Access to appropriate malaria treatment among children in the Chikhwawa district of Malawi

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor of Philosophy by

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Abstract

Access to appropriate antimalarial treatment is essential to reduce the impact of malaria - a major cause of morbidity and mortality in Malawi. This study responds to recent calls to improve access to malaria treatment, by providing insight into existing barriers and making suggestions for improvement. It is among a limited number of studies which explore multiple dimensions of access. A mixed-methods approach was taken to investigate the influence of a number of factors on access to appropriate treatment among children in the Chikhwawa district of Malawi. Two cross-sectional household surveys enabled quantification of differences in health facility attendance between two study areas, which differed in terms of distance from health facility and ethnic and cultural backgrounds. Mean costs associated with childhood fever were calculated and compared between study areas. Qualitative methodologies provided insight into caregivers' behaviour during treatment-seeking and after receiving antimalarials.

The study found that individuals engaged in a three-phased approach to treatment-seeking. During Phase 1 caregivers assessed the illness in order to establish the need for care and appropriate action. Phase 2 involved seeking care outside of the home, in most cases from a health facility. However a number of barriers to health facility attendance were identified, including: geographic location, direct and opportunity costs; women's lack of decision-making and financial autonomy; and perceptions of available care. Health facility attendance did not guarantee appropriate treatment. Adverse events, such as vomiting; lack of understanding of the correct dosing schedule; and challenges associated with administering antimalarials to children impacted on adherence. Treatment failure led to Phase 3, which frequently involved returning to the health facility. However, repeated treatment failure, fear of receiving repeated antimalarial treatment, and advice from health facility staff led caregivers to seek alternative sources of care, such as traditional healers.

This thesis provides a valuable addition to our knowledge of multiple dimensions of access to appropriate malaria treatment. Caregivers experience a number of barriers during treatment-seeking and utilisation of antimalarials, and equity of access remains a challenge. The issues raised within this thesis are specific and targetable, and the findings indicate the considerable potential impact of strengthening the existing community-based treatment and referral system, community-based health education, and diagnosis and treatment at health facility level.

Declaration

I declare that this thesis has been composed by me and that it presents work which I undertook under the guidance of my supervisors David Lalloo and Miguel Sanqoaquin.

Additional support came from the following individuals:

Lindsay Mangham provided guidance during the design and implementation of the economic aspects of the study

Rachel Tolhurst provided guidance during the design and implementation of the qualitative research

Esther Richards provided comments throughout drafting of the thesis

Mavuto Mukaka provided advice on the statistical analysis

The contributions of other individuals, such as my research assistant Andrew Kapinda are clearly stated within the text.

A limited analysis of the first round of the household survey (dry season) data was submitted in part fulfilment of an MSc in Public Health in Developing Countries at the London School of Hygiene and Tropical Medicine.

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Glossary of abbreviations, terms and definitions

Abbreviations

ACT Artemisinin-based Combination Therapy

ACTia Artemisinin-based Combination Therapy in action

AOR Adjusted Odds Ratio

CAG Community Advisory Group
CDH Chikhwawa District Hospital
CHW Community Health Worker

DVR Digital Voice Recorder
FGD Focus Group Discussion

HTR Hard-to-Reach

IDI In-depth Interview

IMCI Integrated Management of Childhood Illness

LA Artemether-lumefantrine

MDHS Malawi Demographic and Health Survey

MLW Malawi-Liverpool-Wellcome Trust

MoH Ministry of Health

MCIS Multiple Cluster Indicator Survey

NGO Non-Governmental Organisation

NTH Near-the-Hospital

OR Odds Ratio
P P-value

PDA Personal Digital Assistant
RDT Rapid Diagnostic Test

RRR Relative Risk Ratio

SP Sulfadoxine-Pyrimethamine

Local language terms

Local terms are presented throughout the text in italics.

Where participants interjected English terms these are shown in bold italics.

Kutentha thupi: Hot body (fever)

(A)Sing'anga: Traditional healer(s)

Ufiti: Witchcraft

Ndiwo: Relish/side dish. According to Chewa traditional belief, a women

may cause illness if she salts her husband's ndiwo while in a 'hot'

state, for instance if she has had an extra-marital relationship

(chapter 6.2.1.1.4)

Local disease terms (see chapter 4 for more details):

Malungo^a: Malaria (also used at times to mean fever)

Malungo ali mu ubongo: Cerebral malaria

Mauka (or masungu)^b: Illness affecting the reproductive tract in adults, believed to be

passed to children through infected breast milk

Nyankhwa: Similar to mauka

Tsempho (or mtsempho)^c: Childhood illness resulting from the breaking of cultural taboos by

either parent

^aPhungu is reported to be the local term for malaria in Tumbuka (chapter 2)

^bLikango, liable and kulipuka are terms reported to be used to refer to mauka elsewhere in the literature (chapter 2)

^cMdulo is used to refer to tsempho elsewhere in the literature, Chikhoso cha moto is a similar concept among the Tumbuka (chapter 2).

Definitions

Hard-to-Reach (HTR): Villages ar

Villages are defined as HTR by the MoH in if they are located more than 8km from a health facility, or are difficult to access due to the presence of rivers or hills. This definition of HTR was used for the selection of villages participating in the household survey. For indepth interviews this definition was extended to include all households a 15 minute or greater walking distance from a health

centre.

Near-the-Hospital (NTH): Villages located 5km or less from Chikhwawa District Hospital.

Primary caregivers: The individual who spends the most time caring for the child.

Probable malaria: A recent episode of illness considered likely to have been malaria

due to it either having been treated as malaria by health facility staff, with or without a positive test result, or where the primary

caregiver's report of a recent febrile episode has been

supplemented by a positive Rapid Diagnostic Test.

Health facility: For the analysis of the proportion of recently febrile children less

than 10 years old who attended a health facility, this was defined as

any public, mission, private or NGO hospitals, clinics or health

centres. The definition was extended to include Community Health

Workers in a supplementary analysis.

Direct costs: Out-of-pocket costs associated with travel to and from a source of

care, consultations, laboratory tests and treatment costs.

Indirect costs: Lost productivity of the caregiver associated with caring for the child

during the illness episode

Chapter 1 Introduction

Chapter 1 Introduction

1.1 Introduction

Within this thesis I present and discuss the findings of a study which aimed to demonstrate how multiple factors interact to determine access to appropriate malaria treatment for children living in the Chikhwawa district of Malawi. The definition of appropriate treatment used within the study is based on the Roll Back Malaria - Monitoring and Evaluation Reference Group indicator of prompt and effective treatment: a recommended antimalarial obtained within 24 hours of fever onset and taken at the correct dosage for the correct duration (RBM, 2000, Smith et al., 2009).

1.2 Background to the research

Malaria is a major cause of child mortality; responsible for 7% of deaths in children under the age of five years globally and 15% of those in Africa in 2010 (Liu et al., Prepublished online 10 May 2012). The impact of malaria is far reaching, including: considerable economic burden on households (Russell, 2004) and reduced economic growth at country level (Gallup and Sachs, 2001); reduced educational attainment and intellectual development due to time lost from schooling and long-term sequelae associated with malaria (Sachs and Malaney, 2002, Chima, Goodman and Mills, 2003); and other consequences of sequelae, such as loss of quality of life.

Recently there has been renewed interest in malaria control. One of the targets of the Millennium Development Goals is to have halved and begun to reverse the incidence of malaria by 2015 (UN, 2002). The Bill & Melinda Gates Foundation is supporting the Global Malaria Action Plan's target for the long-term eradication of malaria (RBM, 2008, Bill & Melinda Gates Foundation, 2011). Critical to achieving these targets is universal access to and utilisation of malaria prevention and treatment strategies (RBM, 2008, WHO, 2011). There are currently a number of effective tools available, such as long-lasting insecticide treated bed nets, indoor residual spraying and artemisinin-based combination therapies (ACT). However, the challenge is ensuring that interventions reach those who need them most. Therefore, interest has shifted towards a focus on equity of access.

The roll back malaria global strategic plan 2005-2015 aims by 2015 to (RBM, 2005):

- Reduce malaria morbidity and mortality by 75% compared to 2005, particularly focusing on the poorest groups across affected countries
- Ensure malaria-related MGDs are achieved, not only by national aggregate data but also among the poorest groups
- Ensure universal and equitable coverage with effective interventions

The guiding principle behind these aims is to achieve equitable, affordable and sustainable access to cure and prevention. In addition the global fund strategy 2012-2016 lists increased investment in programs that address rights-related barriers to access (including those relating to gender inequality) as one of its strategic action points (Global Fund, 2011).

1.3 What is access?

A number of frameworks have been developed to describe access to healthcare. Aday and Andersen developed an early framework (Aday and Andersen, 1974). In their model, access proceeds from health policy objectives; they define inputs as the characteristics of the healthcare system and the population at risk, and outputs as utilisation and satisfaction with services. Andersen later revisited and further developed this model (Andersen, 1995). He defined three parameters to explain access: environmental factors – the healthcare system and environment; population determinants enabling resources and needs; and health behaviour - personal health practices and use of health services. Outcomes were defined as perceived health status, evaluated health status and satisfaction. Penchansky and Thomas defined access as the degree of "fit" between the clients and the system (Penchansky and Thomas, 1981). They subdivided the dimensions of access into availability, accessibility, accommodation, affordability and acceptability. They defined the terms as follows: Availability - the relationship of the volume and type of existing services to the volume and types of needs. Accessibility - the relationship between the location of services and users. Accommodation - the relationship between the organisation of services (such as appointment systems, opening hours etc) and the ability of individuals to accommodate to these and perceptions of their appropriateness. Affordability - the relationship between the prices of services and users' income, ability to pay and entitlement to financing schemes. Affordability also covered perceptions of worth relative to cost and knowledge of prices, total cost and credit arrangements. Acceptability the relationship between users' attitudes towards personal and practical characteristics of providers and vice versa. Within this model, problems associated with any of the dimensions may result in decreased utilisation, lower levels of satisfaction and altered provider practice.

