behaviors

The study's first objective was to assess caregivers' treatment-seeking behavior when managing a child's malaria episode. All caregiver responses to individual question were reviewed, discussed among the research team members and grouped into clusters of common-themed topics. Descriptive statistics (frequencies, means and standard deviations) provided a first overview of summary results.

3.2.12. Determining an "appropriate" antimalarial

A major study objective was to count which children received *"appropriate"* antimalarial treatment vs. those who did not. "Appropriate" antimalarial treatment is defined as having received *only* the Uganda's age-specific first-line malaria treatment for uncomplicated and severe malaria during the course of the illness. For children less than 4 months, "appropriate" treatment included receiving quinine (oral or injectable) or artesunate (injectable or rectal) therapy. For children 4 months and older, "appropriate" was defined to be receiving any ACT and/or artesunate (injectable or rectal) or quinine (injectable). For this study, all ACTs were considered as legitimate first-line treatment. Simply asking a caregiver whether the child had "had received an antimalarial" allowed too much latitude for incorrect, inappropriate combinations, misidentified drugs, or simply lack of knowledge. Therefore, an audit of all medications reported to have been given to manage the current fever episode informed whether the "appropriate" antimalarial criteria had been met for each individual child. In contrast, "*ACT usage*" in this study followed the definition of Fink et al, with "usage" acknowledged if any of the medicines taken during the febrile illness was an ACT.[53] Frequencies for both "appropriate" and other antimalarials received were calculated for the whole of Butaleja District and for each of its sub-counties and town-councils.

3.2.13. Identifying predictors of receiving an "appropriate" antimalarial

A second study objective was to identify whether the likelihood of child receiving an "appropriate" antimalarial could be determined from caregivers' answers to select

survey questions, including questions about caregivers, index child and household demographic characteristics. Initially the focus was more on the content of the survey questions than their answers, with approximately 160 different questions inspected for suitability for inclusion to assess whether the likelihood of a child receiving an "appropriate" antimalarial could be determined from caregivers' answers to these questions. Univariate analyses (using χ^2 test followed by η^2) then examined approximately 160 questions to distinguish whether a child received an "appropriate" antimalarial. During data cleaning and verification, certain free-form or complex responses were recoded into simpler forms (Y/N; present/absent; mentioned/not mentioned; etc.) to allow more direct analysis of correlates of receiving "appropriate" antimalarial or testing for differences among various sub-counties. Questions were retained if: χ^2 test demonstrated associations at or beyond $p<.05$ statistical significance, η^2 of 2.0% or more hence accounting for unexpectedly large fractions of variance, or there was a strong conceptual reason for further examining specific questions. Subsequent binary logistic regression tested for the most power predictors influencing whether a child received an appropriate antimalarial. Examination of the data prior to analysis ensured all predictor variables met the dichotomous level of measurement and multicollinearity would not present a significant problem.

3.2.14. Quantifying caregiver assets and challenges

Beyond determining caregiver answers one-by-one to individual questions, the study's fourth objective was to develop quantitative profiles to assess Assets and Challenges facing caregivers when managing malaria in children five and under. The intent of the profiles was to yield more precise insight to broader answers of educational and environmental importance beyond simple yes/no or present/absent dichotomies. For instance, if caregiver knowledge were a factor, then which caregivers possessed relatively more knowledge and which ones relatively less? A pilot study distilled the educational and environmental information obtained from the surveys into clusters of common-themed questions and operationalized them into 10 scales. The clusters of questions naturally grouped themselves under the seven *a-priori* factors and thematic groupings constituting the survey, representing: Caregiver Assets reflecting attributes which ease the burden of caregiving and Caregiver Challenges which reflect deficits.

Where possible, scales are simple counts across a series of questions (number of times a caregiver relied on a public health sources for information; number of times public health workers helped make critical decisions) or where caregiver responses to Yes/No questions (problems obtaining ACT or problems accessing advice) or numbers of times caregivers lacked any support or assistance and were forced to rely on "no one else (myself)". Since raw scale scores are strongly affected by the numbers of items in each scale (7-19), re-scaled scores are reported throughout. These re-scaled scores are calculated by dividing the raw scores by the number of possible correct responses in each scale, therefore representing the percentage of affirmatively scored items in each scale. These psychometrically justified scales were then used in this study to profile caregivers' Assets and Challenges to inform "where the needs are" and "where to start" public health interventions.

3.2.15. Overview of pilot study: Scale development and validation

The pilot study used caregiver response data from many of the commonly-themed 160 survey questions from the current study to determine systematic response patterns in order to quantify scales of caregivers' Assets and Challenges across the district as a whole and within the 10 sub-counties and two town-councils. An initial inventory of 10-15 survey questions representing each of the seven *a-priori* factors that framed the survey was first tested for scale coherence and examined according to generally accepted scale development procedures including factor analytic verification of a large underlying latent factor and internal consistency (α-reliability) analysis.[54-56]

In the end, 10 scales operationalized the seven factors; two scales were each divided to highlight differences in information sources or decision-making assistance from qualified health professionals vs. reliance on personal resources and a third new scale Precursors to Receiving an Appropriate Antimalarial was introduced. Each scale was then successively refined to maximize its α–reliability. Caregiver Assets included: (1) Precursors to Receiving Appropriate Antimalarial Treatment (α=0.68); (2) Episode Management (α=0.74); (3) Caregiver Knowledge (α=0.51); (4) Assistance with Critical Decision from Health Professionals (α=0.65); (5) Reliable Information Sources (α=0.64); and (6) Initiating or Redirecting Treatment (α=0.65). Caregiver Challenges consisted of

(1) Lack of Information Sources (α=0.59); (2) Lack of Assistance with Critical Decisions (α=0.41); (3) Problems Accessing Advice (α=0.75); and (4) Problems Obtaining Best Antimalarial (α=0.68). Table 3.1 reports the essential statistical properties of these scales (number of items, raw mean and standard deviation, re-scaled mean and standard deviation, range and α-reliability. Eight of the 10 scales' reliabilities exceed George & Mallery's α=0.60 rule-of-thumb of acceptable internal consistency.[57] In addition to having acceptable internal consistency, most of the 10 scales were sensitive to two principal objectives of this study: to discriminate between caregivers of children who received an "appropriate" antimalarial versus those who did not and to distinguish among different regions (sub-counties) within the district.

Table 3.1. Psychometric Properties of 10 Behavior Scales Developed from 160 Butaleja Caregiver Survey Questions

	Respon-dents No.[a]	No. Items	No. Scale Points	Raw		Re-Scaled[b]		Observed Range	Min-Max Possible	% CFV[c]	α-Reliability
				Mean	SD	Mean	SD				
Behavior Scales: Assets											
1. Precursors to Receiving an Appropriate Antimalarial	417	9	9	4.57	2.26	0.51	0.25	0.0-1.0	0.0-1.0	69.7	.68
2. Episode Management	414	16	20	9.55	4.06	0.48	0.21	0.0-0.9	0.0-1.0	66.3	.74
3. Caregiver Knowledge	424	17	17	10.99	2.58	0.65	0.15	0.1-1.0	0.0-1.0	58.2	.51
4. Assistance with Critical Decisions from Health Professional	424	11	11	3.38	1.99	0.30	0.18	0.0-0.8	0.0-1.0	54.7	.65
5. Reliable Information Sources	424	8	16	6.32	3.93	0.40	0.26	0.0-1.0	0.0-1.0	42.2	.64
6. Initiating/Redirecting Actions	420	7	7	2.61	1.79	0.37	0.26	0.0-1.0	0.0-1.0	48.7	.65
Behavior Scales: Challenges											
7. Lack of Reliable Information Sources (Relying on Self)	424	8	8	4.22	1.89	0.53	0.24	0.0-1.0	0.0-1.0	40.5	.59
8. Lack of Assistance with Critical Decisions	424	9	9	1.90	1.47	0.14	0.11	0.0-0.5	0.0-1.0	69.0	.41
9. Problems Accessing Advice	416	7	7	5.21	1.86	0.74	0.27	0.0-1.0	0.0-1.0	44.2	.75
10. Problems Obtaining Best Antimalarial	418	9	9	5.04	2.34	0.56	0.26	0.0-1.0	0.0-1.0	58.1	.68

[a]Respondent number reflects the conservative reliability calculation convention of listwise deletion of information missing for any item on a scale.

[b]Each scale total was divided by its respective number of scale points to yield re-scaled means of comparable magnitudes, presented as a proportion.

[c]Strength of underlying trait: Percentage of common factor variance (CFV) for by all eigenvalues ≥ 1.00.

Sensitivity analysis assessed whether the 10 scales (1) discriminated between caregivers of children who received an "appropriate" antimalarial versus those who did not, (2) distinguished among different regions (sub-counties and town-councils), and (3) examined for differences resulting from different demographic characteristics. Successive one-way ANOVAs followed by η^2 tested each of the 10 scales, whereas χ^2 followed by η^2 tested select demographic variables, using receipt of "appropriate" antimalarial and sub-county as the independent variables. Given the scales' success at discriminating between whether or not a child received an "appropriate" antimalarial and between different regions, they then helped to identify priority areas for future public education interventions in Butaleja District by beginning where the needs are greatest and where the interventions ought to start. Table 3.2 reports the F-discriminitivity of the 10 scales (F-values and p-values) for receipt of an "appropriate" antimalarial treatment and for regional discrimination.

Table 3.2. Discriminitivity of the 10 Scales for Receipt of an Appropriate Antimalarial and Regional differences

Scale↓ Benchmark →	Receipt of Appropriate Antimalarial			Sub-County/Town-Council Location		
Behavior Scales: Assets	**df**	**F**	**p-value**	**df**	**F**	**p-value**
1. Precursors to Receiving an Appropriate Antimalarial	1, 419	112.03	<.000	11, 410	4.60	<.000
2. Episode Management	1, 419	264.93	<.000	11, 410	6.66	<.000
3. Caregiver Knowledge	1, 419	25.45	<.000	11, 410	2.18	.015
4. Assistance with Critical Decisions from Health Professional	1, 419	40.92	<.000	11, 410	5.34	<.000
5. Reliable Information Sources	1, 419	1.56	.213	11, 410	2.52	.004
6. Initiating/Redirecting Actions	1, 419	0.90	.764	11, 410	1.81	.051
Behavior Scales: Challenges						
7. Lack of Reliable Information Sources (Relying on Self)	1, 419	0.12	.726	11, 410	2.56	.004
8. Lack of Assistance with Critical Decisions	1, 419	42.20	<.000	11, 410	2.40	.020
9. Problems Accessing Advice	1, 415	0.21	.645	11, 406	1.47	.140
10. Problems Obtaining Best Antimalarial	1, 416	15.34	<.000	11, 407	1.59	.098

3.2.16. Demographic characteristics

Demographic measures included gender, age, education, occupation, religion, tribe, household size, number of children five years and under, caregiver's relationship to

head of household and to index child, current employment, and socioeconomic status (SES). Following Filmer et al, SES was inferred using 16 measures of housing, water, sanitation, energy sources, transportation equipment, communication devices, information sources, and livestock counts.[58,59] The SPSS v21 Categorical Principal Component Analysis (CATPCA) was used to examined the 16 household attributes. Two large, uncorrelated principal components reflecting household wealth index emerged: (1) dwelling permanence – ranging from less permanent to more permanent household building features (18.9% Principal Component Variance), and (2) durable assets (11.6% Principal Component Variance) - reflecting a geographic location axis from remote or isolated households to those residing in relatively more urban settings (Rurality).

3.2.17. Triggers to taking action

The HBM recognizes an implicit conflict between perceptions, preparedness, or cues to action vs. demographic differences as the most powerful antecedents of the likelihood of taking an "appropriate" action. The final objective of this study examined whether caregiver attributes (10 Assets and Challenges) or demographic differences in religion, tribe, education, gender, age and SES were the most powerful influences determining whether a child received an "appropriate" antimalarial. Stepwise logistic regression contrasted caregiver attributes vs. demographic characteristics to determine which accounted for the largest fraction of variance.

3.3. Results

3.3.1. Overview of educational and environmental behavioral scan

A total of 424 interviews were completed with primary caregivers from households across Butaleja District, representing all 10 sub-counties and two town-councils. All caregivers who met the inclusion criteria agreed to participate. Complete information was provided for 399 children, four surveys were partially completed because caregivers had to attend to other responsibilities and one had missing demographic information. However, all surveys were retained and analyzed for all possible information that was present.

3.3.2. Demographic characteristics

Tables 3.3–3.5 summarize caregivers', index children' and household characteristics. The mean (SD) age of caregivers was 31±10 years, most were female and mother to the index child, about three-quarter were wives to the head of the household, only 21% of the 72 caregivers who reported being the head of the household were female, all caregivers (with the exception of one) resided at the household where interviewed and nearly four-fifths were peasant farmers. While caregivers were diverse with respect to tribe and religion, the majority belonged to the Banyole tribe and the three main religious groups represented were Protestants, Muslims, and Catholics. Most caregivers reported having a low educational level, with four-fifths completing primary level or less of schooling. The mean (SD) age of the index child was 22±16 months, most represented the youngest child in the household, and the proportion of boys to girls was equal. Over 90% of caregivers reported earning no regular wages (79.6% of males and 95.8% of females), and four-fifth of caregivers (73.5% female and 11.2% male) reported farming as their primary occupation. Almost half of the households occupied mud structured houses or homes with only one room, a large majority used traditional pit latrines located outside the home, approximately three-fifths reported owning a radio, and about one-third reported not having any form of transportation.

Table 3.3. Demographic Characteristics of Caregivers (n=424)

Caregiver Characteristics	Mean	SD	Caregiver Characteristics	n	(%)
Age (n=406)	31 years	10	**Currently Working for a Wage (n=420)**		
			No	393	(93.6)
	n	(%)	Yes	27	(6.4)
Gender (n=420)			**Work Done in Last 12 Months (n=420)**		
Female	361	(86.0)	Yes	347	(82.6)
Male	59	(14.0)	No	73	(17.4)
Relationship to Head of Household (n=418)			**Current Occupation (N=419)**		
Wife	310	(74.2)	Peasant farmer	351	(83.8)
Household head	72	(17.2)	Housewife	35	(8.4)
Daughter/son	15	(3.6)	Petty trade/unskilled laborer	16	(3.8)
Daughter-in-law	10	(2.4)	Professional/shop keeper	7	(1.7)
Parent	5	(1.2)	Other	10	(2.4)
Husband	3	(0.7)	**Tribe (n=419)**		
Sibling	3	(0.7)	Banyole	312	(74.5)
Relationship to Index Child (n=424)			Bagwere	55	(13.1)
Mother	335	(79.0)	Bagisu	18	(4.3)
Father	46	(10.8)	Basoga	16	(3.8)
Grandparent	31	(7.3)	Jopadhola	9	(2.1)
Household head	9	(2.1)	Itseso	4	(1.0)
Aunt	3	(0.7)	Other	5	(1.2)
Part of the Household (n=423)			**Religion (n=424)**		
Yes	422	(99.8)	Protestant	211	(49.8)
No	1	(0.2)	Muslim	139	(32.8)
Highest Level of Education (n=419)			Catholic	57	(13.4)
None	73	(17.4)	Born Again Christian	10	(2.4)
Primary incomplete	228	(54.4)	7th Day Adventist	3	(0.7)
Primary complete	48	(11.5)	Other	4	(0.9)
Secondary incomplete	54	(12.9)			
Secondary complete	7	(1.7)			
Post-secondary (technical/ University)	9	(2.1)			

Table 3.4. Demographic Characteristics of Index Children (n=424)

Index Child Characteristics	Mean	SD
Age (n=408)	22 months	16
	n	(%)
Gender (n=424)		
Female	214	(50.5)
Male	210	(49.5)
Birth order (n=423)		
Youngest	410	(96.9)
2nd Youngest	12	(2.8)
3rd Youngest	1	(0.2)

Table 3.5. Demographic Characteristics of Households

Household Characteristics	n	(%)
Caregiver's Perspective of Distance to Nearest Public Health Facility (n=420)		
< ½ Mile	14	(3.3)
½ to < 1 Mile	22	(5.2)
1-5 Miles	308	(73.3)
> 5 Miles	68	(16.2)
Don't know	8	(1.9)
No. Rooms in this Household (n=419)		
0	6	(1.4)
1	225	(53.7)
2	107	(25.5)
3+	81	(19.3)
No. People Usually Sleep in this Household (n=419)		
2-4	146	(34.8)
5-7	202	(48.2)
8+	71	(16.9)
House Structure (n=421)		
Semi-permanent (Mud)	227	(53.9)
Permanent (Brick)	193	(45.8)
Uniport (Tin House)	1	(0.2)
Type of Dwelling (n=415)		
Independent	316	(76.1)
Shared	85	(20.5)
Muzigo	11	(2.7)
Other	3	(0.7)
Type of Toilet Facilities (n=419)		
Traditional Pit/ Latrine	389	(92.8)
Other	23	(5.5)
Bush/filed/forest	7	(1.7)
Type of Fuel Used (n=420)		
Firewood	408	(97.1)
Charcoal	11	(2.6)
Electricity	1	(0.2)
Transportation Owned (n=420, Multiple Responses)		
Bicycle	258	(61.4)
None	155	(36.9)
Motorcycle	21	(5.0)
Motor vehicle/Canoe/Boat	8	(1.0)
Communication Owned (n=419, Multiple Responses)		
Radio	265	(63.2)
Mobile phone	200	(47.7)
None	104	(24.8)
Television (TV)	11	(2.6)
Main Source of Information (n=424, Multiple Responses)		
Word of mouth	312	(73.6)
Radio	312	(73.6)
Mobile phone	53	(12.5)
None	13	(3.1)
Other (TV, print media/mail/posters)	12	(2.8)

3.3.3. Responses to survey questions

Repeated re-reading and team discussions about caregivers' answers to individual questions showed that caregivers' answer patterns formed clusters of common-themed questions, constituting the seven *a-priori* factors and thematic groupings which guided the layout of the educational and environmental behavior survey. Tables 3.6-3.12 (frequencies columns) summarize caregivers' responses grouped according to these clusters: index child's disease presentation, caregivers' knowledge (about disease and treatment), caregivers' practices and management strategies, assistance with critical decision, accessing information resources, caregivers' challenges with accessing advice about malaria, caregivers' challenges with accessing the best antimalarial, and caregivers' perceived ability to initiate independent action.

Table 3.6. Asset Scale: Precursors to Receiving an Appropriate Antimalarial (α=0.68)

Item-by-Item Scale Summary[a]	Response Categories[a]	Actual Frequency		Item/Scale Score (n=424)	
		n	%	Mean	SD
Awareness that government policy recommends ACT	ACT	423	34.4	0.34	0.48
Which AMs cure the best	ACT	423	35.1	0.35	0.48
Given the choice, which AM would you select first	ACT	423	32.1	0.32	0.47
Was child seen by a HP	Yes	421	69.3	0.70	0.46
Where was child seen by HP	PHF	294[c]	72.1	0.50	0.50
Was medicine used for subsequent action	Yes	366[c]	96.6	0.84	0.37
Where was AM (normally) obtained	Regulated outlets[b]	423	52.8	0.53	0.50
Were western medicines kept in home over last 6 months for future use	Yes	416	55.2	0.56	0.50
Types of medicines kept as home remedy for future use on day of the survey	ACT	423	43.4	0.43	0.50
Raw Score				4.57	2.26
Re-Scaled Score (of possible 9 points)				**0.51**	**0.25**

[a]Abbreviations: antimalarial (AM); artemisinin combination therapy (ACT); public health facility (PHF); trained health professional (HP).
[b]Regulated outlets: community health worker; PHF; regulated private outlets.
[c]Number of respondents reflects those to whom question was asked based on conditional branching.

Table 3.7. Asset Scale: Caregiver Knowledge (α=.51)

Item-by-Item Scale Summary[a]	Response Categories[ab]	Actual Frequency		Item/Scale Score (n=424)	
		n	%	Mean	SD
Knowledge About Malaria					
What are the main symptoms of malaria	Classical (fever/chills) Other symptoms Wrong answer	424	43.4 18.6 38.0	1.05	0.90
What is the one main cause	Mosquitoes Mosquito surrogates Wrong answer	424	78.1 2.8 19.1	1.59	0.79
Knowledge About AMs					
How soon after fever best to start AM	Within 24hrs	423	95.3	0.95	0.21
Which AM cures best	ACT	423	35.1	0.35	0.48
Given choice, which AM select first	ACT	423	32.1	0.32	0.47
Which AM cures the worst	Non-ACT	423	94.8	0.95	0.22
Given choice, which AM select last	Non-ACT	423	91.9	0.92	0.27
When is it best to stop AM	Adverse effect/as directed	423	32.3	0.32	0.49
Knowledge About National Policies					
Awareness gov't policy recommends	ACT	423	34.4	0.34	0.48
How soon after onset of fever to start AM	Within 24hrs	423	70.5	0.71	0.46
Is starting AM within 24-hours of fever realistic	Yes	423	93.4	0.93	0.25
Where Can AMs and Advice be Accessed					
Which outlets have the best quality medicines	Regulated outlets[c]	423	75.5	0.75	0.43
Where are ACTs available for free	PHF/CHW	423	74.8	0.75	0.43
Can you get ACT for free when you need it	Free	423	32.8	0.33	0.47
Best individuals to obtain advice from on malaria	HP/CHW	423	78.3	0.78	0.41
Raw Score				10.99	2.58
Re-Scaled Score (of possible 17 points)				**0.65**	**0.15**

[a]Abbreviations: antimalarial (AM); artemisinin combination therapy (ACT); community health worker (CHW); government (gov't); public health facility (PHF); trained health professional (HP).
[b]Calculating item Mean Score: items with 3 response categories result in 3 point scale: 2 points; 1 points; 0 points.
[c]Regulated outlets: CHW; PHF; regulated private outlets.

Table 3.8. Asset Scale: Episode Management (α=.74)

Item-by-Item Scale Summary[a]	Response Categories[ab]	Actual Frequency		Item/Scale Score (n=424)	
		n	%	Mean	SD
First Action Care					
When was first action started	6 hrs 6-24hrs >24hrs	424	73.6 14.2 12.3	1.02	0.51
Ever received first line or second line AM (usage)	First line AM Second line AM Other	424	15.1 5.7 79.2	0.44	0.73
Subsequent Action Care					
Was medicine used for subsequent action	Yes	366[e]	96.9	0.84	0.37
Ever received first line or second line AM (usage)	First line AM Second line AM Other	424	35.4 13.0 51.7	0.84	0.92
Care Over the Course of the Illness					
Was child seen by a HP	Yes	421	69.3	0.70	0.46
Where was the child seen by HP	PHF	294[e]	72.1	0.50	0.50
Was blood test done	Yes	421	20.8	0.21	0.41
Ever received first line or second line AM (usage)	First line AM Second line AM Other	424	42.0 15.8 42.2	1.00	0.92
One main reason for choosing this AM (referred to what child was given)	Rational reasoning[c]	424	52.4	0.52	0.50
How long after 1st symptom was AM started	Within 24 hrs	290[e]	75.1	0.52	0.50
Where was AM (normally) obtained	Regulated outlets[d]	423	52.8	0.53	0.50
General Practice					
Are ACTs easy to find	Yes	417	32.8	0.33	0.47
Are ACTs affordable	Yes	423	16.5	0.17	0.37
Were AM kept in home over last 6 months for future use	Yes	416	55.5	0.56	0.50
ACT in the home on the day of the survey	Yes	423	43.4	0.43	0.50
Given choice, where would obtain AM from	Regulated outlets[d]	423	94.1	0.94	0.24
Raw Score				9.55	4.06
Re-Scaled Score (of possible 20 points)				**0.48**	**0.21**

[a]Abbreviations: antimalarial (AM); artemisinin combination therapy (ACT); community health worker (CHW); public health facility (PHF); trained health professional (HP).
[b]Calculating item Mean Score: items with 3 response categories resulting in 3 point scale: 2 points; 1 points; 0 points.
[c]Rational reasoning: most effective; prescribed by trained HP; always 1st choice; cures malaria; saves life; to treat malaria; recommended on radio.
[d]Regulated outlets: CHW; PHF; regulated private outlets.
[e]Number of respondents reflects those to whom question was asked based on conditional branching.

Table 3.9. Scales: Assistance from Health Professionals with Critical Decisions (α=.65) vs. Self-Dependence (α=.41)

	Asset Scale: Assistance with Critical Decisions from Health Professionals (α=.65)					Challenge Scale: Lack of Assistance with Critical Decisions (α=.41)				
Item-by-Item Scale Summary[a]	Response Categories[a]	Actual Frequency		Item/Scale Score (n=424)		Response Categories[a]	Actual Frequency		Item/Scale Score (n=424)	
		n	%	Mean	SD		n	%	Mean	SD
Assistance with Index Child's Illness										
Which individual assisted you with recognizing child was sick	HP	424	2.6	0.02	0.15	Self	424	24.8	0.3	0.4
Which individual assisted you with recognizing child suffered from malaria	HP	424	25.7	0.26	0.43	Self	424	16.7	0.2	0.4
Assistance with Initiating Care in Index Child										
Who advised you on starting the traditional medicine	HP	112[b]	0.9	0.00	0.04	Self	110[b]	46.8	0.1	0.3
Who advised you on starting any home remedy	HP	239[b]	3.4	0.06	0.24	Self	239[b]	61.9	0.4	0.5
Who advised you on starting medicine from external source	HP	206[b]	12.6	0.06	0.24	Self	206[b]	58.3	0.3	0.5
Assistance with Selecting AM Regimen										
Who decides what form of action to start	HP	424	24.3	0.24	0.43	--	--	--	--	--
Who decided to give this AM	HP	390[b]	70.7	0.65	0.78	Self	390[b]	6.6	0.1	0.3
Who decides which AM to start	HP	423	68.4	0.68	0.47	--	--	--	--	--
Who decides when AM can be started	HP	423	48.1	0.48	0.56	--	--	--	--	--
Who decided when to stop this AM	HP	375[b]	44.8	0.40	0.70	Self	375[b]	39.4	0.4	0.6
Given a choice, who would you go to first for advice	HP	423	78.3	0.78	0.41	Self	423	1.2	0.0	0.1
Where would money come from	--	--	--	--	--	Self	423	35.1	0.4	0.5
Raw Score				3.63	1.99				1.90	1.47
Re-Scaled Score (of possible points)				**0.33 (of 11 points)**	**0.18**				**0.14 (of 9 points)**	**0.11**

[a]Abbreviations: antimalarial (AM); points (pts); trained health professional (HP).

[b]Number of respondents reflects those to whom question was asked based on conditional branching. Home remedy includes home-stock medicines and supportive care

Table 3.10. Scales: Accessing Reliable Information Sources (α=.64) vs. Self-Dependence (α=.59)

	Asset Scale: Reliable Information Sources					Challenges Scale: Lack of Information Sources (Self)				
Item-by-Item Scale Summary[a]	Response Categories[b]	Actual Frequency		Item/Scale Score (n=424)		Response Categories	Actual Frequency		Item/Scale Score (n=424)	
		n	%	Mean	SD		n	%	Mean	SD
Where did you learn the following …										
Information About Malaria										
About malaria	Primary source Secondary source Hearsay	424	2=53.5 1=2.1 0=44.3	1.09	0.99	Self	424	29.7	0.30	0.46
Information About AMs										
This AM was the best (Caregiver's selected)	Primary source Secondary source Hearsay	423	2=37.3 1=1.9 0=60.8	0.76	0.96	Self	423	51.9	0.52	0.50
This AM was the worst (Caregiver's selected)	Primary source Secondary source Hearsay	423	2=12.5 1=0.2 0=87.3	0.25	0.66	Self	423	81.4	0.81	0.39
Information About National Policy										
What AM does the government recommend	Primary source Secondary source Hearsay	423	2=30.0 1=0.9 0=69.1	0.61	0.92	Self	423	67.7	0.68	0.47
When it is best to start an AM	Primary source Secondary source Hearsay	423	2=45.5 1=0.0 0=54.5	0.91	0.99	Self	423	43.6	0.44	0.50
What does the government recommend regarding when best to start an AM	Primary source Secondary source Hearsay	423	2=55.2 1=0.0 0=44.8	1.10	0.99	Self	423	41.0	0.41	0.49
Where ACT can be obtained	Primary source Secondary source Hearsay	423	2=59.4 1=0.0 0=40.6	1.19	0.98	Self	423	31.4	0.31	0.46
About good and poor quality AM medicines	Primary source Secondary source Hearsay	423	2=20.3 1=0.2 0=79.5	0.41	0.81	Self	423	75.2	0.75	0.43
Raw Score				6.32	3.93				4.22	1.89
Re-Scaled Score (of possible pts)				**0.40 (16 pts)**	**0.26**				**0.53 (8 pts)**	**0.24**

[a]Abbreviation: antimalarial (AM); artemisinin combination therapy (ACT); points (pts).

[b]Calculating item Mean Score: items with 3 response categories resulting in 3 point scale: 2 points; 1 points; 0 points.

Table 3.11. Challenge Scales: Problems Accessing Advice (α=.75) and Obtaining the Best Antimalarial (α = .68)

Item-by-Item Scale Summary	Challenge Scale: Problems Accessing Advice					Challenge Scale: Problems obtaining Best Antimalarial)			
	Response Categories	Actual Frequency		Scale Score (n=424)		Actual Frequency		Scale Score (n=424)	
		n	%	Mean	SD	n	%	Mean	SD
Knowing where to go	Problem	420	80.4	0.81	0.39	421	43.4	0.44	0.50
Getting permission to go	Problem	420	92.0	0.93	0.26	421	42.5	0.43	0.50
Finding transportation	Problem	420	58.3	0.59	0.49	421	58.0	0.58	0.49
Access to health professional	Problem	420	67.0	0.68	0.47	421	53.8	0.54	0.50
Access to female health professional	Problem	420	74.5	0.74	0.43	421	50.0	0.50	0.50
Finding time	Problem	420	83.5	0.84	0.36	420	48.8	0.50	0.50
Resources within the community	Problem	416	60.1	0.61	0.49	--	--	--	--
Availability of medicine	Problem	--	--	--	--	421	69.3	0.69	0.45
Health facility is too far	Problem	--	--	--	--	420	64.9	0.65	0.48
Getting money for medicine	Problem	--	--	--	--	420	69.3	0.70	0.46
Raw Score				5.21	1.86			5.04	2.34
Re-Scaled Score (of possible points)				**0.74 (7 points)**	**0.27**			**0.56 (9 points)**	**0.26**

Table 3.12. Asset Scale: Ability to Initiate/Redirect Child's Treatment (α=.65)

Item-by-Item Scale Summary[a]	Response Categories	Actual Frequency		Scale Score (n=424)	
		n	%	Mean	SD
To start independently on a different form of first action	Yes	421	63.0	0.63	0.48
Who makes decision on what form of action to take	Self	424	27.6	0.27	0.45
To independently start on a different western AM	Yes	421	32.8	0.33	0.47
Who makes final decision which western AM to start	Self	423	6.6	0.06	0.25
To independently decide when to start a western AM	Yes	420	62.7	0.63	0.48
Who makes final decision when AM can be started	Self	423	31.4	0.31	0.46
Can you independently decide to stop AM	Yes	420	37.3	0.38	0.48
Raw Score				2.61	1.79
Re-Scaled Score (of possible 7 points)				**0.37**	**0.26**

[a]Abbreviation: antimalarial (AM).

History of index child's disease presentation

While fever within the past two weeks had already been confirmed as part of the household recruitment process, the 346 caregivers who suspected their child had malaria from the outset reported an average of 3.5 different symptoms that alerted them the illness was malaria, for a total of 1,083 symptoms mentioned. Expanding on a classification system by Bartolini and Zammarchi, all symptoms were individually analyzed and clustered into the following five symptom-based categories: (1) subtle warnings signs of a child not being well (10.2%), (2) early phase malaria symptoms (26.9%), (3) classical symptoms (28.5%), (4) severe symptoms (6.1%), and (5) non-malaria symptoms (28.3%).[60]

Collectively, classical symptoms of fever and chills constituted the majority (28.5%) of all symptoms reported (fever by 79.2% of caregivers, chills by 10.1%). Early phase symptoms (26.9%) reported by caregivers included diarrhea (30.1% of caregivers), vomiting (24.0%), weakness (12.4%), malaise (9.0%), and headache (4.6%). Subtle warning signs (6.1%) included poor appetite (by 17.3% of caregivers), crying/irritability (4.9%) and pale eyes (4.3%). One-fifth of caregivers (19.2%) reported symptoms associated with severe malaria, such as unable to eat/drink (9.8%), and

convulsion (4.6%). Misconceptions about malaria presentation were also common among caregivers (88.4%), with large fractions mentioning symptoms such as runny nose (32.9%), sneezing (15.3%), and all types of cough (28.0%).

Caregivers' practices and management strategies

Four themes related to caregivers' practice and malaria management strategies were evaluated. Three of the four themes related to the index child's current episode of fever: (1) first action taken by caregiver, (2) subsequent action taken by caregiver, and (3) care given to the index child over the course of the illness in the last two weeks, and (4) households' general practices.

First action care for the index child.

Doing nothing (or only praying) was reported by very few caregivers (4.5%). Almost three-quarters of index children (73.6%) received some form of action within 6 hours of caregivers noticing the first symptoms and 14.2% between 6 and 24 hours, only 2.8% waited more than 24-hours to receive any action. No information was provided for the remaining 5.0% of the children. In total, 556 actions were provided by 424 caregivers, for an average 1.3 first actions per child. Home management was the most common first action reported by at least 72.64% of caregivers. Home management was defined as any care initiated from the home setting with resources within the household, including home remedy (home-stock medicines and physical supportive care) and traditional herbs. Physical supportive care included non-pharmaceuticals such as: bathing, sponging, and giving tea or water for hydration. About three-fifths (63.9%) of caregivers reported using only one type of action: medicines, supportive care, or traditional herbs; about one-third (29.5%) used two of the three actions; and a small proportion (3.1%) used all three types of actions.

Overall, for the first action, 26.4% of caregivers reported using traditional herbs, 38.2% used supportive care and/or just under two-thirds (62.3%) gave some form of medicine. Almost half (48.8%) of caregivers obtained medicines from an external source and one-third (29.9%) used medicines from their home-stock. Approximately one-fifth (18.4%) reported giving medicines from two sources (home-stock and an external source). The three most common classes of medicines given in various combinations

included: antipyretics (54.7%), antimalarials (24.3% gave one antimalarial and 2.6% gave two antimalarials), and antibiotics (12.7%). Of the 114 children who received any antimalarial, about one-quarter (26.3%) received ACT, one-sixth (16.7%) received quinine and almost three-fifths (58.8%) received other antimalarials. For the first action, "usage" of a first-line antimalarial among the 424 children was 15.1% and for ACT 7.1%.

Subsequent action care for the index child.

Just over five-sixths (86.3%) of index children required a subsequent action to manage their fever, with most (96.9%) children receiving some type of medicine. The three most common classes of medicines given in various combinations with other medicines included: antipyretics (66.0%), antimalarials (56.8%), and antibiotics (36.1%). For the subsequent action, "usage" of a first line antimalarial was about one-third (35.4%) and similar for ACT (33.3%). Of the 241 children who received an antimalarial, 58.5% received ACT, 19.9% received quinine, and 21.6% received other antimalarials. Additionally, a quarter (23.2%) of these children received some form of home management: 9.8% received traditional herbs and 13.4% received physical supportive care and/or home-stock medicine.

Care over the course of the index child's illness (within last two weeks).

About two-thirds (69.3%) of caregivers reported seeking care from a trained health professional (a doctor, nurse or medical attendant), with 72.1% of these visits occurring at public health facilities. Caregivers were 2.3 times more likely to seek care from an external source if they perceived their child's symptoms to be associated with severe malaria, although no statistically significant relationship was found between caregivers' distinction of mild versus severe malaria and whether a child received the first-line antimalarial.

Less than one-quarter (20.8%) of caregivers reported the child to have received a blood test when they presented with the child at an external outlet, although this study was unable to confirm the purpose of these tests. Of those children who were tested, about three-quarter (78.4%) of them were done at public health facilities (representing 32.6% of children seen at the public health facility for assessment of their fever), 14.8% at a private clinic and 9.1% at a drug shop and one was administered by a CHW.

Children whose caregiver reported their child had received a blood test were no more likely to receive an “appropriate’ antimalarial than those reporting no test.

Of the 424 children, nearly a third (31.6%) received no antimalarial whatever; 31.6% received an “appropriate” antimalarial, and 36.8% received subordinate antimalarial treatment. Whether “appropriate” or not, across all households surveyed, “usage" of ACT (41.0%) or of an age-specific first-line antimalarial (42.0%) during the course of the illness occurred for fewer than half the children. Overall, antimalarial use was common (68.4%), but in addition to “appropriate ACT treatment” two categories of subordinate medicating were also evident; (1) antimalarial treatments which did not include ACT (71.8%) and (2) misuse of ACT itself (28.2%). The non-ACT treatments included quinine 38.5%, chloroquine 26.9%, quinine and chloroquine 4.5%, or others (mefloquine, SP, etc. 1.9%). Misused ACTs included administration in conjunction with subordinate drugs for children over 4-months (22.4%) or mis-prescribed for infants under 4-months (5.8%).

Three-quarters (75.1%) of the 290 children who received an antimalarial did so within 24-hours of presenting their first symptoms. While most caregivers (94.1%) who were surveyed expressed that it was their preference to obtain an antimalarial from a public health facility, in actual fact antimalarials were obtained from both public and private outlets: 61.3% from public health facilities, 55.8% from private sector outlets (18.5% from private hospitals/clinics and 37.3% from drug shops which were predominantly unlicensed) and only 1.4% from CHWs. Collectively, a large majority (89.7%) of caregivers who obtained an ACT sourced it from a licensed outlet (public health facility, CHW, or private hospital/clinic), with most (77%) obtaining it from public health facilities. However, of all those who visited a public health facility, only three-fifths (63%) received an ACT and two-fifths (43.2%) received an “appropriate” antimalarial treatment. Nearly four-fifths (81.5%) of caregivers used only one source for obtaining the antimalarial, and with less than one-fifth (18.5% reported using two sources).

General household practice.

Only one-third (32.8%) of the caregivers believed ACT was easy to find within their community and an even fewer (16.5%) alleged ACT was affordable. It was common

practice for caregivers to keep an antimalarial medicine in the home for future use in case their child got sick, with a little over half (55.5%)of caregivers claiming to have kept an antimalarial in the home over the past six months. All ACTs given as part of first action were given from households' home-stock medicines. Whether caregivers believed ACT was easy to find or was affordable made no difference to whether the child actually received an "appropriate" antimalarial, but caregivers who knew that ACT was the government's recommended antimalarial were more likely to receive an "appropriate" antimalarial than those who knew nothing about government recommendations (41.6% vs 26.6%, p<.002).

Caregivers' knowledge

Four themes related to knowledge were evaluated: (1) knowledge about malaria and its cause, (2) knowledge about the management of uncomplicated malaria, (3) knowledge about national policies regarding management of malaria management, and (4) preparedness to respond adequately to an acute episode of malaria.

Knowledge about malaria – its symptoms and cause.

Just over half (55.7%) the caregivers expressed certainty in their ability to recognize malaria. When asked what symptoms were associated with malaria, on average caregivers listed four different symptoms, most of which were indicators of the classical and early phase symptoms associated with malaria (94.8% and 94.6%, respectively). A majority (80.2%) of caregivers reported fever as a sign of malaria, with three-quarters (74.3%) stating they were very certain they would be able to diagnose fever, but only 14.6% recognized chills to be associated with malaria. While collectively early phase symptoms were mentioned most frequently, individually caregiver's knowledge about these symptoms association with malaria was low with only 31.1% mentioning diarrhea, 28.1% malaise/weakness, 26.2% vomiting, 5% headache, and 3.6% pain. Similarly, a small portion (20.3%) mentioned symptoms associated with severe malaria, with the three most common being: unable to eat/drink/breastfeed (8.7%), convulsions (5.4%) and, rapid breathing (2.8%). There were common misconceptions, even among those who had reported correct symptoms, with 60.8% of caregivers linking runny nose and sneezing with malaria and 36.1% associating all types

of cough with malaria. Although not aligned with the medical community, caregivers were generally accurate in reporting a main symptom of malaria. Two-thirds (62.0%) of caregivers reported legitimate indicators of malaria: 43.4% listed one of the two classical symptoms (fever 40.3%, chills 3.1%), 13% listed one of the early phase symptoms (diarrhea 4.2%, malaise 4.2% and vomiting 2.6%), and 9.2% listed subtle symptoms of malaria. However, almost one-third (38.0%) of caregivers reported symptoms not clinically associated with malaria. Regarding the one main cause of malaria, only three-quarter (78.1%) of the caregivers mentioned mosquito bites, 2.8% mentioned a surrogate for mosquito bites such as environmental factors associated with proliferation of mosquitoes, and 19.1% were misinformed mentioning causes such as change in season (6.5%) and ingestion of certain foods and fluids like drinking dirty water, or eating dirty, cold, or certain types of foods (4.8%). A small percentage (5.4%) reported not knowing the cause.