More recently Mcintyre et al further developed the Penchansky model (McIntyre, Thiede and Birch, 2009). They argue that access to care cannot be measured in terms of utilisation, but represents the empowerment of individuals to use healthcare and reflects their capacity to benefit from the services. Their concept of access is based on three interacting dimensions: availability, affordability and acceptability. Underlying these three dimensions are issues such as information and power relations. Their model combines Pechansky's concepts of availability, accessibility and accommodation under the single heading availability; which is said to include the suitability of the location of services; the willingness and ability of services to cater for the specific needs determined by individuals' conditions; the appropriateness of opening times for those requiring the service; and the relationship between services provided and the needs of the population being served. The authors define the remaining terms as follows: Affordability - the individuals' ability to pay for the cost of services where costs include all out-of-pocket costs and costs associated with lost income or productivity as a result of services use. Ability to pay concerns the availability of financial sources, the ability to mobilise such sources and the ability to incur indirect costs. The consequences of costs incurred and actions taken to meet them are also incorporated under affordability. Acceptability is defined as the fit between provider and patient attitudes towards and expectations of each other. Attitudes may be influenced by provider or patient characteristics, such as sex or ethnicity. Expectations may include respect, compliance (of patients), quality of examination and efficiency of services. In addition, beliefs and perceptions may influence acceptability, for instance if an alternative source of care is perceived to be more suitable. Obrist et al define the dimensions of access as availability, accessibility, affordability, adequacy, and acceptability (Obrist et al., 2007). They argue that the degree of access reached is determined by the interplay between the healthcare services and broader policies, institutions, organisations and processes, and the livelihood assets that can be mobilised. Common to all of these frameworks is the presentation of a multidimensional model of access.

A recent systematic review examined the relationship between access to healthcare and under-five mortality in sub-Saharan Africa (Rutherford, Mulholland and Hill, 2010). In addition to traditional variables such as distance and healthcare costs, the authors highlight the link between additional barriers and enablers to access, such as social support and female autonomy, and child mortality. The authors suggest research should assess traditional and additional variables within the same study, reflect geographic and financial barriers and include culturally relevant indicators. Chuma et al reviewed the literature on access to prompt and effective malaria treatment in Kenya (Chuma et al., 2008). They assessed a range of factors affecting access, occurring at the household, health system

and policy levels. They highlight the need for more qualitative studies to be conducted to explore barriers to access and suggest a number of research questions, which include:

What are the main barriers to treatment access and how do they differ between settings and between areas of different endemicity?

What does the community understand and perceive about the recommended drugs for malaria treatment?

What prevents people from accessing prompt and effective treatment, even when these services are provided free at government health facilities?

They criticise many of the studies in the existing literature for focussing on a single dimension of access, commonly distance to health facilities, the availability of antimalarials or utilisation of services (Chuma et al., 2008, Chuma, Okungu and Molyneux, 2010a).

1.4 Justification for the study

This study responds to recent calls to improve access to appropriate malaria treatment, by providing insight into existing barriers, in order that health interventions can focus on the areas of need. It responds to calls to consider equity of access: the research is conducted in a poor, rural district of Malawi and within that district, compares access among two communities which differ in terms of geographical accessibility of health services and cultural and ethnic backgrounds. The study also supports attempts to improve rights related barriers, through investigating intra-household dimensions of access, in particular the role of gender and generational factors.

This thesis addresses a number of gaps in the access literature highlighted above. It has added to a limited number of studies which explore multiple dimensions of access. This study contributes to our understanding of the following household level factors: perceptions of illness; costs of accessing services; provision of finances and distribution of decision-making authority; and perceptions of available care, including perceptions of antimalarials and understanding of appropriate utilisation. Health system factors investigated include distance to facilities, the presence of community health workers (CHWs) and quality of services provided, such as the availability of laboratory testing, opening hours and communication between health workers and caregivers. The Malawian context provides the opportunity to explore access to appropriate treatment within an environment where health facility care is free. Finally this study supports current efforts to deploy CHWs in Malawi by assessing the usefulness of the current system and providing suggestions for improvement.

1.5 Aims and objectives of the thesis

The overall aim of the thesis was to describe barriers and enablers to appropriate malaria treatment among children in the Chikhwawa district of Malawi.

The objectives were as follows:

- 1. Evaluate the use of a mixed-methods approach to investigate access to appropriate malaria treatment;
- 2. Explore interpretations of fever within the Chikhwawa district;
- 3. Describe patterns of treatment-seeking within the Chikhwawa district;
- 4. Explore differences in barriers and enablers to appropriate malaria treatment between those living in hard-to-reach villages and those living near-the-hospital.

1.6 Methodological approach

It would not have been possible to investigate all of the drivers of access included in this study using a single method alone. For that reason a mixture of quantitative and qualitative methods were utilised. This combination of methods enabled the development of a description of access to treatment based on quantifiable factors, such as the household costs of attending a health facility, which was then supported by qualitative descriptions of how and why these factors impacted on households. For example the impact of costs was mediated through various channels; the distribution of authority was not equal within households, and obtaining cash required caregivers to first seek permission and gain support from decision-makers. Such descriptions of each of the stages at which barriers to access are met are necessary for the development of effective interventions.

1.7 Organisation of the thesis

Chapter 2 situates the thesis within the context of the existing literature and the specific environment within Malawi. It firstly places the study within the context of the health system and political and economic situation with in Malawi. It then summarises the literature on treatment-seeking for malaria. This is done by first considering the findings of the international literature, and then highlighting specific findings from Malawi. The importance of investigating antimalarial utilisation is then discussed before a summary of the existing research into this topic is presented.

Chapter 3 presents the methodology developed for this thesis. It initially situates the thesis within the local research environment. It then goes on to describe the approach to the study methodology and details the quantitative and qualitative methods used. The chapter concludes with a consideration of ethical issues associated with methodology and responses to these.

Chapter 4 presents findings related to the first aim of the research:

• To explore how caregivers interpret and respond to childhood febrile illness.

Initially descriptions of the way in which caregivers interpret childhood febrile illness are provided.

The chapter then goes on to present the findings of the quantitative data collection regarding sources of care utilised during recent febrile illnesses. Finally, an overview of responses to childhood febrile illness as identified by the qualitative data collection is provided.

Chapter 5 presents findings related to the second aim of the research:

To investigate barriers and enablers to effective treatment

This chapter draws on findings of the quantitative and qualitative data collection in order to explore the following determinants of access: geographic location; household costs and provision of finances; the intra-household decision-making process; and perceptions of health facility care. The following drivers of perceptions of antimalarial drugs and effective utilisation are presented: adverse events and treatment failure; knowledge of the correct dosing schedule; perceived over-use of treatment; and ease of administration.

Chapter 6 discusses the strengths and weaknesses of the findings presented in chapters 4 and 5. It first considers the study findings in the light of the literature reviewed in chapter 2 and then discusses the implications of the methodological approach described in chapter 3. Suggestions for future research are presented and the chapter concludes with a broad discussion of the implications of the findings overall.

Chapter 2 Literature Review

Chapter 2 Literature Review

2.1 Introduction

This chapter presents an overview of the literature on treatment-seeking for childhood malaria and antimalarial drug utilisation. The review draws on aspects of the literature most relevant to the objectives of the research described in chapter 1 and the results presented in chapters 4 and 5. There is a specific focus on evidence from Malawi, although studies from this area are limited. Gaps in the literature are highlighted to demonstrate the usefulness of the study findings and to allow a critical review of the findings in chapter 6, in light of the existing data.

Section 2.2 situates the research within the Malawian context by providing an overview of the malaria situation in Malawi, the health system structure and brief political and economic background.

Section 2.3 reviews the literature on treatment-seeking. Studies investigating treatment-seeking behaviour for malaria were obtained through searching Medline and Scopus using the terms ['seek*', or 'behav*', or 'belief', or 'access' or perception*] combined with ['fever' or 'malaria']. Three different restrictions were then applied: review articles, studies conducted since the last review (2002), and studies conducted in Malawi. All searches were restricted to studies published in the English language. Studies exploring mass drug administration or chemoprophylaxis were excluded. Additional studies were identified through searches of reference lists and citing articles. Reports from the National Statistics Office of Malawi, Malawi Ministry of Health (MoH), Non-Governmental Organisation (NGOs) and donors were also obtained. Additional sources included libraries and bookshops in Malawi and theses identified through general internet searches. The search was last updated on 12th January 2012.

The importance of understanding local perceptions of malaria is first highlighted, before an overview of the literature on perceptions of malaria within Malawi. Findings regarding the process and drivers of treatment-seeking for childhood fever are then presented separately for the international and Malawi literature.

Finally, section 2.4 then outlines the importance of investigating antimalarial drug utilisation. A previous review of adherence to antimalarials (Yeung and White, 2005) was updated by searching

Medline and Scopus using the same search terms: ['compliance' or 'adherence' or 'prescri*' or 'drug usage'] combined with the new terms ['artemether*' or 'artemisinin' or' dihydroartemisinin' or 'artesunate']. This second set of terms was also combined with [accept* or perception* or belief] in order to identify additional studies investigating factors influencing antimalarial utilisation.

Reference lists were searched and citing articles obtained. The search was last updated on 23rd

February 2012. The methods used to measure adherence are critiqued and current findings of adherence studies presented. A number of factors influencing antimalarial utilisation are then described.

2.2 Background to Malawi

2.2.1 Malaria in Malawi

Malawi suffers from endemic malaria which is a major public health problem (NSO, n.d.-a). It is the leading cause of morbidity and mortality in children less than five years of age and pregnant women, with an estimated six million cases annually (ibid). The MoH in Malawi has highlighted the provision of malaria treatment for children less than five years of age within 24 hours of onset of symptoms as a key objective (MoH, 2007a, NMCP, n.d.).

The majority (98%) of malaria infections in Malawi are caused by *Plasmodium falciparum* and the main mosquito vectors are *Anopheles funestus*, *A. Gambiae*, and *A. Arabiensis* (NSO, 2011). Transmission of malaria is greater in areas with high temperatures and during the rainy season (October to April) and particularly affects the lakeshore and lower Shire Valley (in which the Chikhwawa district lies) (ibid). The Malawi Demographic and Health Survey (MDHS) 2010 highlights the importance of malaria case management in the control of malaria in Malawi; this includes identification, diagnosis and treatment of all malaria cases with effective antimalarial drugs (ibid).