Knowledge about antimalarial medicines.

Most caregivers (95.3%) caregivers believed an antimalarial should be started within 24-hours of noticing fever. In terms of most effective medicines, about four-sixth (68.2%) of caregivers cited an actual antimalarial medicine as being the most effective, and over one-quarter acknowledged not knowing (23.1 %) or citing a range of other class of medications (8.7%) including antibiotics and antipyretics/analgesics. Examples of antimalarials reported included: ACT (35.1%), quinine (17.7%), and chloroquine (13.9%). A similar fraction of caregivers expressed they would select the very antimalarials they listed to cure the best for their children if given the choice (ACT 32.1%, quinine 16.6%, and chloroquine 15.2%), but 16.1% mentioned they would select a non-antimalarial such as antipyretic/analgesic (10.4%) and antibiotic (2.6%), and 18.6% stated they did not know what to select.

In terms of least effective antimalarials, 42.7% reported not knowing, 24.5% stated antipyretic/analgesic, 16.3% mentioned antimalarials other than ACT (chloroquine 9.7% and quinine 5.0%), 5.2% stated ACT and the rest stated a range of other drug classes including antibiotics. As a last-choice antimalarial, only 8.1% mentioned an ACT and one-fifth mentioned other antimalarials (chloroquine13.2% and quinine 9.4%), about

a quarter (22.9%) stated medicines not belonging to the antimalarial class such as antipyretics/analgesics, and the rest (46.4%) said they did not know.

Knowledge about national policies and guidelines.

Only one-third (34.4%) of caregivers reported knowing that the recommended first-line treatment was ACT, but no one was aware that ACT was not recommended in children less than 4 months of age. However, larger portions (70.5%) of caregivers were aware to start an antimalarial within 24-hours of the child experiencing fever, with most (93.4%) reporting that an expectation of starting an antimalarial within 24-hours was attainable.

Knowledge about where to access best antimalarials and advice about malaria.

About three-quarters (75.5%) of caregivers believed that the best medicines were available at public health facilities, pharmacies, private clinics and from CHWs. A similar portion (74.8%) reported ACTs should be available for free at public health facilities and from CHWs, but only 32.8 % expressed they would be able to get an ACT from public sources if they needed it for their child. A comparably high percentage (78.3%) of caregivers identified trained health providers such as doctors, nurses and CHWs to be the best individuals from whom to obtain advice about antimalarials.

Assistance with critical decisions

Three themes related to critical decisions were evaluated relating to actions caregivers had taken on behalf of the index child: (1) getting assistance with recognizing the current illness, (2) getting assistance with selecting the best initial action, and (3) getting assistance with selecting the best antimalarial regimen.

Recognizing the index child's illness.

About four-sixths of caregivers indicated getting help from family members (spouse 50.2%, other family members 18.0%) to help confirm their child was sick and one-quarter (24.8%) reported making this assessment on their own. Very few caregivers indicated seeking immediate assistance from community members (3.1%), trained health professionals (2.6%) and drug shop vendors (0.7%) to help confirm whether their

child was sick. Once it was established the child was sick, in two-fifths of the cases family members (spouse 30%, other family members 12.2%) were the ones to confirm the child had malaria, one-quarter (25.7%) of the caregivers reported consulting with external sources (trained health professionals 25.7%, drug shop vendors 11.6%) and one-sixth (16.7%) reported making this decision on their own. No caregivers reported seeking assistance from a CHW to confirm malaria.

Selecting an initial action.

Almost half of caregivers reported that it was usual for a family member (spouse 41.9%, other family members 3.3%) to decide on the type of action to initiate when malaria is suspected. Almost one-quarter of caregivers reported using external sources such as trained health professionals (24.3%) and drug shop vendors (2.4%) and just over one-quarter (27.6%) mentioned making such a decision on their own. What caregivers reported to be “customary for other children in the household” was markedly different than what was reported to have occurred for the index child.

On average for the district, about one-tenth (5.9%) of caregivers reported getting advice on home remedy from a trained health professional. For the 112 caregivers who reported using traditional herbs as part of their first action for the index child, almost half (46.8%) mentioned making this decision on their own without any assistance. Just under half (47.7%) of caregivers reported making this decision at the advice of a family member (spouse 8.1%, other family members 39.6%), less than 4% sought assistance from community members, one caregiver reported consulting with a trained health professional, one with a traditional healer, but no one reported consulting with a CHW. Similarly, of the 135 caregivers who used home-stock medicines over the course of the illness, almost three-fifths (61.5%) reported making this decision without any assistance. In about one-quarter (28.2%) of the cases was the decision to give a medicine from home-stock done so at the advice of a family member (spouse 21.5%, other family members 6.7%) and in very few instances were external providers consulted (trained health professionals 8.1%, drug shop vendors 2.2%).

Likewise, a little over half (58.3%) of the 206 caregivers who obtained a medicine from an external source reported making this decision on their own without any

assistance. In only about one-quarter (28.7%) of the cases were medicines from an external source given at the advice of a family member (spouse 20.9%, other 7.8%), and for only one-sixth (13.1%) of the cases was this initiated at the recommendation of a provider (trained health professionals 12.6% or drug shop vendors 0.5%).

Deciding on an antimalarial treatment.

A large majority of caregivers (78.3%) indicated that -- given the choice -- they would seek advice from a trained health professional on how to treat malaria for children five and under; less than one-quarter mentioned a family member (spouse 10.9%, other family members 1.9%), drug shop vendor (5.9%), or relying on themselves (1.2%) to make such a decision. However, the usual reported practices within households as well as what actually happened for the index child fell slightly short of what caregivers indicated as their preference.

Less than three-quarters of caregivers (68.4%) reported that it was customary within their household to have trained health professionals decide which antimalarial to start children of five years and under on, one-quarter reported this decision was made by a family member (spouse 17.7%, other family members 0.5%) or themselves (7.8%), and in very few instances were drug shop vendor vendors (5.4%) consulted. Regarding when an antimalarial should be started, just under half (48.1%) of caregivers reported it was customary to have this decision be made by trained health professionals, one-third (31.4%) reported this decision resided with them and about one-fifth reported family members (spouse 15.8%, other family members 1.6%) or drug shop vendors (1.9%) to be involved.

Similarly, contrary to caregivers' claims, fewer actually sought guidance from health providers when obtaining an antimalarial for the index children. On average, the 290 index children received 1.3 antimalarial over the course of their illness. Of these, 194 children received only one antimalarial, 82 received two antimalarials, and 14 received three antimalarials. Overall, for the total 390 antimalarials given during this illness episode, less than three-quarter (70.7%) of the antimalarials were given at the advice of trained health professionals, about one-third were started at the advice of drug shop vendors (17.4%), caregivers themselves (6.6%) or by family members (5.1%), and

on rare occasions CHWs (0.3%) were involved. Caregivers reported giving as many as four courses of antimalarials to an index child. For the first antimalarial given, less than three-quarters (66.2%) of the 290 caregivers reported starting this at the advice of trained health professionals, 21.2% were started at the advice of drug shop vendors, and 7.2% said they made the decision themselves. However, decisions to give additional antimalarial commonly occurred at the advice of health providers. A majority (85.4%) of caregivers reported giving a second antimalarial at the advice of trained health professionals, with few relying on drug shop vendors (6.1%) or themselves (4.9%). Similarly, of those caregivers who gave a third or fourth antimalarial, a large portion indicated these decisions had been made by trained health professionals (78.6% and 100%, respectively), with only 14.2% of caregivers and 7.1 % of drug shop vendors deciding on the third antimalarial.

On the day of the survey, only 15 of the 390 antimalarials were still being given. Of the antimalarials stopped, two-fifths (44.8%) had been stopped at the instruction of trained health professionals, caregivers themselves made this decision in the other two-fifth (39.4%) of the cases, and only rarely were drug shop vendors (9.6%), family members (3.7%) or CHWs (0.3%) involved in this decision. For each course of antimalarial given, both trained health professionals and caregivers played a prominent role in deciding when to stop an antimalarial. For example, four-fifths of the first antimalarials were stopped by caregivers themselves (42.5%) and trained health professionals (41.9%), with drug shop vendors being involved 12.2% of the cases. Similarly, for the second antimalarial given, trained health professionals decided in half of the cases (51.9%), followed by caregivers themselves (40.5%), with family and drug shop vendors being involved in less than 3% of the cases. Just a little over half (57.2%) of children who received a third antimalarial had their medicine stopped by a trained health professional, followed by caregivers making this decision in 35.7% of the cases and the spouse was involved in only 7.1% of the cases. In the two instances were the two children received four antimalarials, their medicine was stopped by a trained health professional.

Accessing information sources

Information sources accessed by caregivers to learn about three knowledge areas were evaluated: (1) information about malaria – its symptoms and cause, (2) information about various antimalarials, and (3) information about national policies related to malaria. All caregiver responses were grouped into one of the following three information source categories: (1) primary sources - defined as those sources which are most mostly likely to provide up-to-date factual information informed by national guidelines and are amiable to regular updates, such as: public health providers (including sensitization programs), informed community members (CHWs and chairpersons), and news media (newspaper, television and radio), (2) secondary sources - defined as those sources whose factual information can get outdated and are less amiable to regular updates, (3) hearsay – included either (a) information received from family or community members who are not trained health providers, or (b) having learned the information on their own and not being able to name any sources external to themselves.

Information about malaria.

Half (53.5%) of caregivers reported learning about malaria symptoms and its cause from primary sources and another half (44.3%) reported learning from hearsay (of which 29.7% mentioned “self” or else said nothing). Very few (2.1%) reported getting their information from secondary sources.

Information about antimalarials.

Hearsay was the most frequently cited source for learning about antimalarials. Two-third (60.8%) of caregivers reported learning about “which antimalarial works the best” from hearsay (of which 51.9% mentioned “self“ or nothing) and only one-third (37.3%) reported learning this from primary sources. Similarly, a little over half (54.5%) of caregivers reported learning about “when it is best to start a child on an antimalarial medicine” from hearsay (of which 43.6% mentioned “self” or said nothing), and 45.5% reported learning this information from primary sources.

A large majority of caregivers (87.3%) reported learning about "worst antimalarials" from hearsay (of which 81.4% mentioned either "self" or said nothing) and less than one-sixth (12.5%) claimed to have learnt this from a primary source. Likewise, a majority of caregivers (79.5%) reported learning about "good and poor quality medicines" from hearsay (of which 75.2% mentioned "self" or said nothing), and less than a fifth (20.3%) reported learning this information from a primary source.

Information about national malaria management policies.

On average, for the district, only one-third of the caregivers report learning about ACT from a primary source. A similar proportion (30.0%) reported learning that the "national policy recommended ACT as the first-line treatment" from a primary source, 69.1% from hearsay (of which 67.7% said "self") and 0.9% from a secondary source. Almost all caregivers (93.4%) reported knowing the national policy regarding "when best to start an antimalarial after noticing fever". Of these, about half (55.2%) reported learning this from a primary source and 44.8% learning this from a hearsay (of which 41.0% mentioned "self" or said nothing). About two-thirds (59.4%) of caregivers reported learning about "where ACT can be obtained from within their community" from a primary source and two-fifths (40.6%) reported from hearsay (of which 31.4% mentioned "self" or said nothing).

Challenges in accessing advice about malaria and its treatment

Seven challenge areas were explored regarding acquiring advice for treating malaria when a child presents with fever: knowing where to go, getting permission to go, having to take find transportation, accessing a health professional, finding the time to go, and having resources within the community.

On average, for the district, over half of the caregivers cited difficulty across all seven areas when wishing to "seek advice for treating malaria". The large majority of caregivers expressed difficulty with getting permission to go (92.0%), finding the time to go (83.5%), and knowing where to go (80.4%). About three-fifth of caregivers stated it was a problem to access a health professional (67.0%), to access resources within the community (60.1%), and to find transportation (58.3%).

Challenges in obtaining the best antimalarial

Nine different challenge areas were explored about how to obtain the best antimalarial to manage malaria in children five and under. Half of caregivers across the district cited problems with seven of the nine items, and two-fifths expressed problems with all nine areas. Nearly three-quarters of caregivers expressed difficulty with getting money for medicine (69.3%) and availability of medicine (69.3%). About three-fifths expressed distance to a public health facility (64.9%) and having to find transportation to obtain the best antimalarial (58.0%) was a problem. About half cited accessing a health professional (53.8%) and finding the time to go obtain the best antimalarial (48.8%) to be a problem. Almost two-fifth reported difficulty with knowing where to go (43.4%) and getting permission to go (42.5%).

Perceived ability to initiate independent action

Caregivers' perceived ability to independently initiate different treatment actions for a child with fever/malaria was evaluated: what form of action to start, which antimalarial to start, when to start an antimalarial and when to stop an antimalarial.

Less than one-third of caregivers reported they commonly made the final decision on which form of action to start (27.6%), less than one-tenth decided on which antimalarial to start (6.6%), and about one-third decided when an antimalarial should be started (31.4%). However, about three-fifths of caregivers believed they could independently start a child on a different form of first action (63.0%) and independently decide when to start an antimalarial (62.7%). Only about a third of caregivers believed they could independently start a child on a different antimalarial (32.8%) or independently stop an antimalarial (37.3%).

3.3.4. Quantitative insights

Predicting receipt of an "appropriate" antimalarial

Of the 424 children, 68.4% had received an antimalarial and 41.0% had received an ACT, but closer inspection showed that only 31.6% received "appropriate" antimalarial treatment" – according to governmental guidelines. As a first step, univariate

analyses identified nine survey items which differentiated significantly whether a child had or had not received an “appropriate” antimalarial at or beyond p<.05. Table 3.13 presents the nine precursors to receiving an “appropriate” antimalarial and a few additional items accounting for unusual fractions of variance (η^2>2%) or possessing other strong conceptual reasons for further testing. Children were most likely to receive an “appropriate” antimalarial if the caregiver reported: being aware that ACT was the nationally recommended antimalarial *(p=0.002)*, that ACT cured the best *(p<.000)*, that they would choose ACT if given the choice *(p<.000)*, or they kept ACT in the home for future use *(p<0.000)*. Children were also more likely to receive an “appropriate” antimalarial if the child was seen by a health professional *(p<0.000)*, if the child was seen at a public health facility *(p<0.000)* or if antimalarials were obtained from public health facilities, CHWs or private hospitals/clinics *(p<0.000)*. Other indicators included caregivers’ gender *(p=0.042)*, and child’s age *(p=0.015)*. Female caregivers were more likely to obtain an “appropriate” antimalarial for their child than were male caregivers, (33.1% versus 20.3%, p=.042), and infants 4 months and lower were distinctly disadvantaged compared to older children who were more likely to receive the “appropriate” antimalarial (7.1% versus 34.6%; X^2 (7, 432)=13.10, p=.000). No other demographic characteristics significantly differentiated whether a child had received “appropriate” antimalarial treatment.

Additionally, a binary logistic regression model determined items which remained associated with the likelihood of receiving an “appropriate” antimalarial when adjusted for other items. The analysis indicated the overall model to be statistically significant (X^2 (4)=173.80, p<.000), with an 83.0% predictive value. The results of the logistic model are shown in Table 3.13. Four survey items remained independent predictors of a child receiving “appropriate” antimalarial, characterized as knowledgeable and pro-active caregivers. In descending order of odds ratio (OR), these items included: (1) caregivers who obtained antimalarials from public health facilities, CHWs or private hospitals/clinics (OR=14.99, p<.000), (2) caregivers who kept ACT in the home for future use (OR=6.36, p<.000), (3) child’s age older than 4 months (OR=5.67, p<.013), and (4) caregivers who reported that given the choice, they would select ACT over other antimalarials (OR=2.31, p<.000).

Table 3.13. Precursors to Whether a Child Received an Appropriate Antimalarial

Survey Questions[a]	Total Respon-dents No.	Univariate Analysis				Multivariate Analysis (binary logistics step-wise regression)						
		df	χ2	p-value	η^2	Step #	Wald (X^2)	p-value	OR	95% CI	% Accuracy of Prediction
Receipt of an appropriate antimalarial in Butaleja (N=424): 32%											
Community Factors											
Is it easy to reach PHF	414	1	0.00	.969	0.000	--	--	NS	--	--	--
Child's Personal Factors											
Age (≤4 months vs Older[b])	423	7	17.34	.015	0.041	4	6.19	.013	5.67	1.44-22.23	83.0
Gender (Male vs Female)	423	1	0.34	.559	0.001	--	--	NS	--	--	--
Birth order	423	2	2.75	.253	0.007	--	--	NS	--	--	--
CGs' Knowledge About AMs											
Awareness gov't policy recommends (ACT vs Other)	423	1	9.59	.002	0.023	--	--	NS	--	--	--
Which AMs cure the best (ACT vs Other)	423	1	17.55	<.000	0.042	--	--	NS	--	--	--
Given the choice, which AM would you select first (ACT vs Other)	423	1	34.60	<.000	0.082	3	8.35	.004	2.31	1.31-4.07	81.4
Knowing when to start an AM after noticing fever (Within 24 hours vs Longer[b])	423	2	0.36	.834	0.001	--	--	NS	--	--	--
Is CG knowledgeable about ACT being available in the community (Y/N)	416	1	0.06	.805	0.000	--	--	NS	--	--	--
Child's Disease Presentation											
Was child seen by a health professional (Y/N)	421	1	12.82	<.000	0.030	--	--	NS	--	--	--
Where was the child seen by the health professional (PHF vs Other)	423	1	21.45	<.000	0.051	--	--	NS	--	--	--
Practice/Management Factors											
Was medicine used for subsequent action (Y/N)	423	1	1.19	.275	0.003	--	--	NS	--	--	--
Where was AM (normally) obtained? (Regulated Outlets[c] vs Other)	423	1	24.25	<.000	0.057	1	71.94	<.000	14.99	8.02-28.02	71.8
Were medicines kept in home over last 6 months for future use (Y/N)	416	1	2.74	.098	0.007	--	--	NS	--	--	--
Types of medicines kept as home remedy for future use on day of survey (ACT vs Other)	423	1	84.92	<.000	0.201	2	44.75	<.000	6.36	3.70-10.93	81.4
CGs' Personal & Demographic Factors											
Gender (Male vs Female)	419	1	4.12	.042	0.010	--	--	NS	--	--	--
Number of children ≤ 5 years (Only 1 vs More[b])	423	5	2.81	.729	0.007	--	--	NS	--	--	--

[a] Abbreviations: accuracy of prediction (Acc of Pred); antimalarial (AM); artemisinin combination therapy (ACT); caregiver (CG); government (Gov't); public health facility (PHF); yes/no (Y/N).

[b] For logistic regression recoded into two categories.

[c] Regulated outlets: community health worker; PHF; regulated private outlets.

Regional differences and receiving an "appropriate" antimalarial

Across the entire Butaleja District, 31.6% of children received an "appropriate" antimalarial, but sharp differences existed among the 10 sub-counties and two town-councils – ranging from 8% in Mazimasa in the rural north-east to 52% in Busolwe Town Council in the more centralized sector of the district (Table 3.14: p=.012). At either extreme, the rate of "appropriate" antimalarial treatment falls far short of the government's own policy of treatment availability – available in any community and free of charge.

3.3.5. Educational and environmental assets and challenges

Comparisons across 10 asset and challenge scales for determining priorities

A further principal objective of the study was to develop quantitative profiles of both Assets and Challenges facing caregivers when managing malaria for their young child to yield more precise insight into their treatment-seeking behaviors. A total of 10 scales developed in a parallel pilot study were used to quantify these profiles. The scales (and therefore the profiles) were refinements of the seven generic factors and thematic groupings constituting the survey itself, but in more structured and psychometrically justifiable form. By definition, such profiles can represent graphically how strongly a person or a group exhibits various tested characteristics, thus a fair amount of information is simultaneously presented in each profile. In this study, behavioral information regarding use of community and environmental resources obtained from the surveys was distilled down into the 10 scales. Because higher scores on six of the scales indicated worthwhile and desirable outcomes in their own right, they were labelled Caregiver Assets: (1) Precursors to Receiving an Appropriate Antimalarial, (2) Episode Management, (3) Caregiver Knowledge, (4) Assistance with Critical Decision from Health Professional, (5) Reliable Information Sources, and (6) Initiating or Redirecting Actions (in the child's medical treatment). Higher scores on the remaining four measures signaled that the caregiver was having trouble managing the current malaria episode, hence these were labelled Caregiver Challenges: (1) Lack of Information Sources (forced to rely on Self only), (2) Lack of Assistance with Critical

Decisions (forced to rely on Self only), (3) Problems Obtaining Best Antimalarial, and (4) Problems Accessing Advice (on treating children with malaria). Thus, profiles with high Asset scores and low Challenge scores identified caregivers who were generally more resourceful, knowledgeable, and managerially competent than those with low Asset/high Challenge profiles. Profiles and the quantitative precision of the scales which constitute them enable more exacting judgments and finely calibrated educational interventions than do simple yes/no answers to survey questions. Further, when profiles are linked to the HBM, treatment-seeking behavior become more evident to Public Health researchers and interventionists to better inform “where the needs are” and “where to start”.

Only rarely did a caregiver correctly identify all the items comprising any single scale. Of the 424 caregivers, only 4 correctly identified all 17 Caregiver Knowledge items; 2 had accessed only credible sources on all 8 Information items, and 10 claimed the Ability to Initiate or Redirect all 7 possible scale items. Average performance was considerably lower. Table 3.6-3.12 (right columns) reports correct responses for each item as a proportion (item scores: Mean and SD), then summarizes the items into an overall scale score (raw and re-scaled). Of the six Asset scales, caregivers averaged highest on Caregiver Knowledge, where on average they correctly identified about 65% of the possible items. They averaged 48% correct Episode Management, 40% of trustworthy Information Sources, 37% of indicators of Ability to Initiate or Redirect their child’s treatment, but only 33% of possible encounters with health professionals to assist in treatment decisions. Similarly, the average caregiver reported problems with 74% of the 7 issues they might encounter in Accessing Advice about treatment for their child, and 56% of the 9 Problems in Obtaining the Best Antimalarial. Caregivers reported that they themselves were their sole information source for 53% of 8 different information gathering encounters and 14% of 9 critical assistance-seeking occasions. As expected, caregivers with higher Asset scores obtained overall lower Challenge results ($r = -0.250$; $p<.000$). Figures 3.3 and 3.4 illustrate the 6 Asset and 4 Challenge profiles of Butaleja caregivers as radar charts, respectively, contrasting where the gaps in treatment-seeking behaviors are most acute. Overall, results showed that the average caregiver accumulated less than half the total possible number of Asset points (45.1%) and about

half the possible number of Challenge points (49.2%), although there was considerable spread within both Assets (SD = 13.4%) and Challenges (SD = 11.0%).

Figure 3.3. Six Asset Scales and Prediction of Receiving an Appropriate Antimalarial across Different Regions of Butaleja District

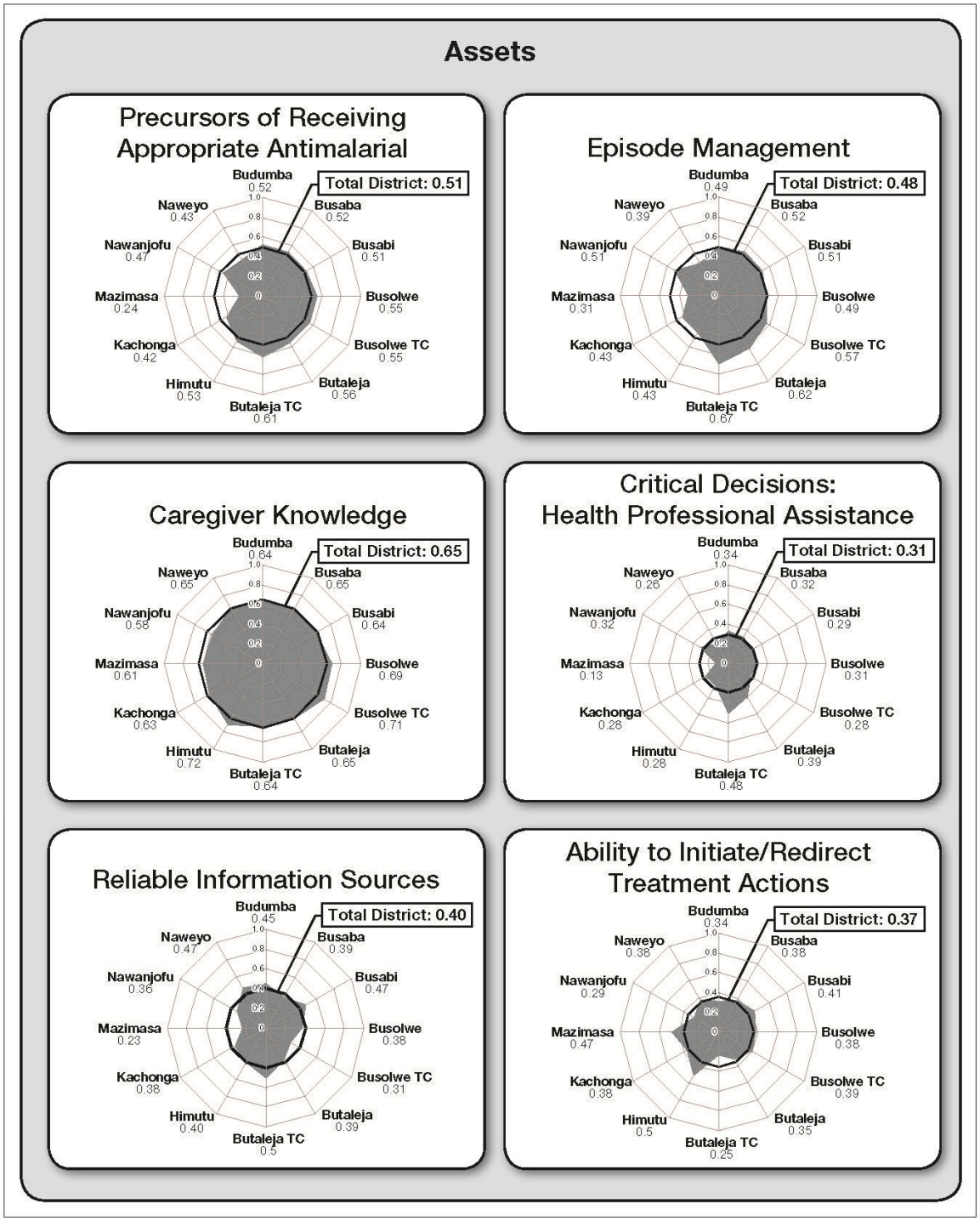
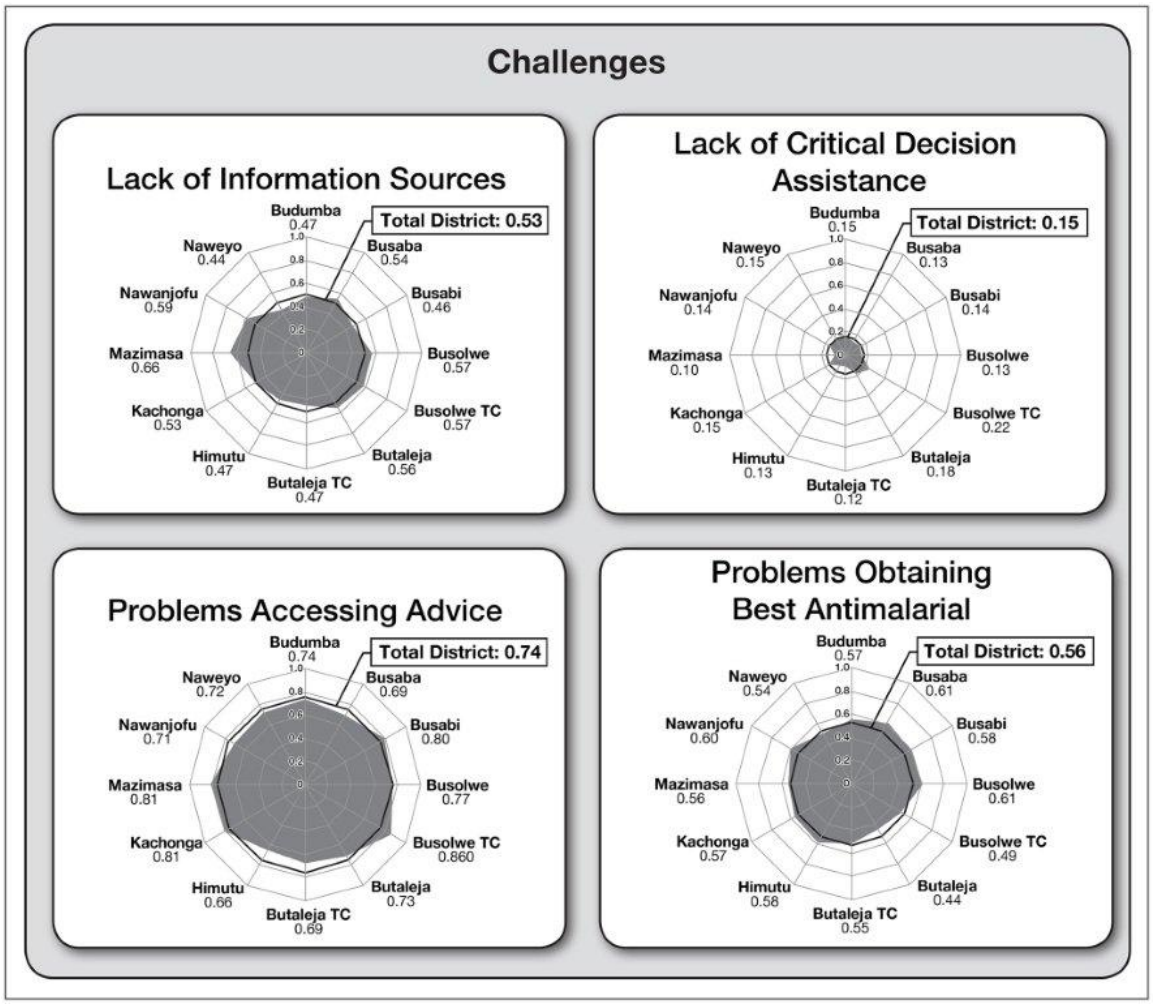


Figure 3.4. Four Challenge Scales and Prediction of Receiving an Appropriate Antimalarial across Different Regions of Butaleja District



Ten Scales and "appropriate" antimalarial prediction

Of the 424 caregivers, 290 reported that their child had received an antimalarial (68.4%), but closer inspection showed that only 134 were "appropriate" antimalarials (31.6%). Four of the six Caregiver Asset scales predicted significantly whether a child actually received an "appropriate" antimalarial (Table 3.14): Precursors to Receiving an Appropriate Antimalarial [η^2=0.211; p<.000]; Episode Management [η^2=0.387; p<.000]; Caregiver Knowledge [η^2=0.057; p<.000]: and ability to obtain Assistance from Health Professional during Critical Decision-making [η^2=0.089; p<.000]). Similarly, two of the

four Caregiver Challenge scales predicted significantly whether a child received an "appropriate" antimalarial, Lack of Assistance with Critical Decision [η^2=0.093; p<.000] and problems encountered in Obtaining a Best Antimalarial [η^2=0.036; p<.000]). Table 3.14 confirms that receipt of an "appropriate" antimalarial is better predicted by four of the six Asset scales and two of the four Challenge scales than by any of the demographic characteristics except for caregiver gender. Thus in HBM terms, perceptions and preparedness outweighed demographics as triggers to seeking an appropriate action.

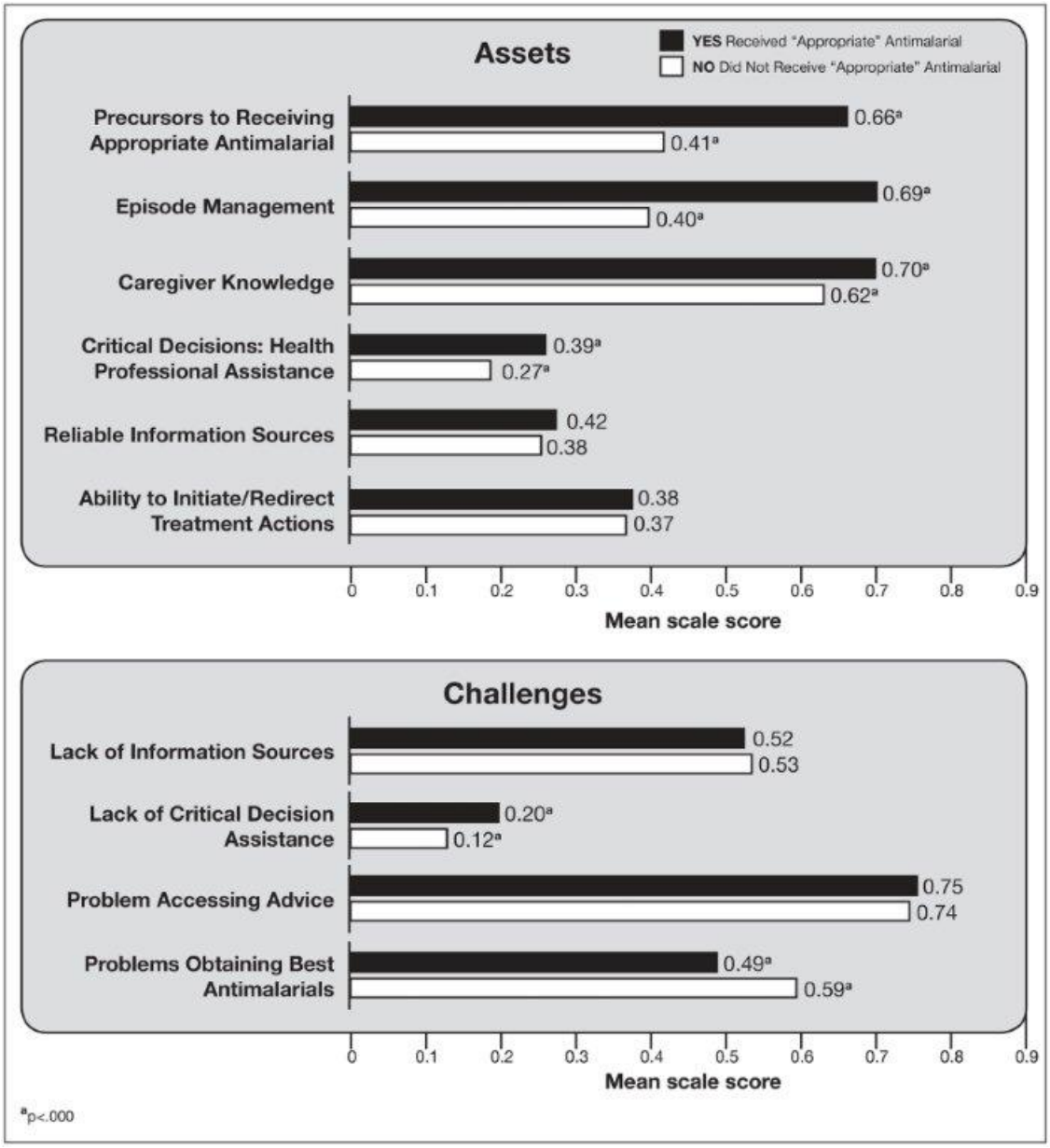
Table 3.14. Sensitivity of the 10 Scales, SES, and Demographics in Predicting Receipt of an Appropriate Antimalarial and Regional Differences

Benchmark → (Scale) Dependent Variables↓	Appropriate Antimalarial[a]				Sub-County/Town-Council Location			
	df	F	p-value	η^2	df	F	p-value	η^2
Behavior Scales: Assets								
1. Precursors to Receiving an Appropriate Antimalarial	1, 419	112.03	<.000	.211	11, 410	4.60	<.000	.110
2. Episode Management	1, 419	264.93	<.000	.387	11, 410	6.66	<.000	.152
3. Caregiver Knowledge	1, 419	25.45	<.000	.057	11, 410	2.18	.015	.055
4. Assistance with Critical Decisions from Health Professional	1, 419	40.92	<.000	.089	11, 410	5.34	<.000	.124
5. Reliable Information Sources	1, 419	1.56	.213	.004	11, 410	2.52	.004	.063
6. Initiating/Redirecting Actions	1, 419	0.90	.764	.000	11, 410	1.81	.051	.046
Behavior Scales: Challenges								
7. Lack of Reliable Information Sources (Relying on Self)	1, 419	0.12	.726	.000	11, 410	2.56	.004	.064
8. Lack of Assistance with Critical Decisions	1, 419	42.20	<.000	.093	11, 410	2.40	.020	.053
9. Problems Accessing Advice	1, 415	0.21	.645	.001	11, 406	1.47	.140	.038
10. Problems Obtaining Best Antimalarial	1, 416	15.34	<.000	.036	11, 407	1.59	.098	.041
Household Wealth (SES)								
Dwelling Permanence	1, 419	0.12	.726	.000	11, 410	3.13	<.000	.077
Rurality	1, 419	0.39	.532	.001	11,410	8.37	<.000	.183
Caregiver Demographics	**df**	**χ^2**	**p-value**	**η^2**	**df**	**χ^2**	**p-value**	**η^2**
Religion	3	4.41	.222	.000	33	138.20	<.000	.073
Tribe	7	6.43	.494	.000	77	182.22	<.000	.023
Gender	1	4.12	.042	.010	11	13.25	.277	.032
Age Category	6	1.73	.943	.003	66	74.30	.226	.024
Education	4	5.35	.253	.000	44	70.14	.007	.047
Benchmark Criteria								
Appropriate Antimalarial[a]	--	--	--	--	12	24.12	.012	.057
Sub-County	12	24.12	.012	.015	--	--	--	--

[a]Appropriate" is defined as having received *only* age-specific Uganda first-line malaria treatment.

Figure 3.5 highlights Asset and Challenge scale differences for caregivers whose child did and did not receive an “appropriate” antimalarial. On the four Caregiver Asset scales which significantly predicted receipt of an “appropriate” antimalarial, the average caregivers whose child did receive an “appropriate” antimalarial were 25% higher on the Precursors to Receiving an Appropriate Antimalarial scale than those whose child did not (66.0% vs. 41.5%). Caregivers of children who received an “appropriate” antimalarial performed better on three additional Asset scales: (1) they scored 29% higher on the Episode Management scale (68.7% vs. 40.1%) (2) they demonstrated 8% higher Knowledge scores (69.9% vs. 62.2%), and (3) they reported 12% more Assistance from Health Professionals at moments of Critical Decision-making (38.6% vs. 27.0%). There were also differences for two of the four Challenge categories they faced. Caregivers whose child did not receive an “appropriate” antimalarial reported 11% higher scores on the scale of “Problems Obtaining the Best Antimalarial (ACT)” than recipients of an “appropriate” antimalarial (59.4% vs. 48.8%). An unexpected pattern observed in this study was that caregivers of children who received of an “appropriate” antimalarial reported a 7% greater tendency to rely only on themselves (not health professionals nor family nor neighbors), than caregivers whose child did not receive an “appropriate” antimalarial (19.7% vs. 12.3%), thus Lacking Critical Assistance when making decisions during an acute episode. While four of the six Asset scales, two of the four Challenge scales and caregiver gender predicted significantly whether a child would receive an “appropriate” antimalarial, a binary logistic regression showed two of the scales to have independent predictive power in detecting whether a child would receive an “appropriate” antimalarial: Episode Management (OR= 21,091.85, p<.000) and Lack of Assistance from health professionals during Critical Decision (OR=46.85, p<.001). The analysis indicated the overall model to be statistically significant (X^2 (2)=210.58, p=.003, R2-pseudo=0.396), with a 82.3% predictive value.

Figure 3.5. Differences in Asset and Challenge scale Scores for Caregivers' Whose Child Did and Did Not Receive an "Appropriate" Antimalarial



High scores on Asset scales (and low scores on Challenge scales) are all worthwhile outcomes irrespective of whether a scale significantly predicts whether a child received an "appropriate" antimalarial. Caregivers need to be equipped with management practice skills, correct knowledge, access to information sources etc. in order to manage future episodes of fever in this index child or with other children. The

elements of the HBM are not specific only to the last febrile episode experienced by the index child in this study, but have applicability across a range of diseases experienced by young children for which fever is a main symptom, across a variety of actions – preventive and curative, and a broad spectrum of socio-psychological modifying factors.

Ten scales and sub-county and town-council (regional) differences

The 10 scales tell a somewhat different story across the sub-counties than simple rates of "appropriate" antimalarial administration. The 10 scales highlighting regional differences in Assets and Challenges influencing caregivers' treatment seeking behavior, serve as a useful guide for where public health interventions ought to begin. Thus, public education programs need to begin in locations where management practices are poor, precursors of receiving an "appropriate" antimalarial are weak, caregiver knowledge is under-realized, critical decision assistance is not readily available, or where information is in short supply.

Seven of the 10 scales (five of the six Asset Scales and two of the four Challenge Scales) were found to be significant discriminators among sub-counties and town-councils, highlighting differences in preparedness, resources, and challenges within these communities for managing malaria in young children when the illness strikes over and over again (Table 3.14). The five Asset Scales to discriminate among the different regions included: availability of health professionals to Assistance with Critical Decision (η^2=0.124, p<.000), Episode Management (η^2=0.152; p<.000), Precursors to Receiving an Appropriate Antimalarial (η^2=0.110; p<.000), access to Reliable Information Sources (η^2=0.063; p=.004), and fluency in malaria-related Knowledge (η^2=0.055; p=.015). Two Challenge Scales also discriminated among the sub-counties. Reported Lack of Information Sources (relying on self only) [η^2=0.064; p=.004] and Lack of Critical Decision Assistance (also relying on self only) [η^2=0.053; p=.020].

In general, Figures 3.3, 3.4, 3.6 and 3.7 are helpful in clarifying where in the district the needs are greatest and public health interventions are most pressing versus where professional health worker assistance is already available, information resources are more plentiful, hence caregiver knowledge and practices are largely in-place.

Figure 3.6. Probability of Receiving an Appropriate Antimalarial across Different regions of Butaleja District

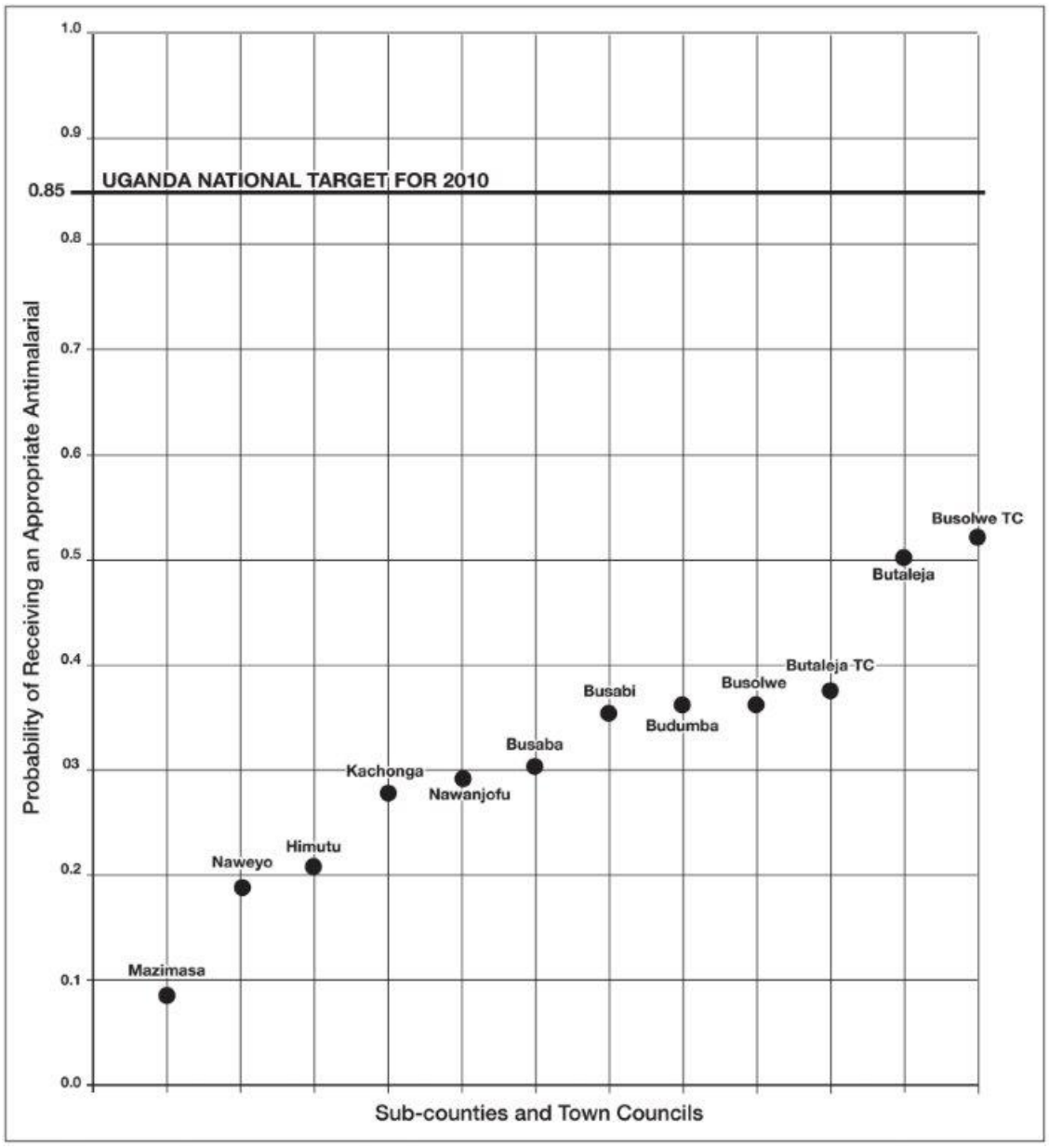
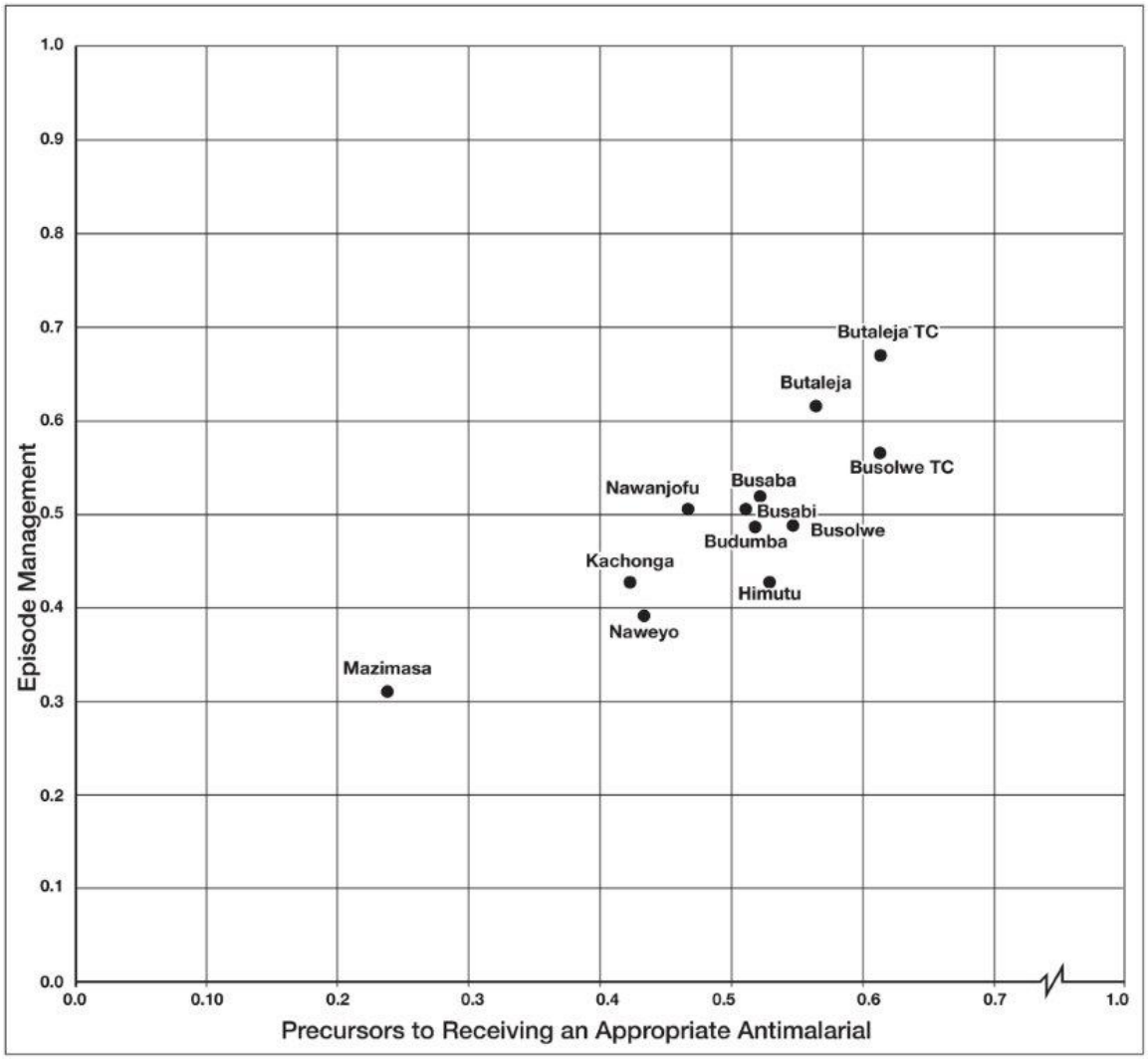


Figure 3.7. Arraying Precursors to Receiving an Appropriate Antimalarial with Episode Management across Different Regions of Butaleja District



Overall, no one region performed particularly well across all 10 scales and not every region was statistically different from every other region for any one scale. Figures 3.3 and 3.4 summarize these results as 'radar plots'. Larger shaded areas represent higher Assets or Challenges for each sub-county (spokes). Thus the large shaded areas for Knowledge Assets or Precursors contrast sharply with few Reliable Information Sources or restricted Critical Decision Assistance. Lopsided or asymmetrical plots indicate high scores in shaded areas and low scores for unshaded sub-counties. Thus for any given scale, low scoring regions were visibly and statistically different from high-

scoring locations. Throughout the figure, sub-county contrasts show how well the various scales separate the sub-counties to allow for public education diagnostics.

Commonly, the town-councils and their surrounds reported favorably (comparatively high Assets and comparatively low Challenges). Notably, caregivers residing in Butaleja (both town-council and sub-county) scored higher on management practices and on precursors to receiving an “appropriate” antimalarial, and they made greater use of professional assistance than did caregivers in any other location. Of all the different regions, Mazimasa sub-county fared worse across five of the six Asset Scales and highest on the Challenge Scale of absence of reliable information.

Figures 3.6 and 3.7 highlight where public education needs are greatest by arraying sub-counties with Precursors to Receiving an Appropriate Antimalarial, and sub-counties with where caregivers reside and by Episode Management scores. Four lower-right sub-counties where Precursors are not in place and where Episode Management skills are weakest are those locations which need immediate public interventions to equip caregivers with the “how-to” practices required for prompt action (Mazimasa, Kachonga, Naweyo, Himutu). The distribution of Assets and Challenges across the regions would indicate Mazimasa to be in greatest need of public health interventions, and might be one of the locations to begin such interventions.

3.4. Discussion

3.4.1. Current treatment practices in Butaleja

This study was unique from other malaria treatment-seeking studies in Uganda because in addition to estimating ACT usage across the study population, this study evaluated the use of “appropriate” antimalarial as defined by the Uganda national guidelines, quantified overall treatment seeking patterns, evaluated responses to determine if any alone or in combination increased predictability of a child receiving an “appropriate” antimalarial, and, lastly, quantified caregiver Assets and Challenges to inform where public health interventions need to begin. Overall, our study established that: (1) a substantial gap remains between Uganda’s national malaria policy and

caregivers' malaria management practices in Butaleja, with only one in five children with fever receiving any blood test whatever and two in five receiving an ACT (alone or in combination with other antimalarials), (2) caregivers whose children received an "appropriate" antimalarial demonstrated greater Assets and about equivalent number of Challenges than those whose child did not, and (3) important regional differences exist within the district for receipt of an "appropriate antimalarial as well as in Asset and Challenge factors influencing treatment-seeking behavior.

3.4.2. Receipt of an "appropriate" antimalarial vs ACT usage

Over the course of the index child's febrile illness, about half were reported to have been seen at a public health facility, a proportion larger than what has been reported nationally and in other eastern Uganda studies (range: 17-26%).[33,50,61-63] In spite of this increased rate of visits at public facilities, "ACT usage" across Butaleja was reported to be 41% and receipt of an "appropriate" antimalarial only 32%. "ACT usage" was acknowledged if any of the medicines taken during the febrile illness was an ACT, whereas "appropriate" antimalarial" treatment was defined as receiving only the age-specific first-line treatment for malaria. While treatment policies vary in SSA, according to the Uganda malaria treatment guidelines, ACT constituted the first-line antimalarial for the 90% of the index children. ACT usage reported in our study was a considerably higher than what has been previously estimated nationally (21-23%), but comparable to 2011 and 2012 national estimates (44%).[50,64-66] None of the Uganda studies explicitly report on the prevalence of "appropriate" antimalarial use, and it was not possible to determine from these studies the percentage of children in whom ACT was the only antimalarial given. In this regard, our study provides valuable insight by illuminating that an increase in ACT usage does not necessarily translate into "appropriate" antimalarial use.

3.4.3. Practice of polypharmacy

The emphasis on ACT usage in other studies is understandable given that prompt treatment with ACT is crucial for preventing malaria deaths young children. However, utilizing ACT usage as the only indicator of success evades much needed

policy discussions around the use of multiple antimalarials to manage malaria in young children. With one in three caregivers in Butaleja reporting using multiple antimalarials to manage malaria in their children, often in combination with non-antimalarials, our study found the practice of polypharmacy to be common. Such a practice has also been observed in other Ugandan studies.[36,50,67] The work by Rutebemberwa et al found a large majority of caregivers in Iganga District had a preference for combination therapy, but caregivers' views about which antimalarials to initially start a child on varied considerably.[36] Polypharmacy raises several concerns, some of which include increased risk of adverse drug reactions, drug-drug/disease interactions, emergence of resistive strains, unnecessary therapeutic intensity and non-drug adherence.[68]

A further issue of concern with polypharmacy is the unnecessary expenditure incurred by households due to redundant drug sales. In their study, Nabyonga-Orem et al established that 82% of caregivers living in mid-eastern districts, which included Butaleja, incurred out-of-pocket expenditures when seeking advice or treatment for the management of malaria in young children, with 70% incurring expenditures linked to acquisition of medicines.[11] For this region, expenditures related to purchase of medications was 16% higher than the national average. While the cost due to drug mis-adventuring has not been estimated for children in Uganda, studies in the west estimate such cost to be in the millions of dollars annually.[69] Future studies therefore need to take a broader approach when evaluating use of antimalarials by also considering the prevalence of "appropriate" antimalarial use. As a next step, studies in Butaleja are needed to understand caregivers' reasons for using multiple antimalarials and their preferences, in order to inform future public health programs to reduce the practice of polypharmacy.

3.4.4. Predictors of receiving an "appropriate" antimalarial

In addition to assessing caregiver and index children's demographic and household socioeconomic factors, this study examined caregivers' responses to 160 different questions representing a variety of treatment-seeking behaviors to identify those that might distinguish whether a child received an "appropriate" antimalarial. While nine of these individual 160 distinguished significantly using univariate analysis, our

logistic regression model identified four independent predictors of receiving an "appropriate" antimalarial: (1) caregivers who obtained antimalarials from public health facilities, CHWs or private hospitals/clinics, (2) caregivers who kept ACT in the home for future use, (3) caregivers who reported that given the choice, they would select ACT over other antimalarials, and (4) child's age older than 4 months. Collectively, the logistic model offered a high predictive value, with 83% of the cases categorized correctly.

While others have found an association between visits to public health facilities and receipt of a first-line antimalarial treatment, our study found visits to a public health facility to be an independent predictor only when an antimalarial was dispensed.[61,70] Additionally, ours is the only study to find caregivers' preference for ACT and their practice of keeping home-stock supplies of ACT to be independent predictors of receiving an "appropriate" antimalarial. With respect to demographic characteristics, only the index child's age was found to an independent predictor. The lack of association with other demographic characteristics was not surprising considering that caregivers in Butaleja were mostly peasant farmers, thus their range of educational and socioeconomic differences may not have been large. National studies in Uganda have also found treatment for fever to vary with a child's age, with fewer children under the age of one reported to have received an antimalarial or an antimalarial within the same or next day compared to 1-5 year olds.[50,65]

Given the inter-correlation among these nine items and the greater insights among caregiver practices they provided, they formed the first strong evidence of treatment-seeking behavior scales among caregivers' survey responses. Further validation and refinement resulted in a Precursors to Receiving an "Appropriate" Antimalarial scale which provided a useful estimate of how caregivers use cues to action and other predictive resources within the district. As evidenced by the average scale score of 51%, caregivers' treatment-seeking behaviors revealed a moderately low utilization of opportunities and local resources which were characteristic of a child's receiving an "appropriate" antimalarial.

3.4.5. Assets and challenges to treatment-seeking

In addition to benefits and barriers, the HBM emphasizes cues and routes to action and self-efficacy as moderating the likelihood of treatment-seeking behaviors.[42,43] To gain further insight into action triggers which influenced caregivers' treatment-seeking behaviors, responses to survey items were distilled into nine additional scales quantifying the different HBM elements into two broad categories of Assets and Challenges. Benefits were profiled by Episode Management scale, and Caregiver knowledge, cues and routes to actions profiled by Reliable Information Sources and Assistance in Critical Decision-Making, self-efficacy profiled by Initiating/Redirecting Treatment Actions, and barriers profiled by Problems with Obtaining Advice, and Problems with Obtaining the Best Antimalarial.

Challenges to treatment-seeking

The high scores observed on two of the Challenge scales may provide one explanation for caregivers' preference for home management. Given the high level of perceived obstacles to seeking external advice and treatment in Butaleja, it is not surprising that almost three out of four caregivers used home management which are convenient, and traditional herbs which can be obtained cost-free from neighboring fields. For seven of the nine items, half of caregivers expressed challenges with obtaining the best antimalarial, with caregivers whose child did not receive an "appropriate" antimalarial reporting a higher scale score than recipients of an "appropriate" antimalarial. On the other hand, the comparatively high score on the Problems with Accessing Advice scale suggest caregivers across Butaleja perceived barriers related to accessing advice to be substantial, irrespective of whether their child received an "appropriate" antimalarial. Collectively, across the two Challenge scales, common obstacles included: finding the time or getting permission to seek advice or treatment; where to access advice, best antimalarial and health providers; the lack of money; finding transportation; and distance to health facilities.

While few studies in Uganda have mentioned time and permission as a challenge to seeking advice or treatment, several Ugandan and SSA studies have reported on access to money, transportation and distance to be important barriers to treatment

seeking for caregivers of children under five.[11,36,50,62,71,72] A possible reason for the lack of time and need for permission may be explained by women caregivers' multiple responsibilities in rural settings. In Butaleja most caregivers are peasant farmers who also manage domestic chores and are responsible for childcare, leaving them with little time to seek prompt advice or treatment outside of the home. Consequently, seeking external care to manage a malaria episode often have numerous ramifications, some of which include loss of productivity from farming, neglect of usual household tasks and reallocation of assets to pay for care.[73] Obstacles to seeking advice and treatment can be particularly taxing when a child falls ill during the farming season, heavy rains when roads become difficult to travel, and if they have to secure transportation and money medicines.[74] Such circumstances require additional time and effort, as well as implicit or explicit permission from their spouse who usually has control over household resources and finances.[36,63,74,75]

As with our study, others have also found cost to be another deterrent to seeking external care, with caregivers resorting to external help only when home management fails or when they perceive their child to be severely ill.[33,63,74,76] Removal of user fees and policy to treat children under five free of charge at public facilities has not translated into free universal access to treatment due to various indirect costs related to such visits. Examples of such costs include the cost of transportation, unofficial fees charged by health providers, and purchase of medicines from private vendors during periods of stock-outs.[63] The share of total out-of-pocket expenditure that goes to medicines has been documented to be greater than other components, indicating medicines bought from the private sector contribute additionally and unnecessarily to the financial burden.[11]

Several studies have reported an inverse association between distance and utilization of health services.[62,77] One possible reason why our study found only a low association between distance to a health facility and usage of ACT may be because we relied on caregivers' estimates rather on objective measures to calculate distances, thus taking into account geographical obstacles.

Episode management of a current febrile illness

The Episode Management scale summarized 16 general practice fundamentals for managing the current episode. In a logistic regression, this scale was found to be the single best predictor of whether a child received an "appropriate" antimalarial, accounting for 39% of total variability. The Episode Management scale therefore represented a surrogate estimate of the likelihood of actually obtaining an "appropriate" antimalarial, with high scores indicating a higher likelihood of a child receiving an "appropriate" antimalarial.

As evidenced by their Episode Management scale score average of 48%, caregivers in Butaleja exhibited a mediocre level of managerial proficiency. While a large majority of caregivers reported initiating some form of action within 24-hours, for three out of four children this represented home management. In Butaleja the use of home management as initial care was more common than what has been reported nationally (42-61%) or in other regions of eastern Uganda (24%).[50,65,78] Similarly, the proportion of caregivers who used traditional herbs was also higher in Butaleja than elsewhere in eastern Uganda (26% vs 19%).[33] Rutebemberwa et al found the use of home management in general, and the use of traditional herbs in specific, to be associated with delayed treatment-seeking at external sources.[33] We did however find that the practice of keeping home-stock medicine, in particular ACT, to be an independent predictor promoting receipt of an "appropriate antimalarial. All ACTs given as part of initial care in our study were sourced from home, this represented 17% of all ACTs given to index children over the course of their illness. The overall percentage of ACTs kept as home-stock in our study was slightly lower than the 24% quoted in national studies conducted in 2009 and 2012.[50,65]

Evaluation of caregivers' management practices also determined that a large majority of caregivers needed to continue treatment with a subsequent action, suggesting most children did not improve with home management alone. Though five out of the seven of all external visits were with trained health provider from public health facilities, only half of all caregivers reported obtaining their antimalarials from public health facilities. A negligible 1% sought care from a CHW. The proportion of caregivers who visited a public health facility over the course of their child's febrile illness was

substantially higher in our study than previously reported for eastern Uganda (17-26%) or nationally (21-24%).[33,50,61-63] In spite of this high rate of advice and treatment seeking at public facilities, ACT usage and mention of a child receiving a blood test remained disconcertingly lower across Butaleja (41% and 21%, respectively) than the 2010 national strategic target of 85%.[13] These percentages were however higher than the 2009 national estimates of 21% for ACT usage and 11% diagnostic testing, and were comparable to what has been observed nationally in 2011 and 2012 (44% for ACT usage and 18-26% for diagnostic testing); confirming a substantial gap between policy and practice.[50,61,64]

Our study found obtaining an antimalarial from public health facilities, CHWs or private hospitals/clinics to be an independent predictor of a child receiving an "appropriate" antimalarial. While visit to a public health facility was significant in the univariate analysis, this did not remain significant in the logistic regression. In contrast, Kemble et al and Littrell et al documented visits to public health sectors to be associated with increased likelihood of receiving a first-line treatment, despite sub-optimal treatment at these centers.[61,70] The findings by Kemble et al findings reflected caregiver practices in an urban setting of Uganda, whereas the analysis by Littrell et al was based on data collected as part of a national survey in 2009. [61,70] Of those who obtained an antimalarial in our study, four out of seven reported doing so from private outlets (licensed and unlicensed), confirming what others have found that private outlets continue to fill the gap between home management, CHWs and public facilities.[33,50,61,78] However, only a third of caregivers in Butaleja reported that ACTs were easy to find in their community and one in six believed ACTs were affordable.

Knowledge about malaria and ACT

Caregiver knowledge was viewed as an Asset since it serves as a modifying factor to condition perceptions about both malaria and its treatment. Thus, assessment of caregivers' knowledge provided valuable insight into caregivers' perceived benefits and further explanation for the low ACT usage across Butaleja. While average Caregiver Knowledge was the highest of any scale (65%), there was considerable variability and substantial knowledge deficiencies in certain key topic areas. In HBM terms, we found that Butaleja caregivers acknowledged high susceptibility for malaria since about four

out of five caregivers readily attributed their index child's fever to malaria and three in four correctly attributed fever to malaria caused by mosquitoes. However, while another four out of five caregivers suspected their child to have severe malaria, only one in five were able to list symptoms associated with severe malaria in order to distinguish it from common malaria or even early warnings. Consistent with other studies, these findings suggest caregivers' perception of severity to be less informed by medical information and more by personal understanding of difficulties that might be associated with malaria.[36,77,79,80]

Though we did not investigate how caregivers appraised severity, based on their high rate of perceived barriers, it is plausible that their notion of severity is tied to obstacles such as cost and time associated with managing malaria as compared to the common cold. While several studies have reported that most Ugandan's' correctly attribute fever to malaria caused by mosquitoes, only the study by Hildenwall et al qualitatively evaluated caregivers' understanding of symptoms associated with severe malaria.[50,65-67,80] Further, Hildenwall et al found little consensus among caregivers about the cause for symptoms related to severe malaria or their proposed action.[80] This disconnect in how caregivers' interpret severity compare to the biomedical community might explain the over-reliance on home management during the initial phase of the illness, with external care sought only if and when the child's illness progresses.[36,80]

Assessment of caregivers' knowledge also indicated caregivers' perceived benefits of ACT were substantially low all across Butaleja, with just one in three caregivers reporting they would select an ACT if given the choice. The low preference for ACT was likely contingent on their low awareness about ACT. Only one in three caregivers was aware that ACT was the government recommended first-line antimalarial or that it cured malaria the best, and only one in four was able to name a setting where they were certain to get an ACT for free if they required it. The proportion of caregivers who reported knowing that ACT was the first-line antimalarial was substantially lower in Butaleja than what had been previous reported in a national study (34% vs 57%), although a comparable proportion reported ACT as the antimalarial which cure malaria the best.[61] Caregivers' preference for selecting an ACT if given the choice was an independent predictor for receipt of an "appropriate" antimalarial in our study.

Sources of information

Most national programs for educating the public on malaria and its treatment in Uganda rely on primary sources such as: news media (newspapers, television and radio), sensitization programs using trained health providers, and informed community members such as chairpersons.[16,81] Results from the study's two information source scales show that across Butaleja, such national programs have had negligible impact at influencing caregivers' treatment-seeking behaviors. Caregivers could name a primary source for only about a third of the eight topic areas pertinent to malaria and its treatment. When primary sources were cited, they were for: learning about malaria, learning when the government recommended starting an antimalarial, and hearing about ACT. Only half of those who had heard about ACT were also aware ACT was the government recommended first-line antimalarial. Those who were knowledgeable about ACT as the government recommended antimalarial were significantly more likely to obtain an ACT compared to those who were unaware of the recommendation. Hearsay from community members, families and/or themselves was the common resource when a primary source was not mentioned.

Other studies have also shown that awareness about ACT does not always translate into believing ACTs are the most effective antimalarial or into increased usage; although none have reported a correlation between knowing ACT is the only government recommended antimalarial and ACT usage.[50,61] These and our findings suggest that information delivered by primary sources either fall short of conveying *key messages* or that information is not transmitted in a fashion where such key messages are easily accessible, retrievable or understood by caregivers.

Decision-making support sources

Caregivers' decision-making was further compromised by low levels of interpersonal cues available to them during periods of acute illness when critical decisions were made. The low 30% score (range: 0-76%) for the Critical Decision Assistance from Health Providers scale suggests that trained health providers' influence was either limited or not sought out, despite three out of four caregivers indicating it was their preference to first seek advice from a health provider. Health providers were most

likely to be consulted regarding selection of an antimalarial, followed by advice about when to start an antimalarial; and least likely to be consulted on decisions during the initial phase of the illness. Children whose caregivers received assistance from trained health professionals were 12% more likely to receive an "appropriate" antimalarial, than who did not. Unfortunately, in this study as in others, seeking care from trained health providers mainly occurred after failure with initial care.[36,63] Given that health provider assistance with critical decision resulted in increased receipt of "appropriate" antimalarial, future public health interventions need to promote early contact with trained health providers who have access to ACT. This access can be through a CHW, a public health center or a trained private vendor.

Well over half of all initial care decisions were made by caregivers on their own or with help from family members. Family members commonly assisted with initial care decisions related to confirming malaria, selecting initial form of actions – western medicines versus alternate forms of actions, and starting a specific herbal medicine. While three out of five caregivers reported to have independently decided to give home-stock medicines or to seek external advice during an acute episode, it is conceivable that such monetary decisions were influenced by their access to household's financial resources. As is customary in many patriarchal societies for men to decide on financial matters, evident from the high scores on the two Challenge scales, it is conceivable that men in Butaleja also have considerable influence where care seeking is associated with cost.[76,82] Access to money to pay for transportation, services, and medicines was perceived by many caregivers as major obstacles to seeking advice and treatment. In such circumstances, caregivers will be more likely to engage in a desired behavior if their spouse also sanctions this behavior. Future public health interventions aimed at influencing caregivers' behavior should therefore target both caregivers and their family members with information for better knowledge, understanding and attitude change.

Overall, 6.1% of caregivers reported a total absence of anyone to assist with critical decisions. Although seemingly counter-intuitive, caregivers whose children received an "appropriate" antimalarial reported 7% *more* instances of having only themselves to rely on when making critical decisions than those whose child did not. One explanation for such an association between reliance-on-self and receipt of an

"appropriate" antimalarial may be that some few of those caregivers *knew* they lacked resources, thus were more determined and successful at obtaining an "appropriate" antimalarial. Further investigation is needed to confirm this relationship especially in remote areas where health professional services are infrequent.

3.4.6. Self-efficacy and independence

While caregivers are active participants in decision-making processes of how to manage their children during acute episodes, their decisions are simultaneously constrained by their circumstances. The Ability to Initiate and Redirect Action scale intended to measure caregivers' sense of self-efficacy regarding independence to alter the course of malaria treatment actions in their children. Across Butaleja overall, caregivers scored comparatively low (37%) on self-efficacy, suggesting a low perceived ability to initiate or redirect action related to treatment of malaria – although in some sub-counties more than others. While three in five caregivers believed they could have independently decided to start their index child on a different form of action or when to start an antimalarial, only one in three indicated it was customary for them to decide on what form of action to start, when an antimalarial could be started or on a different antimalarial for their children five and under. On the surface, these responses might appear inconsistent, but considered in the context of other findings, may not be contradictory. Women's lack of control over household resources and therefore treatment-seeking behavior is well recognized in SSA.[36,63,74,83] Numerous perceived barriers to seeking advice or treatment in our study also suggests that in Butaleja caregivers are often compelled to rely on others for resources. For about half the children, it was usual for the spouse and other family members to be involved in deciding which form of action to start. Given this context, it would be plausible that most caregivers depend on their spouses to make decisions about the overall approach to care and decisions about which home-stock medicines to keep; but only within limited parameters do caregivers independently decide how to manage a child's fever.

We found no significant correlation between self-efficacy and receipt of an "appropriate" antimalarial. One possible explanation for the lack of correlation may be that our definition of self-efficacy was narrowly focused on initiating or redirecting

treatment. The HBM outlines a more general definition of self-efficacy mediated by other factors such as caregiver knowledge, perceived benefits of ACT, problems accessing advice, or problems obtaining the best antimalarial. Further, the HBM suggests that self-efficacy exerts its influence through cognitive, motivational and selection processes; in this regard, perceived benefits and barriers represent important antecedents to caregiver self-efficacy.[84]

3.4.7. Public health interventions required to improved health delivery

Improving caregivers' and their families capacity to obtain "appropriate" antimalarials

Our study confirmed that caregivers reporting they would select an ACT over other antimalarials to be an independent predictor for a child receiving an "appropriate" antimalarial. Future educational and other public health strategies aimed at improving management of malaria in young children should therefore involve and target both caregivers and their family members. In circumstances where health providers are prescribing or dispensing ineffective antimalarials based on presumptive diagnoses, it is likely that caregivers who have a preference for ACT and understand the importance of having a confirmed malaria diagnosis will be more likely to search out and request such treatment.[85,86] On the other hand, those who lack the information to make informed management decisions may limit the demand for effective interventions even when such interventions are available. Accordingly, shaping caregivers' and their family members' knowledge, expectations and personal capacities to promote use of appropriate antimalarials will, in turn, influence health provider and vendor practices to improve their practices. The literature however suggests that emphasis on factual information alone may not be sufficient to improved treatment-seeking behavior, since such behavior depends on several factors.[87,88] The high prevalence of perceived obstacles reported by caregivers in our study also supports the interpretation that health education needs to be more than dissemination of factual information. Such programs need to simultaneously enhance caregivers' personal capacities to make appropriate decisions by enabling them to understand, judge, sift and use factual information in the context of their own circumstances. Thus, promoting this health literacy requires dissemination of health

information in a fashion that is locally relevant, acceptable and engaging to change caregivers' behavior.[88]

Engaging the private sector

In the context of challenges noted in this study, the high prevalence of home management for initial care is not surprising. Future public health initiatives need to continue efforts to improve access to appropriate "antimalarial" treatments in rural communities such as Butaleja. While regular stock-outs of ACT has been reported to be an important cause for sub-optimal practices at public health facilities, the literature also suggests that health professionals in private and public outlets often do not prescribe recommended antimalarials even when they are present and available.[61,89,90] For public outlets, these findings suggest implementation of national malaria management policies and training of health professionals within the public sector has not been sufficient to ensure appropriate case management is delivered consistently at all times. Among licensed private outlets, the lack of trained vendors and the cost and quality of antimalarials sold at many of these premises in rural areas has been a longstanding concern.[85]

In an effort to increase consumer access to effective antimalarials at private outlets, a national subsidy program (the AMFm program) was introduced two months prior to the start of the current study. This program offered licensed private outlets with training on malaria management followed by supply of subsidized ACT for sale to the public. Given that obtaining an antimalarial from a trained provider at public and private outlets was found to be an independent predictor of a child receiving an "appropriate" antimalarial, our findings strongly support such an initiative to fill an important gap between home management and public facilities. However, the AMFm training and ACT subsidy scheme has limited their network to licensed drug vendors, excluding all unlicensed vendors from this initiative despite their prominence and reach in rural settings.[25] Consequently in parishes where this study was conducted and where 81% of private outlets were operated by unlicensed drug vendors, the increased availability and market share of ACT observed at licensed private outlets across the nation was not observed for unlicensed private outlets whose personnel remain untrained.[51] Our study suggests that limiting ACT access to only public health facilities and licensed private

outlets in rural settings such as Butaleja is unlikely to improve quality malarial management to acceptable levels across the entire population spectrum. Future public health initiatives therefore need to continue efforts to improve access to effective treatment in rural communities, by strengthening the health system as a whole - including training of all licensed and unlicensed private providers.

Treatment closer to home

The current strategy of using CHWs as part of iCCM program to improve access to prompt, effective and free treatment is a step in the right direction. At the time of this study, CHWs in Butaleja did not distribute ACTs, thus explaining the low caregiver consultation rates with CHWs observed in our study. However, in other regions of Uganda where concerted community-based efforts have been undertaken to train or re-train CHWs as part of the iCCM, the uptake of CHWs has varied.[29,33,50] Ajayi et al reported utilization rates to be high by sensitized caregivers under study conditions, but it was unclear why despite extensive marketing almost half of caregivers opted to not access care from CHWs or why nearly half visited a CHW 24-hour after first noticing fever in their children. Rutebemberwa et al on the other hand reported a surprising low CHW consultation rate of about 15% in rural Districts of Iganga-Mayuge, where most of the population is poor and faced with numerous obstacles when seeking advice or treatment.[33] In the Iganga-Mayuge region, caregivers who used traditional herbs were more likely to use private outlets over CHWs, suggesting there may be a category of caregivers in rural settings that might be difficult to reach through CHW programs.

Perceived poor treatment and regular stock-outs at public facilities have been common reasons noted for seeking advice and treatment from private outlets.[33] Similar perceptions can also undermine CHWs role – given they are an extension of the public system – resulting in caregivers continuing to purchase antimalarials from private outlets.[91] To-date, there still remains a gap in our understanding of optimal models to implement and scale-up in the face of inadequate and inconsistent remuneration practices and frequent stock-outs of medicines and supplies in public sector services. The commercial sector – largely unlicensed in rural areas – will likely continue to play a pivotal role in providing antimalarials. It would be worthwhile to investigate the feasibility of including such vendors who are already financially independent within the iCCM,

using training and subsidies offered to licensed vendors, with payment based on contributions and/or transfers or targeted exemption for appropriate treatment delivered.[33]

Where to begin public intervention

While the HBM highlights the interplay of perceptions of susceptibility, seriousness, barriers, and benefits with the modifying factors of cues to action and demographic variables, our study found that the strongest links existed between treatment-seeking aspects of 'knowing what to do and why' and obtaining the correct medication for the child. For the most part, demographics such as caregiver gender, age, schooling, religion, tribe, or household wealth (in terms of either dwelling permanence or asset type) made little difference. However, geographic location within Butaleja was a powerful indicator of knowledge, management practices, access to reliable information sources, availability of health professional assistance with critical decision, and ultimately whether their child would receive the "appropriate" antimalarial. Since caregivers are too often unaware of what to do or where to turn for assistance, public education programs need to begin where the need is greatest, and that differs from one sub-county to another.

Recognizing that our study was a cross-sectional "snapshot" of caregivers' most recent episode-management incident reminds that future incidents will also need to be managed, and managed better. Thus, public education programs about knowledge, treatment-seeking, episode management, available resources, and how to access ACT are more worthwhile for future public health than for yesterday's – and can be first introduced into Butaleja's neediest sub-counties, refined, and transferred to new locations that are less critical.

3.4.8. Limitations

The findings from this study need to be considered in the context of potential limitations. First, since this was a cross-sectional study, causality cannot be inferred. Second, the study relied on caregivers' self-reported information. This approach is subject to recall and reporting biases and caregivers could have forgotten certain

information or reported what they believed were socially desirable responses. However, we believe that through our methodology we were able minimize these biases. For example, recall bias was minimized by focusing on the youngest child who became sick in the previous two weeks of the survey and by having the index child present during the interview to trigger caregivers' recall to details about the febrile episode. Similarly, reporting bias was minimized by assuring caregivers that their information would remain confidential and by ensuring privacy during the interview. Third, misclassification of treatments given to index children could have occurred if caregivers misrepresented or were mis-informed as to what medicines were given to the index children. To aid with recall and identification, caregivers confirmed their verbal responses by confirming them against photographs printed on laminated posters of medicines commonly for malarial in Butaleja. Further, case-selection was based on presumptive diagnosis rather than on confirmed diagnosis of malaria, which could have resulted in selection of some cases which may not have been malaria. Given that fever commonly serves as a proxy for malaria at the household level and at most external settings where care is sought in Butelaja, and fever is commonly managed as malaria, our selection process followed real life practices. However, since the study was conducted during a high malaria transmission season, the sensitivity of fever being malaria was likely high, thereby minimizing misclassification of illness.

3.5. Conclusions

Using the HBM as a template to evaluate caregivers' treatment-seeking behavior provides helpful guidance for intervention strategies. The HBM is a value-expectancy theory which states that individuals are most likely adopt a desired action if they see that assessed benefits outweigh assessed barriers. Our study results suggest that Butaleja's caregivers' seeming low motivation to change treatment-seeking behaviors may result from high perceived barriers to - and low perceived benefits from ACT. Thus, two sets of interventions are required: one to minimize barriers to obtaining advice and treatment, and the other to improve caregivers' perceived benefits about ACT and their ability to navigate current health system to obtain ACT in prompt and efficient fashion.

The first treatment encounter outside the home is important if children are to get prompt and appropriate treatment. Therefore, for the quality of malarial management to improve for young children, government support and national policies should extend not only to services supported by public programs but should include all actors – especially those who often provide first levels of care. In addition to health professionals, CHWs and licensed private operators, these policies and supports should include unlicensed private outlets, village support groups, caregivers and relevant family members.

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Chapter 4.

Patterns of Treatment-Seeking Behaviors among Caregivers of Febrile Young Children: a Ugandan Multiple Case Study

4.1. Introduction

In 2010, there were an estimated 216 million episodes of malaria worldwide and 655,000 deaths.[1] Approximately 81% of these episodes and 91% of deaths were reported in the Africa Region, and nearly 86% of the deaths were in children under five. Globally, malaria has been reported as the third cause of death in 2010, after pneumonia and diarrhoea.[2] Among those who survive, many are left with persistent anemia, impaired brain function or paralysis.[3] The highest burden is in children because they lack the naturally acquired immunity to the parasite.[4-6] Reducing child mortality from treatable diseases has become a global priority.[5,7] In a 2000 summit in Abuja, Nigeria, African leaders pledged to halve malaria mortality by 2010.[8] Accordingly, two of the United Nation's Development Goals focus on reducing this unacceptable high level of child mortality rate.[9] Prompt treatment with effective drugs is the cornerstone of malaria management. One proposed declaration and plan of action from the African summit was to ensure by 2005 at least 60% of those suffering from malaria have prompt access to, and are able to correctly use, affordable and appropriate treatment within 24 hours of the onset of symptoms.[8] However, despite several large-scale efforts to develop and disseminate effective drugs, the Abuja target continues to be elusive, with over 39,000 children each year dying of malaria in Uganda.[10] A key impediment to achieving this target has been inadequate access to health facilities and to effective treatment at the population-level.[7,11-15] The literature suggests that a large proportion of caregivers delay seeking appropriate care for their children, many children are treated presumptively, and

many others receive ineffective medicines obtained from the private sector rather than treated at public health facilities.