A nationwide Multiple Indicator Survey conducted in 2006 and the MDHS 2010 found that 35% of children aged less than five years had been ill with fever in the previous two weeks (NSO, 2008, NSO, 2011). The Malawi National Malaria Indicator Survey 2010 found a slightly higher proportion of children less than five years to have had fever in the previous two weeks (39%) (NSO, n.d.-a). Fever prevalence was greatest for those aged 12 to 23 months in all three surveys (40%, 41% and 47.4% respectively) and then decreased with age. Results from the Chikhwawa district were comparable with the nationwide results; 37% of children less than five years in the Chikhwawa district had been ill with fever in the previous two weeks. The multiple indicator and demographic and health surveys found fever to be less common among children of mothers with secondary or higher education,

when compared to mothers with less education¹, and all three surveys found fever to be less common among children from households in higher wealth quintiles.

2.2.2 Malawi Health system structure

The health system in Malawi is highly centralised and vertically managed, however ongoing efforts are being made towards decentralisation (Government of Malawi, 2002). The health system is divided into four levels: at the top (tertiary level) a limited number of referral hospitals are located in the major urban centres of Blantyre, Lilongwe and Mzuzu. Beneath this there are district hospitals (secondary level), then health centres and clinics (primary level) and finally the community level. Primary healthcare delivered through health centres and clinics aims to improve maternal and child health and promote early treatment of common illnesses, the secondary level is designed for the treatment of more complex conditions and the specialisations are provided at tertiary level through the referral hospitals (ibid). At community level, treatment is available through health posts situated in some hard-to-reach (HTR) villages. Villages are defined as HTR by the MoH if they are located more than 8 km from a health facility or if access is limited due to the presence of geographic obstacles such as rivers or hills. There are also a considerable number of Christian Health Association of Malawi operated health facilities, which account for 26% of all non-private facilities and a number of other non-profit and privately run facilities (NMCP, n.d.). The public health system in the Chikhwawa district comprises the district referral hospital, one rural hospital, one mission hospital and 14 HCs which cater for the district's population of approximately 450,000. In addition there are 26 Community Health Worker (CHW) operated health posts.

Malawi suffers from a severe lack of adequately qualified medical staff, largely due to internal and external "brain drain", attributed to poor pay and career development opportunities (2002). There is one general medical practitioner and 20 nursing professionals per 100,000 people (NMCP, n.d.). The majority of qualified medical doctors operate within the referral hospitals, whilst district hospitals are generally run by clinical officers with the support of nurses. Health centres are mainly staffed by CHWs (locally referred to as health surveillance assistants), often supervised by a single clinical officer. CHWs in Malawi are the lowest cadre of MoH clinical staff. They receive a basic salary and carry out a wide range of roles from delivering health education messages to functioning as laboratory assistants. Due to the human resource shortages within the health system, the training of CHWs as frontline workers within the community has been prioritised (MoH, 2007a). Each CHW covers a population of around 1000 people for delivering community based interventions (ibid).

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¹ The Malawi National Malaria Indicator Survey 2010 does not present results according to maternal education

However during preliminary research for the study it was established that the majority of CHWs in the Chikhwawa district split their time between the community and health centres and some spend little to no time in the community. The deployment of CHWs at community level has been advocated in improving equity and access to services (ibid). However dissatisfaction with care provided at community and primary level has led to massive bypassing of these levels of the health system leading to large numbers of attendees at secondary level facilities (2002).

In some HTR villages, CHWs operate from health posts and use a locally adapted version of the Integrated Management of Childhood Illness (IMCI) guidelines to deliver a basic package of care. These CHWs undergo a three-day training after which they treat children less than five years of age according to the treatment algorithm with minimal supervision. During training the CHWs receive a manual for the identification and referral or treatment of sick children (MoH, 2008a, MoH, 2008b). This manual specifies that febrile children should be treated with antimalarials at village level, which was the practice when SP (sulfadoxine-pyrimethamine) was the first-line treatment for malaria within Malawi. However since the change to ACTs in 2007 health posts no longer have stocks of antimalarials and CHWs are instead directed to refer all febrile children to the nearest health facility (MoH, 2007b). There are concerns about the adequacy of training of CHWs in the treatment of common childhood illnesses (MoH, 2007a).

2.2.3 Brief political and economic background of Malawi

Malawi is a landlocked country bordered by Mozambique, Tanzania and Zambia. It is divided into three administrative regions: the central region, which is home to the capital city Lilongwe; the southern region, home to the largest city, Blantyre, which is regarded as the commercial capital; the Northern region is home to Mzuzu, the second-largest city, formerly the country's capital. These three regions are subdivided into a total of 28 districts, each named after their capital. The districts are then subdivided into 161 Traditional Authorities (TA). The TAs are made up of groups of villages; individual villages are headed by a village headman or headwomen and village groups are headed by group village headmen/headwomen. The major languages spoken in Malawi are Chichewa, English, Chitumbuka and Chiyao. Primary education is conducted in Chichewa, however secondary education is conducted in English, which serves as the business language and is widely spoken in urban areas. Chitumbuka is mostly used in the northern region and Chiyao is mainly used in lakeside areas. There are a number of other regional languages. At the time of the 2008 Population and Housing Census, the population of Malawi was 13,077,160 (NSO, n.d.-b). The population density has been increasing, with the southern region being the most densely populated (ibid). The majority of the population are

Christian (83%), but Muslims also make up a substantial proportion (13%) (ibid). The average household size in 2008 was 4.6 and 43% of individuals were living in traditional dwellings, 34% in semi-permanent dwellings and 23% in permanent dwellings (ibid). The majority of the population were engaged in small-scale subsistence farming; in rural areas 81% of the active population over 15 years old were subsistence farmers (NSO, 2005a). The 2005 integrated household survey reports the proportion of the population living below the poverty line² (ibid). Fifty-two percent live beneath the upper poverty line and are classed as poor, 22% live beneath the lower property line, and are considered ultra poor. The southern region holds the largest proportion (60%) of individuals living beneath the poverty line. In 2008 85% of the population were living in rural areas (NSO, n.d.-b). Those living in rural areas are twice as likely to be poor as those in urban areas (NSO, 2005a). In the Chikhwawa district 66% of individuals live beneath the poverty line and 32% beneath the lower poverty line.

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² The proportion living below the poverty line is measured by calculating welfare as the total annual per capita consumption expenditure reported by a household and the poverty line as the subsistence minimum required for the cost of basic needs.

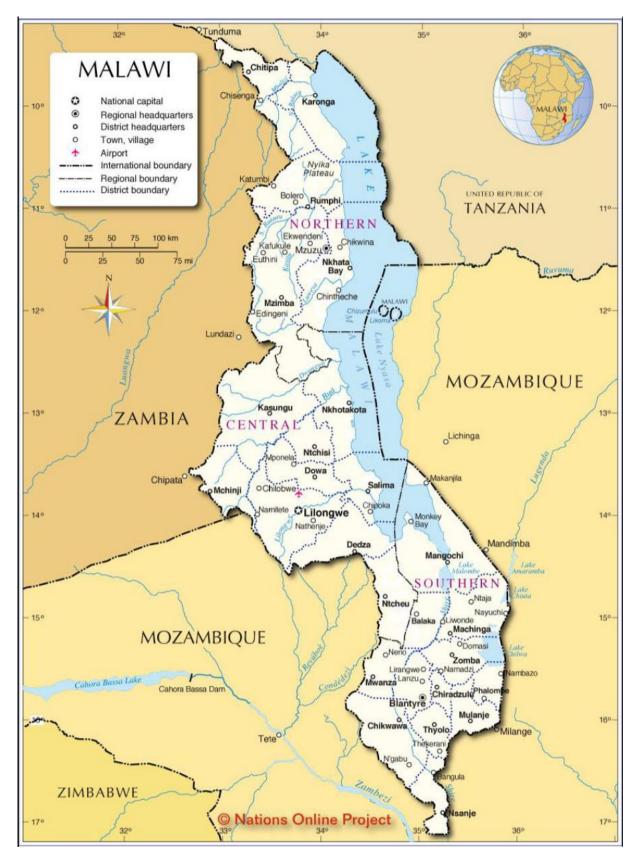


Figure 2.1 Administrative map of Malawi

Malawi has experienced a history of challenging political rule. Malawi was under colonial rule from 1891 to 1964 when it gained independence and became a single party state, under Hastings Banda. Banda led a highly organised but strict rule: control was maintained through physical violence, implied violence and the setting up of a national network of informers (Lwanda, 2005). During this period there was limited political and academic freedom, elements of traditional culture were discouraged and literature and performing arts were censored (ibid). The first democratic elections were held in 1994, after which Bakili Muluzi became president, followed by Bingu wa Mutharika. During wa Mutharika's political reign, Bakili Muluzi was accused of misappropriating \$11 million of money from international donors during his time in power, the case is ongoing. During wa Mutharika's second term in office, he was accused of increasing elements of dictatorship which has led to tensions with the international community, and Britain in particular. Britain's envoy to Malawi was expelled in 2011 after a diplomatic cable was leaked in which he described wa Mutharika as autocratic and intolerant, this led to the expulsion of Malawi's acting ambassador from Britain. Governance issues during wa Mutharika's second term led to huge reductions in aid being received which, combined with questionable economic decisions, led to further destabilisation of the economy and a continuous lack of basic commodities. Wa Mutharika died suddenly of a heart attack in April 2012 after which the vice president Joyce Banda became president. This led to the immediate resumption of diplomatic relations with Britain and pledges of donor support.