Changing these practices will require more than policy changes; it will require an understanding of steps taken by caregivers when treating their children's malaria, and an explication of factors that predispose, enable and reinforce desirable treatment-seeking behaviors. Several causes have been proposed for the gap between policy and practice:

1. At the community level - a large number of Ugandans in rural settings have limited access to publicly funded health facilities, regulated pharmacies and trained health professionals due to severe shortages of health professionals and low capacity of the healthcare system.[16] This has resulted in a proliferating unregulated private drug delivery sector that is untrained and unlicensed, but which has become a major source of drug delivery.
2. At the household level - there are inappropriate self-management practices and over-reliance on unlicensed drug vendors for antimalarial drugs.[15]
3. At the service level - there are limited health resources, inadequate malaria information to consumers and ineffective antimalarial drugs dispensed by unlicensed drug vendors.[15-17]
4. At the government level - resources are unavailable to enforce existing drug vendor regulations which is compounded by the predicament that such enforcement would create in compounding the suffering of millions who do not have access to regulated health facilities and trained health professionals.[16,18]

Numerous studies have found large percentage of drugs and/or drug dosages dispensed by unlicensed drug vendors to be inappropriate; hence, their prominence represents a major challenge to ensuring access to and use of effective drugs.[12,17] The popularity of unlicensed drug vendors stems from the fact that they: provide easy access to medicines, do not require patients to wait in long queues or travel long distances, offer a range of drugs that can be purchased in any amount, and without the need for prescription.[15,19,20] Further, consumer demand also influences these vendors' practices, who often succumb to selling what the customer demands. Consequently, when consumers lack the ability to make appropriate drug decisions, they often limit the demand for effective interventions.[21] Accordingly, shaping customer expectations to influence vendor practices is essential to achieving the Abuja targets in sub-Saharan Africa.[20,21] A comprehensive strategy to improve caregivers' management of malaria for

young children requires an understanding of elements which need to be enhanced and supported. This in turn, requires information on caregivers' current treatment seeking patterns and their experiences with the health system.

This investigation's case study approach captured unique situations to illustrate special attributes and aspects of treatment-seeking during a malaria episode; including both good practices and weaknesses in care-giving. Exploratory case studies can also uncover unrecognized factors influencing caregiver practices, help explain factors already identified, and determine factors that can be used as leverage points for defining a health promotion program. This study's objective was to examine treatment-seeking patterns and experiences of eight caregivers while managing the fever (presumed malaria) episode in their youngest child of five years and under. Specifically, this study explored (1) the sequence of treatment steps taken by caregivers, (2) treatment options available to them when visiting sources external to their home, (3) challenges they encountered when seeking treatment, (4) financial and social burdens associated with malaria, and (5) caregivers' knowledge about what is the best antimalarial for young children. The study sought to generate a broad perspective on treatment-seeking behavior by caregivers who treated their children and whose child experienced one of three different outcomes: (1) the child was cured (positive outcome), (2) the child survived but experienced a permanent disability (negative outcome), or (3) the child died (negative outcome). This study focused on the child's most recent febrile episode resulting in the outcome of interest.

4.2. Methods

This qualitative exploratory study was conducted in Butaleja District, Uganda as part of a baseline assessment for a larger study to examine caregivers' treatment-seeking behaviors for children of five years and under with presumed malaria. A multiple case study methodology was implemented to interview eight caregivers over a period of two weeks in August 2010. Research assistants from the District were recruited to conduct the case study interviews. Further, case studies were exploratory in order to understand caregivers' treatment-seeking practices -- whether anticipated or emergent -- and to determine factors influencing these practices. Ethics approval for the project had

been previously obtained from the Child Health and Development Centre Ethical Centre at Makerere University, the Uganda National Council for Science and Technology, the Office of Research Ethics Simon Fraser University and the University of British Columbia British Columbia's Behavioral and Research Ethics Board.

4.2.1. Setting

The study investigated caregivers in Butaleja District located in rural eastern Uganda approximately 38 km southwest of the nearest large city Mbale and 210 km northeast of the capital Kampala.[22] Butaleja District is bordered by Budaka District to the north, Mbale to the east, Tororo to the south east, Bugiri to the south, and Namutumba to the west Butaleja's administrative structure consists of 10 sub-counties (mostly rural) and two town councils (designated urban centres). Based on the 2002 national census, the population of Butaleja District for 2010 was estimated at 206,300, with approximately 44,300 children under five.[23] The predominant ethnic group is the Banyole tribe and the predominant spoken language is Lunyole.[22] The district normally experiences two major rainfall periods between May and October, although it commonly experiences unpredictable rainfall patterns that result in severe flooding creating swamps, submerging gardens, destroying roads and leaving many families homeless.[24] The district's economy is chiefly subsistence farming, with almost four-fifths of the population deriving its livelihood from crop production.[24] Poverty is generally a society-wide phenomenon, although women are likely to be poorer than men because they lack independent sources of income and so have less access to resources.[23]

Malaria was the highest ranked cause of morbidity in the District in the period 2007-2009, with about eight in every 10 persons experiencing malaria/fever symptoms.[23] Health services in Uganda are provided by both public and private sectors. The public health infrastructure in Uganda is stratified into four levels: hospital at the district level, Health Centre (HC) III at the sub-county level, Health Centre (HC) II at the parish level and Health Centre (HC) I at the village level.[25] According to documents from the Regional District Office of Butaleja (K. Mweru, MD, written communication, April 2011), at the time of this study the District had one public hospital located in Busolwe town council, 11 HC IIIs located across eight sub-counties, 11 HC IIs located in select

parishes across seven sub-counties, and a network of HC I comprised of volunteer community health workers (CHWs) scattered in villages across the district. The main hospital and HC IIIs were regulated to provide inpatient and outpatient services, including the administration and dispensing of: quinine (oral and injection), artemisinin-based combination therapy (ACT) and sulfadoxine/pyrimethamine (SP); whereas HC IIs offered a limited range of outpatient services, including the administration and dispensing of: quinine (oral and injection), artemisinin injection, ACT and SP. CHWs were authorized to dispense antimalarials, but none were provided with ACTs at the time of the study. While it is advocated by the ministry of health that every sub-county have at least one HC III and every parish have one HC II, at study time the district fell short of this goal. Additionally, in 2006, the Uganda National Malaria Control Programme introduced a policy to provide cost free ACT at all levels of the health system (levels I to public hospitals), supplied as the Coartem® brand.[26] This formulation is composed of a fixed combination of 20 mg of artemether and 120 mg of lumefantrine, supplied in pre-packed weight- and age-specific forms. Other ACT brands could also be purchased from private outlets, with subsidized pricing offered only at licensed private outlets through the Affordable Medicines Facility – Malaria (AMFm) scheme.[27] The District however had no pharmacies and only a few licensed drug shops located mostly in town centres and market areas. The largest fraction of private vendors included unlicensed private vendors distributed across the district who did not have formal training in the management of malaria.[28] Table 4.1 summarizes public and private outlets available at the time of the study in sub-counties and parishes where study participants resided.

Table 4.1. Distribution of public health and private outlets in sub-counties (parishes) where the eight cases resided

Cases (CS): sub-county (parish)→ Outlet type ↓	CS 01: Himutu (Kaiti)	CS 02: Busaba (Buwihula)	CS 03: Nawanjofu (Bingo)	CS 04: Naweyo (Kaiti)	CS 05: Butaleja (Nakwasi)	CS 06: Naweyo (Kaiti)	CS 07: Naweyo (Kaiti)	CS 08: Busabi (Malangha)
Health centre III	--	--	1	--	1[a]	--	--	--
Health centre II	--	--	1	--	1	--	--	1[a]
Private clinic	--	--	--	--	--	--	--	--
Pharmacies	--	--	--	--	--	--	--	--
Drug shop (Licensed)	--	2	--	--	--	--	--	--
Drug shop (Unlicensed)	--	4[a]	3	5[b]	--	5[a]	5[b]	--
General shop (Unlicensed)	--	--	--	1	--	1	1	--
Market stall (Unlicensed)	--	--	--	--	--	--	--	--
Kiosk (Unlicensed)	--	--	--	--	--	--	--	--
Mobile vendor (Unlicensed)	--	--	1	--	--	--	--	--
Total outlets		**6**	**6**	**6**	**2**	**6**	**6**	**1**

[a]One drug shop located in the village where caregiver resided.
[b]Three drug shops located in the village where caregiver resided.

4.2.2. Study sample

The target population consisted of caregivers who resided within Butaleja District, had at least one child five years and under with a febrile illness within the past two months, who provided most of the child's day-to-day care, was able to understand and speak the local dialect of Lunyole, and who was willing and able to provide consent to participate in the study. Using purposive sampling, caregivers were recruited who had unique experiences managing malaria in a child of five years and under, resided in different regions of the District, and who were willing to discuss their experiences. As part of an earlier household survey process, the research team had identified households with caregivers who appeared eager to share their treatment-seeking experiences along with an annotation of whether their child had recovered uneventfully from a febrile episode or had experienced a negative outcome. At survey time, these caregivers had also been asked if (1) they would agree to be contacted again for a more in-depth discussion about their experiences with managing malaria in one of their youngest children, and (2) for their permission to share their name and contact information with study's recruitment team. A list of potential caregivers for the cases

study was then created with caregivers classified according to their experiences: (1) those who sought treatment external to their home and the child improved or those who did not seek external care and the child survived, (2) those who sought treatment external to their home but the febrile illness persisted resulting in some form of disability, (3) those who sought treatment external to their home but the treatment failed and the child died. Names of potential caregivers from each of the categories were written on slips of paper, folded, put it in a container and drawn randomly using a ballot process. Caregivers were subsequently contacted by the study team and invited to participate. The first eight consenting caregivers became the case study participants.

4.2.3. Data collection

Case study interviews were carried out by two trained research assistants, each paired with an experienced research team member fluent in both English and the local dialect of Lunyole. Each research assistant was responsible for conducting and recording the interview. The study team traveled to the individual caregivers' homes to conduct the interviews. While an interview guide was provided to the research assistants for areas to explore, the interviews were largely unstructured and pursued information provided by caregivers rather than adhering to a rigid protocol. Research assistants offered occasional prompts to keep the conversations flowing about the child's history preceding the fever episode, signs and symptoms, treatment they sought – where and why, challenges they faced, length of the episode, child's status following the episode, possible improvements to caregiving; nevertheless, each case study was a conversation rather than a structured interview. Data from case studies were collected in the local language over two to four visits, each lasting no more than one hour. Because Lunyole is not a written language, each conversation was verbatim translated into English by the research assistants as they took interview notes. To ensure quality and accuracy, all conversations were audiotaped with the permission of all participants. Components of the conversation dealing with medications used during the child's treatment were verified by asking caregivers to identify photos of each drug or medicine from a poster-sized collection of images of known drugs and their various brand names thus minimizing problems of recall or unknown drug names. All transcriptions along with their respective recordings were reviewed by the research assistant and their respective supervisor

within 24 hours of completion. At the end of each day, the research assistants met with the senior member of the research team to debrief and share critical perspectives.

The two research assistants had been recruited as a part of the larger project in which they had already gained extensive field experience with qualitative and quantitative date collection prior to the case study interviews. Both research assistants were originally residents from the District and possessed university degrees. They were therefore fluent in verbal and written English as well as Lunyole. Additionally, research assistants had received a week's training on the purpose, objectives and actual data collection strategies in order to acquaint themselves with the issues under investigation and with the interview process.

4.2.4. Analysis

A combination of quantitative and qualitative methods was used to summarize the data. All caregivers responses were transcribed onto Microsoft Word documents, formatted, and entered into a qualitative data analysis computer program (QDA Miner) for subsequent coding, thematic analysis and interpretation. All transcripts were reviewed and coded using a constant comparative method. As a first step, authors independently reviewed all transcripts line-by-line identifying both anticipated and emergent themes. The themes were then discussed, debated and where necessary relabeled or regrouped into themes using open, axial and select coding techniques.[29] Once the labeling was completed, the themes were grouped into categories. Both quantitative and qualitative data from the interviews were entered into spreadsheet format (Microsoft Excel) and analyzed consistent with the study's overall objectives for specific indicators, patterns and trends in both anticipated and emergent outcomes. Qualitative research issues of trustworthiness and replicability (validity and reliability) were verified by examining the number of times each theme was mentioned by different caregivers – either in the affirmative or negative. Inter-rater reliability was assured by repeated cycles of theme identification, definition, and reconciliation until all raters concurred on the coding system and ultimately agreed on which utterances represented which codes.[30] Data were subsequently rendered into tables, figures and charts and discussed in this report and others.

4.3. Results

Eight caregivers (seven female and one male) participated in the case studies (CS). Children generally experienced one of three outcomes from their febrile illness and treatment received: (1) a positive outcome where the child improved (CS 06, 07, 08), (2) a negative outcome where the child survived but experienced an irreversible disability (CS: 01, 02, 03), or (3) a negative outcome where the child died (CS: 04, 05). Caregivers' and their index children's demographic characteristics are summarized in Table 4.2. Caregivers' ages ranged from 22 to 45 years, and their index children's ages ranged from two months to four years at the time of the febrile episode. All caregivers were peasant farmers living in monogamous households. Two of the caregivers had completed some level of post-secondary education, five had some level of primary schooling, and one had no formal education. Five of the caregivers reported being protestant, one was Muslim, and two made no mention of their religious affiliations. The eight caregivers represented seven of the 10 sub-counties in Butaleja District.

Table 4.2. Caregivers' and index child's demographic characteristics

Cases → Demographics ↓	CS 01	CS 02	CS 03	CS 04	CS 05	CS 06	CS 07	CS 08
Household Information								
Sub-county	Himutu	Busaba	Nawanjofu	Naweyo	Butaleja	Naweyo	Naweyo	Busabi
Parish	Kaiti	Buwihula	Bingo	Kaiti	Nakwasi	Kaiti	Kaiti	Malangha
Caregivers' Demographic Characteristics								
Age	30 years	28 years	42 years	43 years	22 years	30 years	45 years	25 years
Education	Partial primary	Partial secondary	Partial primary	Partial primary	Partial primary	None	Partial secondary	Partial primary
Occupation	Farmer	Farmer	Farmer	Farmer	Farmer	Farmer	Farmer	Farmer
Religion	Protestant	Protestant	Protestant	Not Available	Not Available	Muslim	Protestant	Protestant
Marriage status	Yes Monogamy	Yes Monogamy	Yes Monogamy	Yes Monogamy	Yes Monogamy	Yes Polygamy	Yes Monogamy	Yes Monogamy
Spouse's occupation	Farmer	Mechanic	Farmer	Farmer	Farmer	Farmer	Farmer	Teacher
No. Children	5	2	9	7	4	6	6	5
Index Child's Demographic Information								
Gender	Male	Female	Female	Male	Female	Male	Male	Male
Age	3 years	4 years	3 years	1 year	2 years	2 months	1 year	1 year

4.3.1. Case study summaries

Case Study (CS) 01: (Date of episode not discussed). At 10 pm, the caregiver noticed that her child was feverish and convulsing. She initiated home management with Coartem®, Panadol® and physical supportive therapy using a wet cloth to decrease the fever before taking the child to a public health facility the following morning. The public facility (Kangalaba HC III) offered no treatment but instead referred the child to a hospital in the neighboring district of Mbale for blood transfusion. At the hospital, the child was admitted and given six quinine injections over three days and two-week worth of quinine syrup. Post-discharge the child's vision worsened and the left hand became lame. Over the next month, the caregiver took the child to visit optometrists and doctors in the district of Tororo and was told the child had received too much quinine and nothing could be done to help the child.

Case Study (CS) 02: (Episode two years prior interview). At 4 am, the caregiver noticed her child was ill with fever and convulsing. The caregiver initiated home management with traditional remedy (smearing pounded onions of the child's body and giving the child to drink some), and then at 10 am took the child to a public health facility (Busaba HC III). At the public facility the child was given a blood test, Septrin®, Panadol®, and quinine tablets, and was told to buy additional quinine syrup from a private drug vendor. Because the child continued to convulse, the caregiver continued to give quinine syrup daily for about a year, while periodically returning to the same public facility as well as visiting the local drug shop to find some relief for her child's convulsions. However, no further tests or different treatments were offered. When the child suddenly stopped speaking she stopped the quinine and reverted back to using traditional remedies (bathing in mululusa and tomato leaves) for a period of one month. She eventually stopped using the traditional remedies when the child did not respond and, a year later, at the suggestion of a friend, she inquired about anticonvulsant tablets at a HC III and got referred to the main hospital where the child received additional quinine and convulsion tablets. The child now receives anticonvulsant tablets daily which the parents obtain from the hospital on a weekly basis. While the frequency of convulsions decreased, the child lost the ability to speak.

Case Study (CS) 03: (Episode two months prior interview). At 5 pm, the caregiver noticed her child had a swollen stomach and was feverish, vomiting and convulsing. She initiated home management with tradition remedy (smearing pounded onions on the child's body) to lower the child's fever, and at 10 am the next day visited a private drug shop in Busolwe. The drug vendor assessed the child to have cerebral malaria and gave the child an injection and various tablets including Panadol®. The caregiver returned the next day for the same medicines. The child's fever gradually improved after two-weeks, but to this day continues to experience convulsions and a swollen stomach.

Case Study (CS) 04: (Episode five years prior interview). At 4 pm, the caregiver noticed her child was ill with fever and short of breath. She initiated home management with Panadol®, Septrin® and supportive therapy using a wet cloth. The following day at 7 am when she saw the child's condition had worsened, she took the child to a public health facility (Nabiganda HC II). No treatment was given at the facility, instead the child was referred to a hospital in the neighboring district of Mbale for blood transfusion which took two and a half hours to reach. When the child arrived at Mbale the doctors ordered blood tests, but during the three hours while the tests were being run the child died.

Case Study (CS) 05: (Episode five months prior interview). At 5 pm, the caregiver noticed her child was ill with fever, vomiting, coughing and experiencing diarrhea. She initiated home management with supportive therapy using a wet cloth to cool the child's fever before visiting a public health facility at 6 pm (Nakwasi HC III). At the health facility the child received Coartem® and was told to buy quinine syrup from a drug shop. Despite treatment, the child continued to worsen. The caregiver returned to the HC twice over the subsequent two months without any improvement. Three months later, the caregiver took the child to a private drug vendor because the public facility was closed. There the child was given tablets to treat worms, the child appeared to improve after the initial dose but quickly turned for the worst and died.

Case Study (CS) 06: (Episode two months prior interview). In the morning the caregiver noticed that her child was short of breath but decided to do nothing until the next morning when the child's condition worsened, at which time she visited a private drug shop. The drug vendor gave the child Aspirin® for three days which the caregiver

administered. No additional medicines were purchased because the household could not afford to buy more medicines. The caregiver said it took two weeks for the fever resolved on its own.

Case Study (CS) 07: (Episode two months prior interview). At 9 am, when the caregiver noticed the child was ill with fever, chills, and vomiting, he initiated home management with Panadol®. Later the same day when there was no improvement the child was taken to a private drug shop. The drug vendor took a blood test, gave the child two quinine injections, and the child gradually improved over a few days eventually returning to normal.

Case Study (CS) 08: (Episode two months prior interview). At 7 am, the caregiver noticed her child was feverish and not being her usual self. She initiated home management with Coartem®, Panadol® and mululusa, and used supportive therapy with wet cloth to reduce the fever, but the child's conditioned continued to worsen. At 10 am the next day, the child was taken to a public health facility (Muhuyu HC II) where the child was given more Coartem®, Panadol®, some kind of injection and Rene Coldease®. The child's illness was cured in 3-4 days.

4.3.2. Case study findings

Eight broad themes summarize caregivers' treatment seeking patterns for the reported febrile episodes, their experiences, what they knew and what they learned. These include: (1) how caregivers' recognized their child's illness, (2) the sequence of treatments sources and treatment practices involved, (3) factors which influenced caregivers' treatment-seeking decisions, (4) challenges they encountered with seeking care at public health facilities, (5) the burden of cost associated with managing malaria, (6) the burden of living with a negative outcome from malaria, (7) caregivers' knowledge about ACT, and (8) caregivers' perspectives of how management of malaria could be improved. Table 4.3 illustrates the sequence of care received by the child, the initial symptoms and the time of day when symptoms were first noticed, the different external sources visited and treatments received during these occurrences, and outcome(s) at the end of each treatment phase. Table 4.4 outlines caregivers' treatment-seeking

experiences when seeking treatment from an external source for the episode of fever in question. Tables provide a “running description” of history, treatments, caregiver experiences, and subsequent reflection. Entries in the tables are arranged in order of the episode’s outcome: child recovered, child survived but with deficits, or the child died.

Table 4.3. Caregivers' Treatment Seeking Actions and Sequence

	Positive Outcome: Child Recovered			Negative Outcome: Child Survived but with Deficits			Negative Outcome: Child Died	
Cases →	**CS 06**	**CS 07**	**CS 08**	**CS 01**	**CS 02**	**CS 03**	**CS 04**	**CS 05**
1st Action	**Time:** 12 am **Setting:** Home **Trigger:** "Difficulty breathing", "wheezing", "congested", weak", "not playing", "crying", "sneezing", "cough" **Blood Test:** No **Treatment:** None **Outcome:** Breathing worse & thick mucus	**Time:** 9 am **Setting:** Home **Trigger:** "Shivering", "sweating", "heat", stomach "bubbling", "eyes were red", "vomiting" **Blood Test:** No **Treatment:** Panadol® **Outcome:** Shivering ↓, no other improvement	**Time:** 7 am **Setting:** Home **Trigger:** "Not eating", "not playing", "crying", "hot body", "rash", "mucus", "cough" **Blood Test:** No **Treatment:** Wet cloth, mululusa, Coartem®, Panadol® **Outcome:** Worse	**Time:** 10 pm **Setting:** Home **Trigger:** "Fever", "convulsing", "not breastfeeding/eating" **Blood Test:** No **Treatment:** Wet cloth, Coartem®, Panadol® **Outcome:** Fever not relieved	**Time:** 4 am **Setting:** Home **Trigger:** "Fever", "eyes became red". "stayed there in such a state", "convulsing", " weak" **Blood Test:** No **Treatment:** Smeared pounded onions on body **Outcome:** Fever ↓, on-going convulsions	**Time:** 5 pm **Setting:** Home **Trigger:** "Vomit", "hot body", "eyes staring and convulsed", "stomach swollen" **Blood Test:** No **Treatment:** Smeared pounded onions **Outcome:** Eyes back to normal but still looked like a dead person	**Time:** 4 pm **Setting:** Home **Trigger**: "Weak", "retching", "hot body", refused to eat, "breathless" **Blood Test:** No **Treatment:** Wet cloth, Panadol®, Septrin® **Outcome:** Could not stand & had a weak neck	**Time:** 5pm **Setting:** Home **Trigger:** "Cough", "diarrhea", "vomit", "hot body" **Blood Test:** No **Treatment:** Wet cloth **Outcome:** Fever ↓, then visited HC
2nd Action	**Time:** Next day (am) **Setting:** Drug shop **Trigger:** Previous symptoms + "fever" **Blood test:** No **Treatment:** Junior Aspirin® from drug shop x 3 days, no money to buy more medicine **Outcome:** Fever resolved x 2 weeks	**Time:** Same day (evening) & next day (morning & evening) **Setting:** Drug shop **Trigger:** No improvement **Blood Test:** Yes **Treatment:** Quinine injection, quinine & Panadol® tablets **Outcome:** Improved gradually	**Time:** Next day (10 am) **Setting:** Muhuyu HC II **Trigger:** Worsened **Blood Test:** No **Treatment:** Some kind of injection, Coartem®, Panadol®, Rene Coldease® **Outcome:** No fever, cured in 3-4 days	**Time:** Next day (am) **Setting:** Kangalaba HC III **Trigger:** Previous symptoms + "fever" **Blood Test:** No **Treatment:** None, referred to Busiu hospital in Mbale for blood test. Told to feed milk & porridge **Outcome:** Referred to Mbale hospital	**Time:** Same day (10 am) **Setting:** Busaba HC III **Trigger:** "Fever", "coughing", "convulsions" **Blood Test:** Yes **Treatment:** Septrin®, quinine tablets, Panadol® tablets, and told to buy quinine syrup **Outcome:** Told has cerebral malaria (with convulsions), convulsions ↑ to 8-15 x day	**Time:** Next day (10 am) & following day (10 am) **Setting:** Drug shop **Trigger:** "Vomit", "convulsions", "hot body", "blank stare", "swollen stomach" **Blood Test:** No **Treatment:** Told has cerebral malaria. Injections x 2 days, tablets: ibuprofen, 4 green, 6 white, 8 Panadol® **Outcome:** Cured in 2 weeks. Still has swollen stomach & convulsions	**Time:** Next day (7 am) **Setting:** Nabiganda HC II **Trigger:** Worsened **Blood Test:** No **Treatment:** None, told could not treat before receiving blood transfusion. Referred to Mbale hospital. **Outcome:** Travelled to Mbale.	**Time:** Same day (6 pm) **Setting:** Nakwasi HC III **Trigger:** "Cough", "diarrhea", "vomit" **Blood Test:** No **Treatment:** Coartem®. Told to buy quinine syrup from drug shop. **Outcome:** Symptoms not improve, body started to swell & condition worsened
3rd Action	X	X	X	**Time:** Same day **Setting:** Admitted in Mbale x 3 days **Trigger:** Referred **Blood Test:** Yes **Treatment:** Blood transfusion. Told to buy water for drip, 6 quinine injections, paracetamol, quinine syrup x 2 weeks, plus other pills **Outcome:** Improved but sight affected, left hand became lame, on-going convulsions	**Time:** 2 weeks later **Setting:** Drug shop & Busaba HC III **Trigger:** Daily convulsions 8-15 x day **Blood Test:** No **Treatment:** Quinine syrup daily x 1 year from drug shop & Busaba HC **Outcome:** Child stopped talking after 1 year	X	**Time:** Same day (~2 ½ hours later at 11 am) **Setting:** Mbale hospital **Trigger:** Referred **Blood Test:** Yes **Treatment:** None started for 2 hours while at the hospital **Outcome:** Waited for 2 hours for treatment - child died.	**Time:** 2 weeks later **Setting:** Nakwasi HC III **Trigger:** Worse, body started to swell **Blood Test:** No **Treatment:** Coartem® plus quinine syrup from drug shop. **Outcome:** No improvement
4th Action	X	X	X	**Managing Negative Outcome** **Time:** 2 days later **Setting:** Tororo hospital **Trigger:** Decreased vision **Blood Test:** No **Treatment:** None **Outcome:** Told quinine caused child to become lame & affected eyesight	**Time:** 1 year later **Setting:** Home **Trigger:** Child not talking **Blood Test:** No **Treatment:** Stopped quinine, started mululusa & tomato leaves baths x 1 month, then gave up **Outcome:** Month later visited Budumba HC III when a friend told her convulsion drugs available there	X	X	**Time:** 1 month later **Setting:** Nakwasi HC III **Trigger:** No improvement **Blood Test:** No **Treatment:** Coartem®. Told to buy quinine syrup & other medicines from drug shop **Outcome:** Improved, but then fell ill again ~3 months later
5th Action	X	X	X	**Managing Negative Outcome** **Time:** 1 month later **Setting:** Mbale hospital **Blood Test:** No **Trigger:** Examine eyes/lame hand **Treatment:** None **Outcome:** Told nothing could be done: look after child, feed passion fruits & milk	**Time:** 5 months later **Setting:** Busolwe hospital **Trigger:** Referred from Budumba HC III **Blood Test:** No **Treatment:** Quinine injection, convulsion tablets refilled weekly **Outcome:** On-going convulsions but less frequent	X	X	**Time:** ~3 months later **Setting:** Drug shop **Trigger:** Sick again & Nakwasi HC III closed **Blood Test:** No **Treatment:** For worms **Outcome**: Thought was improving but later that day vomited blood & died

Table 4.4. Caregivers' Experiences with External Sources

	Positive Outcome: Child Recovered			Negative Outcome: Child Survived but with Deficits			Negative Outcome: Child Died	
Cases →	**CS 06**	**CS 07**	**CS 08**	**CS 01**	**CS 02**	**CS 03**	**CS 04**	**CS 05**
1st Action	**Nearest PHC Accessed:** No **Reason not using PHC:** Stock-outs, told to go to drug shop, health professionals. are rude, & cost of transport **Used:** Drug shop ~1 mile	**Nearest PHC Accessed:** No **Reason not using PHC:** Lack of staff, stock-outs, & cost of transport **Used:** Drug shop ½ mile	**Nearest PHC Accessed:** Yes **Used:** Muhuyu HC II	**Nearest PHC Accessed:** No **Reason not using closest PHC:** stock-outs **Used:** Kalabangha HC III ~5 miles	**Nearest PHC Accessed:** Yes **Used:** Busaba HC III ~ 3 miles	**Nearest PHC Accessed:** No **Reason not using PHC:** verbal abuse from health professionals, no injections given, lack of examination & stock-outs **Used:** Drug Shop ~3 miles	**Nearest PHC Accessed:** Yes **Used:** Nabiganda HC II	**Nearest PHC Accessed:** Yes **Used:** Nakwasi HC III
	Setting: Drug shop **Experience:** • Took child ~ 12 hours from start of symptoms • No blood test done • No information about illness given • Vendor suggested antimalarial syrup, but refused as had no money • Caregiver requested Aspirin® for 3 days. No money to buy more drugs • Cost was 100UGX, willing to pay up to 500UGX • Continued to be sick but no additional medicines given. Gradually resolved	**Setting:** Drug shop **Experience:** • Took child ~ 9 hours from start of symptoms • Blood test done but not told of results • No information about illness given • Bought medicines • Cost was 2,000UGX • Improved gradually	**Setting:** Muhuyu HC II **Experience:** • Took child after 1 day from start of symptoms • Had to wait 4 hours before being seen • Was examined • No blood test done • No information about illness given • Received free medicines • Cured in a few days	**Setting:** Kalabangha HC III **Experience:** • Took child~ 12 hours from start of symptoms • Was examined • No blood test done • Told was anemic, had high fever • No medicines given • Referred to hospital in neighboring district of Mbale because had no blood to transfuse • Subsequent action taken	**Setting:** Busaba HC III **Experience:** • Took child ~ 6 hours from start of symptoms • Waited 30 minutes before health professionals arrived • Blood test done • Told had malaria & convulsions from fever • Received free medicines & told to buy more from drug shop • Not improved, convulsions worsened • Subsequent action taken	**Setting:** Drug shop **Experience:** • Took child ~ 17 hours from start of symptoms • Provider was busy but was provided immediate care because saw child was in a bad state, told others to wait while she treated the child • No blood test done • Examined, touched & looked at eyes • Told to cover child with blanket , hold him so doesn't fall down, & to return the next day • Bought medicines • Cost was 13,000UGX for day 1; 7,500UGX for day 2 • Malaria resolved gradually, but stomach remained swollen & child continued to convulse	**Setting:** Nabiganda HC II **Experience:** • Took child ~ 15 hours from start of symptoms • No blood test done • Told was anemic • Received no medicines • Told would not treat because needed to first receive blood transfusion • Child referred to hospital in neighboring district of Mbale • Subsequent action taken	**Setting:** Nakwasi HC III **Experience:** • Took child ~ 1 hour from start of symptoms • No blood test done • No information about illness given • Received free medicines & told to buy more from drug shop • Did not improve • Cost not shared • Not improved, body swollen, could not eat • Subsequent action taken
2nd Action				**Setting:** Busiu hospital in Mbale **Experience:** • Health professionals ignored her child even when asked for help • Blood test done but not told of results • Told to buy water for drip, quinine injections, quinine syrup for 2 weeks and other oral medicines, and then to come back • Cost was 15,000UGX • Malaria resolved, but eye sight affected, could not see, left hand became lame, experiences convulsions regularly	**Setting:** Drug shop & visited Busaba HC III & Busolwe hospital x 1 year **Experience:** • Gave quinine syrup for 1 year on advice from neighbors, health professional, & drug vendor. But stopped when child stopped talking • At Busaba HC III & Busolwe hospital given quinine injections, & bought quinine syrup from drug shop every 2 weeks • Cost 2,500UGX every 2 weeks • At times sent away from Busaba HC III because of stock-outs • At Busaba HC III & Busolwe hospital never referred for convulsions • Blood test never repeated • Malaria resolved, but left unable to speak and brain-damaged		**Setting:** Mbale Hospital **Experience:** • Took blood test but not told of results • Caregiver asked to get blood cross-matched at the laboratory, then to buy blood & transfusion kit • Child died before blood could be purchased • Health professional gave no information about illness • No treatment started during the 3 hours at the hospital, arrived 11 am & died at 1 pm • After child died, body cleaned & wrapped, returned to family	**Setting:** Nakwasi HC III **Experience:** • Returned in 2 weeks, then frequently over 4 months. Last visit at drug shop because HC was closed • Would improve some, but illness would come back • Same treatment at HC as 1st action • Free medicines & told to buy more from drug shop • No blood test • No information about illness given • Last visit at drug shop, given tablets for worms, child died later that day

Recognition of malaria

"Recognition" examines how caregivers identified their child was suffering from malaria. It captures the most common symptoms recognized, the time of day when symptoms were first noticed, and how this affected caregivers' treatment–seeking decisions (Table 4.3).

Symptoms and time of recognition.

With the exception of one caregiver, "fever" or "hot body" was the most common symptom mentioned, followed by coughing/congestion observed in cases that had positive outcomes as well as ones where the child died (CS: 04, 05, 06, 08). Convulsion was mentioned only by those caregivers whose child had survived with a negative outcome (CS: 01, 02 and 03), and it commonly accompanied fever. Some of the other primary symptoms mentioned included "red eyes", "diarrhea", "swelling of the body", "pain within body", "the child not eating", "vomiting", and "making excessive noise". The responses from the case studies showed that for all three children with positive outcomes (CS: 06, 07, 08), their symptoms were noticed early in the morning. Conversely, for those children who died or survived with a negative outcome, their caregiver first noticed their symptoms at night.

Treatment actions

The steps taken by caregivers to treat their children once the initial symptoms were noticed were termed *Treatment Actions*. Included in this theme are the different steps taken by caregivers, treatment sources accessed, types of treatments received, and outcome at the end of each treatment occurrence (Table 4.3). The multiple steps taken by caregivers represent treatment failures and attempts to seek additional care to resolve the febrile episode, as well as manage adverse outcomes from the illness. The treatment sources accessed were classified as either home management or external treatment which typically included a public health facility or a private drug vendor. Home management was defined as any care initiated from the home setting with resources within the household, such as physical supportive care, western medicines, and/or traditional remedies. Time to seeking external treatment or where treatment was sought appears to have had little influence on the outcome of the illness. Treatment at public

health facilities was rarely successful, with four of the five children who visited a public health facility as part of their first external care experiencing a negative outcome. Of the two children who died, one died at a referral hospital and the other at home after several visits to a public health facility with repeat treatment failure.

First action.

All but one caregiver (CS: 06) initiated treatment with some form of home management soon after noticing fever. The one caregiver (CS: 06) who did not initiate home management, opted to simply wait and observe the child for the first day, and initiated the first treatment on the next day with Junior Aspirin® obtained from a private drug vendor when the child's symptoms worsened. Across the seven cases, three types of home management treatments were seen: western medicines, physical supportive therapy, and traditional remedies. Examples of physical supportive care included bathing the child in cool water, washing the child with a cool cloth or sponging the child to relieve fever. Western remedies used in home management included Coartem®, Panadol®, Septrin®, and quinine syrup. Traditional remedies included smearing onion paste over the ill child or sitting the child in a bath of herbs such as mululusa.

Western medicines were the most popular home management, with two positive outcome cases (CS: 07, 08) and two of the negative outcome cases (CS: 01, 04) receiving some type of medicine. There is no strong pattern separating the cases with positive and negative outcomes in terms of which western medicines were given. Both children who were given an antimalarial received Coartem® (one with a positive one with a negative outcome). On the other hand, supportive care only was used mostly by those who experienced a negative outcome (CS: 01, 03, 04, 05), with only one positive outcome case reported to have used supportive care (CS: 08). Children were given supportive care with/out western medicines. Traditional remedies were only used by three caregivers (CS: 02, 03, 08), two of whom later went on to experience a negative outcome, only one used it in combination with a western medicine (ACT).

Just over half of the caregivers representing children with a negative outcome (CS: 01, 02, 03, 05) reported initiating home management only as a "first aid" measure, with the intent to seek subsequent treatment from an external source first thing in the

morning. Whereas the remaining caregivers (CS: 04, 07, 08) indicated they decided to seek additional care from an external source only after noticing their child's condition had worsened.

> I had Panadol® and I gave her, and I still saw that her condition was still bad. I tried to take her to the health unit.(CS: 07)

> I did not go to the health unit on that very day because I had trusted that bathing him with mululusa and giving him Coartem® and Panadol® would help. When I got to know that the fever had worsened, when it dawned to morning, I took him to the health unit.(CS: 08)

Caregivers started treatment at home because they had western medicines at home and trusted that they would cure the child:

> I knew that this [Panadol®] and this [Septrin®] treats, treats a bit fever little bit … In the health unit, the health providers teach us [to] use [Panadol® and Septrin®].(CS: 04)

> I know that Panadol® could reduce a bit the pain in the body…. The health provider told me, that this one [Panadol®] reduces painful body.(CS: 07)

Second and subsequent actions.

Table 4.3 shows that all second and most subsequent actions took place externally and outside the home for all caregivers. Case 02 was the exception, as she reverted from visiting external sources and obtaining quinine treatment during subsequent actions to using traditional remedies from home when her child stopped speaking and she found western medicines were not helping. Three of the caregivers (CS: 02, 05, 07) reported visiting an external source within the same day, whereas the remaining caregivers went the next day. However, all caregivers whose child experienced a negative outcome reported seeking care within 24 hours of noticing initial symptoms. The most common second action (and first external source) for five of the caregivers involved going to a public health facility, with four opting for the nearest facility (CS: 02, 04, 05, 08). Of the cases with a positive outcome, only one (CS: 08) was taken to a public health facility, the other two received treatment at private drug shops. On the other hand, all but one case with a negative outcome (CS: 01, 02, 04, 05) sought their first external treatment from a public health facility. All children who were subsequently referred to higher level health facility or those who required further

treatment experienced a negative outcome. The most common medicines given or prescribed by external outlets were Panadol® tablets and/or some form of quinine. Only two children received Coartem® and both were at a public facility. Table 4.4 illustrates caregivers' experiences when seeking external care and whether or not they accessed their nearest public health facility.

Treatment in an ensuing malaria episode.

While the intent of this study was to focus principally on the single febrile episode leading to the outcome in question, some of the illnesses never subsided and children either continued to experience mild fever or experienced frequent recurrent infections, which made it difficult to separate the original episode from new infections. As such, half of the cases (CS: 03, 06, 07, 08) mentioned their treatment-seeking experiences with a subsequent febrile episode as well. Two caregivers (CS: 03, 07) sought external care from a drug shop as they had done in the first episode, but one caregiver (CS: 08) opted for a drug shop over public health facility in the subsequent episode. One case (CS: 06) continued to take no action since the household "had no money to buy medicines".

Factors affecting decisions

Decision factors examined how caregivers' previous experiences and advice from family members influenced their decision about drug used and sources accessed. All cases shared some examples of how their previous experiences had influenced their preference for certain drugs and/or treatment sources.

Past experiences influencing drug use.

Previous experience(s) with a western medicine was an important factor influencing caregivers' decisions for the current febrile episode, as were experiences with current episodes at influencing future decisions. We found cases with positive outcomes (CS: 06, 07, 08) were more likely to share both good and bad past experiences with drug use influencing current decisions, whereas those who had experienced a negative outcome (CS: 02, 03, 04) shared only good experiences with drug use. The following quotes illustrate why caregivers favored specific medicines.

> Whenever we fell sick our parents took us to health units [to obtain medicines]. So mululusa … I know nothing about it because I have grown up taking medicines…. I cannot give mululusa to my child.(CS: 03)

> Okay I get him those medicines [Panadol® and Septrin®] because … they are the ones that I had [in the home] because I normally use and they work.(CS: 04)

> I normally buy Panadol®, it's the one that I usually give them and they swallow…. At times I give them Panadol® and they get cured well.(CS: 06)

> The fever [malaria] can match with quinine [uses quinine to treat].(CS: 07)

> I knew it because whenever I go with my child to the health unit, I am first given Panadol® and Coartem®. So, if I would pack some [Panadol® and Coartem®] ... I can use them in case of a malaria attack…. From personal experience, whenever I use Panadol®, it relieves me of the fever and high temperature.(CS: 08)

Similarly, caregivers avoided the use of certain medicines because of previous undesirable experiences with certain medicines. The following quotes are examples of some of these experiences:

> I used to see, if the child was just deteriorating … I would give [Coartem®]. Then I saw … it [Coartem®] … did not cure, did not cure at all, then I abandoned it [Coartem®] … without seeing any change….(CS: 06)

> We used to use chloroquine long time ago but whenever I would use it, it would itch my body, my whole body. So I no longer use that chloroquine.(CS: 08)

Past experiences influencing source of care.

Caregivers' previous experiences with public health facilities and private outlets also contributed to their decision about which external source to use. With respect to negative experiences at public health facilities, caregivers discussed examples such as stock-outs or treatment failure influencing their decision to not return to that facility. Such poor experiences were not exclusive to cases with positive or negative outcomes (CS: 01, 03, 04, 06, and 07). As illustrated in Tables 4.3 and 4.4, caregivers still visited public facilities despite their frustrations with services at public facilities (CS: 01, 04).

> It is another child's that have … taken. On that particular day medicines had got finished from public health facilities [Namulo HC II and Kangalaba HC III], so that is when I took the child [index child] there to the drug shop. But even when she treated the child did not cure. So, I waited till they brought medicines to Nalusaga [Kangalaba HC III], that is when I took child to Nalusaga for treatment since he had failed to cure with the treatment given to him by the drug shop. At Nalusaga, that is where the child got cured.… I took my child to … Namulo HC II … but he failed to improve so I stopped going there.(CS: 01)

> The reason why I decided to go to the private [drug shop] is because I lost one of my children from that Busolwe hospital.(CS: 03)

> They [drug vendors] provide for us with medicine, because at times we go to the government health units [and] medicines are not there, that's why we go to the clinics [drug shops].(CS: 04)

> The government [HC] okay we have it in Naweyo but it does not always have medicine. They always tell you [to] come back another time. Even if you go there is nothing you get, the health providers are proud, so for me, it does not help us well.(CS: 06)

> In Naweyo [HC] when you go, when you go at times, you find that there is no health provider, and at times when you find the health providers, he writes for you [prescribes] and at times tells you that there is no medicines then you come back empty-handed or with nothing.(CS: 07)

Advice influencing treatment sources.

Advice from family or friends also influenced caregivers' decision of where to seek external treatment. All caregivers cited receiving such advice either during the initial phase of the illness or during subsequent actions when the child had not improved. Most caregivers, three of the five with negative outcomes (CS: 02, 03, and 05) and all with positive cases (CS: 06, 07, 08), mentioned taking the advice given to them. Comparing the quotations with caregivers' actions in Table 4.3 confirms that such advices was followed.

> … [in] 2010 … we were told [by friends] about tablets that treat convulsions, that those tablets were found in Busolwe. So, that is when we went to Busolwe to obtain those tablets.(CS: 02)

> My mother told me not to dress up the child in any clothes but to wrap the child in a baby shawl and proceed directly to the health unit. When he convulsed, I ran very fast and [wrapped] wet cloth over his body. I then

> looked for a bicycle and rushed him to a clinic [drug shop] in Busolwe.(CS: 03)
>
> My husband used to tell me that we take the child to the clinic [HC]. Now, when the illness attacks the child and it was severe … [I] discuss with my husband and … go to the clinic [HC].(CS: 05)
>
> Now, the person [caregivers' sister] tells me that take the child to the health unit and the child will cure of fever [malaria].(CS: 06)
>
> So when … I knew that it was fever and I called the child's mother [the wife], the mother also touched, touched her and saw that she was badly off and I told her we take the child to the health unit maybe the health provider can help us.(CS: 07)
>
> He [the husband] tells me that take the child to health unit.(CS: 08)

Advice given to caregivers influencing treatment choices.

Advice from family and friends also influenced caregivers' treatment choices for their child. Three of the cases, representing both positive and negative outcomes (CS: 02, 03, 08), who were given advice about which source to access also spoke about receiving advice on how to treat their child. The only three cases to use traditional remedies (CS: 02, 03, 08) stated that they had done so because on advice received by a friend, mother or grandmother. Only one caregiver (CS: 02) reported using a western medicine (quinine) at the advice of people she met on the road and at boreholes. Others used western medicines which had previously been recommended to them by health providers.

> There is a friend of mine who had a child who also used to convulse, so that friend of mine is the one that advised me to use the onion [so] I pounded the onions, had her drink some and smeared the rest on her body…. I would narrate [tell] the child's illness to her [my friend] and she would tell you what to do.(CS: 02)
>
> Others [people from the village who she met on the road and at boreholes] would tell me that "I also had a child that used to convulse like yours, I continued to give her that quinine syrup until she got fine/cured"…. So, we used to give her the quinine.… We continued buying and giving her that quinine syrup. They [people from the village] gave us advice to continue giving her that quinine syrup so whenever the syrup would get finished, we would still buy more quinine syrup and give it to her.(CS: 02)

> I got a wet cloth and pass it over his body again and again. [Then] my mother and mother-in-law said “if you pound onion and smear it all over his body, because it could be evil spirits [causing the convulsions] and the evil spirits can smell the onions and they run off. [So] I got onions and smear them all over his body. Those old women told me [and] … I first thought that it was evil spirits. But later on … in my opinion … this was malaria not evil spirits, evil spirits no way. It was malaria, he has grown up with this febrile convulsions … I decided to go to the health unit so that they could tell me. At the health unit, they told me that it is the cerebral malaria that had come during child's young age of one week.(CS: 03)

> I was at my parents' home when the child fell ill. I had gone to mourn a dead relative when the child was ill. So at the funeral, my grandmother advised me to use mululusa.(CS: 08)

Caregivers also relied on advice given by health providers during previous interactions. Two of the cases with positive results (CS: 07, 08) and one whose child had a negative outcome (CS: 04) initially managed their child using home management with a western medicine based on advice received from health professions during a previous interactions. Although only one caregiver (CS: 08) indicated she had been told been told by a health provider to use Coartem® when she herself got sick from malaria, so she believed it to be appropriate for her child. The advice for cases 04 and 07 did not follow the government recommendations for treating malaria (Table 4.3).

> In the health unit, the health providers teach us to use this [Panadol®] and this [Septrin®].(CS: 04)

> I go to the health provider [at drug shop] and he tells me that go and mix this Panadol® and give her.(CS: 06)

> The health provider [Drug Shop Vendor] told me, that this one [Panadol®] reduces painful body.(CS: 07)

> I learnt [about Coartem®] because I also normally fall sick. So, when I fall sick and go to a health provider and explain to her about my illness, she tells me to go and swallow Coartem®, Panadol® and the other tablets for coughing whose name I do not remember. She tells you that “for every tablet … you will notice the body heat and fever being relieved”. So on that first day when I noticed [child had fever] I gave him the Coartem.(CS: 08)

Challenges while seeking care at public health facilities

Treatment-seeking at public health facilities was associated with several challenges, with all caregivers mentioning one or more of these challenges. Challenges made up the largest part of the case study discussions and were not always specific to the current febrile episode in question. Despite the many challenges expressed by caregivers, a large majority took their child to public facilities on multiple occasions when their child did not improve. The most frequently voiced challenges included getting to a public health facility and the quality of service once at the public facility. Examples of challenges encountered once at public facilities included regular medication stock-outs, getting the runaround by the health staff, incivility of the staff, and the cost of medicines (Table 4.4).

Access to public health facilities.

Lack of access to public health facilities resulting from long geographic distances was a major concern for all caregivers as most often had to walk on foot to get there. Caregivers' frustration with access is illustrated in the following three quotes:

> The challenge I face was to be referred to Businghu [Busiu Hospital in Mbale] yet [because] I did not have the means to get there. So I kept thinking about what to do. So then, I asked my husband about what we could do…. Transportation from Nalusaga [Kangalaba HC III] to Businghu, costs 5,000 UGX using a taxi…. So it was my husband that found a way out. I guess he borrowed money from a friend. So with that money we went to Businghu.(CS: 01)

> We walk [7 miles to Busolwe], we walk with our feet, that is when we have failed to get money. At times, we ride on the bicycle but when we fail to use the bicycle, we walk on foot to the hospital to get the medicines.(CS: 02)

> It is there the clinic [drug shop] that was near, the other one [the HC] is far. And also I was challenged in form of money to go to the health unit.(CS: 07)

Availability of health providers.

Further complicating access to treatment was the unavailability of health providers when caregivers arrived at public facilities. Challenges of low staffing or absenteeism were experienced by several of the caregivers (CS: 02, 03, 04, 05, 07, 08).

> The challenge I faced is that I got there before the health providers. The health providers were not at the health unit by the time I got there. It was open and there was an askari [watchman] but the health providers had not yet come. That is the challenge that I faced. But as soon as they [the health providers] got there [30 minutes later], they worked on my case.(CS: 02)

> They [health professionals at Bingo HC II] do not have enough capacity to handle such a condition of a child so that is why they refer you to Busolwe main hospital.(CS: 03)

> The health provider at times is busy with his work, can take long or he is having other patients. So there, we face also a challenge there.(CS: 07)

> Our health unit has only one health provider, I went there around 10:00 am and by 2:00 pm my child had not received any medical attention…. [Eventually] She touched and felt the boy's body heat with the back of her hand so with that, I guess she recognized what she should do with the child and the medicines to give for treatment.(CS: 08)

Access to medicine.

Once at a public health facility, a primary complaint voiced by six of the caregivers was unavailability of medications (commonly referred to as “stock-outs”) at the Level II and level III public facilities (CS: 01, 02, 04, 05, 06, 07). Table 4.4 shows that blood tests were rarely taken, but when performed at all, were mostly available at higher level public health facilities, thus limiting the spectrum of care available at lower level public facilities.

> There are those [health facilities] that are nearby but I don’t go … because at times the medicines are finished … so you say let me obtain help from the other HC. [Health providers at Nalusaga: Kangalaba HC III] told me that for us here, we do not have medicines for your child but you go to Businghu [Busiu hospital in neighbouring Mbale District], so then she wrote for me a reference letter and I went to Businghu.(CS_01)

> I found challenges in mostly when I went and found no medicines there. I used to take her to the clinic [HC] when the illness is severe….(CS: 05)

> … at times when you find the health providers, he writes for you [prescribes] and at times tells you that there is no medicines then you come back empty-handed with nothing.(CS: 07)

Getting the runaround.

Parallel to the issue of stock-outs is the "runaround" given to caregivers when a public health facility is out of medicines. In circumstances when public facilities are experiencing stock-outs, caregivers are either referred to another public facility to manage the child or they are sent to a private drug vendor with a prescription to purchase their medicines, resulting in further delay in treatment. Caregivers whose child experienced a negative outcome were those who most often described getting the runaround. (CS: 01, 02, 03, 04, 05). Case 01 provides a good instance of a caregiver being sent to multiple locations, first because of stock-out at a nearby facility, then because of suffering an irreversible adverse outcome from over-medication. In the end the caregiver is told there was nothing that could be done for her child.

> It started with fever and then the child started to convulse, so I took him to health unit at Nalusaaga [Kangalaba HC III]…. They referred me to Busiu hospital [in neighbouring Mbale District], so I took him to Busiu hospital … and they told me to go buy water for the drip … for blood and water. After they discharged us, the child showed improvement but then the child's sight became poor, child could no longer see property so they told us that "maybe the quinine that was given to the child was too much"…. So then, we took him to Tororo, thinking that, maybe the eyes had a problem, that maybe the eyes were sick. We went to Tororo to check/examine the eyes and the eyes did not have any infection and they told us that maybe the medicine was too much, the quinine that they injected the child with was too much. So, when the child was curing in the process, this hand [holds the boys left hand that is lame] became lame. And even now, something attacks the brain and the brain stops working well … and the child falls down.... So, then, that is how he is, I look after him and such state.(CS: 01)

> I went to Budumba HC III people told me that "there are health providers who occasionally go there. They treat children that convulse. They have medicines that they give out freely". So with that, I went there. I went there with my daughter who is ill and I spoke to the health provider who told me that those have providers that treat convulsing children no longer went to Budumba HC III so he told me to go to Busolwe. He told me to go to Busolwe hospital so that is when I started to go to Busolwe.(CS: 02)

> They [health professionals at Bingo HC II] do not have enough capacity to handle such a condition of a child so that is why they refer you to Busolwe main hospital.(CS: 03)

> At Nabiganda [HC II], we did not get any treatment. When we reached, they [the health providers] told us that "we are not going to treat the child". Take him to Mbale [hospital]…. They said that the child, the blood is finished [child is anemic] so you go to Mbale. When I reached the health unit [Mbale hospital] they told us to buy a … set and a cannula … [so can draw] the child's blood … they removed blood from him and they told us we take it and test it [get blood cross-matched at laboratory] so that they get [right] blood [and] they can give him. (CS: 04)

Negative experiences at public health facilities.

All caregivers expressed some level of discontent with the level of services they received, as well as with how they were treated by health providers at public health facilities. Once again, these complaints were more pronounced among caregivers whose child experienced a negative outcome compared to those whose child had a positive outcome. The complaints commonly involved failure to receive appropriate services and lack of attention at health facilities.

> When they tested [the child's blood], they did not tell me the illness that my child was suffering from.(CS: 01)

> The challenge I faced is that I got there before the health providers. The health providers were not at the health unit by the time I got there. It was open and there was an askari [watchman] but the health providers had not yet come. That is the challenge that I faced. But as soon as they [the health providers] got there [30 minutes later], they worked on my case.(CS: 02)

> That unit at Bingo HC II, when I go there, I am given only Panadol®, they do not examine the child, they do not even measure the child's temperature…. They [health professionals at Bingo HC II] do not have enough capacity to handle such a condition of a child so that is why they refer you to Busolwe main hospital…. Since we smeared him with onions, we could not dress him up, but still the truth is that he had no clothes of his own…. The health provider said that "why have you brought the child when he is naked" [the health provider at the government facility was angry that the child was not clothed].(CS: 03)

> On reaching Mbale, they started examining him, they removed blood from him and they told us we take it and test it [get blood cross-matched at laboratory] so that they get [right] blood [and] they can give him. On

> reaching [since] 11 o'clock they had not given us [the child] blood, the child at 1 PM he died.(CS: 04)
>
> The health provider just looks at you and he feels proud … [like] he own things, goes and comes back. Even if you go there is nothing you get, the health providers are proud.… So there is nothing you get, the way you have gone, is the way you come back [child is ignored and not treated].(CS: 06)
>
> The health provider at times is busy with his work, can take long or he is having other patients. So there, we face also a challenge there.(CS: 07)
>
> Our health unit has only one health provider, I went there around 10:00 am and by 2:00 pm my child had not received any medical attention…. [Eventually] She touched and felt the boy's body heat with the back of her hand so with that, I guess she recognized what she should do with the child and the medicines to give for treatment.(CS: 08)

Burden of cost

The cost burden associated with treating malaria in their young children was a significant concern for all caregivers in this study. Caregivers reported incurring a variety of costs during the process of seeking treatment, including costs associated with: having to purchase medications from private outlets during periods of stock-outs, taking transportation to reach a public facility, managing a child febrile episode when there is treatment failure or treatment (or lack of) results in negative outcomes.

The cost of medicines.

Medication stock-outs at public facilities inevitably required caregivers to purchase medications from private vendors for the health provider at the facility to administer or the caregiver to give to their child at home. This resulted in significant medication costs to households, thus negating the existing national treatment policy requiring children five and under seen at public facilities be treated for free. All caregivers in this study mentioned experiencing such medication costs.

> After testing it, they [health facility] then wrote down for me the medicines to buy for injecting child with.(CS: 01)
>
> Because there was no quinine syrup at Busaba HC III, they told me to go and buy from anywhere. So I went to that drug shop and I asked if they

had the syrup and they told me that they had it and that it costs 2500UGX.(CS: 02)

I face challenges when I could go to Jabusiba [Nakwasi HC III] and there is no treatment and they could tell me to go and buy. [But] malaria could not improve and it came back, she [the child] started swelling … I had to take her back again to the HC.(CS: 05)

There are times when you go to the health unit and do not find any tablets there. So, if there are no medicines at the health unit and are lucky enough you find the health provider there, she can ask for a book [write a prescription] in which she write the tablets which you have to buy for your child's illness.(CS: 08)

Costs associated with finding time and taking transportation.

Making time and finding transportation to reach public health facilities or private clinics was another factor adding to the burden of cost. All caregivers mentioned the cost of transportation as a burden, except for one case with a positive outcome (CS: 08) who was given Coartem® from a public health facility to keep at home for future use. Getting the runaround and being sent to several public health facilities and drug shops in order to receive treatment adds another layer of transportation costs. In some cases, such costs deterred people from seeking care at public facilities.

The challenges that I face were about money because transportation to Nalusaga [Kangalaba HC III] on a motorcycle costs 1500UGX …. The [next] challenge I face was to be referred to Businghu [Busiu hospital in Mbale] yet [because] I did not have the means to get there. Transportation from Nalusaga to Businghu, costs 5000UGX using a taxi. So I kept thinking about what to do. So then, I asked my husband about what we could do. So it was my husband that found a way out. I guess he borrowed money from a friend. So with that money we went to Businghu.(CS: 01)…

I had also footed, walked on foot up to the health unit… With the transportation problem, if I have money, the motorcycle is easy to use but the problem is money. You may want to use the bodaboda [motorcycle for hire] but when you do not have the money. Don't you see?.... The bodaboda guys [motorcycles] tell you to pay 4000UGX to and from Busolwe hospital.(CS: 02)

The child had malaria when he was still very young, just one week old. We were reluctant to take him to the health unit. I did not take him to any health units at all [because] we failed to get money for treatment.… So that is how this cerebral malaria started.(CS: 03)

> Transport [is a challenge] in the way that you may not be having a bicycle. And so the children fall sick, you need to find a way to the HC.(CS: 04)

> I lacked transport to reach me to other HC … In terms of money of getting a car, motorcycle, like that.(CS: 05)

> I have never gone to Busolwe hospital … because it is far and also transport, the money is too much [for transportation to Busolwe].(CS: 07)

Cost of managing negative outcomes.

Another important contributor to the cost burden were costs associated with managing negative outcomes of a malaria episode. Children who survived with a disability presented further costs to their families by requiring medicines to treat impairments resulting from the severity of the illness or because of inappropriate management of the malaria episode. Three of these children (CS: 01, 02, and 03) survived but with a negative outcome, all required on-going treatment and time.

> So, when the child was curing in the process, this hand [holds the boys left hand that is lame] became lame. And even now, something … like epilepsy … attacks the brain and the brain stops working well … and the child falls down…. So, then, that is how he is, I look after him and such state.(CS: 01)

> Those [convulsion] tablets are found in Busolwe hospital, they are distributed every Friday, they give you tablets to last a whole week. So every Friday, we get those tablets for her…. We walk [7 miles to Busolwe], we walk with our feet, that is when we have failed to get money. At times, we ride on the bicycle but when we fail to use the bicycle, we walk on foot to the hospital to get the medicines.(CS: 02)

> The child's illness has caused us a lot of poverty because when it [convulsion] catches him, we do not have money. We have to work in other people's gardens to pay for the cost [medicines and transportation]. So now, I do not know what to do to make the child's illness to get cured for good.(CS: 03)

Sources of money.

A further primary hurdle faced by most caregivers who obtained treatment for their child was the difficulty in obtaining money. Caregivers stated they had to seek credit from private vendors, borrow money from friends, obtain money from their spouse

and family, deposit household goods, do extra work in exchange for money or sell household goods to pay for treatment.

> So then, I asked my husband about what we could do. So it was my husband that found a way out. I guess he borrowed money from a friend…. So with that money we went to Businghu [Busiu Hospital].(CS: 01)

> The challenges that we faced, we faced hard time when looking for money … often cannot find any money. We leave our own gardens to go and started digging other peoples' gardens. They give us portions of land in their gardens to dig an in return they would give us money. Which we used to pay for the treatment expenses [at a Busolwe drug vendor]. (CS: 03)

> [Sometimes] I deposited the gomesi [dress] as security and obtained money … [from] a woman at a bar in the trading centre … when I wanted to buy the medicine for injection and tablets…. [Another time] I borrowed a bicycle which my husband deposited [as] security…and then he used the money to pay for the tablets and other medicines and then he also paid for the bodaboda. After that is when I go to the health unit or the other private clinic at Busolwe [to buy the medicine].(CS: 03)

> I take her to a clinic in Lelesi [drug shop] and they treat her with quinine … and tell me to come back with the money later. Then afterwards I look for money. You go, then someone gives you a garden, you dig, then in exchange she gives you money [and you pay the shop].(CS: 05)

> I am challenged in a way of money…. If am to go to the health provider [public health facility], they will tell me that they need money [before give treatment] yet I do not have [so] I [have to] go to borrow and to help me treat the child.(CS: 06)

> In terms of money, you just borrow the transports means. So you find that you have to borrow.(CS: 07)

Burden of living with a negative outcome

Living with a negative outcomes resulting in irreversible physical and/or mental disabilities generates unique burdens for both the child and the household. Unlike other cost burdens that can be discharged in a season or so, physical and mental defects last for the lifetime of both child and household.

Effect on the child.

Negative physical effects on the child were the most common burden mentioned and included decreased mobility, sight and mental capacity. Cases 01, 02, 03, and 05 all had children who experienced prolonged episodes of malaria, hence considerable suffering as illustrated in these caregiver reports:

> So when the child was curing in the process, this hand [refers to boy's left hand] became lame. And even now, something … like epilepsy … attacks the brain and the brain stops working well it throws him down and the child falls down. I guess you can see the scars due to that [child to several wounds and sores on the foreheads and at the chin]. So then that is how he is, I look after him and such state.(CS: 01)

> Convulsions fever caused her to stop talking and the brain became affected, she became mentally disturbed, affected and ill… She used to speak very well. She used to say every word. She would welcome visitors and even thanked me for the food that I may have cooked after she had eaten it. She used to speak everything…. She stopped talking and after week, even the mental system stopped functioning.(CS: 02)

> He [still] suffers the convulsions. Stomach swells very much. Whenever he convulses, [stomach] too swells up and it can continue to swell up to three months nonstop. He also does not eat … as for the stomach that one failed to get back to normal. In fact, it only continues to swell and swell even more. [The child's stomach is very swollen like a balloon].(CS: 03)

> Body swells, both her [the child's] legs and her hands. The cheeks would also swell, she would have diarrhea, she would cough, mucus would come out of the nose and her body would get very hot…. She continuously fell sick. God himself decided to take her. But I tried a lot to give her treatment and I was defeated, then the child died.(CS: 05)

Effect on the household and caregiver.

For children experiencing negative outcomes, the entire household is also impacted, adding to the burden of cost, requiring constant and vigilant care dealing with socially inappropriate behaviors from the child, and living with sadness.

> So when the child was curing in the process, this hand [Refers to boy's left hand] became lame. And even now, something … like epilepsy … attacks the brain and the brain stops working well … and the child falls down…. So, then, that is how he is, I look after him and such state.(CS: 01)

> If she still could speak, she would by now have already welcomed you, greeted you. She used to even thank me for cooking after she had a meal [caregiver is now very emotional, close to tears]. But from the time she stopped talking, that is the same time during which her mental capacity was lost, and now she is mentally unstable. (CS: 02)
>
> Before getting mentally incapacitated, she would go and defecate in the latrine but right now, she just defecates anywhere that she finds. It can even be here right now, she can come and defecates here…. She can even go and defecate in the house.(CS: 02)
>
> Now in that year, it was in the ninth month of the year, 2010, that is fine we were told [by friends] about tablets that treat convulsions, that those tablets were found in Busolwe. Those tablets are found in Busolwe hospital, they are distributed every Friday, they give you tablets to last a whole week. So every Friday, we get those tablets for her … we walk on foot [7 miles] to the hospital to get the medicines … when we have failed to get money for bodaboda [transport].(CS: 02)
>
> Whenever he catches the malaria, I do not want to leave him all by himself, I need to move with him all around [wherever] I go…. I go with him. When he gets a severe attack, and yet I have got no money, [I] still and move with him wherever I go [even when gardening].(CS: 03)
>
> That child's illness has caused us a lot of poverty because when it catches him, we do not have money.(CS: 03)

Knowledge of government recommended medicine

Caregivers reported a variety of beliefs about using western medicines or traditional remedies to treat malaria in young children. Preference for western medicine over traditional medicines to treat malaria was expressed by all caregivers, although some did mention traditional remedies also had role in some instances. Seven of the cases (CS: 01, 03, 04, 05, 06, 07, 08) acknowledged hearing about ACTs (or Coartem®), but only one (CS: 04) of the four cases asked to name the government recommended antimalarial correctly stated ACT/Coartem® (Table 4.5). Thus, not all caregivers who had heard of ACT or Coartem® recognized that Coartem® was an example of ACT, and not everyone was familiar with ACT or Coartem® being the government recommended antimalarial (Table 4.5). Additionally, only two sought out Coartem® to keep at home for future use (CS: 01, 08) which they initiated as part of home management, and only one caregiver (CS: 08) requested that their child's current episode be treated with an ACT (or Coartem®) when visiting an external source.

> I know that the Western [medicines] work better than the traditional [because] I know that [Coartem®] works on malaria.(CS: 01)
>
> [Western medicine] works speedily/fast and traditional treats but not much…. I know also that traditional ones also work ... here in the village, we have our local or traditional medicine … if she vomits, they help her in not vomiting … it works [the traditional].(CS: 07)
>
> Myself. I knew that Coartem® also would play an important role in child's body…. I had got the Coartem® from the health provider at Muhuyu HC II because she is my husband's friend. Previously, the child had been ill and had been given Coartem® to give to him. But on top of that, the health provider gave me other [additional] Coartem® to use later on in the future just in case any of my child got sick with malaria…. I learnt because I also normally fall sick … when I fall sick and go to a health provider and explain to her about those conditions, she tells me to go and swallow Coartem®.(CS: 08)

Table 4.5 summarizes caregivers' knowledge about ACT (and Coartem®), whether the child received it, and where they normally obtained it. We found that no febrile illness was treated in accordance with government malarial policy: receiving a confirmatory diagnosis for malaria and initiating a first-line antimalarial (quinine for those less than four-months and ACT for those greater than four-months) within 24 hours of fever onset. While seven of these eight children were older than 4 months at the time of the febrile episode, and therefore eligible to receive an ACT, only three ever received it during the course of their illness.

Table 4.5. Caregivers' knowledge of government recommended antimalarials

Knowledge questions → / Cases (CS) ↓	Does CG know the first-line gov't antimalarial?	Has CG heard of ACTs?	Has CG heard of Coartem®?	Does CG know Coartem® is an ACT?	Where did CG hear about ACTs?	Was child given an ACT during this malaria episode?		Where does CG usually obtain ACTs?
						From home (Yes/No)	From 1st external source (Yes/No)	
Positive Outcome: Child Recovered								
CS 06	No	No	Yes	No	N/A	No	No (DS)	PHF for free (not this episode)
CS 07	No	Yes (But gives wrong examples[b])	No	No	• Drug shops • Gov't health providers • Radio	No	No (DS)	No evidence ACT was ever obtained
CS 08	N/A	N/A	Yes	N/A	N/A	Yes (leftover)	Yes (PHF)	PHF for free
Negative Outcome: Child Survived but with Deficits								
CS 01	N/A	Yes	Yes	No	• Gov't health providers • Radio	Yes (leftover)	No (PHF)	PHF for free
CS 02	No	No	No	N/A	• Not heard	No	No (PHF)	Never for this index child
CS 03	N/A	Yes	No	No	• Radio	No	No (DS)	PHF for free (not this episode)
Negative Outcome: Child Died								
CS 04	Yes (Says ACTs & Coartem®)	Yes	Yes	Yes	• Gov't health providers • Radio	No	No (PHF)	PHF for free (not this episode)
CS 05	N/A	N/A	Yes	N/A	N/A	No	Yes (PHF)	PHF for free

[a]Abbreviations: Artemisinin Combination Therapy (ACT); Caregiver (CG); Government (gov't); Drug Shop (DS); Not Applicable (N/A) - In some of the interviews these issues were not discussed; Public Health Facility (PHF).
[b]Examples given: Antibiotics, Aspirin, quinine, chloroquine.

Lessons learned and suggestions for future improvements

Caregivers reported they had learned from this experience, and discussed how this will change their future treatment-seeking behaviors. They also made suggestions about what they believed need to occur within the health system to improve malarial treatment for children five and under.

How this experience changed caregivers' treatment seeking behaviors.

The experiences from this febrile episode influenced treatment-seeking behavior for all caregivers whose child had experienced a negative outcome (CS: 01, 02, 03, 04, 05), and all had several things to say during this portion of the interviews. Only one caregiver whose child had a positive outcome (CS: 08) participated in this discussion. Only one caregiver whose child survived with a disability (CS: 03) said she would not treat her children with quinine. One caregiver (CS: 01) stated that while she herself would not give quinine she would give it if it was recommended by a health provider, even though she now believes Coartem® is the best.

> I know that it [Coartem®] works best on malaria … I cannot use quinine again because I got him lame. Now I take him to a health provider who would know how to handle my son's malaria…. [However] If it is a health provider [who recommends it], I do not refuse to use the quinine because it is the rule from the health provider.(CS: 01)

> I have learnt that I should not use lots of quinine. I was told about the effects of quinine so now I also know that quinine damages the brain and mental capacity if you use it in large amounts. [Now] when she gets malaria, we give her these very [convulsion] tablets that we obtain from Busolwe hospital on Fridays.(CS: 02)

> Nowadays when he gets sick did normally do not give him [quinine] injections…. I bathe him. If I have money, I get him some Panadol® so that the fever is relieved a bit.(CS: 03)

Both caregivers whose child died said they would initiate treatment more promptly, one (CS: 04) by making sure she had Coartem® at home to initiate as home

management, the other (CS: 05) still remained uninformed about the first-line antimalarial treatment.

> I [have learned to quickly] take her to the health unit. Okay I [get] him those tablets [Panadol® and Septrin®] because one time I had gone and they are the ones that I normally get for treatment. I even use these for myself for treatment.(CS: 04)

> Okay when it comes [fever], I usually have Coartem® in the house, so when the sickness comes, it is the one that I usually give before I rush her to the health unit.(CS: 05)

Two of the cases, one with a positive outcome (CS: 08) and one with a negative outcome (CS: 02), stated that they had learned from their experience to not use traditional remedies.

> I used [traditional meds] but they failed so I give up on them.(CS: 02)

> I used it but it [mululusa] did not heal my child. So now, I do not use it. I realized that it [mululusa] wastes time.(CS: 08)

Three of the five cases with a negative outcome (CS: 02, 03, 04) indicated they would in the future seek care from a public health facility.

> Now, what I have learnt is that if any other child has or suffers a convulsion, I do not follow anyone's advice of what to use to treat the child. I know that I have to go to the health provider whom I explained to him he advises me accordingly.(CS: 02)

> Whenever he gets fever, it comes quickly and is severe. So I always have to rush him to a health unit.(CS: 03)

> I [would] take her [immediately] to the health unit [previously treated the child at home and only took the child to a health unit when symptoms got worse].(CS: 04)

Of the cases who said what they would do differently, only one case (CS: 03) talked about a subsequent episode – despite the fact that future febrile episodes were virtually inevitable. Comparing the two episodes (the febrile episode in question and the subsequent fever episode), shows that she had previously used a drug shop as her external source, but in the subsequent episodes she visited a public health facility.

In addition to treatment-seeking behavior, caregivers (CS: 01, 02, 03, 07, 08) discussed the need to improve preventive measures and overall well-being of the child.

> If you have tea, for example in the morning you can give it to the child and the child takes passion fruits, if they are available you can give him to drink.(CS: 01)
>
> To sleep in a clean place. You should sweep where they sleep even if they only sleep on a papyrus mat.(CS: 02)
>
> Not giving them cold food in the morning since it is cold, it has parasites. So it is better that you prepare and give children warm food like porridge to eat.(CS: 03)
>
> The child needs to be treated and she gets good feeding, the sleeping should be good, and caring for her full-time.(CS: 07)
>
> If child has a poor appetite, always try to give him variety. If child fails to eat something, try and give him something else to eat. Do not just ignore the child without giving him something to eat. Try your best to give him various foods to eat until child gets something that he desires to eat. In that way, I am helping to give care to child who has malaria. So that the child doesn't stay the whole day hungry and yet he is suffering from the sickness as well.(CS: 08)

Four of the five cases with negative outcomes (CS: 01, 02, 03, 04) mentioned that nets were an important way to improve caregiving. While only two of these four cases (CS: 01, 04) reported actually using nets in their home, one (CS: 01) qualified the use of nets by saying that there was no way to avoid malaria.

> They [children five years and under] sleep under the net…. You cannot avoid or prevent yourself from a mosquito. At times, you can be seated and it comes and bites you. So in case you have medicine it helps us.(CS: 01)
>
> They have to sleep under the net.(CS: 02)
>
> Sleeping under the mosquito net. So that the mosquitoes do not bite them for the whole night.(CS: 03)
>
> By sleeping under the mosquito nets…. Yes [I use nets at home].(CS: 04)

Suggestions for improving health delivery at the systems level.

Caregivers' suggestions for improving health delivery were directed toward alleviating challenges they faced when seeking treatment from public health facilities. Three suggestions made by half of the cases with both positive and negative outcomes (CS: 01, 02, 05, 08) were to bring health services closer to their home, to have more personnel at public facilities and to have medicines available at the facilities.

> I think that the government should help us and build health units that are nearby so that even us who stay for we can start moving shorter distances to the health units.(CS: 01)

> What I see is that if they could get the health units close by, it would be good because you can thereby speedily rush the child there, even yourself, you can easily get to the health unit if it is nearby.(CS: 02)

> They [should] bring for us help by giving and providing us with tablets/medicines in village.(CS: 05)

> So, at least, various roles can be shared up [have more staff to do the different tasks]. One health provider can be dispensing the tablets and the other health provider can be injecting, rather than just one person giving out tablets and at the same time injecting and at the same time receiving the patients. You can imagine, of about 30 people or 25 people, how can one health provider attend to all those people at once.(CS: 08)

Four other caregivers (CS: 03, 04, 05, 07) suggested they were interested in being given more medicine by the public health facilities. Both cases 05 and 07 said that the types of medicine they want are ACTs. While case 05 reported she had heard of Coartem® and her child had received Coartem® at the public health facility; case 07 was less familiar with Coartem® but had been told it was the first-line government recommended antimalarial by the research assistant conducting the household survey as part of the larger study. Two caregivers (CS: 05, 06) also indicated that public health facilities need to provide them with information on how to better care for their child.

> They [public health facilities] should immunize for malaria.(CS: 03)

> They [public health facilities] should provide for us with medicine because at times we go to the government health units [and] medicines are not there, that's why we go to the clinics [drug shops].(CS: 04)

> They [public health facilities] should bring for us help by giving and providing us with tablets and medicines … specifically Coartem® … in village…. [Additionally] I would love to be told when the child fall sick and doesn't want to eat what do I do.(CS: 05)
>
> It [public health facilities] needs to be having the capacity [to treat] when you take them [children] to the health unit…. The health providers should direct you how to treat that malaria.(CS: 06)
>
> We want government to brings for us mosquito nets, and also those [ACT] medicines they give us and be in the house as first aid so that we know what to do for the child very fast.(CS: 07)

4.4. Discussion

While case studies do not allow generalizability to a large population, they do provide greater insight into individual behaviors. These case studies offer valuable testimony of eight caregivers' circumstances, experiences and challenges with treatment-seeking in Butaleja District in rural Uganda. In our study we examined the sequential steps taken by caregivers to manage their child's febrile illness, their experiences with the various sources they visited and challenges they encountered during this process. Despite the variability in outcomes – illness improved, negative outcome with disability and negative outcome resulting in death, caregivers generally shared similar practices, experiences and challenges. Among the themes extracted from this study, the following summarizes the key findings:

- Caregivers had a pluralistic approach to treatment, with many taking multiple steps in an attempt to resolve their child's febrile episode and to avoid adverse outcomes,
- Treatment seeking in most instances started within the home using physical supportive care, western medicines, and/or traditional remedies. A quarter of ACTs given as part of initial treatment were sourced from home,
- All subsequent actions involved one or more external sources. While the use of public health facility was as common as use of private outlets, regular stock-outs at public facilities meant that more treatments were obtained from private outlets,
- Use of multiple treatments was common both within the home setting as well as with public health facilities. Such polypharmacy included both effective and ineffective treatments,

- Most caregivers reported visiting an external source within the same/next day of noticing fever in their child. But further delays in receiving treatment from external sources was likely a common occurrence due to the use of home management, distances that need to be travelled, and long wait times and medication stock-outs once at public facilities. Thus, actual treatment often did not begin until 24-48 hours after the first appearance of fever,
- An exceedingly small proportion of children received an ACT or a diagnostic blood test, and no child seen at public facilities received treatment in accordance with the national guidelines,
- Several caregivers expressed a preference for public health facilities because of their belief that providers at these facilities are more qualified and experienced. In spite of this, several challenges compelled caregivers to seek treatment from private outlets, and
- Distances to health facilities, regular supplies and medication stock-outs, direct and indirect costs associated with treatment-seeking, and inadequate service at public health facilities were commonly cited as significant obstacles limiting caregivers' ability to adequately manage malaria in their children.

4.4.1. Home management

Similar to other regions in Uganda and sub-Saharan African countries, most caregivers in our study initiated treatment with home management either as a primary approach to treat the febrile illness or as a temporary measure before seeking treatment from an external source.[19,31] Home management commonly involved the use of supportive treatment, traditional herbs, and/or western medicines kept in the home for future use. Home medicines were mainly sourced from private drug shops or public health facilities, and some instances were leftover from previous treatments. Only one caregiver opted to do nothing other than observe the child as their initial act. While just under half of the caregivers reported that they did not intend to seek external care when they initiated home management, all caregivers whose child did not improve sought treatment from an external source within the same/next day. The strategy to start with home management allows caregivers to wait in hope the less expensive home medicines will suffice, postponing direct and indirect expenses associated with seeking external treatment.[32] This approach also enables those wishing to seek further treatment to secure money, liquid assets, or find alternate source of labor to pay for these expenses.[19,31,33-36] The practice to seek help from external sources only when home management is perceived to have failed or if the child is presenting with symptoms

reflecting severe illness such as vomiting or diarrhea, has also been observed in several other regions of Uganda, sub-Saharan African countries, as well as south Asia.[19,33-37] Thus, despite caregivers reporting a preference for public health facilities, direct and indirect costs frequently compel them to start with home management.[35,37] As evident in our study, the delay in seeking external often results in the child's condition progressing from mild to severe, resulting in negative outcomes such as irreversible disability or death.

4.4.2. Use of multiple treatment sources

Getting the runaround at public health facilities was a common occurrence in our study. A greater proportion of caregivers in our study chose public health facilities over private outlets (ration of 5:3) for their first external source, although three of the five were later referred to private drug shops to purchase medications for the child. Consequently, more caregivers obtained their treatments from private outlets than public facilities. Furthermore, half of the caregivers required multiple visits to the same or different sources because their child either did not improve, the child went on to suffer an adverse outcome, or public facilities where they were visiting were experiencing stock-outs of medicines and/or blood supply. In a few instances caregivers were referred to higher levels public health facilities for more invasive treatment without any treatment initiated at the primary external source. Consequently, similar to what other researchers in sub-Sahara Africa have observed, caregivers in our study vacillated between multiple sources, travelling long distances and incurring numerous costs in an attempt to find a cure.[32,38,39]

4.4.3. Use of multiple treatments

The practice of using multiple treatment approaches to manage children was common in our study. This practice of polypharmacy likely occurs in caregivers' hope that at least one approach or synergistic effects from the combination of treatments will help cure malaria in their child.[19,32] "Multiple treatments" included the use of multiple western medicines together, and sometimes in combination with supportive care and traditional remedies. While polypharmacy was common with home management, this

practice was also observed with public health facilities and private drug shops. Our results are in line with other studies that have found traditional and modern treatments, both effective and ineffective, to coexist. [19,32,40] A rural study conducted in Mali found caregivers often sought care from HCs when home remedies did not alleviate symptoms, but then they returned to traditional therapy if treatment from the HC failed. In our study, one caregiver reported reinstating a traditional remedy when the child failed to improve, supplementing the treatment prescribed by the health facility.