2.3 Treatment-seeking behaviour for 'malaria'

The following paragraphs divide the literature on treatment-seeking behaviour for malaria into three main sections. The first explores perceptions of malaria, with a particular focus on evidence from Malawi (section 2.3.1). Perceptions of malaria are divided into perceived symptoms, local fever terminology and perceived causes. Secondly, the international and Malawi literature on patterns of treatment-seeking is presented (sections 2.3.2 and 2.3.3). Thirdly the international and Malawi literature on the factors influencing responses to childhood fever is presented (sections 2.3.4 and 2.3.5). Within the section an overview of the issues is presented before more detailed descriptions of factors specifically relevant to the objectives presented in chapter 1 and results presented in chapters 4 and 5: seasonality; geographic location; socio-cultural determinants; and costs.

2.3.1 Perceptions of malaria

2.3.1.1 Why is it important to understand perceptions of malaria?

Perceptions regarding the causes of and appropriate responses to malaria symptoms determine what action, if any, is taken by patients or caregivers. A report by the Special Programme for

Research & Training in Tropical Diseases (TDR) highlights studies which indicate a link between misconceptions about the cause, prevention or treatment of malaria, and the use of ineffective prevention and treatment strategies (Ahorlu et al., 1997, Lipowsky, Kroeger and Vazquez, 1992, Heggenhougen, Hackenthal and Vivek, 2003). The authors argue that "Understanding people's perceptions of malaria, and the factors which influence these perceptions, must be a central part of mounting successful interventions" (Heggenhougen, Hackenthal and Vivek, 2003, p.37).

McCombie highlights the importance of investigating local illness categories through identifying the great variation between cultures (McCombie, 1996). The review outlines four categories of understanding. In the first two 'malaria' is recognised as a distinct disease: in the first category this is combined with good knowledge of symptoms and aetiology of malaria; in the second knowledge of symptoms is good, but with limited knowledge of aetiology. In the second two categories there is no illness concept that correlates with malaria: in the third category malaria-like illnesses are grouped under a broader illness category; and in the fourth there are several illness categories with malarialike symptoms. Even where individuals have a good understanding of the biomedical definition of malaria, specific differences in the symptom presentation or context of illness, such as who the patient is and their social situation, may lead to differences in interpretation of disease category, and therefore response (Winch et al., 1996, McCombie, 1996). For instance among the Yao ethnic group of Malawi, convulsions in young children may be perceived to be caused by Kambanga, most frequently attributed to witchcraft, whereas adults are not perceived to suffer from this illness (Launiala and Honkasalo, 2010). Health interventions need to be designed with recognition of such differences in order to avoid messages being reinterpreted locally to account for such belief patterns. Furthermore, malaria intervention programs must go beyond taking account of local beliefs and incorporate local terminology as far as possible (Winch et al., 1996).

2.3.1.2 Perceptions of malaria in Malawi

2.3.1.2.1 Perceived symptoms of malaria in Malawi

A number of studies have looked at individuals' perceptions of symptoms associated with malaria in Malawi (Launiala and Honkasalo, 2010, Chibwana et al., 2009, Muula and Chimalizeni, 2004, Muula and Chamba, 2004, Munthali, 2005): two defined the local term used to describe malaria as *malungo* (Chibwana et al., 2009, Launiala and Honkasalo, 2010); two did not mention which term was used (Muula and Chimalizeni, 2004, Muula and Chamba, 2004). The final one was conducted within a Chitumbuka speaking area and defined the local term used as *phungu*, although the English term malaria was said to be widely used and the predominant term used by the younger population

(Munthali, 2005). Participants in these studies mentioned a large number of symptoms perceived to be associated with malaria/malungo, these are grouped according to the studies in which they were mentioned as follows: fever/high fever, vomiting/nausea and feeling cold/chills/shivering/rigours (Launiala and Honkasalo, 2010, Chibwana et al., 2009, Muula and Chamba, 2004, Muula and Chimalizeni, 2004, Munthali, 2005); diarrhoea (Launiala and Honkasalo, 2010, Chibwana et al., 2009, Muula and Chimalizeni, 2004, Muula and Chamba, 2004); body pain or aches and headache (Muula and Chamba, 2004, Muula and Chimalizeni, 2004, Launiala and Honkasalo, 2010); loss of appetite or refusing to suck/eat (Chibwana et al., 2009, Muula and Chimalizeni, 2004); loss of consciousness; lethargy/weakness (Muula and Chamba, 2004, Muula and Chimalizeni, 2004); irritability, bulging fontanelle, rash, cough, groaning and sunken eyes (Chibwana et al., 2009); sweating and malaise (Muula and Chimalizeni, 2004).

Across the studies participants were unclear about the signs of severe malaria such as anaemia and convulsions: in one study few participants were able to link convulsions and anaemia to malaria; convulsions, and to a lesser extent anaemia, were attributed to epilepsy and witchcraft (Chibwana et al., 2009). In another study participants were unsure whether anaemia could cause malaria; some felt it could, but this was described as arising from loss of fluid through sweating, vomiting and diarrhoea, and in the case of one participant as a result of eating too much citrus fruit (Muula and Chimalizeni, 2004). Elsewhere most of the participants stated that they did not know the cause of convulsions, whilst others said they may occur if traditional practices have been ignored, such as if a woman with a child suffering from convulsions passes behind the pregnant woman the illness may be transferred and experienced by the newborn baby (Munthali, 2005). Alternative perceived causes included the child being touched by an individual who had recently been engaged in sexual intercourse, and the child having eaten eggs (ibid). Traditional healers in the study stated that traditional medicines may not work if the child is suffering from epilepsy (ibid).

2.3.1.2.2 Local fever terminology in Malawi

A study conducted in the Zomba district investigated the diagnostic accuracy of local terminology bymalaria screening (Bisika, 2009). Mothers' descriptions of their child's illness were compared to smear microscopy. Local terms selected for study included *malungo*, the official term for malaria; *kutentha thupi*, meaning hot body; *kutsegula m'mimba*, the official term for diarrhoea and; *kukhsomola*, which means coughing. The terms *malungo* and *kutentha thupi* showed the greatest accuracy. However, despite being general terms, the sensitivity of both *malungo* and *kutentha thupi* were below 50%, indicating a large number of mothers of children with malaria did not recognise

that their child had the illness. The same author notes elsewhere that whilst familiar with the symptoms of malaria, individuals use various terms and concepts to label and interpret these symptoms, and use the word *malungo* to mean fever, malaria or fever from other causes (Bisika, 1996). Similar results were found in a study conducted among pregnant women in the Mangochi district: 83% of parasitaemic women did not report experiencing symptoms of malungo, whilst 11% who did report symptoms of malungo were not parasitaemic (Helitzer-Allen and Kendall, 1992). The authors acknowledged the potential role of asymptomatic parasitaemia and imperfect smear microscopy in this finding; however they suggested that some of the discrepancy arose from the fact that the term *malungo* is a broad term covering different subcategories, each with its own aetiology and set of symptoms. They argued that this led to challenges in the way individuals interpreted questioning regarding *malungo*, and difficulty in interpreting responses. This lack of correlation between local disease definitions and biomedical definitions has also been demonstrated elsewhere in Africa (Agyepong, 1992).

Other terms identified, which relate to perceptions of fever in Malawi, include mauka and tsempho. Mauka is a condition whereby the child experiences febrile illness associated with concurrent maternal illness. The symptoms of mauka in the mother have been differentially translated in the literature as Trichomonas vaginalis (Maliwichi-Nyirenda and Maliwichi, 2010, Morris, 1985), growths or sores (Chibwana et al., 2009, Tolhurst et al., 2008b) and haemorrhoids (Stannus, 1910 cited in Morris, 1985, p.28). There appear to be regional differences in terminology used and interpretation; other terms such as likango and libale have been said to be used interchangeably with mauka, but may originate from other traditions within Malawi (Morris, 1985, Tolhurst et al., 2008b). Kulipuka has been reported to be used to refer to a form of malungo in children associated with mauka blisters in the parent (Helitzer-Allen and Kendall, 1992). Mdulo (or Tsempho) is another previously reported perceived cause of childhood febrile illness (Morris, 1985, van Breugel, 2001). Mdulo has been said to be a deeply rooted component of the Chewa culture (van Breugel, 2001). Mdulo has been translated as pulmonary tuberculosis and kwashiorkor (a form of protein-energy malnutrition) (Morris, 1985). One author states that an individual presenting with signs of mdulo will most frequently be treated for anaemia (Rangeley, 1948 cited in van Breugel, 2001, p.171). It has also been said to not be equated with a single biomedical disease, but rather covers a variety of illnesses (van Breugel, 2001). Mdulo is perceived to arise as a result of breaking social taboos which govern family morality (ibid). Mdulo features in the Malawi HIV/AIDS and malnutrition literature (Lwanda, 2004, Peltzer and Simaka, 1997). However despite being associated with childhood febrile illness, only one reference to mdulo was identified in the malaria literature (Launiala and Honkasalo, 2010).

This referred to the perception that extramarital relations may be harmful during pregnancy - the description did not involve childhood febrile illness. A study among the Tumbuka identified a similar concept: *chikhoso cha moto* was described as fever arising when a child under the age of five, who would normally be classified as 'cold', comes into contact with someone who is 'hot', such as a person involved in sexual intercourse (Munthali, 2005).