4.4.4. Delays in Treatment

While most caregivers responded to their child's symptoms on the same day with home management, some versions of home management no doubt caused delay in seeking treatment from external sources to later in the day or the next day. For many children this wait was too long, with some children's condition progressing from mild to severe. In some cases the wait may have been longer as caregiver waited for home remedies to take effect. Appearance of illness at night was another deterrent to seeking immediate treatment at an external source, since caregivers waited for the sun to rise. Once at a public facility, medication stock-outs caused still further delays by requiring caregivers to secure additional funds and to travel further distances to a private outlet where medicines could perhaps be purchased. Other barriers encountered at public facilities by caregivers in our study included long wait times and unavailability of staff. Prompt treatment with antimalarial is defined by the World Health Organization (WHO) and the Uganda National Malaria Control Strategy as administration of treatment within 24 hours of onset of fever.[7,41] Research exploring health system practices in Uganda and other sub-Saharan African countries has confirmed delay in treatment to be a common occurrence, usually associated with lack of sufficient and appropriate staffing, long wait times , and unavailability of medications.[33-36,42-44] Thus, despite the fact that half our study's caregivers reported seeking care from a public facility within 24 hours, treatment may not have been initiated within those same 24 hours.

4.4.5. Prompt diagnosis and treatment with appropriate antimalarial

Only a small proportion of eligible children in our study received an ACT from an external source (25%), despite revised guidelines prompting its use, recent initiatives to improve its access from private licensed facilities, and more ambitious national targets for treating malaria. The Uganda National Malaria Control Strategy recommends that all suspected cases of malaria be confirmed diagnostically, and those testing positive receive a first-line antimalarial within 24 hours of fever onset.[7] The target set by the Uganda Malaria Control Strategic Plan was to have 85% of children under five receive correct treatment according to the national treatment guidelines with 24 hours of the onset of symptoms by year 2010.[7] For uncomplicated malaria, the first-line antimalarial consists of oral quinine for children younger than four months and ACT for those older than four months. For severe malaria, treatment is initiated with injectable quinine followed by oral quinine or ACT depending on the child's age. Additionally, in circumstances where a child needs to be referred to another health facility, both the WHO 2010 guideline and Uganda National Malaria Control Strategy recommend initiating treatment with rectal or intramuscular artesunate, artemether injectable or intravenous quinine *prior to referral*.[7,41] For most children in our study, diagnosis was primarily presumptive. Only two children received a confirmatory blood test for malaria at their first external visit, one at a public facility and another at a private outlet. In two of the three instances where ACT was given, it was initiated as part of home management. However, only one child was later maintained on the ACT when seen at the public health facility, the other was switched to oral quinine. Overall, one caregiver reported initiating ACT after visiting a public facility. Thus, in this study, public facilities were not dependable sources for receiving treatment as outlined by the national malaria policy. Children were no more likely to receive an appropriate antimalarial treatment if they were first seen at a public facility as opposed to a private outlet. The low use of ACTs in our study is in line with national and regional findings in Uganda which show the usage of ACT to be at 21% in 2009 and 44% in 2012, with an even lower proportion demonstrated to receive an ACT within the same/next day (18% in 2009 and 36% in 2012).[45,46] For those children in this study who died from a protracted case of fever, one died in spite of receiving an ACT. One possible explanation for the death may be the lack of proper

clinical assessment and overall management by the public facility. Since many childhood illnesses share common symptomatology such as fever, fatigue, weakness, nausea and diarrhea, diagnostic testing for malaria is integral to a child receiving appropriate treatment. As observed in this study and reported by other, in circumstances where quality of services are poor and public health facilities are not adequately resourced, experiencing a negative outcome is not only inevitable but unfortunately predictable, suggesting the need to strengthen case management.[39,43]

4.4.6. Stock-outs of ACT at public health facilities

For children in our study, it is possible that public health facilities may not have prescribed an ACT because they were already aware that few private drug shops - which are mostly unlicensed in Butaleja District -- carry it. With funding from the Global Fund, Uganda implemented a national program in Spring of 2011 to disseminate ACTs through licensed private outlets at a subsidized cost.[27] However, purchase of ACTs from a licensed private outlet was beyond the reach of many caregivers, as most are poor and cannot afford to travel long distances to licensed private outlets. Half of the caregivers in our study relied on public health facilities to obtain an appropriate antimalarial, and the use of unlicensed private outlets was in large part due to unavailability of medicines at public facilities. In fact two caregivers in our study reported obtaining ACTs from public health facilities well in advance of an illness and keeping it at home for future use because of frequent stock-outs. Thus, in Butaleja District public facilities were not reliable sources of ACTs; and while unlicensed private vendors were an important source of antimalarial treatment, they were not licensed to sell ACTs.

4.4.7. Caregivers prefer public health facilities despite challenges

Distances to health facilities were a note of concern by all caregivers, as many lacked resources such as money and transportation to travel to these facilities. Among those who were able to reach a health facility, they were further burdened by long wait times, medication and supply stock-outs, staff shortages, inattentive staff, staff that exhibited poor attitudes, and staff who delivered an overall poor quality of care. Despite such unpleasant experiences, many caregivers still expressed greater preference for

public health facilities, with just over a half choosing public facilities as their first external source when their personal attempts to resolve the illness failed. As has been suggested by others, caregivers' preference for public facilities may be associated with the belief that providers at these facilities are more qualified and experienced than those at private outlets.[19,34,47] Knowledge of such obstacles impeding access to prompt and appropriate treatment at public facilities in Uganda is not new and have been reported by many others.[19,44,48,49] Our study however points to the fact that such challenges continue in spite implementation of national malaria control policies and training of public providers to improve case management.[14] The literature suggests that interventions more far-reaching than health provider training are needed to improve care at public facilities.[19,48,49] These include implementing regular and adequate supervision, improving worker motivations and perceptions, improving customer service and communication between staff and caregivers, changing political and economic environment and incentives, mitigating misappropriation of drugs to ensure continuous stock of ACT, and removal of ineffective antimalarials from facilities.[19,48,49] Until such time as practices at public health facilities meet guidelines, promoting the use of public facilities will remain problematic. Public health researchers and program implementers need to consider multifaceted approaches involving all key stakeholders – including both caregivers and unlicensed drug vendors, to improve prompt and effective management of malaria in young children.

4.4.8. Recommendations

To minimize the economic burden associated with travelling long-distances to reach public facilities, there have been recent national initiatives to bring public services closer to the community through the introduction of integrated community case management (iCCM) program. Although at the time of this study, iCCM had not yet been introduced in Butaleja District, this program is aimed at delivering prompt, adequate and free treatment to children under five for malaria, pneumonia, and diarrhea.[50] The iCCM builds on the original Uganda Home Based Management of Fever Program (HBMF) instituted in 2002, which was temporarily phased out with the change of the first-line antimalarial treatment policy from chloroquine+sulfadoxine/pyrimethamine (CQ+SP) to ACT in 2004.[7] The iCCM program is delivered by a cadre of CHWs recruited by the

community who are supported and supervised by health professionals from public facilities. While short-term studies have demonstrated care delivered by CHWs to be effective under study conditions where close supervision and uninterrupted supply of ACT is assured, long-term effectiveness still needs to be demonstrated.[51,52] Some of the challenges levelled against the original HBMF included frequent medication stock-outs and absenteeism of CHWs.[53] Given that iCCM is governed under the public health structure, it also runs the risk of being plagued by similar problems.[52,54] Current data from national and regional studies indicate that to-date there has been a less than optimal uptake of CHW services through the iCCM program.[45,48,55] Whether this low uptake is a consequence of earlier negative experiences with the HBMF program, communities becoming unaccustomed to using CHWs due to their demise in 2004, and/or fear and distrust of current iCCM protocols because they may not aligned with local beliefs and expectations factors, still needs to be investigated. What we do know from previous treatment seeking behavior studies is that poor quality of care and/or stock-outs can undermine the potential impact of providing free health care.[33]

A study from neighboring Districts in eastern Uganda found an inverse relationship between the use of traditional herbs and visits to CHWs, with those inclined to use traditional herbs more likely to visit private outlets than CHWs.[55] Results from our study along with findings from other studies indicate that the private sector continues to play a pivotal role in the management of fever for children five and under in Uganda.[19,45,48,55,56] Most caregivers our study used private drug shops because these outlets were easy to access, they had a constant supply of medicines, and they provided prompt and friendly service. Among those who visited a public health facility, many were referred to a private drug shop during periods of medication stock-outs or to purchase additional medicines, perpetuating this practice of using private outlets. In the case of the latter, one might expect that visits to private outlets posed an additional and unnecessary burden on caregivers. If public facilities are to refer caregivers to private outlets, going directly to a private outlet may be even cheaper. Therefore, if the quality of case management is to improve, all services used by caregivers need to improve, including those of unlicensed drug shop vendors, since most are staffed by people with little to no medical training.[15,56] The current policy to limit dissemination of AMFm subsidized ACTs to only licensed private outlets has not resulted in acceptable malaria

management practices in Butaleja District, where large proportion of the population relies on unlicensed outlets. One option would be to extend the ACT subsidy program along with the necessary training to the unlicensed private sector to address the current gap between policy and practice.[15] Given that most unlicensed vendors are first and foremost part of the communities they service, another possibility would be to consider including them into the CHWs scheme. Extending the inclusion criteria of CHWs to include private vendors may mitigate the concern of medicine stock-outs afflicting public outlets, since private vendors can offer a constant supply of ACTs.

Since caregivers already source their treatments from private outlets and public health facilities, educating caregivers is another important element to meet national objectives of prompt and appropriate treatment for children five and under. For many years, social scientists have advocated that acceptance of any healthcare intervention will ultimately depend on individuals' accepting and demanding such interventions.[57] It is therefore vital to extend public health education programs to educate caregivers and their families about the current malarial treatment guidelines and to influence what they seek out and obtain for their children. In our study, most caregivers reported hearing of ACT, but only one was aware that ACT was the government-recommended first-line antimalarial. This study documents the wide use of Panadol and quinine, even though quinine is not the first-line antimalarial for children older than four-months and Panadol offers only symptomatic relief but is not curative. Given the low levels of awareness of the first-line antimalarial, it is not surprising that most caregivers did not request an ACT. Other studies evaluating caregivers' understanding of antimalarials in rural eastern Uganda have found caregiver to commonly confuse non-antimalarials with antimalarials, with many opting for combination therapies which include ineffective medicines.[19,34] In a secondary analysis of the 2009 Uganda ACTWatch study, Littrell et al reported that caregivers requested an antimalarial by name to varying degrees, and when they did so they typically request for ineffective medicines.[48] Thus, in circumstances where caregivers lack the appropriate knowledge, the literature indicates that they will often limit the demand for effective interventions even when it is available.[58]

The low use of diagnostic tests to confirm suspected case of malaria was also a concern in our study. Studies exploring community acceptance of routine diagnostic

procedures to confirm malaria have identified disturbing findings. For instance, in Uganda, it was reported that community members generally feared getting their children's blood tested for malaria because of concern that their child could get infected with HIV in the process, the blood would be used to test for HIV rather than malaria or that the blood could end up in the wrong hands and be used for witchcraft.[59] Another study in Nigeria reported that while community members acknowledged the importance of testing for malaria, many remained doubtful about the reliability of the tests, especially when results are negative.[60] However, it is not clear how caregivers in our study viewed the use of blood tests to establish malaria in child prior to initiating treatment, as they neither advocated for it nor rejected it. Given that those who are informed about the benefits of diagnostic testing are more likely to advocate for its use when seeking treatment for their child, this study and others clearly highlight the need to develop targeted education for caregivers around diagnostic testing and prompt treatment with first-line antimalarials.[59,60]

4.4.9. Limitations

Case study methodologies offer unique opportunities to explore and examine complex phenomena within natural contexts, and -- in the case of this study – through multiple lenses.[61] The intent of this study was to document individual cases to capture thick descriptions of unique situations and to illustrate special attributes and aspects of care giving during a malaria episode, as well as to determine factors influencing caregiver practices as leverage points for defining a health promotion program. Despite their advantages, case study limitations need to be recognized and findings from this study need to be interpreted accordingly. First, case study methodologies generally use smaller sample sizes than found in most quantitative studies, thus this study makes no claim to generalizability. Second, case studies are subject to selection bias because each case is purposively selected by the research team to explore specific experiences. In our study, results represent insights from eight caregivers, thus the study findings are not necessarily representative of all caregiver experiences in Butaleja District. Third, the research was conducted retrospectively and therefore was subject to recall bias. While it was possible to minimize recall bias for those caregivers whose children had a positive outcome by limiting the discussion to the very last fever episode, it was difficult to

minimize it from a methodological perspective for cases that experienced negative outcomes, as it required caregivers to reflect back to an episode that may have occurred over a year ago. Thus, recall bias may have resulted in omission or over-emphasis of certain discrete but relevant steps.

4.5. Conclusions

Findings from our study propose that these eight caregivers in Butaleja District generally share similar practices, experiences and challenges when seeking treatment for children five and under, with few children ever receiving treatment in accordance with the Uganda national guidelines.

To improve timely access to ACT, our results support the need to include all key stakeholders in future public health interventions aimed at improving malaria management in young children. While this inevitably will include public health providers both within public facilities as well as those affiliated outreach programs such as iCCM, given the weak infrastructure and limitations of government supported programs, focusing on these groups alone will not be sufficient. As noted in this study and acknowledged by other researchers, the unlicensed private sector of drug vendors play an essential role in the management of fever for children in rural settings where licensed private outlets are far and few. Despite their prominence, unlicensed providers have traditionally been overlooked in national efforts to improve timely access to affordable ACTs. Thus, future health delivery models need to consider how unlicensed vendors can be leveraged to help attain the 2010 national target -- to have 85% of children under five receive antimalarial treatment as per guidelines. In addition to focusing on service delivery, future public health interventions need to better inform households on how best to manage malaria in young children, to improve caregivers' capacity to take the necessary actions, and to advocate for appropriate treatment.

4.6. References

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Chapter 5.
Discussion, Limitations, Recommendations, and Conclusions

5.1. Discussion

This research responds to a rural community's expressed desire to improve malaria care for children five and under in Butaleja District of Uganda. Community elders, health providers and District health offices identified the under-use of effective antimalarials during acute episodes as the chief concern. As a first step to inform future public health programs in Butaleja, this study undertook formative research to examine and evaluate caregivers' treatment-seeking behaviors for managing uncomplicated malaria. The overall study is anchored on the HBM introduced by Hochbaum, Rosenstock and Kegels to explore factors which might facilitate or hinder these behaviors. The HBM is a value-expectancy theory which proposes that health behaviors are most likely adopted when individuals believe the benefits of taking an action outweighs perceived barriers to taking the action, and if they perceive they can successfully execute this action. Thus, the HBM served as a valuable organizing tool for examining studies reported elsewhere in the literature, for developing an inventory of questions to include in the survey, and for evaluating the case study data.

As part of the larger research effort, three-sub studies were carried out: (1) a literature review which included a systematic review on caregivers' treatment-seeking behavior in Uganda since the institution of ACT as first-line treatment for malaria; (2) a field study using household survey to understand current behaviors and the extent to which children received an "appropriate" antimalarial in Butaleja District, and to determine which behaviors, assets and challenges influenced receipt of an "appropriate" antimalarial; and (3) a field study using a multiple case study approach to illustrate special attributes and aspects of treatment-seeking during a malaria episode.

Collectively, the research findings provide an understanding of prevailing gaps between policy and practice in Butaleja District and insights into public health strategies which may help mitigate these gaps. Findings from each of these three studies and their implication to future public health interventions are presented in this dissertation report as three manuscripts published as Chapter 2, 3, and 4, respectively. This final Chapter provides a synopsis on the key contributions of the three manuscripts to the overall research, summarizes important limitations within which current findings need to be considered, recaps recommendations regarding future interventions, and finally offers some concluding observations. All discussion pertaining to the literature review are drawn from Chapter 2; accordingly, unless otherwise specified, all citations supporting this discussion are summarized in Chapter 2.

The literature review identifies *P. falciparum* as the most predominant and virulent specie of the *Plasmodium* parasite responsible for malaria in sub-Saharan Africa (SSA). If not treated within 24-hours, malaria caused by *P. falciparum* can progress rapidly from mild to severe resulting in significant morbidity and mortality. In Uganda, malaria is responsible for 39,000 to 110,000 annual child deaths. Given the economic burden associated with malaria, there have been significant global and national efforts to improve case management through strengthening of the health delivery system. Similarly, there have been efforts to prevent malaria through dissemination of vector control strategies such as indoor residual spraying and insecticide treated nets to local communities. Despite these efforts, the evidence has yet to show a decrease in malaria burden for Uganda, with children under five experiencing on average four episodes annually. Consequently, though vector control is the primary strategy for sustained malaria control, case management through prompt treatment continues to be the mainstay.

The 2010 target for case management set by the Uganda National Malaria Control Strategic Plan was to have 85% of children under five with fever receive an antimalarial treatment as per national guidelines. Guidelines included receiving a confirmation diagnosis by microscopy or rapid diagnostic test followed by a first-line antimalarial within 24-hours of the onset of fever. For uncomplicated malaria, this consists of oral quinine for children less than four months of age and ACT for those older

than four months. Contrary to recommendations by the WHO, quinine as monotherapy is recommended as the second-line treatment. The use of quinine as a second line agent remains a concern given that it is readily accessible, it has lower cure rates than ACT, and adherence is a challenge due to its prolonged and complex regimen and side effects. Most recent initiatives to improve case management include the gradual rolling out of the Integrated community case management of childhood illness (iCCM) program using Community Health Workers (CHWs) to bring public services for malaria, pneumonia, and diarrhea closer to the community; and, since Spring 2011, the national dissemination of subsidized ACTs to licensed private outlets through the AMFm program. At the time of this research, the dissemination of subsidized AMFm ACTs to licensed private outlets was well underway; however the iCCM program had yet to be introduced in Butaleja District. As a result, providers trained in appropriate malaria management are only available for consultation at public and licensed private facilities. Efforts to improve treatment at unlicensed private providers have been overlooked even though they remain an important source of antimalarials in rural settings.

Findings from all three studies establish that while global and national initiatives have improved access and use of ACTs for children under five since 2004, these initiatives to-date have not been sufficient to meet the 2010 85% national target. While a range of results have emerged from the three studies, the following select findings provide valuable insight to understanding the gap between policy and practice.

5.1.1. Knowledge, perceived effectiveness and use of ACT

Findings from all three studies (the literature review and the two field studies) confirm that treatment with ACT is far from universal. A large majority of children with fever continue to be treated presumptively and often with ineffective drugs, with only a small fraction receiving an appropriate antimalarial. Increased awareness about ACT among caregivers has not always translated to a change in behavior.

- Prior to the field studies, the literature review identified less than a quarter of children with fever nationally received an ACT and about one in six received it within 24-hours. Since the field studies, the proportion of children nationally who received an ACT increased to about two in five and those who received it within 24-hours increased to about one in three. Nationally, this increase coincides with the introduction of AMFm and the iCCM programs. While this

increase represents an important stride toward improving access and use of ACT, it still represents less than half of children with fever ever receiving an ACT during the course of their febrile illness. Further, the overall proportion of antimalarials obtained remained unchanged from pre-AMFm period, suggesting the observed increase in ACT usage represents a shift in the type of antimalarials dispensed. The review notes that almost a third of antimalarials acquired by caregivers continue to include quinine and/or chloroquine.

- The quantitative field study found one-third of children with fever received no antimalarial. The usage of ACT in Butaleja was 41%, confirming the low usage of ACT reported by national studies (37-44%) in 2011 and 2012. However, the actual use of "appropriate" antimalarial reported in the field study was much lower at 32%. This field study is the only study to estimate the proportion of children receiving an "appropriate" antimalarial - defined as having received *only* the age-specific first-line malaria treatment for uncomplicated and severe malaria during the course of the illness. This estimate did not consider the concurrent use of non-antimalarials, nor did it consider whether or not a child received a diagnostic test.
- As with the literature review, the quantitative study found only about a fifth of children with fever received a blood test, although this study was unable to confirm the purpose of these tests.
- The literature review showed an important discrepancy between caregivers' knowledge about ACT, what they believed to be the most effective antimalarial, and what they actually obtained for their young child. In comparing the proportion of caregivers who reported knowing ACT was the first-line antimalarial, national studies report that a substantially lower proportion mentioned ACT as the most effective antimalarial, and an even lower fraction actually obtained an ACT for their child. Similarly, studies evaluating the use of AMFm ACTs nationally report less than half of caregivers who reported having seen or heard of the AMFm ACTs ever reported purchasing an ACT with an AMFm logo.
- While this discrepancy between knowledge about ACT, perceived efficacy, and use did not hold true in the quantitative field study, the case study findings parallel that of the literature review. Findings from the quantitative field study report a much lower proportion of caregivers in Butaleja were knowledgeable that ACT was the first-line antimalarial than reported nationally in a previous year (34% vs 57%); and a similar proportion (35%) perceived ACT to be the most effective antimalarial. In contrast, a larger proportion obtained an ACT (41%) over the course of the child's illness, although only 32% of caregivers obtained an "appropriate" antimalarial treatment.
- Conversely, awareness about ACTs or Coartem® was higher in the case study, with seven of the eight caregivers acknowledging having heard of it at the time of the febrile episode in question. In spite of this high level of awareness, only three of the seven sought out an ACT for their child (two to keep at home for future use and one when visiting an external source). Seven of the eight children in the case study were older than four months at the time

of the current febrile episode and therefore eligible to receive an ACT. Further, only one of the four caregivers asked to name the first-line government antimalarial was able to correctly respond with "ACT".

- While past studies have investigated "time to initiating an antimalarial or an ACT from point of initial fever", little was known about the "time to initiating *any* treatment from the point of noticing the first symptoms". Hence, both these field studies provide a unique understanding about how quickly caregivers' respond with *any* treatment. In Butaleja, a large majority (over four out of five) of caregivers initiated some form of action within the same/next day (24-hours). Given that most caregivers act promptly to manage fever but few initiate ACT within the first 24-hours, implies that most caregivers' treatment-seeking decisions do not align with recommendations from the biomedical community.

5.1.2. Types of sources accessed

Findings from all three studies confirm that treatment-seeking in Uganda is pluralistic, with home management being an important initial source of treatment. Additionally, over the course of a child's illness, a large majority seek treatment from external sources, with private outlets representing a substantial proportion of external sources visited. Few caregivers across all three studies report seeking treatment or ACT from CHWs.

- For initial treatment, national studies reported two to three out of five caregivers relied on home management. Among those children who received an ACT, almost one-quarter were sourced from home. The field studies confirmed home management to also be a common first response for caregivers in Butaleja, this was observed among 73% in the household survey and seven of the eight caregivers in the case study. A little over half of caregivers in the survey reported keeping an antimalarial in their home for future use over the preceding six months. While one-quarter of ACTs in the case study were sourced from home, this proportion was lower in the survey at about one in six.
- Over the course of a child's illness, the literature review suggests that in 2009-2010 a larger proportion chose private outlets over public health facilities. While the field studies also found the use of private outlets to be common, visits to public health facilities was higher in Butaleja than reported in the literature. Almost half of the caregivers in both the survey and the case study report visiting a public health facility. However, unlike in the quantitative study where almost three out of five caregivers report obtaining their antimalarial from a public facility, many of the caregivers in the case study obtained their medicines from private outlet because of stock-outs at public facilities.

- As with the literature review, both field studies note many caregivers are averse to visiting a public health facility because of undesirable previous experiences and/or challenges with obtaining treatment from public facilities. However, despite such experiences and adversities, many caregivers still sought care from a public facility, especially when their child failed to improve.
- The literature review found less than one in seven caregivers sought treatment from CHWs, with those using traditional remedies less likely to visit a CHW or a public health facility. The field studies found the use of CHWs to be even lower, this may be due to the iCCM model yet to be introduced in Butaleja.

5.1.3. Knowledge, perceptions and preferences about malaria treatment

Findings from all three studies confirm that caregivers' perception about medication efficacy is diverse and often influenced by prior experiences and local household and community beliefs. Caregivers' knowledge about antimalarials also varied, with few able to differentiate between antimalarials and non-antimalarials, most using non-antimalarials for the management of malaria, many preferring the use of combination therapy, and most combining polypharmacy with traditional remedies and supportive physical therapy.

- As with the systematic review, findings from both field studies propose that most caregivers in Butaleja preferred western medicines for managing malaria, although their views about which medicine represented the best differed. While for most caregivers this preference was associated with the belief that western medicines were more effective than traditional remedies, the lack of knowledge about traditional herbs was also cited as a reason for using western medicines. Among those who did use traditional remedies, they did so because they were free, accessible, and they or their family members believed them to be effective. The proportion of caregivers who used traditional remedies was higher in Butaleja than reported in the literature review.
- In the case study, there was no strong pattern separating children who had a positive outcome from those who had negative outcomes with respect to whether they received a traditional remedy or the type of western medicine received as part of home management.
- Advice offered from family, friends and health providers on a previous interaction commonly influenced caregivers' initial treatment choices. Among caregivers who initiated a traditional remedy in our case study, many did so at the advice of a friend, mother or grandmother. Similarly, among those who used a western medicine as part of home management, most reported their choice of medicine was influenced by a health provider during a previous

illness; only one caregiver reported making this decision based on hearsay from villagers.

- For initial treatment, the household survey indicated four-sixths of caregivers received help from family members to confirm their child was ill, with a quarter making this assessment on their own. During this initial period, almost half got advice from family members on the type of action to take (traditional vs supportive vs western medicine), and about one-quarter made this decision on their own. In instances where a traditional remedy was used, almost half of these decisions were influenced by family members and the other half made independently by caregivers. Of those who obtained a western medicine from an external source, almost three out of five caregivers made this decision on their own. For a large number, the choice of western medicine was influenced by what they had been previously told by a health provider.

5.1.4. Knowledge about malaria

All three studies confirm that while caregivers' understanding of what causes malaria and their knowledge about malaria as a cause of fever has increased appreciably over the years, important misconceptions remain widespread.

- Caregivers' understanding of the cause of malaria was generally high across the studies, although in Butaleja this knowledge was lower by 10% compared to that reported in national studies and lower by 20% compared to finding from other eastern regions of Uganda.
- Across all three studies, fever was found to be the best-known malaria symptom, with four in five caregivers mentioning fever. However, unlike in major national studies where just over three-quarters of caregivers reported fever as the main symptom, in Butaleja under half of caregivers recognized fever as the main symptom. Further, in Butaleja, just a little over half expressed certainty with recognizing malaria.
- The literature review found caregivers' knowledge on other clinically recognized symptoms of malaria or on their misconceptions about malaria to be less well studied. This research makes an important contribution on this matter. Findings from Butaleja agree with the one qualitative study in the review that found caregivers to be less familiar with symptoms other than fever, and misconceptions to be common among caregivers.
- Complementing results from the field studies is the finding from the literature review that most caregivers do not share the notion that fever is a non-specific sign associated with several childhood illnesses or that a child could suffer from more than one illness at a time. Accordingly, any symptom combination involving fever is routinely interpreted to be malaria and managed as malaria.
- While the literature review found that a large majority of caregivers respond promptly to fever, none of the studies reviewed examined caregivers' knowledge about government recommendations on when to start a child with

fever on an antimalarial. To this end, the quantitative field study addressed an important gap by informing about caregivers' knowledge regarding what the government recommends. With just under three-quarters of caregivers in Butaleja District reporting knowing that the government recommended starting an antimalarial within 24-hour of noticing fever, this knowledge was fairly high but not universal. Still – despite this knowledge, consistent with the literature review, only about half of caregivers in Butaleja initiated an antimalarial within the 24-window.

5.1.5. Challenges with obtaining advice and treatment for malaria

All three studies report that while caregivers expressed a preference for receiving advice or treatment from public health workers because of their qualifications, for many their practices favored private outlets over public facilities. All three studies identified a number of factors influencing caregivers' information and treatment-seeking practices.

- In the literature review and the field studies, several challenges were identified with obtaining treatment from public health facilities. These included: distance, transportation cost, regular stock-outs, poor service and unavailability of staff.
- For Butaleja, over half of caregivers cited difficulty across all seven areas explored regarding seeking advice for treating malaria, and across seven of the nine items related to obtaining the best antimalarial.
- Among the many challenges voiced by caregivers in Butaleja, more than three-quarter mentioned "getting permission to go", "finding the time to go", and "knowing where to go" to be most problematic when seeking advice; and almost four-sixths mentioned "getting the money", "health facility is too far", and "availability of medicine" to be the most challenging aspects of obtaining the best antimalarial.
- Challenges with visiting public health facilities made up the largest part of the case study discussions, with all caregivers expressing one or more such difficult experiences irrespective of their child's outcome. As with the quantitative study, finding money was identified as particularly arduous, with many needing to negotiate credit from private vendors, borrow money from friends, obtain money from their spouse and family, deposit household goods, do extra work in exchange for money or sell household goods to pay for treatment. Other challenges commonly included caregivers getting the runaround by health staff and delay in children receiving treatment.
- The case study identified that the time of day when a child's symptoms were first noticed-added further delay in receiving treatment. Among children experiencing a positive outcome, their symptoms were always noticed early in the morning, with two of the three children's malaria resolving with two treatment actions – home management and treatment from one external source. Conversely, all children experiencing negative outcomes had their

symptoms noticed at night or early dawn, and all required multiple steps at external sources subsequent to home management.

- As per the literature review, caregivers in both field studies were most likely to visit a public facility if the child's illness progressed despite home management. A large majority of caregivers in Butaleja continued treatment with a subsequent action, suggesting most children did not improve with home management alone. In the case study, half of caregivers reported taking their child to public facilities on multiple occasions because their child did not improve. In many such instances, caregivers were referred to a second facility because the first was not equipped to provide the necessary care or they were sent to a private drug vendor with a prescription to purchase medicines because of stock-outs, resulting in further cost and treatment delay.
- Findings from the case study demonstrate that among those caregivers whose child survived but experienced an irreversible disability, the family incurred additional burdens of time and cost to manage these impairments.

5.1.6. Predictors of receiving an appropriate antimalarial

Both the literature review and the quantitative study identified a variety of issues which predicted receiving ACT. While the literature primarily reports on predictors for receiving ACT, the quantitative field study takes a step further to determine predictors of ACT within the context of receiving an "appropriate" antimalarial treatment. Since caregivers have at their disposal multiple treatment approaches and resources, understanding which educational and environmental factors influence caregivers' behaviors helps determine the relevant interventions specific to Butaleja. The quantitative field study stands unique in that in addition to caregiver and index children's demographic and household socio-economic factors, it evaluates 160 different questions representing a variety of behaviors to determine if any could distinguish whether or not a child received an appropriate antimalarial. This approach identified nine statistically significant predictors for receipt of an appropriate antimalarial:

1. Being aware that ACT is the nationally recommended antimalarial;
2. Knowing that ACT cures the best;
3. Caregivers stating that they would select ACT over other antimalarials if given the choice;
4. Keeping ACT in the home for future use;
5. Having the child be seen by a health professional;
6. Visiting a public health facility;

7. Obtaining an ACT from a public health facility, community health worker, or private hospitals/clinics;
8. Caregiving by females; and
9. Favoring older child over infants.

An additional binary logistic regression model determined that four predictors remained associated with the likelihood of receiving an "appropriate" antimalarial when adjusted for other items:

1. Caregivers who obtained antimalarials from public health facilities, CHWs or private hospitals/clinics (OR=14.99),
2. Caregivers who kept ACT in the home for future use (OR=6.36),
3. Caregivers who reported that given the choice, they would select ACT over other antimalarials (OR=2.31) and
4. Child's age older than 4 months (OR=5.67).

While others have found an association between visits to public health facilities and receipt of a first-line antimalarial treatment, our study found visits to a public health facility to be an independent predictor only when an antimalarial was dispensed.

5.1.7. Factors influencing caregiver behaviors

In addition to estimating the proportion of children who received an "appropriate" antimalarial, determining predictors of a child in Butaleja District receiving an "appropriate" antimalarial, and understanding caregivers' malaria-related treatment-seeking behaviors, a key research objective was to explore factors influencing these behaviors. The current study -- anchored on Hochbaum, Rosenstock and Kegels' HBM -- explores such factors and identifies problem areas amiable to future public health interventions. The HBM postulates that health behaviors are most likely to be adopted when perceived assets outweigh challenges. Guided by the HBM, by the literature on caregivers' treatment-seeking behaviors, by measurement experts, malaria content experts and key informants from the target population, seven educational and environmental factors were identified *a priori* for developing an inventory of questions to include in the survey. These factors included: malaria-related knowledge, episode management, assistance with critical decision, access to information sources, problems with accessing advice, problems with obtaining the best antimalarial, and perceived

ability to initiate/redirect actions. Behavioral information relating to these seven factors were subsequently distilled down into 10 scales to: (1) quantify caregivers' Asset and Challenge profiles for Butaleja, (2) determine whether caregiver attributes (10 Assets and Challenges) or demographic or SES differences were the most powerful influences determining whether a child received an "appropriate" antimalarial, and (3) highlight differences between difference regions within Butaleja District.

- The study is unique in its quantification of both Assets and Challenges facing caregivers when managing malaria, yielding more precise insight into caregivers' treatment-seeking behaviors.
- Four of the six Caregiver "Asset" scales predicted significantly whether a child actually received an "appropriate" antimalarial: (1) Precursors to Receiving an Appropriate Antimalarial (accounting for 21% of the variance); (2) Episode Management (accounting for 39% of the variance); (3) Caregiver Knowledge (accounting for 6% of the variance); and (3) ability to obtain Assistance from Health Professional during Critical Decision-making (accounting for 9% of the variance). Similarly, two of the four Caregiver "Challenge" scales were significant predictors of whether a child received an "appropriate" antimalarial: (1) Lack of Assistance with Critical Decision (accounting for 9% of the variance), and (2) problems encountered in obtaining a best antimalarial (accounting for 4% of the variance).
- Caregivers' demographic characteristics were found to be less important as predictors of whether a child received an appropriate antimalarial than their access to Assets and Challenges they routinely encountered. Thus in HBM terms, perceptions and preparedness outweighed demographics as triggers to seeking an appropriate action.
- Other scales were found not to be significant predictors, most likely because caregivers across Butelaja were equally compromised on these Assets and Challenge Scales.
- The 10 Assets and Challenges scales also highlight important regional differences within Butaleja, serving as useful guides where to focus public health interventions. Thus, public education programs need to begin in locations where management practices are poor, precursors to receiving an "appropriate" antimalarial are weak, caregiver knowledge are under-realized, assistance with critical decision is not readily available, or where information is in short supply.

5.2. Limitations

Limitations specific to each study are discussed within their respective chapters. This discussion chapter provides a brief summary of key limitations common to using a

retrospective study design in the quantitative field survey study and qualitative case study to evaluate caregivers' treatment-seeking behavior with management of malaria.

Given that retrospective studies are based on events that have already taken place, this design requires thinking back in time to evaluate specific behaviors and factors which may have influenced these behaviors. As a result, the possible influences of confounding variables cannot be ruled out, allowing for an association between two variables to be observed but not for causal inferences to be drawn. In view of that, the survey data analysis also employed step-wise regression tests to estimate the independent effect of various variables while adjusting for potential confounders.

Another disadvantage of retrospective designs is their susceptibility to biases such as selection bias, recall bias and response bias. Case-selection was based on presumptive diagnosis rather than on confirmed diagnosis of malaria, even though fever was common to all cases. This could have resulted in misclassification of the febrile illness as malaria and selection of some cases which may not have been malaria. Such a bias could result in a sample that is under-represented of true malaria cases, resulting in systematic error. Given that fever commonly serves as a proxy for malaria at the household level and at most external settings where care is sought in Butelaja, and fever is commonly managed as malaria, the selection process followed real life practices. Furthermore, the study was conducted during a high malaria transmission season, where the sensitivity of fever being malaria was likely high, thereby minimizing misclassification of illness.

Data for both studies were collected using self-report from caregivers, introducing the possibility of recall and reporting bias. Varying ability to recall accurate or complete information about specific symptoms, treatments, and/or treatment steps are important issues to contend with in such studies. To minimize recall bias, the household survey study focused on the youngest child who had become sick in the previous two weeks of the survey and by having the index child present during the interview to trigger caregivers' recall to details about the febrile episode. Additionally, in both field studies – survey and case study, to aid with recall and identification of western medicines used, caregivers confirmed their verbal responses by confirming them against photographs

printed on laminated posters of medicines commonly used for malaria in Butaleja. However, more difficult to mitigate was the potential differential recall that may have arisen in the case study between caregivers whose child had a positive outcome and regained health versus those who had a negative outcome resulting in disability or death. Such bias could result with caregivers intentionally distorting responses to give socially desirable responses (response bias), or those whose child experienced a negative outcome recalling certain fact more vividly than others and/or emphasizing them more so than cases with a positive outcome.

To increase validity of the results collected, the analysis used methodological triangulation to explore caregivers' treatment-seeking behaviors using three separate sources of data collected using different methodologies – a systematic analysis of current literature regarding caregivers' treatment-seeking behavior in Uganda, a quantitative study cross-sectional field survey and a qualitative inquiry multiple case study. The use of a mixed-methods approach for triangulation also offered the opportunity to better understand complex issues, as well as to uncover new and conflicting perspectives.

Lastly, Since it is plausible to expect that the current field studies may have positively influenced caregivers knowledge and practice, and over time there may be new national and community-based interventions to improve availability and use of ACT, inferences from the field studies needed to be made in the context of the calendar year in which the data was collected (2011).

5.3. Recommendations: Future Research and Interventions

Specific recommendations resulting from the two field studies – the household survey and case study analysis are summarized in Chapters 3 and 4, respectively. The three recommendations presented below arise from consideration of the studies as a whole, and are intended to minimize barrier to obtaining advice/treatment and improve caregivers' perceived benefits of ACT:

5.3.1. Strengthen publically funded health delivery

The field studies identified that despite caregivers reporting that obtaining an ACT from public health facilities was an important predictor for receipt of an "appropriate" antimalarial, treatment at public facilities remained suboptimal for many children in Butaleja. While a large proportion (84%) of the 212 children seen at public health facilities were reported to receive an antimalarial, only one in three children received some kind of a blood test, and three in five were given an ACT. There has been much effort over the past decade to strengthen case management at public health facilities. These initiatives have included: removal of user fees from public facilities, implementation of national malarial control policies to guide practice, delivery of pre-packaged ACT for dissemination free of charge, training of public health worker, and providing workers with job aides. Supported by findings from this research, case management at public facilities in Butaleja needs further improvement – even to achieve governments own 85% target. The literature suggests that more extensive interventions than health provider training must be entertained to improve care at public facilities. These should include: preventing stock-outs of first-line antimalarials by implementing effective drug supply management, implementing regular and adequate supervision, improving worker motivations and perceptions, improving customer service and communication between staff and caregivers, changing political and economic environment and incentives, mitigating misappropriation of drugs to ensure continuous stocks of ACT, and removing ineffective antimalarials from facilities and from the private or unlicensed market.

Furthermore, there is a need to strengthen case management at the community level through sustainable iCCM models. To minimize the burden of travelling long-distances to reach public facilities, there have been recent national initiatives to bring public services to manage malaria, pneumonia, and diarrhea for children under five closer to the community through iCCM program. The iCCM builds on the original Uganda Home Based Management of Fever (HBMF) model instituted in 2002, where treatment is delivered by a cadre of CHWs recruited by the community but supported and supervised by public health facilities. At the time of this study, iCCM had not been introduced in Butaleja District. While short-term studies have demonstrated iCCM to be

effective when delivered under close supervision and an uninterrupted supply of ACT is assured, long-term effectiveness still needs to be demonstrated. Some of the challenges levelled against the original HBMF included frequent medication stock-outs and absenteeism of CHWs. Given that iCCM is governed under the public health structure, it also runs the risk of being plagued by similar problems. Current data from national and regional studies indicate that to-date there has been a less than optimal uptake of CHW services through the iCCM program. Whether this low uptake is a consequence of earlier negative experiences with the HBMF program, communities becoming unaccustomed to using CHWs due to the demise of the HBMF in 2004, and/or fear and distrust of current iCCM protocols because they may not align with local beliefs and expectations factors, still needs to be investigated. What is known from previous studies is that poor quality of care and/or stock-outs can undermine the potential impact of providing free health care.

5.3.2. Redefine and expand current health system to include unlicensed private outlets

Results from both field studies confirm that the private sector plays a pivotal role in the management of fever for children five and under in Butaleja. Most caregivers in Butaleja use private drug shops because these outlets were easy to access, they have a constant supply of medicines, they provide prompt and friendly service and/or they are referred to by public health providers during periods of medication stock-outs or to purchase additional medicines. In Butleja, as in many rural settings, most private outlets consist of unlicensed drug shop vendors who have little to no medical training. Given their prominence in malaria management, it is imperative to strengthen the health system as a whole and extend training and support to these providers. One option is to extend the ACT subsidy program currently limited to licensed private outlets to also include unlicensed private vendors conditional on the necessary training. Additionally, given that most unlicensed vendors are part of the communities they serve, it would be worthwhile to investigate the feasibility of including such vendors within the iCCM scheme. Extending the inclusion criteria of CHWs to include private vendors may mitigate the concern of medicine stock-outs afflicting public outlets, since private vendors are already financially independent and can therefore offer a constant supply of ACTs. Models to support unlicensed vendors may be different from those of the public

providers. Future studies will be needed to determine outlets which are frequently visited by caregivers in Butaleja, as well as to understand their practices, knowledge, and factors which influence their fever management decisions in children five and under.

5.3.3. Increase household's capacity to obtain "appropriate" treatment

Future public health initiatives need to consider both educational programs to improve household members' knowledge, perceptions, and preference as well as community-based interventions to reduce common barriers to enable them to obtain what is understood to be the best antimalarial.

For many years, social scientists' health belief models have advocated that acceptance of any healthcare intervention will ultimately depend on individuals' accepting and demanding such interventions. This notion was also supported by findings from our quantitative field study, where we found that children whose caregivers were best informed were those most likely to receive "appropriate" treatment. This included children whose caregivers reported they would select an ACT if given the choice and those who sought out an ACT to keep it in the home for future use. Given that the best informed caregivers are most likely to obtain an "appropriate" treatment, this study clearly highlight the need to develop targeted public health interventions that shape caregivers' knowledge, perceptions, preferences, expectations, and personal capacities, and do so by emphasizing culture, individual empowerment and community development – concepts central to health literacy. Such programs need to consider elements of knowledge about malaria and its recommended treatment; the roles of confirmatory diagnostic, preventive measures, common and critical misconceptions; sources of best antimalarials; best practices (when and how to access "appropriate" advice and treatment and role of home management); and lastly their roles as advocates for their young children. Given the role of other family members in influencing decisions and of spouses securing the necessary resources when western medicines and/or external sources need to be accessed, public interventions should also consider other key household members.

Additionally, since self-efficacy is a critical element in determining whether caregivers and their households ultimately seek out a beneficial treatment, public health programs need to implement interventions that increase personal capacity by mitigate common barriers. The Health Belief Model suggests that health behaviors are adopted based on assessments about benefits and challenges to action. In circumstances where challenges outweigh benefits, individuals are least likely to take a preferred action and they will often limit the demand for effective treatment even when it is available. To this end, those caregivers who believe barriers to obtaining an ACT to be higher than the perceived benefits of using it are less likely to venture out and obtain an ACT. The quantitative field study demonstrates caregivers' perceived benefits of ACT to generally be low across Butaleja and their perceived challenges for obtaining an "appropriate" antimalarial to be comparatively high, with several Assets and Challenges to be important predictors of receiving an "appropriate" antimalarial. This included Assets such as knowledge about malaria and its treatment, the practice of taking "appropriate" actions on behalf of their child, and having access to reliable resources when making treatment decisions. Most significant Challenges included absence of assistance when making critical treatment decisions and problems encountered in obtaining the best antimalarial. Within this context, it is not surprising that less than half of the children in Butaleja receive an ACT and an even smaller proportion receives an "appropriate" antimalarial. Interventions to mitigate common challenges may need to be targeted at individual households as wells as to whole communities. Examples of such community-based interventions may include community financing schemes to help with seeking treatment from private outlets and community supported transportation modalities to reduce logistic barriers to seeking prompt treatment.

5.4. Conclusions

This research agenda represents the first study series of its kind to explore caregivers' treatment-seeking behaviors in the rural/remote District of Butaleja in eastern Uganda. The current study responds to a community's desire to improve malaria treatment for the very young in Butaleja District. The chief concern among community elders was the under-use of effective antimalarials during acute episodes of the illness.

Given that those five and under are most susceptible to adverse events from malaria and that they primarily rely on caregivers' to seek out "appropriate" treatment on their behalf, the goal for this research was to explore caregivers' treatment-seeking behaviors for malaria in children five and under to inform future public health initiatives. This study makes several important contributions to the existing literature:

- Since the introduction of the national AMFm program to improve ACT access through dissemination of subsidized ACTs, this research is the first comprehensive mixed-methods approach to evaluate caregivers' treatment-seeking behaviors in rural/remote Uganda.
- While several studies have been conducted in Uganda since the introduction of ACT, these have not provided a collective understanding of the findings, as well as the extent to which national initiatives have impacted caregivers' treatment-seeking behaviors. To this end, the current systematic review makes an important contribution by highlighting what is already known and proposes areas where future research is necessary.
- The systematic review informs how caregivers' knowledge about malaria has evolved over the years, of their knowledge and preferences for different antimalarials, of the common sources used to obtain antimalarials, and of the various structural and economic factors influencing caregivers' choices on whether to access public or private outlets. Studies also identified select determinants associated with accessing public facilities and services over private outlets and of receiving an ACT.
- In addition to confirming findings from the literature review, this program of research uniquely provides further scope and depth on treatment-seeking for malaria in young children. For example, this research informs how malaria is recognized and treated within the home, about the diversity and adequacy of home management, and the time to initiating any treatment from the point of noticing first symptoms. The research also enlightens on the role of household and community members in advising caregivers on management of malaria, the spouse's role in securing resources to obtain medicines and seek treatment from external sources, and how previous experiences influence where and how treatment is sought. Furthermore, the findings inform of the various challenges encountered when seeking treatment from external sources, the ramification of an episode of malaria on the household as a whole and on the child, and the burden of managing an acute episode of malaria and caring for a child that has suffered irreversible deficits from malaria.
- The field study survey is the first to differentiate and quantify both the "usage" of ACT and the use of "appropriate" antimalarial treatment. Previous studies have estimated the "usage" of ACT to establish the proportion of children who received antimalarial treatment in accordance with national guidelines. However, "usage" as defined in the literature acknowledges receipt of ACT irrespective of whether or not a child received other antimalarials. In contrast,

the measure “appropriate” antimalarial as established in this study only acknowledges receiving an antimalarial in accordance with national guidelines if the first-line is the only antimalarial received. Given that national guidelines promote use of first-line antimalarials as the only reasonable option, and polypharmacy with less effective antimalarials can result in delay of receiving the preferred treatment, increased risk to adverse reactions and unnecessary costs, the “appropriate” antimalarial measure is deemed to be a better indicator of success.

- The quantitative field survey’s analysis examined the impact of some 160 different questions representing a broad variety of caregiver behaviors on children who did and did not receive an “appropriate” antimalarial. Previous studies primarily considered treatment sources accessed by caregivers and caregivers’/index children’s demographic and household socio-economic factors, but limited their assessments only to ACT “usage”.
- In addition to considering questions specific to caregiver and household demographic/socio-economic status and index child’s illness, the quantitative field study is exclusive in its use of the Health Belief Model as a theoretical guide to designing a treatment-seeking behavior questionnaire representing key “Asset” and “Challenge” factors. Furthermore, the Model provided a framework for developing quantitative profiles to assess Assets and Challenges facing caregivers when managing malaria in their young children, thus yielding more precise insights to broader answers of educational and environmental importance than simple answers to individual questions as is common in previous studies.
- The qualitative multiple case study is the only case study to evaluate caregivers’ treatment-seeking behavior in Uganda since the introduction of ACT.
- This qualitative eight-case study is unique in that it explores treatment-seeking behaviors across three different segments of caregivers: those whose child experienced a positive outcome (child improved), those with a negative outcome where the child experienced a permanent deficit, and those with a negative outcome where the child died.
- This qualitative case study is the first in Uganda to elucidate the sequence and treatment steps undertaken by caregivers to manage malaria in their child. The in-depth analysis provides useful insights into how caregivers think about malaria management and their experiences as it relates to a specific episode. This study therefore expands on various factors influencing treatment-seeking behavior, as well as reveals how the illness and its outcome impact the household and caregivers themselves.

Collectively, this research supports previous finding of the gap that continues between the national malaria management policy and local practice. Overall, this study confirms that caregivers in Butaleja District generally share similar practices, experiences and challenges when seeking treatment for children five and under, with

few children ever receiving treatment in accordance with Uganda's own national guidelines. While removal of user fees and distribution of ACTs at public health facilities and licensed private outlets have had some impact at increasing the use of ACT in young children, the national target for 2010 of having 85% of children receive treatment for fever in accordance to treatment guidelines was far from achieved by the summer of 2011. Thus, continuing efforts are needed to improve case management at both the national and local level. This research agenda highlights the importance of not relying solely on providers associated with the public health system and licensed private outlets, but to consider the full spectrum of stakeholders involved in providing malaria management, including unlicensed private outlets, caregivers, and relevant family members.

Appendix A.

Household Survey

a) **GREET THE PEOPLE YOU WILL FIND AT EACH HOUSEHOLD**: Good morning/afternoon

b) **ASK FOR THE CAREGIVER OR RESPONSIBLE ADULT HOUSEHOLD MEMBER.**

c) **INTRODUCE YOURSELF THUS:** I am (name of interviewer), a research assistant with the Butaleja malaria project, a partnership between the University of Makerere and Canada

d) **EXPLAIN THE PURPOSE OF YOUR VISIT:**
The purpose of my visit is to discuss with the caregiver problems with malaria in children 5 years of age and under in this household

e) **ASK THE CAREGIVER OR ADULT HOUSEHOLD MEMBER WHETHER THERE ARE ANY CHILDREN 5 YEARS OF AGE AND UNDER IN THE HOUSEHOLD:**
- ☐ YES → CONTINUE DOWN THIS PAGE
- ☐ NO → STOP THE INTERVIEW AND GO TO THE NEXT HOUSEHOLD

f) **IF NOT SPEAKING TO THE CAREGIVER, ASK TO SPEAK WITH THE CAREGIVER OF CHILDREN 5 YEARS OF AGE AND UNDER IN THE HOUSEHOLD.**

g) **ASK:** Did any of your children 5 years of age and under experience fever in the last 4 weeks?
- ☐ YES → OBTAIN INFORMED CONSENT AND START INTERVIEW
- ☐ NO → STOP THE INTERVIEW, GO TO THE NEXT HOUSEHOLD

PART 1: Questions for all caregivers
PART 2: Questions for caregivers whose children received western **anti**malaria medicines
PART 3: Questions for caregivers whose children did not receive any **anti**western malaria medicines
PART 4: Questions for all caregivers

INTERVIEWER'S VISIT INFORMATION: **DATE:** DAY: _____ MONTH: _____YEAR: _____

INTERVIEWER'S NAME: _____

RECORD BEGINNING TIME:_____

RESULT OF VISIT (If caregiver refuses to participate, provide reason):

_____

_____

_____

IDENTIFICATION

HOUSEHOLD NUMBER: _____/_____/_____

NAME OF HEAD OF HOUSEHOLD: _____

HEALTH SUB DISTRICT: 1._____ 2._____

BUTALEJA SUB-COUNTY: _____ **PARISH:** _____

VILLAGE: _____

NAME OF CAREGIVER: _____

IS CAREGIVER PART OF THIS HOUSEHOLD? 1. YES ☐ 0. NO ☐

WHAT IS CAREGIVER'S RELATIONSHIP TO HEAD OF HOUSEHOLD

1. Wife	2. Husband	3. Daughter	4. Son	5. Sister	6. Brother	7. Grandchild	8. Mother
9. Father	10. Son-in-law	11. Daughter-in-law	12. Aunt	13. Uncle	14. Grandparent	15. Household head	
16. Other (Specify): _____							

CAREGIVER PART OF THIS HOUSEHOLD? 1. YES ☐ 0. NO ☐

INFORMATION OF ALL CHILDREN 5 YEARS AND UNDER WITH FEVER IN THE LAST 4 WEEKS (STARTING WITH THE YOUNGEST)

	Name	Sex	Birth date Month/Year	Age (years)
Youngest		1.Male; 2.Female		
2nd Youngest		1.Male; 2.Female		
		1.Male; 2.Female		
		1.Male; 2.Female		
		1.Male; 2.Female		
		1.Male; 2.Female		
		1.Male; 2.Female		

SELECT THE YOUNGEST TO BECOME THE INDEX CHILD FOR THIS INTERVIEW

WHAT IS CAREGIVER'S RELATIONSHIP TO INDEX CHILD:

1. Wife	2. Husband	3. Daughter	4. Son	5. Sister	6. Brother	7. Grandchild	8. Mother
9. Father	10. Son-in-law	11. Daughter-in-law	12. Aunt	13. Uncle	14. Grandparent	15. Household head	
16. Other (Specify): _____							

PART 1. QUESTIONS FOR ALL CAREGIVERS

(DIRECTIONS TO INTERVIEWER) ASK: "I now want to ask you about this child's illness related to this fever episode."

1. What first sign(s) and symptom(s) did you see your child have when s/he had the illness we are now talking about? **(CIRCLE ALL THAT APPLY)**

1. Feeling cold (Chills/Shivering)	6. Fever/high temperature/hot body	11. Decreased Urination	16. poor appetite	21. Nausea
2. Body ache	7. Headache	12. Black Stools	17. Vomiting	22. Jaundice (Yellow colour)
3. Chest pains	8. Joint /muscle pain	13. Unable to sit	18. Weakness	23. Unable to eat/drink/ breastfeed
4. Cough	9. Malaise	14. Pale eyes	19. Abnormal/Rapid breathing	24. Unconsciousness (coma)
5. Diarrhea	10. Abdominal Pain	15. Pale palms	20. Convulsions	96. Other (specify)_____

2. What time of the day were the first sign(s) and symptom(s) first noticed?

1. Morning	3. Dusk/early evening	5. Midnight to dawn
2. Afternoon	4. Night time	

3. Which individual assisted you in recognizing this child was ill?

HEALTH PROFESSIONAL:	OTHER (RELATION TO CAREGIVER):		
1. Doctor		7. Grandmother	11. Drug shop personnel
2. Pharmacist	4. Spouse	8. In-Law	12. Traditional healer
3. Nurse	5. Father	9. Sibling	13. No one else (Myself)
96. Other (specify) _____	6. Mother	10. Neighbour	97. Other (specify) _____

4. Is this child still ill from this fever episode?

1. Yes	0. No	

5. What illness was (is) this child suffering from?

1. Malaria	4. Enlarged spleen	7. Pneumonia	96. Other (specify)_____
2. Diarrhea	5. Fever	8. Stomach wounds	
3. Tuberculosis	6. Measles	90. Don't know	

6. Which individual assisted you in recognizing that this child was suffering from this illness?

HEALTH PROFESSIONAL:	OTHER (RELATION TO CAREGIVER):		
1. Doctor	4. Spouse	7. Grandmother	11. Drug shop personnel
2. Pharmacist	5. Father	8. In-Law	12. Traditional healer
3. Nurse	6. Mother	9. Sibling	13. No one else (Myself)
96. Other (specify) _____		10. Neighbour	97. Other (specify) _____

(DIRECTIONS TO INTERVIEWER):

IF MALARIA WAS *NOT SUSPECTED* and THIS WAS DIAGNOSED BY HEALTH PROFESSIONAL, THEN STOP THE INTERVIEW FOR *THIS* CHILD.

ASK QUESTIONS 1 TO 6 FOR THE *NEXT YOUNGEST* CHILD 5 YEARS OF AGE AND UNDER WITH FEVER IN THE PAST 4 WEEKS.

IF *NO CHILDREN* HAVE FEVER OR WERE DIAGNOSED AS NOT HAVING MALARIA BY HEALTH PROFESSIONAL, THEN STOP INTERVIEW AT THIS HOUSEHOLD.

Thank caregiver for their time and answers; let them know this information will still be useful in this study.

7.	Can you tell me the <u>one main</u> sign or symptom of malaria in a child 5 years and under?				
	1. Feeling cold (Chills/Shivering) 2. Body ache 3. Chest pains 4. Cough 5. Diarrhea	6. Fever/high temperature/hot body 7. Headache 8. Joint /muscle pain 9. Malaise 10. Abdominal Pain	11. Decreased Urination 12. Black Stools 13. Unable to sit 14. Pale eyes 15. Pale palms	16. poor appetite 17. Vomiting 18. Weakness 19. Abnormal/Rapid breathing 20. Convulsions	21. Nausea 22. Jaundice (Yellow colour) 23. Unable to eat/drink/ breastfeed 24. Unconsciousness (coma) 90. Don't know 96. Other (specify) _____
8.	Can you tell me <u>other</u> signs and symptoms of malaria in a child 5 years and under? **(CIRCLE ALL THAT APPLY)**				
	1. Feeling cold (Chills/Shivering) 2. Body ache 3. Chest pains 4. Cough 5. Diarrhea	6. Fever/high temperature/hot body 7. Headache 8. Joint /muscle pain 9. Malaise 10. Abdominal Pain	11. Decreased Urination 12. Black Stools 13. Unable to sit 14. Pale eyes 15. Pale palms	16. poor appetite 17. Vomiting 18. Weakness 19. Abnormal/Rapid breathing 20. Convulsions	21. Nausea 22. Jaundice (Yellow colour) 23. Unable to eat/drink/ breastfeed 24. Unconsciousness (coma) 90. Don't Know 96. Other specify) _____
9.	What is the <u>one main</u> cause for malaria?				
	1. Cold or changing weather 2. Drinking dirty water 3. Eating cold cornmeal	4. Eating dirty food 5. Eating immature sugar cane 6. Eating bad food	7. Getting soaked with rain 8. Mosquito bites 9. Witchcraft	10. Birds 11. Dirty household surrounding 90. Don't know	96. Other (specify)_____
10.	Where have you heard or seen information about malaria?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
11.	Was this child seen by a health professional (doctor, nurse or medical attendant)?				
	1. Yes, where _____				0. No
12.	Was a blood test done to confirm whether or not the child had malaria?				
	1. Yes, **IF YES,** where was the test done _____				0. No

(DIRECTIONS TO INTERVIEWER): *SELECT ONE OPTION* ONLY (13.1 or 13.2) TO ANSWER BUT NOT BOTH:

OPTION 13.1. **IF THE CHILD *WAS SUSPECTED* TO HAVE MALARIA**

13.1.1 Can you tell me what signs and symptoms alerted you that this child might have malaria? (**CIRCLE ALL THAT APPLY**)

1. Feeling cold (Chills/Shivering) 2. Body ache 3. Chest pains 4. Cough 5. Diarrhea	6. Fever/high temperature/hot body 7. Headache 8. Joint /muscle pain 9. Malaise 10. Abdominal Pain	11. Decreased Urination 12. Black Stools 13. Unable to sit 14. Pale eyes 15. Pale palms	16. poor appetite 17. Vomiting 18. Weakness 19. Abnormal/Rapid breathing 20. Convulsions	21. Nausea 22. Jaundice (Yellow colour) 23. Unable to eat/drink/ breastfeed 24. Unconsciousness (coma) 90. Don't Know 96. Other specify) _____

13.1.2. In your opinion, was this child's malaria mild or severe?

1. Mild	2. Severe

OPTION 13.2. **IF THE CHILD WAS *NOT SUSPECTED* TO HAVE MALARIA:**

13.2.1. What signs and symptoms alerted you that this child might not have had malaria? **(CIRCLE ALL THAT APPLY)**

1. Feeling cold (Chills/Shivering) 2. Body ache 3. Chest pains 4. Cough 5. Diarrhea	6. Fever/high temperature/hot body 7. Headache 8. Joint /muscle pain 9. Malaise 10. Abdominal Pain	11. Decreased Urination 12. Black Stools 13. Unable to sit 14. Pale eyes 15. Pale palms	16. poor appetite 17. Vomiting 18. Weakness 19. Abnormal/Rapid breathing 20. Convulsions	21. Nausea 22. Jaundice (Yellow colour) 23. Unable to eat/drink/ breastfeed 24. Unconsciousness (coma) 90. Don't Know 96. Other specify) _____

(DIRECTIONS TO INTERVIEWER) SAY:
"I want to now ask you about the very first action that was taken when this child had this episode of fever we are now talking about."

14. What form of action did your child receive? **(CIRCLE ALL THAT APPLY)**

1. No action 2. Home remedy	3. Traditional remedy 4. Prayer	5. Western medicine

IF ACTION INCLUDED TRADITIONAL OR HOME REMEDY, LIST WHAT THEY WERE BELOW:

TRADITIONAL REMEDY	HOME REMEDY

- **IF ACTION INCLUDED WESTERN MEDICINES, LIST THE NAMES OF ALL MEDICINES UNDER Q.26a - IN SPACE PROVIDED FOR *FIRST ACTION***

15. When was the very first action started after fever was noticed?

1. No action was started 2. Immediately (within 6 hour) 3. Same day (within 1 day or 24 hours)	4. Next day (on the 2nd day or beyond 24 hours) 5. More than 2 days later (more than 48 hours) 96. Other (specify)_____

(DIRECTIONS TO INTERVIEWER): REFER TO Q.14 and SELECT ALL OPTIONS (FROM Q.16.1, 16.2, 16.3 and 16.4) THAT APPLY. *CHOOSE* ANSWERS FROM THE *TWO* TABLES PROVIDED BELOW

OPTION 16.1. SELECT IF *NO FORM* OF ACTION or *ONLY PRAYER* WAS PROVIDED:

16.1.1. Why was no form of action provided? REASON FOR A PARTICULAR ACTION (Specify number): _____

16.1.2. Who advised you on not starting any form of action?

HEALTH PROFESSIONAL (Specify number): _____ ☐ OTHER RELATION TO CAREGIVER (Specify number): _____

OPTION 16.2. SELECT IF *TRADITIONAL REMEDY* WAS PROVIDED:

16.2.1. Why was traditional remedy provided? REASON FOR A PARTICULAR ACTION (Specify number): _____

16.2.2. Who advised you on starting the traditional remedy?

_ HEALTH PROFESSIONAL (Specify number): _____ ☐ OTHER RELATION TO CAREGIVER (Specify number): _____

OPTION 16.3. SELECT IF *HOME REMEDY* WAS PROVIDED:

16.3.1. Why was home remedy provided? REASON FOR A PARTICULAR ACTION (Specify number): _____

16.3.2. Who advised you on starting the home remedy?

HEALTH PROFESSIONAL (Specify number): _____ ☐ OTHER RELATION TO CAREGIVER (Specify number): _____

OPTION 16.4. SELECT IF *WESTERN MEDICINE* WAS PROVIDED:

16.4.1. Who advised you on starting the western medicine?

HEALTH PROFESSIONAL (Specify number): _____ ☐ OTHER RELATION TO CAREGIVER (Specify number): _____

TABLE: REASONS FOR A PARTICULAR ACTION

1. Fever was not serious, waiting for fever to get worse before seeking treatment	2. Usually first wait and see if fever will go away No money to buy drugs 3. No transportation to buy medicine	4. The place to obtain medicine was too far away 5. No one in the household had time to obtain treatment	6. Did not know where to go to get treatment 7. Medicines not available at drug shop 8. Medicines not available at health facility	9. Fever went away 10. No medicines at home 11. No drug shop open 12. No health facility open 13. Not recommended by _____	96. Other (specify): _____

TABLE: LIST OF HEALTH PROFESSIONALS and OTHER RELATION TO CAREGIVER

HEALTH PROFESSIONAL:	OTHER (RELATION TO CAREGIVER):		
1. Doctor	4. Spouse	7. Grandmother	11. Drug shop personnel
2. Pharmacist	5. Father	8. In-Law	12. Traditional healer
3. Nurse	6. Mother	9. Sibling	13. No one else (Myself)
96. Other (specify) _____		10. Neighbour	97. Other (specify) _____

(DIRECTIONS TO INTERVIEWER): ASK THE FOLLOWING QUESTIONS *WHETHER OR NOT* ANY FORM OF FIRST ACTION WAS TAKEN

17. If you had a choice, what different form of action would you have selected for this child to treat the current fever episode we are now talking about? **(CHOOSE ALL THAT APPLY)**

1. No change, same action 2. Traditional remedy	3. Home remedy 4. Prayer	5. Western Medicine 96. Other (specify) _____

18. Could you have independently decided to start this child on a different form of action or would you have required permission?

1. Yes	0. No

19. Who makes the final decision on what form of action to start?

HEALTH PROFESSIONAL:	**OTHER (RELATION TO CAREGIVER):**		
1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____

20. Do you believe that the first action for this child would have been different if the child was of the opposite sex?
(READ ANSWER FROM Q.14 TO THE CAREGIVER OF THEIR FIRST ACTION)

1. Yes , **IF YES,** How? _____ Why? _____	0. No

21. Do you believe that the first action for this child would have been different if the child was one of your other children 5 years of age and under?
(READ ANSWER FROM Q.14 TO THE CAREGIVER OF THEIR FIRST ACTION)

1. Yes , **IF YES,** How? _____ Why? _____	0. No

22. After this first action, was there a need for further action in this child?

1. Yes. **IF YES, SAY:** I want to ask you what forms of actions were used subsequent to the first action?	0. No, **IF NO, ASK:** "What was the main reason for you to not use any western medicines"? (Specify number From table below) _____

23. Were home remedies used?

1. Yes **IF YES ASK:** what? _____	0. No

24. Were traditional remedies used?

1. Yes **IF YES ASK:** what? _____	0. No

25. Were western medicines used?

1. Yes **IF YES, LIST ALL WESTERN MEDICINES UNDER Q.26b**	0. No, **IF NO, ASK:** "What was the main reason for you to not use any western medicines"? (Specify number From table below) _____

TABLE: REASONS FOR NOT USING WESTERN MEDICINE

1. Fever was not serious, waiting for fever to get worse before seeking treatment	2. Usually first wait and see if fever will go away 3. No money to buy drugs 4. No transportation to buy medicine	5. The place to obtain medicine was too far away 6. No one in the household had time to obtain treatment	7. Did not know where to go to get treatment 8. Medicines not available at drug shop 9. Medicines not available at health facility	10. Fever went away 11. No medicines at home 12. No drug shop open 13. No health facility open 14. Not recommended by _____	96. Other (specify): _____

26.	(DIRECTIONS TO INTERVIEWER): LIST OF *ALL* WESTERN MEDICINES USED (FROM Q.14 and Q.25)	26a. WESTERN MEDICINES USED IN FIRST ACTION (FROM Q.14)	26b. WESTERN MEDICINES USED ON SUBSEQUENT ACTION (FROM Q. 25)
		1.	1.
		2.	2.
		3.	3.
		4.	4.
		5.	5.
		6.	6.

27.	(DIRECTIONS TO INTERVIEWER): DETERMINE IF WESTERN antiMALARIA MEDICINES WERE USED BY COMPARING THE LIST GENERATED ABOVE IN Q.26 WITH THE WESTERN antiMALARIA MEDICINE LIST PROVIDED IN THE TABLE BELOW (USE PICTURES AS SUBSTITUTE FOR LIST)	
	1. Yes, IF YES, LIST THE antiMALARIA WESTERN MEDICINES USED, STARTING WITH FIRST 1. _____ 2. _____ 3. _____ 4. _____ 5. _____ 6. _____ GO TO PART 2 (Q. 28).	0. No, IF NO, GO TO PART 3 (BLUE PAGES)

TABLE: WESTERN antiMALARIA MEDICINE LIST

Amodiaquine	Artesunate	Clindamycin	Isoniazid	Pyrimethamine	Sulfalene
Arteether	Atovaquone	Dapsone	Lumefantrine	Pyronaridine	Sulfamethoxazole
Arteflene	Cloroquine	Dihydroartemisinin	Mefloquine	Quinidine	Sulfamethoxypyrazine
Artemether	Chlorproguanil	Doxycycline	Naphthoquine	Quinine	Sulfametopyrazine
Artemisinin	Cinchonidine	Halofantrine	Piperaquine	Rifampicin	Tafenoquine
Artemotil	Cinchonine	Hydroxychloroquine	Proguanil	Sulfadoxine	Tetracycline

Other: _____

PART 2. (DIRECTION TO INTERVIEWERS): THIS SECTION IS FOR CAREGIVERS WHOSE CHILDREN *RECEIVED antiMALARIA* WESTERN MEDICINES (REFER TO Q. 27)

INTERVIEWER, SAY: "I now want to ask you about <u>each</u> of the **anti**malaria western medicine that was given to this child".

(DIRECTIONS TO INTERVIEWER): LIST HERE ALL WESTERN antiMALARIA MEDICINES FROM Q.27	28. Who decided this child should be given this **anti**malaria medicine? (SELECT FROM LIST BELOW)			29. What was the <u>one main</u> reason for choosing this **anti**malaria medicine? (CHOOSE FROM LIST BELOW)
	HEALTH PROFESSIONAL:	OTHER (RELATION TO CAREGIVER):		1. Already in the home 2. Only one available at drug shop 3. Cheapest one at drug shop 4. Recommended by drug shop provider 5. Considered the most effective 6. Prescribed by medical practitioner 7. Traditional or herbal medicine or prayer was not sufficient 96. Other (specify) _____
	1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	4. Spouse 5. Father 6. Mother 7. Grandmother In-Law 8. Sibling	9. Neighbour 10. Drug shop personnel 11. Traditional Healer 12. No one else (Myself) 97. Other (specify) _____	
	_ HEALTH PROFESSIONAL Specify number: _____ ¯ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____
	_ HEALTH PROFESSIONAL Specify number: _____ ¯ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____
	_ HEALTH PROFESSIONAL Specify number: _____ ¯ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____
	¯ HEALTH PROFESSIONAL Specify number: _____ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____
	_ HEALTH PROFESSIONAL Specify number: _____ ¯ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____
	_ HEALTH PROFESSIONAL Specify number: _____ ¯ OTHER (RELATION TO CAREGIVER) Specify number: _____			Specify number: _____

30. Can you tell me the names of <u>other</u> western **anti**malaria medicines available in your community? **LIST BELOW ALL OTHER WESTERN antiMALARIA MEDICINES AVAILABLE IN THE COMMUNITY**

31.	Of the western **anti**malaria medicines you have mentioned, which do you think cures malaria the best in children child 5 years and under? _____				
32.	Where did you learn this **anti**malaria medicine was the best?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
33.	Of the western **anti**malaria medicines you have mentioned, which one cures malaria the worst in children child 5 years and under? _____				
34.	Where did you learn this **anti**malaria medicine was the worst?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
35.	If you had a choice, which western **anti**malaria medicine would you select first for this child's malaria? _____ Why? _____				
36.	If you had a choice, which western **anti**malaria medicines would you select last for this child's malaria? _____ Why? _____				
37.	Could you have independently decided to start this child on a different western **anti**malaria medicine or would you have required permission?				
	1. Yes, can start independently	0. No, would require permission			
38.	Who makes the final decision about which western **anti**malaria medicine your child can be started on?				
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____	
39.	Which western **anti**malaria medicine does the government recommend for children child 5 years and under? **(CIRCLE FROM LIST BELOW or PICTURES)**				

Amodiaquine	Artesunate	Clindamycin	Isoniazid	Pyrimethamine	Sulfalene
Arteether	Atovaquone	Dapsone	Lumefantrine	Pyronaridine	Sulfamethoxazole
Arteflene	Cloroquine	Dihydroartemisinin	Mefloquine	Quinidine	Sulfamethoxypyrazine
Artemether	Chlorproguanil	Doxycycline	Naphthoquine	Quinine	Sulfametopyrazine
Artemisinin	Cinchonidine	Halofantrine	Piperaquine	Rifampicin	Tafenoquine
Artemotil	Cinchonine	Hydroxychloroquine	Proguanil	Sulfadoxine	Tetracycline

Other: _____

40.	**IF CAREGIVER IS AWARE THE GOVERNMENT RECOMMENDS "ACT", ASK:** Where did you learn about what the government recommends?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
41.	In your opinion, how effective are the government recommended **anti**malaria medicines "ACT" compare to your "best" choice (**REFER TO Q.31**)?				
	1. Less effective 2. Same effectiveness		3. More effective 90. Don't know	95. Caregiver selected "ACT" as best **anti**malaria medicine	

42.	**IF CAREGIVER *KNOWS* THAT THE GOVERNMENT RECOMMNENDS "ACT" (FROM Q.40), BUT THIS *WAS NOT* THE *VERY FIRST* antiMALARIA MEDICINE USED (REFER TO Q.27) IN THIS CHILD, ASK:** Why did you not use "ACT" as the very first **anti**malaria medicine in this child?

	1. Fever was not serious, waiting for fever to get worse before seeking treatment 2. Usually first wait and see if fever will go away	3. No money to buy "ACT" 4. No transportation to buy "ACT" 5. The place to obtain "ACT" was too far away	6. No one in the household had time to obtain "ACT" 7. Did not know where to go to get "ACT"	8. "ACT" not available at drug shop 9. "ACT" not available at health facility 10. Fever went away 11. No "ACT" at home	12. No drug shop open 13. No health facility open 14. Not recommended by ____________ 96. Other (specify): ____________

43.	**IF CAREGIVER IS *NOT* AWARE THAT THE GOVERNMENT RECOMMENDS "ACT" AS FIRST LINE, THEN TELL CAREGIVER:** The government now recommends "ACT" as first line.
44.	**REFER TO Q.35, DETERMINE IF "ACT" WAS SELECTED AS CAREGIVER'S FIRST CHOICE?**

	1. Yes	0. No. **IF NO, ASK:** Knowing this, would your first **anti**malaria medicine choice be different?	
		1. Yes	0. No

45.	Many different factors can prevent caregivers from getting the best western **anti**malaria medicines for a child. When you think your child is ill with malaria and want to get medicine for them, is each of the following a big problem, a small problem, or no problem for you?			
	1. Knowing where to go	Big problem	Small problem	No problem
	2. Getting permission to go	Big problem	Small problem	No problem
	3. Having to find/take transportation	Big problem	Small problem	No problem
	4. Access to health professional (ie: doctor, nurse)	Big problem	Small problem	No problem
	5. Access to female health professional	Big problem	Small problem	No problem
	6. Finding time	Big problem	Small problem	No problem
	7. Availability of medicine	Big problem	Small problem	No problem
	8. Health facility is too far	Big problem	Small problem	No problem
	9. Getting money for medicine	Big problem	Small problem	No problem
	10. Can you tell me two other factors that might be big problems for you ____ ____			

46.	**INTERVIEWER SAY:** "I now want to ask you about each of the western **anti**malaria medicines that were given to this child".

	(DIRECTIONS TO INTERVIEWER): LIST OF ALL antiMALARIA MEDICATIONS FROM Q.27	47. How long after the first symptom was this western **anti**malaria medicine started?	
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________
		1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)____________

48.	Can you tell me how soon after noticing fever in a child 5 years and under is it best to start a western **anti**malaria medicine?				
	1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)			4. More than 2 days later (after 48 hours) 96. Other (specify)_____	
49.	Where did you learn when it is best to start a western **anti**malaria medicine?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
50.	In your opinion, how long is too long to start a western **anti**malaria medicine in a child 5 years and under?				
	1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (2 days or beyond 24 hours)			4. More than 2 days later (after 48 hours) 96. Other (specify)_____	
51.	According to the government recommendations, when should a western **anti**malaria medicine be started after noticing the fever in children 5 years and under?				
	1. Immediately (within 6 hours) 2. Within 24 hours (1 day) 3. Within 48 hours (2 days)		4. After 2 days 5. Anytime 90. Don't Know	96. Other (specify)_____	
52.	**IF THE CAREGIVER PROVIDES AN ANSWER FOR Q.51, ASK:** "Where have you seen or heard what the government recommends?"				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
53.	**IF FOR Q.51 THE CAREGIVER DOES NOT KNOW *or* GETS THE ANSWER WRONG, GIVE THE FOLLOWING INFORMATION:** "The government recommends starting a western **anti**malaria medicine within 24 hours (or 1 day) of first noticing fever in children 5 years and under".				
54.	In your opinion, is the government recommended start time of 24 hours for western **anti**malaria medicines realistic in children 5 years and under?				
	1. Yes			1. No. Why? _____	
55.	Can you independently decide <u>when</u> to start a western **anti**malaria medicine for your child or would you have required permission?				
	1. Yes			0. No	
56.	Who makes the final decision <u>when</u> western **anti**malaria medicine can be started in your child?				
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____		**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____
57.	When do you think it is best to stop a western **anti**malaria medicine in children 5 years and under?				
	1. Within 1 day (24 hours) 1. Within 2 days (48 hours) 2. After 2 days later (after 48 hours)	2. If child has bad reaction 3. Took all the medicines that was recommended	4. Gave what I had 5. Symptoms got better 6. When there is no improvement		96. Other (specify) _____
58.	Can you independently decide when to stop a western **anti**malaria medicine for your child?				
	1. Yes			0. No	

LIST OF ALL antiMALARIA MEDICINES GIVEN TO THIS CHILD FROM Q.27	59. **INTERVIEWER SAY:** "I now want to ask you <u>when you stopped</u> each of the western **anti**malaria medicine that was given to this child, starting with the first **anti**malaria medicine"						
	60. Can you tell me when this **anti**malaria medicine was stopped? (SELECT ANSWER FROM LIST BELOW)	61. Why was this **anti**malaria medicine stopped? (SELECT ANSWER FROM LIST BELOW)	62. Who decided when to stop this **anti**malaria medicine? (SELECT ANSWER FROM LIST BELOW)			63. Did this child use all of this **anti**malaria medicine that was obtained? (SELECT ANSWER FROM LIST BELOW)	
	2. Immediately (within 6 hours) 3. Within 1 day (24 hours) 4. Next day (within 2 days/48 hours) 5. More than 2 days (after 48 hours) 96. Other (Specify) _____	1. Finished medication 2. Saved some for later 3. Was instructed 96. Other (Specify) _____	**HEALTH PROFESSIONAL:** 1. Doctor 2. Pharmacist 3. Nurse 96. Other, (specify) _____	**OTHER (RELATION TO CAREGIVE)** 4. Spouse 5. Father 6. Mother 7. Grandmother 8. In-Law 9. Sibling	10. Neighbour 11. Drug shop personnel 12. Traditional Healer 13. No one else (Myself) 97. Other (specify) _____	1. Yes 0. No.	**IF NO, ASK:** Why did the child not finish all the medicines? 1. Child had bad reaction 2. Took the amount that was recommended 3. Symptoms got better 4. When there is no improvement 96. Other (Specify) _____
1.						Yes; No	
2.						Yes; No	
3.						Yes; No	
4.						Yes; No	
5.						Yes; No	
6.						Yes; No	

LIST OF ALL MALARIA MEDICINES DETERMINED FROM Q27	Interviewer say: "I now want to ask you about how you obtained each of the western **anti**malaria medicine that was given to this child"						
	64. Where was each of the medicines obtained from? (SELECT ANSWER FROM LIST BELOW)		65. Who obtained the medicines? (SELECT ANSWER FROM LIST BELOW)	66. What was the one main reason for obtaining this medicine from this source? (SELECT ANSWER FROM LIST BELOW)		67. **FOR EACH, IF A PUBLIC HEALTH FACILITY WAS NOT USED AS A SOURCE, ASK:** Why? (SELECT ANSWER FROM LIST BELOW)	
	1. Community Health Worker 2. Drug shop 3. Public Health Facility 4. Neighbour 5. Pharmacy 6. Homestock, **IF HOMESTOCK, ASK** original source	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals 11. Petrol stations 12. Traditional healer 96. Other (specify)	1. Myself 2. Spouse 3. Father 4. Mother 5. Grandmother 6. In-Law 7. Sibling 8. Neighbour 96. Other (specify) _____	1. Close by/easy to reach 2. Reputation for quality treatment 3. No service cost 4. Availability for inexpensive medicine 5. Provides credit for purchases 6. Fast Service	7. Friendly Service 8. Felt illness was uncomplicated 9. Source equipped to handle severe illnesses 10. Qualified Health Professional 96. Other (specify): _____	1. Far/not easy to reach 2. Reputation for poor quality treatment 3. Expensive service 4. Expensive medicine 5. No credit 6. Slow Service 7. Unfriendly Service 8. Felt illness was uncomplicated	9. No time to go 10. No transportation 11. Closed 12. Had medicines at home 13. No one available to take child 14. Advised to not go by _____ 96. Other (specify): _____

68.	If you had a choice where would you go to obtain a western **anti**malaria medicine for this child? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility 4. Neighbour	5. Pharmacy 6. Homestock 7. Grocery store	8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 96. Other (specify) _____

69.	Where can "ACT" be obtained in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility 4. Neighbour	5. Pharmacy 6. Homestock 7. Grocery store 8. Kiosk	9. Mobile providers 10. Private clinics/hospitals 11. Petrol stations 12. Traditional healer	90. Don't know 96. Other (specify) _____
70.	Where have you seen or heard information where "ACT" can be obtained?			
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
71.	Would you say "ACT" are easy to find in your community at any time when the need arises?			
	1. Yes	0. No		

INTERVIEWER SAY: "I now want to ask you about <u>how</u> each of the western **anti**malaria medicine given to this child was <u>obtained</u>".