2.3.1.2.3 Perceived causes of malaria in Malawi

Each of the studies described above went on to describe perceived causes of fever or malaria. In addition two further studies were identified which described perceived causes (Helitzer-Allen and Kendall, 1992, Ager et al., 1996). It is useful to understand perceived causes of fever broadly: not all biomedically defined malaria cases are necessarily perceived as malaria, and responses to episodes of actual malaria may differ greatly according to the perceived cause. Restricting the investigation of perception of illness to those illnesses perceived as malaria may therefore fail to capture information regarding perceived causes of relevant illness. Only one study was identified which investigated causes of childhood fever broadly; this study was conducted in the Mwanza-Nena district (Chibwana et al., 2009). Although malaria was recognized to be a cause of fever, participants in this study attributed childhood fever to other biomedical causes, such as pneumonia; poor sanitation; cham'mimba (a local term for uterine contraction during delivery); coldness; sleeping without a blanket; soaking in the rains; malnutrition; playing in the dust; not bathing the child; eating un-boiled food; playing in water; and falling down during play. In addition illnesses affecting the reproductive tract of the mother (mauka) were also considered an important cause of fever in young children (ibid). This finding supports studies in the international literature which identified different types of perceived febrile illnesses, the symptoms and aetiologies of which overlapped with the biomedical definition of malaria (Ahorlu et al., 1997, Winch et al., 1996, Kamat, 2006, Launiala, 2010). The remaining studies conducted in Malawi present perceived causes of malaria specifically, defined as malungo, phungu, or the English term malaria. Differing results were identified regarding perceived causes of malaria; in a qualitative study conducted in the Mangochi district, participants mentioned cold weather, bathing in the lake, hard work, unsafe water, poor diet and ignorance in addition to mosquitoes as causes of malaria (malungo) (Launiala and Honkasalo, 2010). This differed slightly from another study in the same district which described seven subcategories of malungo, defined by their cause rather than symptoms: mosquitoes, weather, hard work, spirits or witchcraft, other airborne methods, dirty food or water and Kulipuka (a form of malungo associated with mauka blisters in the parent) (Helitzer-Allen and Kendall, 1992). This leads to challenges in interpreting exactly what sort of illness experience is assigned to each aetiology. In the Rumphi

district most participants, especially younger men and women, mentioned mosquitoes as the cause of malaria (phunqu); other perceived causes included exposure to cold weather, the consumption of cold foods, fever caused by the child's contact with someone who has involved in sexual intercourse and witchcraft (Munthali, 2005). In a study conducted in Mponda 66% (N = 50) of participants attributed malaria to mosquitoes, while the remaining 34% mentioned other causes such as bad air, wind or water (Ager et al., 1996). Interpreting findings of this study is challenging as neither symptoms experienced nor terminology used were described (Ager et al., 1996). Studies conducted in the Blantyre district found descriptions of the causes of malaria (term used not specified) to match more closely with the biomedical model: in a quantitative study 90% of primary school teachers assigned the cause of malaria to the female Anopheles mosquito (Muula and Chamba, 2004), and in a qualitative study primary school pupils also identified the female Anopheles mosquito as being responsible for malaria (Muula and Chimalizeni, 2004). However gaps in knowledge were seen in the Blantyre district, for instance not being vaccinated was mentioned as a risk factor for malaria by 13% of primary school teachers (Muula and Chamba, 2004). In urban areas, such as Blantyre, individuals are likely to be highly exposed to information regarding the biomedical model of malaria and achieve higher levels of education; however it is possible that concurrent or overlapping illness concepts exist, although were not investigated.

2.3.2 Patterns of treatment-seeking: findings from the international literature

Three reviews relevant to the assessment of responses to childhood fever were identified, two of these covered treatment-seeking broadly (McCombie, 1996, Williams and Jones, 2004) whilst the other focused on self-treatment (McCombie, 2002). All three provided narratives of the social science literature, including both quantitative and qualitative studies. Williams and Jones (2004) provided a review of the sub-Saharan Africa literature, studies were grouped as being from East, West or Southern African; McCombie's reviews were not limited by location (McCombie, 1996, McCombie, 2002). The majority of febrile illnesses were found to receive treatment in some form, however in most cases home treatment was utilised in the first instance (McCombie, 1996, Williams and Jones, 2004). Despite the frequency of reported self-treatment, many studies did not provide details of types of self-treatment (McCombie, 1996). Where a definition of home treatment was provided it varied between studies and included tepid sponging, use of local herbs, and drugs purchased from informal sources, left over from a previous illness episodes, or obtained from neighbours (Williams and Jones, 2004). A number of studies indicated that a high proportion of individuals purchased tablets, however most did not specify the drug or dosage (ibid).

The perception that the set of symptoms corresponding to the biomedical definition of uncomplicated malaria reflect a mild, common illness initially treatable using home methods was common throughout studies from all three areas of sub-Saharan Africa (Williams and Jones, 2004). The prioritisation of home treatment has been found to result in delayed health facility attendance (McCombie, 1996); however in most cases initial reactions to fever are prompt, with some sort of action taking place within 48 hours of recognition of symptoms (Williams and Jones, 2004). Further, treatment tends to be started earlier in those who utilise self-treatment in the first instance compared to those who attend a health facility (McCombie, 1996). This was found to be the case in a study conducted in the Blantyre district of Malawi: most children who received home treatment during their recent febrile event did so within two days of illness onset and those who received an antimalarial drug did so more promptly if they used home treatment compared to those who were taken to a health facility (Holtz et al., 2003). However, most home treatments did not include an appropriate antimalarial, only 3.9% (12) of children received prompt appropriate treatment at home (ibid).

Seeking care from multiple sources was commonly reported in studies from across sub-Saharan Africa and Asia (McCombie, 1996, Williams and Jones, 2004). The review by Williams and Jones (2004) found most sub-Saharan Africa studies reported simultaneous use of several strategies. Individuals tended to seek care from a health facility once shop bought drugs and other home methods were perceived to have failed or be insufficient (McCombie, 2002, Williams and Jones, 2004). McCombie (1996) found studies from within each geographic region (sub-Saharan Africa, Asia and America) reported wide variations in the proportion of individuals utilising formal healthcare, which included hospitals, clinics, dispensaries, private practitioners and village health workers (McCombie, 1996). There were also variations within studies between different subgroups, such as urban-rural differences. Inter-country, urban/rural and district level variations were seen in the sources of care available, although most populations were found to operate within a pluralistic system (Williams and Jones, 2004). Utilisation of health facilities in the first instance was found to be more frequent in situations where antimalarials were difficult to obtain from informal sources of care and/or where public facilities were closer, inexpensive or free (Williams and Jones, 2004). However even where biomedical and traditional sources were available, accessible and well known, individuals still opted for home methods (Williams and Jones, 2004).

Studies from across sub-Saharan Africa reported a wide range of types of traditional healers, including spiritual healers, wound healers, bone setters, and other individuals who may not be considered traditional healers such as older knowledgeable women from whom advice may be sought (Williams and Jones, 2004). The use of traditional healers as a primary source of care for uncomplicated malaria was found to be uncommon in all three reviews, however convulsions frequently implicated a supernatural or spiritual cause, perceived to require treatment by a traditional healer (McCombie, 1996, McCombie, 2002, Williams and Jones, 2004). The review by Williams and Jones (2004) found most studies reported the use of traditional healers as an adjunct to biomedical treatment of convulsions, however a number of studies from East and West Africa found traditional healers to be used as the primary source of treatment for convulsions.

More recently a review of the literature was conducted on barriers to prompt and effective malaria treatment in Kenya (Chuma et al., 2009a). Many of the findings support those of the earlier reviews. The majority of treatment-seeking was found to occur in the informal sector; self-treatment with antipyretics was the most common first response (ibid). Treatment-seeking delays were common, and individuals attended an informal source of care more promptly than formal (ibid). However the authors highlighted that there was large in-country variation in the proportion of fevers initially treated at home, ranging from 5% to 83% (Nyamogo, 2002, Munguti, 1998). They also pointed out that while studies commonly reported treatment-seeking from multiple sources, those studies which investigated the proportion of individuals who utilised more than one source found that the majority (75%-87%) utilised a single source (Ruebush et al., 1995, Guyatt and Snow, 2004). Children were found to be more likely than adults to be treated in the formal sector and to be treated more promptly (Chuma et al., 2009a).

2.3.3 Patterns of treatment-seeking: findings from Malawi

A number of studies have investigated patterns of treatment-seeking for childhood fever within Malawi (Maroon, 2010, Ashorn, 2003, Slutsker et al., 1994, Holtz et al., 2003, Masangwi et al., 2010, Kazembe, Appleton and Kleinschmidt, 2007a, NSO, 2008, NSO, 2011, Mota et al., 2009, Munthali, 2005, Chibwana et al., 2009, Vaahtera et al., 2000). Only four of these studies used qualitative methodology (Maroon, 2010, Ashorn, 2003, Chibwana et al., 2009, Munthali, 2005); two of which investigated treatment-seeking broadly but covered aspects of treatment-seeking for fever (Maroon, 2010, Ashorn, 2003); the other two investigated patterns of treatment-seeking for malaria or fever specifically, one of which was conducted among the Tumbuka of northern Malawi (Munthali, 2005) and the other in southern Malawi (Chibwana et al., 2009). One of the quantitative studies involved

monthly visits to households for a year in order to collect morbidity data for illnesses categorised as diarrhoea, ARI, malaria, and other diseases (Vaahtera et al., 2000). Caregivers were also asked about sources of care utilised during these episodes of illness. The remaining studies used data from crosssectional household surveys. An additional mixed-methods study discussed aspects of perceived appropriate use of antimalarial treatment, but focused on malaria in pregnancy (Helitzer-Allen and Kendall, 1992). The qualitative studies identified similar patterns of treatment-seeking in Malawi to those seen elsewhere. Home methods such as tepid sponging and purchasing of shop bought drugs such as aspirin were reported to be the most frequent first response, health facilities were then utilised if symptoms did not improve (Munthali, 2005). Illness perceived to be caused by mosquitoes was considered to require antimalarial treatment, whereas that caused by the weather or hard work was felt to require only aspirin (Helitzer-Allen and Kendall, 1992). In the majority of cases, individuals were found to prioritise treatment from formal health facilities over attendance at traditional healers, who tended to be utilised if the initial cause of action was perceived to have failed (Maroon, 2010). However some individuals were found to perceive that the choice between traditional healers and government health facilities was a matter of preference and in some cases the closer proximity of traditional healers was given as a reason for selection (ibid). Traditional healers were reported to be the only appropriate treatment source for illness caused by bewitchment (Maroon, 2010, Helitzer-Allen and Kendall, 1992), or where the child's illness was suspected to be caused by mauka or chikhoso cha moto (Chibwana et al., 2009, Munthali, 2005). Individuals also prioritised attendance at a traditional healer if the child suffered from convulsions or splenomegaly, in which case health facilities were utilised as a last resort (Munthali, 2005). Traditional medicines were used if individuals lacked the money to purchase drugs from shops and in situations where government health facilities lacked supplies of drugs (ibid).

Treatment-seeking behaviour in Malawi was found to be highly pluralistic; individuals combined multiple methods successively or simultaneously (Ashorn, 2003). Individuals utilised a number of available sources of care; traditional and biomedical treatments were available from the private sector, such as shops (ibid). Individuals were also able to choose between types of treatment available through the folk sector, which included religious healers, non-religious healers and elderly people who possess knowledge of the treatment of ailments using herbal preparations (ibid). Home treatment was reported to include tepid sponging, bathing with cold water, giving drinking water, visiting herbalists to cure *mauka*, covering the child with warm clothes and giving antipyretics (Chibwana et al., 2009). Home treatment with antimalarials was infrequently mentioned and references were to SP rather than a recommended antimalarial; participants also explained that

treatment with antimalarials usually occurred after home methods used during the first 24 hours had failed (ibid). Health workers participating in the same study stated that women often report having given antibacterial treatment at home before attending the health facility.

A nationwide survey conducted in 1992 found that 52% (289/557) of recently febrile children had attended a formal health facility (Slutsker et al., 1994). Similar results were found during the collection of morbidity data between August 1995 and February 1998; a medical professional was consulted in 59% of 386 malaria episodes, a traditional healer in 13%, and no care in 34%³ (Vaahtera et al., 2000). Again, in a survey conducted in the Blantyre district of Malawi in February 2000, 58% (171/292) of recently febrile children were taken to a health facility (Holtz et al., 2003). However an analysis of data from the MDHS conducted the same year found a much smaller proportion (28%) of children to have attended a formal health facility, despite the fact that the majority of caregivers engaged in some sort of action in response to their child's febrile illness (Kazembe, Appleton and Kleinschmidt, 2007a). Of the 4245 caregivers whose child had suffered from a recent febrile episode, 35% purchased drugs, 27% used other home methods, 4% use traditional medicines and 6.4% did not seek care. A survey conducted in the Zomba district of Malawi in 2004 also found that the majority of caregivers of recently febrile children sought some form of care for their child's illness: care was sought for 96.1% (N = 90) of children aged less than five years and 97.9% (N = 65) of those aged 5 to 14 years (Mota et al., 2009). However, like elsewhere a large proportion were treated in the informal sector: 56.6% of children less than five years and 40.7% of children aged 5 to 14 years were taken to the formal health sector. In addition even where formal sources of care were utilised this was often at a later stage in the treatment-seeking process. A large proportion of children for whom care was sought were taken to an informal source of care, such as a shop, in the first instance (<5 years 62.4%; 5-14 years 69.7%) and of these, 34% of children under the age of five years and 21% of children aged 5 to 14 years switched to formal source of care in the second instance. Switching from formal to informal sources of care was also seen; although it was less common. A 2010 survey conducted in the Chikhwawa district of Malawi found a much larger proportion (85.76%) of individuals stated that they would usually take a child with malaria-like symptoms to a health facility or use medication from a health facility (Masangwi et al., 2010). There are however challenges with interpreting this data due to the possibility of a discrepancy between actual and reported behaviour, since the questions did not refer to actual febrile episodes.

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³ Percentages do not add up to 100% as in some cases multiple sources of care were utilised.

The nationwide Multiple Cluster Indicator Survey (MCIS) conducted in 2006, MDHS 2010 and malaria indicator survey 2010 assessed antimalarial utilisation (NSO, 2011, NSO, 2008, NSO, n.d.-a). Antimalarial utilisation has been found to be strongly associated with health facility attendance in Malawi (Slutsker et al., 1994). The MCIS found a low proportion (24.9%) of recently febrile children to have been treated using an appropriate antimalarial drug, and only 21.1% were treated with an antimalarial within 24 hours of fever onset; a larger proportion (49%) were given non-antimalarial drugs such as paracetamol. Data were segregated by district: in the Chikhwawa district 28.3% of children with fever in the previous two weeks were treated with any appropriate antimalarial and 24.3% received an appropriate antimalarial within 24 hours of onset of symptoms. These figures differ from the findings of the later MDHS 2010 and malaria indicator survey 2010, both of which found a larger proportion (43.4% and 30.9% respectively) of recently febrile children under the age of 5 to have received an antimalarial drug. This may suggest an improvement in access to antimalarials between the 2006 and the 2010 surveys. This possible change in treatment-seeking over time may be related to the changing drug policy between these two time periods (see section 2.4) and highlights the importance of updating the literature. The MDHS 2010 found 28.2% to have received an antimalarial drug on the day of fever onset or the next day, whereas the malaria indicator survey found the proportion to be lower (21.9%). In an intervention study conducted in Lilongwe, Malawi CHWs were recruited to deliver artemether-lumefantrine (locally referred to as LA) from CHW operated clinics (Akweongo et al., 2011). In a post-intervention survey 64.7% (801) of children who had suffered a febrile illness during the previous two weeks were taken to a CHW and received LA; 73% (590) of these received the first dose within 24 hours of illness onset.

2.3.4 Factors influencing treatment-seeking: findings from the international literature

Williams and Jones (2004) described the treatment-seeking decision-making process as being influenced by prior illness and treatment experiences, local beliefs, recognition of a combination of symptoms, available sources of care and perceptions of available medications. Knowledge of malaria aetiology influences the decision-making process but is not sufficient to ensure attendance at a formal health facility (ibid). In the review of access to prompt and effective malaria treatment in Kenya by Chuma et al. (2009a), poor perceptions of care and available medications, and perceived alternative causes of illness were found to hinder health facility attendance. The earlier McCombie (1996) review found that distance from health facility, cost, time lost from work and difficulty with access were reasons for delayed or absent health facility utilisation. Equally these same factors were found in McCombie's later review to influence the decision to self-treat rather than seek care from a

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⁴ An appropriate antimalarial included SP, chloroquine, amodiaquine, quinine and ACTs.

health facility include (McCombie, 2002). Utilisation of sources of care other than government health facilities, such as licensed and unlicensed shops, informal drug sellers, private and NGO clinics and hospitals, was driven by greater flexibility of opening hours, greater number of facilities, more dependable stocks of drugs, personal knowledge of staff and perceived lower costs (Williams and Jones, 2004, McCombie, 1996). In addition use of drug sellers was influenced by their greater proximity to households compared to public health facilities, tendency to respond to individuals' demands for particular medications, perceived friendliness and the option of negotiating over costs or receiving drugs on credit (Williams and Jones, 2004). A recent review of the literature was conducted to investigate what factors attract patients to different sources of care in African settings; the findings support those of the earlier reviews (Kizito et al., 2012). Regardless of source of care, patients were found to be attracted by lower costs; greater proximity; positive manner of staff; perceived quality of services provided, including medicines and skills of provider; patient choice; and timeliness of services (ibid). By contrast high direct and indirect costs, drug and equipment shortages, distance, negative staff attitudes, and inflexible opening hours led to dissatisfaction with services and reduced utilisation of public health facilities (Williams and Jones, 2004, McCombie, 1996, Chuma et al., 2009a). Reasons for not seeking care outside the home in the initial stages of illness included lack of money, illness starting at night, the belief that the symptoms could be treated at home and differing interpretations of the seriousness of similar symptoms (Williams and Jones, 2004). In a study conducted in Kenya, 61.5% of individuals who did not seek treatment reported lack of money as the main barrier (Chuma, Okungu and Molyneux, 2010a). Perceived severity of illness has also been found to determine responses; more severe illness was associated with prompt health facility attendance in a number of studies (Williams and Jones, 2004, McCombie, 1996, McCombie, 2002, Chuma et al., 2009a).

2.3.4.1 The influence of seasonality on responses to childhood fever

Seasonality has an important influence on treatment-seeking (Williams and Jones, 2004, Chuma et al., 2009a, Chuma et al., 2006). Heavy rains during the wet season may lead to poor quality or absent roads (Williams and Jones, 2004, Ribera and Hausmann-Muela, 2011). The demands of farming may restrict time available for attending health facilities or even monitoring the illness (Williams and Jones, 2004, Chuma, Okungu and Molyneux, 2010a, Ribera and Hausmann-Muela, 2011). Finances may be limited during the hunger season impacting on the ability to pay fees (Williams and Jones, 2004, Chuma et al., 2009a, Chuma, Okungu and Molyneux, 2010a). Spending money on treatment, rather than investing in farming during the farming season has consequences later in the year (Tolhurst et al., 2008a). In addition strategies for obtaining cash in case of sickness may also be

reduced due to limited business opportunities and difficulty in finding loans (Ribera and Hausmann-Muela, 2011). Where work is available, for instance working on other people's land, time spent engaged in these activities can detrimentally affect an individual's own farm productivity and therefore nutritional sources for the year ahead (Ribera and Hausmann-Muela, 2011). Perceptions of illness severity have been found to differ according to season: A study investigating the household costs of illness (not specific to malaria) in Burkina Faso found individuals identified fewer episodes of illness during the wet season, and perceived a smaller proportion of illness episodes to be severe; the authors assigned this finding to individuals altering their perception of illness during the farming season, when farming was prioritised over illness treatment-seeking (Sauerborn, Adams and Hien, 1996, Sauerborn et al., 1996). Season has also been found to influence the availability of services; problems of drug shortages have been reported to be common during the peak illness season (Chuma et al., 2009b). In Kenya, direct costs of malaria were found to be greater in the wet compared to the dry season (Chuma et al., 2006). This finding was explained in terms of the availability of casual work and farm income during the wet season, when individuals are busy and so opt for treatment options which avoid long waiting times, such as private clinics (ibid).

2.3.4.2 The influence of geographic location on responses to childhood fever

The sources of care utilised show urban-rural variation, with those living in rural areas tending to prefer traditional medicines and home treatment, and those in urban areas utilising formal health facilities and antimalarial drugs more frequently (McCombie, 1996). Those in urban areas also tend to have better access to formal health facilities (Chuma et al., 2009a). Some of the differences seen between urban and rural residents may be accounted for by differences in education, income and access (McCombie, 1996). There is also a relationship between malaria incidence and treatment preferences (Chuma, Okungu and Molyneux, 2010b, McCombie, 1996). Individuals in higher incidence communities are less likely to recommend seeing a doctor and more likely to self treat, perhaps reflecting familiarity with symptoms and treatment (McCombie, 1996), and the perception of those in higher incidence communities that uncomplicated malaria is not serious (Winch et al., 1996).