LIST OF ALL MALARIA MEDICINES DETERMINED FROM Q27	72. **REFER TO Q.65, IF CAREGIVER OBTAINED THE antiMALARIA, ASK**: Did you have money to pay for this medicine?					
	1. Yes	0. No				
	IF YES, ASK: Where would that money would have come from?					
		1. Spouse 2. Father 3. Mother	4. Grandmother 5. In-Law 6. Sister	7. Brother 8. Neighbour	9. Drug shop personnel 10. Traditional Healer	11. No one else (Myself) 96. Other (specify) _____
	Yes;	No				
	Yes;	No				
	Yes;	No				
	Yes;	No				
	Yes;	No				
	Yes;	No				

73.	Are "ACT" available in your community affordable for you? **(CIRCLE ALL THAT APPLY)**			
	1. Yes	0. No		
74.	If you could obtain "ACT" from a shop for your child, how much could you afford to pay? _____			
75.	Where are "ACT" available *<u>for free</u>* in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____
76.	Where can "ACT" be obtained *<u>on credit</u>* in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____
77.	In the last 6 months, have you ever kept western **anti**malaria medicines to use later just in case one of your children got malaria?			
	1. Yes	0. No		

78. What type of western **anti**malaria medicines do you keep in your house? Can I see these? **(RECORD DRUG NAME – BRAND AND GENERIC, EXPIRY DATES)**			79. Did you purchase or borrow the western **anti**malaria medicines you keep in your house?		80. **ASK: WHERE antiMALARIA MEDICINES WERE PURCHASED or BORROWED FROM (SELECT FROM TABLE: LIST OF PROVIDERS BELOW).**
Brand Name	Generic Name	Expiry date (Month/Year)			
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	

TABLE: LIST OF PROVIDERS

1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers	10. Private clinics/hospitals 11. Petrol stations 12. Traditional healer

81. What is the difference between good and poor quality western **anti**malaria medicines?

_____

82. Where did you learn about <u>poor</u> quality western **anti**malaria medicines?

1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____

83. **IF FAKE AND EXPIRED ARE NOT MENTIONED, STATE THE FOLLOWING:**
"The government considers fake and expired western **anti**malaria medicines to be of poor quality".

84. Have you ever been sold a <u>poor quality</u> western **anti**malaria medicine?

1. Yes	1. No

85. Do you know which outlets in your community have the <u>best</u> quality "ACT"? **(CIRCLE ALL THAT APPLY)**

1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____

86. Do you know which outlets in your community have the <u>worst</u> "ACT"? **(CIRCLE ALL THAT APPLY)**

1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____

87. For each of the provider(s) you mentioned, I now want to ask you what information you received from each of these individuals. I will list different information, please state "yes or no" if you received this information
(DIRECTION TO INTERVIEWER): GO THROUGH EACH PROVIDER LISTED IN Q.80

	Community Health Worker	Drug shop	Public Health Facility	Neighbour	Pharmacy	Homestock	Grocery Store	Kiosk	Mobile Provider	Private clinics / Hospitals	Petrol Stations	Traditional Healer	Other (specify) _____
a. How malaria is caused	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
b. How malaria can be prevented	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
c. What is the best western **anti**malaria medicine for children	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
d. How to administer the medicine	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
e. The importance of completing the full course of medicine	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
f. What to do if the child vomits the medicine	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
g. What to do if the child does not get better	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
h. What foods to give the child with the medicine	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
i. Storing the medicine at home	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
j. Did they offer you any other advice?	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
k. What additional information would you have liked to have received?													
l. Compared to doctor/ nurse, how knowledgeable was this provider?	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N
m. Where do you think this provider learned how to treat malaria?	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N	Y N

88. When you obtain a western **anti**malaria medicine for your child, what kind of <u>additional</u> information would you like to receive from the person who is giving you the medicine?

_____ _____ _____ _____

_____ _____ _____ _____

89.	If you had a choice to go anywhere to obtain advice on how to treat malaria in your children 5 years of age and under, who would you go to <u>first</u>?				
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling	10. Neighbour 11. Drug shop personnel 12. Traditional healer	13. No one else (Myself) 97. Other (specify) _____
90.	**IF SPOUSE NOT MENTIONED ASK:** You have not mentioned your spouse, why? _____				
91.	Many different factors can prevent caregivers from getting <u>advice</u> for treating malaria in children 5 years and under. When you think your child is ill with malaria and want to get the best advice, is each of the following a big problem, a small problem or no problem for you?				
	a. Knowing where to go		Big problem	Small problem	No problem
	b. Getting permission to go		Big problem	Small problem	No problem
	c. Having to take transportation		Big problem	Small problem	No problem
	d. Access to health professional (ie: doctor, nurse)		Big problem	Small problem	No problem
	e. Access to female health professional		Big problem	Small problem	No problem
	f. Finding time		Big problem	Small problem	No problem
	g. Resources within the community		Big problem	Small problem	No problem
	h. Can you tell me <u>two</u> other factors that might be a <u>big</u> problem for you: _____ _____				

PART 3. FOR CHILDREN WHO *DID NOT RECEIVE ANY* WESTERN MEDICINES (INCLUDING WESTERN antiMALARIA MEDICINES)

92. Even though your child did not receive any western medicines, can you tell me the names of all western **anti**malaria medicines available in your community? **(DIRECTION TO INTERVIEWER: USE LIST OF antiMALARIA MEDICINES FROM TABEL BELOW or PICTURES**

TABLE: WESTERN antiMALARIA MEDICINE LIST

Amodiaquine	Artesunate	Clindamycin	Isoniazid	Pyrimethamine	Sulfalene
Arteether	Atovaquone	Dapsone	Lumefantrine	Pyronaridine	Sulfamethoxazole
Arteflene	Cloroquine	Dihydroartemisinin	Mefloquine	Quinidine	Sulfamethoxypyrazine
Artemether	Chlorproguanil	Doxycycline	Naphthoquine	Quinine	Sulfametopyrazine
Artemisinin	Cinchonidine	Halofantrine	Piperaquine	Rifampicin	Tafenoquine
Artemotil	Cinchonine	Hydroxychloroquine	Proguanil	Sulfadoxine	Tetracycline

Other: _____

93. Of the western **anti**malaria medicines you have mentioned, which do you think cures malaria the best in children 5 years of age and under?
_____

94. Where did you learn this **anti**malaria medicine was the best?

1. Wall painting	5. Medicine package	9. Radio	12. Other community members. Specify	15. Through barazas
2. Calendar	6. Leaflet (flyer)	10. Family members. Specify	_____	16. TV
3. Drug shop provider	7. Newspaper	_____	13. Fellow workers	17. No one else (Myself)
4. Health care staff	8. Posters	11. Neighbour	14. Through training course	96. Other (specify) _____

95. Of the western **anti**malaria medicines you have mentioned, which one cures malaria the worst in children 5 years and under?
_____

96. Where did you learn this **anti**malaria medicine was the worst?

1. Wall painting	5. Medicine package	9. Radio	12. Other community members. Specify	15. Through barazas
2. Calendar	6. Leaflet (flyer)	10. Family members. Specify	_____	16. TV
3. Drug shop provider	7. Newspaper	_____	13. Fellow workers	17. No one else (Myself)
4. Health care staff	8. Posters	11. Neighbour	14. Through training course	96. Other (specify) _____

97. If you had a choice, which of these western **anti**malaria medicines would you select first for this child's malaria?
_____ Why? _____

98. If you had a choice, which of these western **anti**malaria medicines would you select last for this child's malaria?
_____ Why? _____

99. Can you independently decide to start this child on a western **anti**malaria medicine or would you require permission?

1. Yes	0. No

100.	Who makes the decision about which western **anti**malaria medicine your child can be started on?			
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____
101.	What western **anti**malaria medicines does the government recommend for children 5 years and under? **(CIRCLE ALL THAT APPLY)**			

	Amodiaquine	Artesunate	Clindamycin	Isoniazid	Pyrimethamine	Sulfalene
	Arteether	Atovaquone	Dapsone	Lumefantrine	Pyronaridine	Sulfamethoxazole
	Arteflene	Cloroquine	Dihydroartemisinin	Mefloquine	Quinidine	Sulfamethoxypyrazine
	Artemether	Chlorproguanil	Doxycycline	Naphthoquine	Quinine	Sulfametopyrazine
	Artemisinin	Cinchonidine	Halofantrine	Piperaquine	Rifampicin	Tafenoquine
	Artemotil	Cinchonine	Hydroxychloroquine	Proguanil	Sulfadoxine	Tetracycline

Other: _____

102.	**IF CAREGIVER IS AWARE THAT THE GOVERNMENT RECOMMENDS "ACT", Ask:** Where did you learn about what the government recommends?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
103.	**IF CAREGIVER IS *NOT* AWARE THAT THE GOVERNMENT RECOMMENDS "ACT" AS FIRST LINE, THEN TELL CAREGIVER:** "The government now recommends "ACT" as first line"				
104.	In your opinion, how effective are "ACT", compare to your best choice **(REFER TO Q.93)**?				
	1. Less effective 2. Same effectiveness	3. More effective 90. Don't know	95. Caregiver selected "ACT" as best antimalaria		
105.	**REFER TO Q.97, WAS "ACT" SELECTED AS CAREGIVER'S FIRST CHOICE WESTERN antiMALARIA MEDICINE?**				
	1. Yes,	0. No, **IF NO, ASK:** Knowing this, would your first **anti**malaria choice be different?			
		1. Yes	0. No		
106.	Can you tell me how soon after noticing fever in a child 5 years and under is it best to start a western **anti**malaria medicine?				
	1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)_____			
107.	Where did you learn when it is best to start a western **anti**malaria medicine?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
108.	In your opinion, how long is too long to start a western **anti**malaria medicine in a child 5 years and under?				
	1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (2 days or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)_____			
109.	According to the government recommendations, when should a western **anti**malaria medicine be started after noticing a fever in children 5 years and under?				
	1. Immediately (within 6 hours) 2. Same day (within 1 day or 24 hours) 3. Next day (on the 2nd day or beyond 24 hours)	4. More than 2 days later (after 48 hours) 96. Other (specify)_____			

110.	**IF THE CAREGIVER VOLUNTEERS AN ANSWER FOR Q.109, ASK:** "Where have you seen or heard what the government recommends"?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
111.	**IF THE CAREGIVER DOES NOT KNOW WHAT THE GOVERNMENT RECOMMENDS or GETS THE ANSWER IN Q.109 WRONG, GIVE THE FOLLOWING INFORMATION:** "The government recommends starting an **anti**malaria medicine within 24 hours (or 1 day) of first noticing fever in children 5 years and under."				
112.	In your opinion, is the government recommended start time of 24 hours for western **anti**malaria medicines realistic in children 5 years and under?				
	1. Yes	0. No, Why? _____			
113.	Can you independently decide <u>when to start</u> a western **anti**malaria medicine for this child or would you require permission?				
	1. Yes	0. No			
114.	Who makes the final decision <u>when</u> western **anti**malaria medicine can be <u>started</u> in your child?				
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____	
115.	When do you think it is best to stop a western **anti**malaria medicine in children 5 years and under?				
	1. Within 1 day (24 hours) 2. Within 2 days (48 hours) 3. After 2 days later (after 48 hours)	4. If child has bad reaction 5. Took the amount that was recommended	6. Gave what I had 7. Symptoms got better	8. When there is no improvement 96. Other (specify)_____	
116.	If a western **anti**malaria medicine is started in this child, who makes the final decision about when to stop the medicine?				
	HEALTH PROFESSIONAL: 1. Doctor 2. Pharmacist 3. Nurse 96. Other (specify) _____	**OTHER (RELATION TO CAREGIVER):** 4. Spouse 5. Father 6. Mother	7. Grandmother 8. In-Law 9. Sibling 10. Neighbour	11. Drug shop personnel 12. Traditional healer 13. No one else (Myself) 97. Other (specify) _____	
117.	Can you independently decide when to stop a western **anti**malaria medicine for this child if one was started?				
	1. Yes	0. No			
118.	Where do you normally obtain western **anti**malaria medicines for this child?				
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____	
119.	What is the <u>one main</u> reason for obtaining western **anti**malaria medicines from this source?				
	1. Close by/easy to reach 2. Reputation for quality treatment 3. No service cost	4. Availability for inexpensive medicine 5. Provides credit for purchases 6. Fast Service	7. Friendly Service 8. Felt illness was uncomplicated	9. Source equipped to handle severe illness 10. Qualified Health Professional 96. Other (specify): _____	
120.	**IF A PUBLIC HEALTH FACILITY IS NOT STATED IN Q.118 FOR OBTAINING A WESTERN ANTIMALARIA MEDICINE, THEN ASK** why? **(CIRCLE ALL THAT APPLY)**				
	1. Far/not easy to reach 2. Reputation for poor quality treatment 3. Expensive service	4. Expensive medicine 5. No credit 6. Slow service 7. Unfriendly Service	8. Felt illness was uncomplicated 9. No time to go 10. No transportation Closed 11. Had medicines at home	12. No one available to take child 13. Advised to not go by _____ 96. Other (specify): _____	

121.	Who normally obtains western **anti**malaria medicines for this child? **(CIRCLE ALL THAT APPLY)**			
	1. Myself 2. Spouse 3. Father	4. Mother 5. Grandmother	6. In-Law 7. Sibling	8. Neighbour 96. Other (specify) _____
122.	If you had a choice where would you go to obtain a western **anti**malaria medicine for this child? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 96. Other (specify) _____
123.	Where can "ACT" be obtained in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 96. Other (specify) _____

124.	Where have you seen or heard information where "ACT" can be obtained?				
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____

125.	Would you say "ACT" are easy to find in your community at any time when the need arises?	
	1. Yes	0. No
126.	In the last 6 months, have you ever kept western **anti**malaria medicines to use later just in case one of your children got malaria?	
	1. Yes	0. No

127. What type of western **anti**malaria medicines do you keep in your house? Can I see these? **(RECORD DRUG NAME – BRAND AND GENERIC, EXPIRY DATES)**			128. Did you purchase or borrow the western **anti**malaria medicines you keep in your house?		129. **ASK WHERE FROM, SELECT FROM TABLE: LIST OF PROVIDERS**
Brand Name	Generic Name	Expiry date (Month /Year)			
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	
			Purchase	Borrow	

TABLE: LIST OF PROVIDERS

1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers	10. Private clinics/hospitals 11. Petrol stations 12. Traditional healer

130.	If you were to obtain a western **anti**malaria medicine where would the money have to come from? **(CIRCLE ALL THAT APPLY)**			
	1. Myself 2. Spouse 3. Father	4. Mother 5. Grandmother 6. In-Law	7. Sibling 8. Neighbour 9. Drug shop personnel	10. Traditional healer 96. Other (specify) _____

131.	Are "ACT" available in your community affordable for you?	
	1. Yes	0. No
132.	If you could obtain "ACT" from a shop for this child, how much could you afford to pay? _____	

133.	Where are "ACT" available *for free* in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't Know 96. Other (specify) _____
134.	Where can "ACT" be obtained *on credit* in your community? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't know 96. Other (specify) _____
135.	What is the difference between good and poor quality western **anti**malaria medicines? _____			
136.	Where did you learn about poor quality western **anti**malaria medicines?			
	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 96. Other (specify) _____
137.	**IF FAKE AND EXPIRED ARE NOT MENTIONED, STATE THE FOLLOWING:** "The government considers fake and expired western **anti**malaria medicines to be of poor quality."			
138.	Have you ever been sold a poor quality western **anti**malaria medicine?			
	1. Yes	0. No		
139.	Do you know which outlets in your community have the best quality "ACT"? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't Know 96. Other (specify) _____
140.	Do you know which outlets in your community have the worst "ACT"? **(CIRCLE ALL THAT APPLY)**			
	1. Community Health Worker 2. Drug shop 3. Public Health Facility	4. Neighbour 5. Pharmacy 6. Homestock	7. Grocery store 8. Kiosk 9. Mobile providers 10. Private clinics/hospitals	11. Petrol stations 12. Traditional healer 90. Don't Know 96. Other (specify) _____
141.	Many different factors can prevent caregivers from getting the best western **anti**malaria medicines for a child. When you think your child is ill with malaria and want to get medicine for them, is each of the following a big problem, a small problem or no problem for you?			
	a. Knowing where to go	Big problem	Small problem	No problem
	b. Getting permission to go	Big problem	Small problem	No problem
	c. Having to take transportation	Big problem	Small problem	No problem
	d. Access to health professional (ie: doctor, nurse)	Big problem	Small problem	No problem
	e. Access to female health professional	Big problem	Small problem	No problem
	f. Finding time	Big problem	Small problem	No problem
	g. Availability of medicine	Big problem	Small problem	No problem
	h. Health facility is too far	Big problem	Small problem	No problem
	i. Getting money for medicine	Big problem	Small problem	No problem
	j. Can you tell two other factors that might be a big problem _____ _____			

142.	When you obtain a western **anti**malaria medicine for your child, what kind of information would you like to receive from the person who is giving you the medicine?								
How malaria is caused	How malaria can be prevented	What is the best western malaria medicine for children under 5 years of age?	How to administer the western malaria medicine to your child at home	The importance of completing the full course of western malaria medicine	What to do if the child vomits the western malaria medicine after the medicine has been swallowed?	What to do if the child does not get better following the treatment	What foods to give the child with the western malaria medicine	How to store the western malaria medicine at home	Other, Specify _____
143.	Compared to a doctor or nurse, how knowledgeable about treating malaria is the person where you normally go to obtain your western **anti**malaria medicines?								
	1. Less knowledge		2. Same knowledge		3. More knowledge				
144.	Where do you think this person who gives you the western **anti**malaria medicines has learned about how to treat malaria? _____								
145.	If you had a choice to go anywhere to obtain advice on how to treat malaria in this child, who would you go to <u>first</u>?								
	NON-HEALTH PROFESSIONAL: 1. Nobody (Myself) 2. Spouse 3. Father		4. Mother 5. Grandmother 6. In-Law 7. Sibling		8. Neighbour 9. Drug shop personnel 10. Traditional Healer 96. Other (specify) _____		**HEALTH PROFESSIONAL:** 11. Doctor 12. Pharmacist 13. Nurse 96. Other (specify) _____		
146.	**IF SPOUSE NOT MENTIONED ASK:** You have not mentioned your spouse, why?								
147.	Many different factors can prevent caregivers from getting <u>advice</u> for treating malaria in children 5 years and under. When you think your child is ill with malaria and want to get the best advice, is each of the following a big problem, a small problem or no problem for you?								
	a. Knowing where to go					Big problem	Small problem	No problem	
	b. Getting permission to go					Big problem	Small problem	No problem	
	c. Having to take transportation					Big problem	Small problem	No problem	
	d. Access to health professional (ie: doctor, nurse)					Big problem	Small problem	No problem	
	e. Access to female health professional					Big problem	Small problem	No problem	
	f. Finding time					Big problem	Small problem	No problem	
	g. Resources within the community					Big problem	Small problem	No problem	
	h. Can you tell <u>two</u> other factors that might be a <u>big</u> problem for you: _____ _____								

PART 4. PREVENTION QUESTIONS FOR ALL CAREGIVERS				
148.	How many mosquito nets does your household have? _____			
149.	Who slept under the mosquito nets last night? _____			
150.	Which time of the year do you use the mosquito nets?			
	1. During the dry season	2. During the rainy season	3. Throughout the year	4. Not used
151.	**IF THERE ARE MOSQUITO NETS, ASK TO SEE THE NETS and LIST BELOW: OBSERVE OR ASK THE BRAND(s)** **LIST: 1. Permanent" net, 2. Brand A, 3. Brand B, 4. Brand C, 5. Brand D, 6. DK brand, 7. Pretreated net; 8. Other (specify) _____**		152. **FOR EACH NET, OBSERVE IF ALL NETS ARE HANGING**	153. **FOR EACH NET ASK:** How many months ago was the net last soaked or dipped?
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
			Yes No	_____ Months; _____Years; Not sure
154.	Do any of your nets have holes in them?			
	1. Yes	0. No		
155.	How many months ago were the interior walls of your house sprayed? _____ Months; _____Years; Not sure			
156.	Who sprayed the walls in your house?			
	1. Government worker/program 2. Household member 3. Private Company	90. Don't know 96. Other (specify) _____		

IF YOU SUSPECT FEVER or MALARIA IN YOUR CHILD, HOW CERTAIN ARE YOU THAT:	No Certain at all		So-so Certain		Completely Certain	
157. You can recognize fever in your child when your child has fever?						
158. You can recognize malaria in your child when your child has malaria?						
159. You would know where to obtain the best advice for treating your child?						
160. You would be able to obtain the government recommended "ACT" to treat your child's malaria?						
161. You would know when to start the western **anti**malaria medicine for your child?						
162. You would know how often each day to give the western **anti**malaria medicine to your child?						
163. You would know how to give the western **anti**malaria medicine to your child?						
164. You would know if your child has recovered from malaria?						
165. You would know when to stop giving the western **anti**malaria medicine to your child?						
(DIRECTIONS FOR INTERVIEWER): SAY TO THE CAREGIVER: "I now will ask you questions about Beliefs related to Malaria from 3 different viewpoints, starting with What do most people in this community believe, then What does your family believe, and ending with What do you personally believe. For each statement, tell me who thinks it is true and who thinks it is false."	**What do most people in this community believe?**		**What does your family believe?**		**What do you personally believe?**	
166. Malaria is totally preventable.	True	False	True	False	True	False
167. It is possible to cure all children from malaria.	True	False	True	False	True	False
168. No matter what you do, some children will die from malaria.	True	False	True	False	True	False
169. Children almost never die from malaria.	True	False	True	False	True	False
170. Left untreated, most children will die from malaria.	True	False	True	False	True	False
171. Some children can be cured from malaria using only home remedies.	True	False	True	False	True	False
172. Some children can be cured from malaria using only traditional medicines.	True	False	True	False	True	False
173. It is okay to first try to treat malaria at home before going to see a doctor or a nurse.	True	False	True	False	True	False
174. It is okay to use western medicine only if traditional medicines do not work.	True	False	True	False	True	False
175. It is okay to use a traditional medicine before trying western medicines.	True	False	True	False	True	False
176. Sometimes it is okay not to use western medicines to treat malaria.	True	False	True	False	True	False
177. Traditional medicines are best for curing malaria.	True	False	True	False	True	False
178. Western medicines are always best for curing malaria.	True	False	True	False	True	False
179. It is best to start a western **anti**malaria medicine within one day after noticing fever in your child.	True	False	True	False	True	False
180. A blood test is necessary to confirm malaria before starting any treatment.	True	False	True	False	True	False
181. It is okay to stop a western **anti**malaria medicine as soon as the fever goes away.	True	False	True	False	True	False
182. It is important for your child to take all the western **anti**malaria medicines s/he has been given.	True	False	True	False	True	False

183. Government clinics are the best place to obtain western **anti**malaria medicines.	True	False	True	False	True	False
184. Most malaria is caused by mosquito bites.	True	False	True	False	True	False
185. Burning mosquito oils is best for preventing malaria.	True	False	True	False	True	False

186. What is the main reason that children die from malaria?

What do most people in this community believe?	What does your family believe?	What do you believe?
_____	_____	_____
_____	_____	_____
_____	_____	_____

SAY TO CAREGIVER: "For the next statements tell me which medicines are the best or worst, and who thinks so"

187. Which western **anti**malaria medicines are best and worst for curing malaria?	**What do most people in this community believe?**		**What does your family believe?**		**What do you personally believe?**	
a. Loose Tablets?	Best	Worst	Best	Worst	Best	Worst
b. Syrups?	Best	Worst	Best	Worst	Best	Worst
c. Capsules or Tablets from bottles?	Best	Worst	Best	Worst	Best	Worst
d. Medicines in packages?	Best	Worst	Best	Worst	Best	Worst
e. Powder to mix with water?	Best	Worst	Best	Worst	Best	Worst

188.	What is your top two preferred sources of information? How accessible is each? **(SELECT FROM TABLE: LIST OF INFORMATION SOURCES)**			
	a. PREFERENCE #1	Very Accessible	So-So Accessible	Not Accessible
	b. PREFERENCE #1	Very Accessible	So-So Accessible	Not Accessible

LIST OF INFORMATION SOURCES

	1. Wall painting 2. Calendar 3. Drug shop provider 4. Health care staff	5. Medicine package 6. Leaflet (flyer) 7. Newspaper 8. Posters	9. Radio 10. Family members. Specify _____ 11. Neighbour	12. Other community members. Specify _____ 13. Fellow workers 14. Through training course	15. Through barazas 16. TV 17. No one else (Myself) 97. Other (specify) _____

189.	What is the distance from home to the nearest public health facility?		
	1. <1/2km 2. ½ to < 1km	3. 1km – 5km 4. More than 5km	5. Can you tell me the exact distance? _____ km
190.	What is the distance from home to the nearest drug shop (regulated)?		
	1. <1/2km 2. ½ to < 1km	3. 1km – 5km 4. More than 5km	5. Can you tell me the exact distance? _____ km
191.	What is the distance from home to the nearest drug shop (unregulated)?		
	1. <1/2km 2. ½ to < 1km	3. 1km – 5km 4. More than 5km	5. Can you tell me the exact distance? _____ km
192.	What is the distance from home to the nearest traditional healer?		
	1. <1/2km 2. ½ to < 1km	3. 1km – 5km 4. More than 5km	5. Can you tell me the exact distance? _____ km
193.	In your opinion, how easy to reach are public health facilities (clinics or hospitals) in your community?		
	1. Very Easy	2. So-so	3. Very Difficult / 90. Don't Know
	DIRECTIONS FOR INTERVIEWERS: FOR THE NEXT 12 QUESTIONS, OBSERVE AS MUCH AS YOU CAN  **DO NOT ASK UNLESS YOU MUST**		
194.	What type of dwelling does the household live in? 		
	1. Hut 2. Independent house	3. Muzigo 4. Shared house	5. Uniport 6. Other (specify) _____
195.	How many people usually sleep in this household? _____		
196.	How many rooms in this household are used for sleeping?  _____		
197.	What type of roof does the house have? 		
	1. Cement 2. Grass or thatch	3. Iron sheets or tin 4. Mud	5. Shingles 6. Tiles / 7. No Roof 8. Other (specify)
198.	What is the main material of the floor? 		
	1. Finished floor: cement, tiles, linoleum, carpet, polished wood, or stones	2. Natural floor: earth, sand, dung, or clay	3. Rudimentary floor: wooden planks, palm, or bamboo 4. Floating house / 5. Iron sheets 96. Other (specify) _____
199.	What is the main source of water for drinking in this household? 		
	1. Borehole or well 2. Bottled water	3. Brought-in (jerry can, tanker truck) 4. Piped or tap water	5. Rain water 6. Surface water (stream, river, pond, lake, dam, spring) / 96. Other (specify) _____
200.	What kind of toilet facilities does this household use? 		
	1. Bucket 2. Bush/ field/ forest	3. Composting toilet 4. Flush toilet	5. Traditional pit toilet/ latrine 6. Ventilated improved pit latrine / 96. Other (specify)
201.	Is this toilet shared with other households?		
	1. Yes	0. No	
202.	What types of walls are there in the house? 		
	1. Cardboard 2. Clay or mud	3. Iron sheets 4. Palm/ bamboo/ thatch/ straw	5. Wood 6. No walls / 96. Other (specify)

203.	What is the main type of fuel used by this household for cooking?			
	1. Agricultural crop 2. Charcoal 3. Coal 4. Dung	5. Electricity 6. Firewood 7. Kerosene/ paraffin	8. Natural gas/ liquid petroleum gas (LPG) 9. Solar 10. Straws/ shrubs/ grass	11. No food cooked in household 96. Other (specify) _____
204.	How many of the following livestock does this household have?			
	1. Chicken 2. Cow	3. Duck	4. Goat 5. Sheep	
205.	Does this household have any of the following?			
	1. Electricity	2. Solar Power		
206.	**TRANSPORTATION:** Does this household own any of the following? **(CIRCLE ALL THAT APPLIES)**			
	1. Motor vehicle 2. Motorcycle	3. Bicycle 4. Canoe/ boat	5. Donkey	
207.	**COMMUNICATION:** Does this household own any of the following? **(CIRCLE ALL THAT APPLIES)**			
	1. Radio 2. Television	3. Mobile phone 4. Fixed phone	5. Postal address 6. Email address	
208.	**INFORMATION:** What is the household's main source of information? **(CIRCLE ALL THAT APPLIES)**			
	1. Radio 2. Television 3. Print Media	4. Post Mail 5. Hand Mail	6. Word of Mouth 96. Other (specify)	
209.	Does this household own any other land?			
	1. Yes	0. No	90. Don't Know	
210.	Does this household own the land on which the house sits?			
	1. Yes	0. No, why? 1. No, not paying rent (squatting) 2. No, not paying rent at the consent of the owner 3. No, pays rent 4. Other (specify)		
211.	How many acres/ hectares of land does this household own in total? _____			
212.	What is the main source of the household's livelihood?			
	1. Subsistence farming 2. Employment income	3. Business enterprise 4. Cottage industry	5. Property income 6. Family support	7. World Food Program support 96. Other (Specify) _____
(DIRECTIONS FOR INTERVIEWER): THE SUBSEQUENT QUESTIONS ARE DIRECTED TO THE CAREGIVER				
213.	Sex of caregiver			
	1. Male	2. Female		
214.	What is your age (years)? _____			
215.	What religion are you affiliated with?			
	1. Catholic 2. Protestant	3. Muslim 4. Seventh Day Adventist	96. Other (specify): _____	
216.	What tribe do you belong to?			
	1. Banyole 2. Bagwere	3. Bagisu 4. Japaghola	5. Basoga 6. Itseso	7. Baganda 8. Basamia	9. Banyankole 10. Acholi	96. Other (specify): _____

217.	Have you ever attended school?		
	1. Yes **IF YES, ASK:** What is the highest level of education you have achieved?		0. No
	1. No education 2. Primary incomplete 3. Primary complete	4. Secondary incomplete 5. Secondary complete 6. Post Secondary (technical)	7. Post Secondary University 90. Don't know
218.	Have you done any work in the last 12 months for a wage?		
	1. Yes	0. No	
219.	Apart from your <u>own</u> housework, are you currently working for a wage?		
	1. Yes	8. No	
220.	What is your occupation? That is, what kind of work do you mainly do?		
	1. Housewife 2. House keeper 3. Peasant farmer	4. Petty trader 5. Shop keeper 6. Unskilled labourer	7. Professional 8. Unemployed 96. Other (specify) _____

<u>INTERVIEWER'S OBSERVATIONS: TO BE FILLED IN AFTER COMPLETING INTERVIEW</u>

RECORD FINISHING TIME _____

COMMENTS ABOUT RESPONDENT:

_____

_____

_____

COMMENTS ON SPECIFIC QUESTIONS:

_____

_____

_____

_____

SUPERVISOR'S OBSERVATIONS:

_____

_____

_____

_____

NAME OF THE SUPERVISOR: _____ DATE: _____

Appendix B.

Case Study Topics

Guide for Case study

Note to Interviewers

These case studies are intended to relay unique experiences of caregivers who treated their child five years or less for malaria. This may include a number of different scenarios such as: a child whose illness was resolved, a child whose illness persisted and developed a physical problem, child who was treated but died, and a child whose treatment failed and was referred for further treatment. These cases will help highlight good practices and clarify weaknesses in care-giving. Case studies will be sought from caregivers. They will be probed to give detailed description of an illness episode, how they discovered that the child had fever, events, accounts, experiences information on treatment and challenges faced as it relates to one child five years of age and under who experienced malaria in the past four weeks.

The caregiver should give you some information about self and the family:

- History, the period preceding the illness episode of their child
- Sign and symptoms that they identified
- Treatment they sought, why, after how long and where? Challenges in seeking treatment, and costs associated with treatment
- Length of the illness episode
- Challenges they faced
- Status of their child after the illness episode. Change in their child's condition.
- What can be done to improve care giving for children 5 years and younger, suffering from Malaria?
- Any other issues.

NB: Allow the caregiver to tell her own story.

Date and Time of Interview:
_____
Others present during Interview?
_____
Sub-County:
_____
Parish:
_____
Village:
_____

Case Study Protocol; Version 1.0. December 15, 2010

Appendix C

Consent Forms

This thesis used (1) secondary data from a previous survey conducted in Butaleja Uganda, and (2) data from multiple case studies conducted as part of my thesis research. Included are Consent Forms for the original studies.

THE UNIVERSITY OF BRITISH COLUMBIA

276 – 2146 East Mall
Vancouver, BC, Canada V6T 1Z3
[redacted]
www.pharmacy.ubc.ca
[redacted]

Consent Form for Caregiver Survey
Reducing malaria related child mortality in Uganda:
defining a sustainable community self-management program

Principal Investigator:
Dr. Rosemin Kassam, Associate Professor
Faculty of Pharmaceutical Sciences, University of British Columbia, Canada,
Co-Investigators:
Dr. Richard O. Adome, Makerere University, Uganda

Study Purpose:
It is estimated that over 39,000 children under the age of five die yearly from malaria in Uganda. This study is being conducted in Butaleja, Uganda, in partnership between the University of Makerere and Canada through the University of British Columbia, to understand behaviors of caregivers with respect to malaria management in children under five years of age. This study is funded by the Canadian Institute of Health Research in Canada. It is hoped that information obtained from this study will help define a program that can improve care for malaria in children less than five years of age in your District of Butaleja. We will be conducting this study intermittently from November 1, 2010 to March 30, 2012.

Study Procedures:
You are being invited to participate in this study because you are a mother/caregiver with a child under 5 years of age who has experienced fever in the past four weeks. You are being asked if you would like to participate in a survey interview to discuss your experiences, beliefs and practice with malaria as it relates to your child who is less than five years of age. The discussions will be conducted in Lunyole and will be recorded on a digital recorder and on paper.

If you are willing to participate, we ask that you allow the research assistant to spend some time with you to conduct a personal survey interview lasting approximately 1½ hour.

If you participate in a survey, a select few of you may also be asked for your

willingness to participate in a more in-depth one-on-one interview called a case study at a later time. This interview may initially last from 1 to 1/½ hour depending on your availability and preference with subsequent interviews, if necessary, will be shorter and will be scheduled at your convenience.

Confidentiality:
If you consent to participate you are guaranteed that your name and personal identifiers will not appear anywhere in the data or in the final report. Instead you will be assigned a number. The signed consent form will be kept separate from the data to protect your identity. Only members of the research team will have access to the consent form and study data. After all the data have been gathered from digital recording, the recordings will be erased. The recorders and transcribed data will be kept in a locked filing cabinet at the research office in Butaleja and later in a locked filing cabinet at the University of British Columbia in Canada. Please note that only limited confidentiality can be offered for individuals who participate in focus group sessions.

Benefits to you:
The short-term benefit to you will be that you will be informed of the most recent government recommendations for treating malaria in children less than five years of age. In the long-term your experiences and discussions will help Canadian and Ugandan researchers, scholars, and leaders understand vulnerabilities you may be facing when caring for malaria in your children less than five years of age. This information will help us to plan more an appropriate, practical and sustainable community-based interventions for your community of Butaleja to improve malaria care in children less than five years of age.

Risks and discomforts:
There are no known risks associated with participating in this study. There are no sensitive questions involved in the survey interview, focus group or case study.

Contact for information:
In case you have questions regarding your rights as a research participant, contact Dr. Jessica Jitta, Chairperson of the Child Health and Development Centre (CHDC) ethical committee on Telephone numbe[redacted] or the secretariat of Uganda National Council for Science and Technology, Nasser Road, Kampala, on Tel[redacted] If you have any questions about this study you may contact Dr. Rosemin Kassam in Vancouver at the University of British Columbia at the following phone number: [redacted] or via e-mail at: [redacted] and by mail: Faculty of Pharmaceutical Sciences, University of British Columbia, 2146 East Mall. Vancouver, BC. CANADA. V6T 1Z3.

Contact for concerns about rights of research participants:
If you have any questions as a research subject you may contact the University of British Columbia Office of Research Services at 1-604-822-8598. Application number H10-02909.

Consent for participation and Withdrawal:
Your consent in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time with no consequence. You are in no way waiving your legal rights if you chose to sign this form. If you choose to participate and are able to sign your name, please do so below, indicating that this form has been read by you or to you by the research assistant. Your signature also indicates you have received a copy of this consent form for your own records and that you consent to participate in this study.

_____
NAME (please print first and last name)
(The signature of a witness is not required for behavioural research)

_____
SIGNATURE

_____
DATE

SFU SIMON FRASER UNIVERSITY
THINKING OF THE WORLD

Consent Form for Case Study Interviews.
Study - Developing a Sustainable Health Promotion Model to Improve Practices of Caregivers of Young Children with Malaria by Enhancing Local Resources

Principal Investigator
Dr. Rosemin Kassam, Associate Professor University of British Columbia. Study is being conducted under the auspices of Simon Fraser University, Canada

Co-Investigators
Dr. Robert S. Hogg, Simon Fraser University, Canada
Dr. Chris Lovato, University of British Columbia, Canada
Dr. Gary Poole, Adjunct Simon Fraser University, Canada
Dr. Patricia Spittal, University of British Columbia, Canada
Dr. Richard O. Adome, Makerere University, Uganda

Introduction (Purpose and Procedure)

Hullo I am …… The Universities from Canada and Uganda – Makerere University are conducting a study to understand behaviors of caregivers with respect to malaria management in young children five years and under in your district. Specifically, we want to understand your knowledge, practice, attitudes, beliefs, and factors influencing your decisions. You have been identified as one of the key person who can give us useful information for this purpose. We are interested in your personal views and experiences with regard to management of malaria. Please feel free to raise any issues that may be of concern to you. The discussions will be either in English or Lunyole according to your choice and will take a friendly conversation in which you will be free to express your experiences and what is important to you. The information you will give us will help in improving in management and care of malaria cases among children less than five in the district. Your views will be taken in confidence and will not be identified with you as an individual. Since the information you are about to give is very important to this study, I will request you to allow us record the discussions with a digital recorder and on paper, but you will not be identified by name on the tape. If you are willing to participate, we will ask that you allow the study team members to spend

some time with you and conduct a personal interview lasting approximately 1 hour per day for 1 to 2 days.

Your participation in this study is **voluntary**; that means you are free not to respond to any of the questions that you may not be comfortable with. If you consent to participate you are guaranteed that your **name and personal identifiers will not appear anywhere** in the data or in the final report. Instead you will be assigned a number. **Security of data** will be ensured. The signed consent form will be kept separate from the data to protect your identity. Only members of the research team will have access to the consent form and study data. After all the data have been gathered from digital recording, the recordings will be erased. The recorders and transcribed data will be kept in a locked filing cabinet at the research office in Butaleja during the study period and later physically transported by the research team to a locked filing cabinet at the University of British Columbia in Canada where it will be kept for 5 years. Data will be destroyed in June of 2016. At the end of this study, you will **not be contacted for more information** without your permission.

The short-term **benefit** to you will be that you will be informed of the most recent government recommendations for treating malaria in children five years and under. In the long-term your input will help Canadian and Ugandan researchers, scholars, and leaders understand vulnerabilities caregivers may be facing when caring for malaria in your children less than five years of age. This information will help us to plan more an appropriate, practical and sustainable community-based interventions for your community of Butaleja to improve malaria care in children less than five years of age.

There are no known **risks** associated with participating in this study. There are no sensitive questions involved in these interviews. The research has been approved by the Uganda Institutional Review Committee of Child Health and Development Centre.

Contact for Information

In case you have questions regarding your rights as a research participant, contact Dr.

Jessica Jitta, Chairperson of the Child Health and Development Centre ethical committee on Telephone number [redacted] or the secretariat of Uganda National Council for Science and Technology, Nasser Road, Kampala, on Te [redacted] If you have any questions about this study you may contact Dr. Rosemin Kassam in Vancouver at the University of British Columbia at the following phone number: [redacted] or via e-mail at: [redacted] and by mail: Faculty of Pharmaceutical Sciences, University of British Columbia, 2146 East Mall. Vancouver, BC. CANADA. V6T 1Z3. A report of the findings will be disseminated or fed back to the community when the study is completed (in 2012). Additionally, you along with others who have participated in this study will be invited by your District officers and community leaders to attend a community event in Butaleja where the research team will share the study results.

Canadian Contact for Concerns About Rights of Research Participants

If you have any questions or complaints as a research subject you may contact Dr. Hal Weinberg, Director of Office of Research Ethics Simon Fraser University Burnaby, B.C. Canada V5A 1S6 at [redacted] or [redacted] Application number [2011s0113]

Consent for Participation and Withdrawal

Your consent in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time with no consequence. You are in no way waiving your legal rights if you chose to sign this form. If you choose to participate and are able to sign your name, please do so below, indicating that this form has been read by you or to you by the research assistant. Your signature also indicates you have received a copy of this consent form for your own records and that you consent to participate in this study.

NAME (please print first and last name)

(The signature of a witness is not required for behavioural research)

SIGNATURE

DATE