2.3.4.3 Costs associated with health facility attendance

As discussed above (section 2.3.4), costs associated with treatment-seeking may prevent individuals from using or delay attendance at health facilities; cause individuals to opt for sources of care with perceived lower cost, where costs can be negotiated or credit used; and cause individuals to opt for home-based methods during the initial stages of illness. There are three main categories of costs

that act as barriers to health facility attendance. Firstly, health service costs have been linked to absence of health facility attendance (Baume, Helitzer-Allen and Kachur, 2000, Hill et al., 2003). A review of health financing found the introduction of user fees to be associated with a fall in health facility utilisation (Palmer et al., 2004). Secondly, other out-of-pocket costs associated with health facility attendance have been found to prevent utilisation; these include costs associated with transport, accommodation, medications and other essentials such as food (McCombie, 1996, Rutherford, Mulholland and Hill, 2010). Thirdly, individuals must consider the opportunity costs associated with travelling to the facility, waiting for and receiving treatment that could otherwise be spent engaged in other essential activities such as farming, collecting water and food, cooking etc (Thaddeus and Maine, 1994).

2.3.4.4 Socio-cultural determinants of responses to fever

Williams and Jones (2004) found a limited number of papers investigating social, cultural and economic dimensions of power relations as factors that may influence decision-making ability. The importance of gender in malaria prevention and decision-making has been increasingly recognised (Heggenhougen, Hackenthal and Vivek, 2003, RBM, 2005, Kvinnoforum and RBM, n.d.), however few studies have been conducted to investigate the treatment-seeking process from a gender perspective (Williams and Jones, 2004, Launiala, 2010, Tolhurst and Nyonator, 2006). Most of the issues identified by Williams and Jones (2004) were related to the position of women in their household and social networks. Issues identified included restrictions on women's ability to seek care from male health workers and limited freedom of women to express their needs and discuss their illness. In African settings, women tend to achieve lower levels of education, which is associated with lower levels of knowledge related to malaria and reduced frequency of health facility utilisation (ibid). Prompt health facility attendance was found to be hampered by women's lack of decision-making authority and control of finances, which poses a particular problem for treatment-seeking as women were usually the first to recognise childhood illness (ibid). Women's ability to seek care was further limited by heavy workloads making large demands on their time (ibid). Studies conducted since the time of the review have added to our understanding of the role of gender: Treatment-seeking was found to be delayed in the absence of the father, who was generally responsible for decision-making (Hildenwall et al., 2008, Tolhurst and Nyonator, 2006). In Ghana, women were largely financially dependent on husbands, and experienced challenges during treatment-seeking if their husband did not financially support them or disagreed with them about the appropriate response to the illness, or if they were unmarried (Tolhurst et al., 2008a, Tolhurst and Nyonator, 2006). However, in situations where women were able to pay, this provided them

with greater decision-making responsibility (Tolhurst et al., 2008a). Other dimensions of intrahousehold relationships were also found to influence the treatment-seeking process. Elders, particularly mothers-in-law were influential, partly due to their control over resources (Tolhurst and Nyonator, 2006), but also due to ownership of the child by the fathers' family (Tolhurst et al., 2008a). A quantitative study conducted in Senegal found that in most cases (70.9%), the decision to seek care outside of the home was a collective process involving two or more individuals, such as the mother, father and other relatives (Franckel et al., 2009). The role each individual played and decision-making outcomes were determined by features of the family structure, such as: household size; whether the father was resident; the ratio of children to adults in the household; and, which other relatives resided within the compound (ibid). In addition features of the household structure such as whether the household head was male or female and whether the relationship was polygamous also influenced the decision-making process (Tolhurst, 2004, Richards, 2011).

2.3.5 Factors affecting treatment-seeking for malaria in Malawi

A number of factors were found to be associated with health facility attendance in Malawi, such as child age, perceived severity of illness and educational level. In a nationwide study conducted among caregivers of children aged less than 10 years, formal health facility attendance was associated with age; younger children (less than four years of age) were more likely to be taken to a health facility compared to older children (OR 2.7, 95%Cl 1.9-3.9) (Slutsker et al., 1994). A study conducted in the Zomba district also found younger children were more likely to attend a formal source of care compared to older children, with adults being least likely (Mota et al., 2009). The nationwide survey found that children whose caregivers perceived their illness to be severe were more likely to be taken to a health facility (OR 1.7, 95%CI 1.2-2.4) (Slutsker et al., 1994). This was supported by a study conducted in the Blantyre district which found that children were more likely to be taken to a health facility if their caregiver perceived the illness to be malaria (74.9% vs. 62.7%, P=0.04) and if the illness was of longer duration (4.1d vs 2.5d, P<0.001) (Holtz et al., 2003). Caregivers were found to categorise fever as mild if children were able to play and severe if they were unable to play (Chibwana et al., 2009). Health workers and caregivers participating in the same study reported that caregivers wait until the illness is serious before attending a health facility. Evidence for an association between health facility attendance and educational level of the household head was mixed: in one study children were more likely to attend if the household head had primary or secondary education compared to no education (OR 1.5, 95%Cl 1.0-2.2) (Slutsker et al., 1994). However elsewhere, caregivers were less likely to state that they usually attended a health facility for febrile illness compared to no or traditional care if their partner had no education compared to

secondary or higher education (Relative Risk Ratio 0.75, 95%CI 0.65-0.88); and those with primary education were more likely to attend a health facility compared to those with secondary or higher education (RRR 1.25, 95%CI 1.06-1.47) (Kazembe, Appleton and Kleinschmidt, 2007a).

Exposure to the media and ethnicity were found to influence treatment-seeking (Kazembe, Appleton and Kleinschmidt, 2007a). Those who read the newspaper or listened to the radio daily were more likely to attend a health facility (RRR newspaper 1.28, 95%CI 0.98-1.66; RRR radio 1.15, 95%CI 1.04-1.27). Ethnic differences were associated with choice of provider; compared to the Ngonis, the Chewas⁵ were less likely to attend a health facility (RRR 0.82, 95%CI 0.75-0.95)⁶. As previously outlined, perceived quality of the services provided has an important influence on treatment-seeking decision-making. Although not analysed for the influence on treatment-seeking, when asked about problems faced at the health facility, 73% of participants in a study conducted in the Chikhwawa district cited long waiting times or absent staff (Masangwi et al., 2010). In the Mwanza-Neno district caregivers also mentioned long queues, lack of a specific clinician for children less than five years, limited opening hours and poor treatment by health workers as challenges experienced at the health facility (Chibwana et al., 2009). Health workers also acknowledged they sometimes treat careseekers badly, as a result of being understaffed, overworked and tired (Chibwana et al., 2009). Caregivers and health workers mentioned drug shortages and lack of diagnostics as responsible for preventing individuals attending health facilities (ibid).

2.3.5.1 The influence of seasonality on responses to childhood fever

Only two studies were identified which made reference to season within the context of treatment-seeking behaviour in Malawi. They both provided evidence of perceived seasonal variation in illness experience, and found similar results. The first reported that *malungo* was perceived to be worse in the wet season (Helitzer-Allen and Kendall, 1992). The other found that *malungo* caused by mosquitoes was considered particularly worrisome and was recognised to be more common during the wet season (Launiala, 2010).

2.3.5.2 The influence of geographic location on responses to childhood fever

Distance from health facility, availability of transport and urban/rural residence were found to be associated with health facility attendance. In a study conducted in the Chikhwawa district, the majority of participants (73%) mentioned distance or transport as the main obstacle to attending the

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⁵ The Chewas are the predominant ethnic group in the Chikhwawa district.

⁶ Ngoni was used as the reference; Tumbukas were also less likely to attend a health facility, while there was no difference between the Ngonis and the Senas, Yaos, Tongas and Lomwes.

nearest health facility (Masangwi et al., 2010). Similarly, in the same study, individuals living more than 2km from a health facility were less likely to state that they would take their child to the health facility if they had malaria-like symptoms than those living within 1km (β^7 = -0.88; 95% CI: -1.52 - -0.23), and they were more likely to buy malaria drugs from a market (β = 0.92; 95% CI: 0.18 - 1.65). This study also investigated the influence of CHWs; those living in areas without a CHW were less likely to state that they would take their children to a health facility (β = -0.56; 95% CI: -0.86 - -0.26), and more likely to use shop bought drugs (β = 0.51; 95% CI: 0.20 - 0.82), or use traditional or other methods or do nothing (β = 0.70; 95% CI: -0.024 - 1.44 p = 0.06).

An analysis of data from the MDHS 2004 found that those who stated that they experienced difficulties with the time or transport required to attend the health facility were less likely to attend a health facility compared to no or traditional care (RRR time 0.87, 95%CI 0.79-0.96; RRR transport 0.81, 95%CI 0.73-0.89) (Kazembe, Appleton and Kleinschmidt, 2007a). In qualitative studies conducted in the Mwanza-Neno and Rumphi districts, participants explained that long distances to the health facility cause them to rely on shop bought drugs and only attend the health facility if there is no improvement (Chibwana et al., 2009, Munthali, 2005). In addition the risk that the health facility may not have any medication, and the availability of shop bought medications nearer the home, influenced decisions for individuals who were long distances from the health facility (Munthali, 2005). However participants explained that financial constraints, lack of knowledge of the correct dosage and fear of expired drugs from shops hamper access to antimalarials (Chibwana et al., 2009). The data on the influence of urban/rural residence on health facility utilisation and antimalarial access are less clear. An analysis of data from the older MDHS 2000 found no difference in coverage of children receiving antimalarials within 24 hours of fever onset according to area of the country or urban/rural location (Kazembe, Appleton and Kleinschmidt, 2007b). However the analysis of the 2004 data found that those living in urban areas were more likely to utilise a health facility treatment than no or traditional treatment compared to those in rural areas (RRR 1.31, 95%CI 1.16-1.49) (Kazembe, Appleton and Kleinschmidt, 2007a). A study conducted in the Zomba district found access to antimalarials was greater among those living in urban compared to rural areas, however the study was not adequately powered to assess statistical significance (Mota et al., 2009).

7 Hierarchical binary logistic models with Bayesian estimation

2.3.5.3 Costs associated with childhood fever

All aspects of healthcare delivered through the public health system are free of cost to the user in Malawi; there are no user fees associated with treatment, tests or consultations. Despite this a nationwide survey conducted in 1994 found that households in Malawi experienced considerable annual costs associated with the treatment of malaria, and that these costs accounted for a high proportion of annual income for those in very low income households (Ettling et al., 1994). Total direct and indirect costs accounted for 32% of annual income in very low income households and 4.2% of annual income in low to high income households. A more recent study (2004) conducted in the Zomba district found household out-of-pocket costs of fever episodes were greatest for those in urban areas (USD 1.05) followed by those in peri-urban areas (USD 0.36), with those in rural areas experiencing the least cost (USD 0.21), although differences were not statistically significant (Mota et al., 2009). This study found informal sources of care to be widely utilised. Although not statistically significant, mean total costs were greater for those who utilised formal public services compared to informal services; out-of-pocket costs for recent febrile episode among children less than five years old were USD 0.38 for formal sources of care and USD 0.25 for informal sources (P=0.40). For those aged 5 to 14 years total out-of-pocket costs were USD 0.43 for formal and USD 0.42 for informal sources (P=0.82). The small sample size of this study (<5 years: N=82: 5-14 years: N=59) may have accounted to some extent for the lack of significance of the findings. Informal sources of care were associated with shorter travel and waiting times and a greater frequency of older children missing work or school. Costs associated with travel to and from the health facility and associated time costs are expected to be greater for those living further from health facilities. In addition if distance from facility results in delayed attendance, this may be associated with further cost. However no studies were identified which quantified such differences.

2.3.5.4 Socio-cultural determinants of responses to fever

Only one of the studies identified investigated the role of intra-household determinants of treatment-seeking for childhood malaria in Malawi. Health workers and caregivers highlighted the lack of women's decision-making authority as contributing to delayed care seeking (Chibwana et al., 2009). Participants stated that men only respond once the situation becomes serious. In addition absence of male decision makers was said to lead to treatment-seeking delays, as women may be required to wait for their return.

Men in Malawi have been found to be responsible for household finances, which has consequences for women's access to care (Launiala, 2010). Men demonstrated concern about their ability to provide financially when necessary, and women expressed powerlessness where men were unable or unwilling to support them (ibid). Pregnant women were found to have limited decision-making responsibility, rather decision-making was within the remit of the woman's husband and parents (Tolhurst et al., 2008b). Gender differences in access to care have been clearly demonstrated. Younger women have been found to be less likely to access HIV counselling and testing than younger men (Nyirenda et al., 2006) and women have been found to report later to health facilities (Simwaka et al., 2006). Women's access to treatment is further hampered by the fact they have to seek permission from men before purchasing drugs for fever (ibid). Men have been reported to prioritise access to treatment for themselves over that of their partners in financial considerations (ibid). A study conducted in the Thyolo district found long travel times to the health facility and waiting times to be a particular problem for women, who had to balance multiple demands on their time such as housework, cooking and childcare, and productive roles, such as farming, in addition to treatmentseeking (Nyirenda et al., 2006). The large number of responsibilities held by women also led to problems with medication adherence due to forgetting to administer medications to children. Men, unlike women, did not cite transport as a problem; perhaps due to greater access to financial resources. The relationship between men and women was also found to have positive outcomes on treatment-seeking in studies where husbands were supportive of their wives attending antenatal sessions (Launiala, 2010, Helitzer-Allen and Kendall, 1992). In addition chemoprophylaxis use during pregnancy was greater among married compared to unmarried women (Helitzer-Allen and Kendall, 1992).

Other aspects of family structure have been found to influence access to care in Malawi. Research among the Yao revealed tensions between the responsibility held by a woman's husband, and that by her family (Launiala, 2010). The husband is considered to be the owner of the wife through the marriage, yet more senior ownership of the wife traditionally lies with the maternal uncle; as a result the husband takes responsibility for decision-making in less severe cases, but in serious cases responsibility is taken by the woman's uncle (ibid). Women may also consult their mother or grandmother; female elders are perceived to hold important knowledge regarding traditional treatments (ibid) and have important decision-making power within the household (Tolhurst et al., 2008b, Launiala, 2010, Bezner Kerr et al., 2008).

2.4 Antimalarial drug utilisation

The following paragraphs review the literature on antimalarial drug utilisation. Section 2.4.1 introduces the topic by outlining the importance of investigating antimalarial drug utilisation. Section 2.4.2 discusses methods used to measure adherence, after which section 2.4.3 summarises the literature on adherence to the current antimalarials. Finally, section 1.1.1 presents an overview of the literature on factors influencing utilisation of antimalarial drugs.

2.4.1 Why is it important to investigate antimalarial drug utilisation

Artemesinin-based Combination Therapies (ACTs) are highly efficacious (Falade et al., 2005, Menan et al., 2011, Ogbonna and Uneke, 2008), however there are many barriers to ensuring that these drugs reach those that need them and that they are used appropriately. Lower adherence to antimalarial treatment is associated with worsening of symptoms and an increased risk of treatment failure and re-infection rates (Achan et al., 2009, Checchi et al., 2006, Duarte and Gyorkos, 2003, Okonkwo et al., 2001, Smithuis et al., 2004, Depoortere et al., 2005). LA was introduced as the first line treatment for malaria in Malawi in 2007 and is also the first line treatment in many other SS-African countries. Since the introduction of ACT drugs there has been an increase in concern over adherence to antimalarials. Inappropriate drug taking has been linked to the speeding of drug resistance. Development of resistance to artemisinin derivitives has been slow; however should resistance become widespread there are few alternatives at our disposal (White, 2010).

The previous first line, SP, was a single dose therapy, leaving little room for poor adherence; by comparison the dosing schedule of ACTs is complex, and the issue of adherence more challenging. According to the manufacturer's instructions the first dose of LA should be taken immediately on being dispensed, the second 8 hours after the first, the third 24 hours after the first and the following doses every twelve hours for a total of 3 days. Efforts have been made to assess a once daily regime, however reduced efficacy was found due to the dose limited absorption of lumefantrine (Ashley et al., 2007). The taking of LA is further complicated by the fact that optimal absorption of lumefantrine requires concurrent fat intake (Ezzet et al., 2000). This is particularly challenging in SS-Africa where total fat intake is low; absence of food or milk with which to give the medication has been given as a reason for non-adherence (Depoortere et al., 2004b, Gerstl et al., 2010). However, good response to LA had been seen even without concomitant fat intake (Kabanywanyi et al., 2010, Borrmann et al., 2010).

It is important to assess the acceptability of any newly introduced drug, and previous issue of acceptability were seen in Malawi when drug policy was changed from Chloroquine to SP (Munthali, 2005). The MoH in Malawi is considering distributing ACTs from community based health posts in Malawi; a good understanding of factors influencing utilisation in this context will assist the effective development of such an intervention.

2.4.2 How is adherence measured?

Methods to measure adherence include reported adherence, pill counts, electronic counters or blood or urine drug assays. Measuring adherence is challenging as participants are often aware that full adherence is desirable and this may result in changes in behaviour and recall or disclosure issues (Bell et al., 2009, Twagirumukiza et al., 2010). Studies in Malawi have demonstrated inaccurate reporting of drug taking by caregivers (Nwanyanwu et al., 1996, Bell et al., 2009, Helitzer-Allen and Kendall, 1992). The use of electronic monitoring devices built into medicine bottles has highlighted how verbal reports can overestimate actual adherence (Bell et al., 2009, Twagirumukiza et al., 2010, Garber et al., 2004). However such devices are not without their limitations; individuals may take several tablets out of the bottle at one time, individuals are known to 'play' with the caps and the use of the study bottle itself may alter behaviour (Bell et al., 2009). Reported adherence was often validated by checking available packages for any remaining tablets; however absence of tablets does not necessarily indicate that tablets were consumed by the individual to whom they were prescribed, nor does it account for taking tablets at the wrong time of the day or overdosing through taking within a short period of time, which has also been reported (Depoortere et al., 2004b, Beer et al., 2009, Kachur et al., 2004, Depoortere et al., 2004a, Reilley et al., 2002). Blood drug levels have been compared between supervised and unsupervised drug taking groups (Na-Bangchang et al., 1997, Marsh et al., 1999, Piola et al., 2005) or 'marker' drugs have been added in order to measure adherence (Shwe, Lwin and Aung, 1998, Qingjun et al., 1998). However assays are not available for all antimalarials and have differing reliability (Sarrassat, Sakho and Le Hesran, 2009, Souares et al., 2009). A study conducted in Uganda found mean lumefantrine day three and seven concentrations to be significantly lower in unsupervised versus supervised individuals (Piola et al., 2005). Yet another study conducted in the same country found day three lumefantrine plasma levels did not differ between adherent and non-adherent individuals (Fogg et al., 2004). This is similar to findings from Bangladesh, Tanzania and Malawi where day 7 lumefantrine levels did not differ between adherent and non-adherent individuals (Bell et al., 2009, Rahman et al., 2008, Simba et al., 2012). It

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⁸ Adherence was assessed by interview and blister package inspection

is possible that the relative importance of adherence on lumefantrine plasma concentration may be limited by other factors such as diet and weight or age-banded dosing (Rahman et al., 2008).

2.4.3 How high is adherence to ACTs?

A review of antimalarial drug utilisation was published in 2005 (Yeung and White, 2005). However at the time few studies had been conducted investigating utilisation of ACTs and since then many countries have adopted ACTs as the first line treatment for malaria. The authors highlighted that the findings of studies that used less effective drugs may not be relevant to new highly effective treatments (ibid). Studies assessing adherence to ACT were found to vary both in study design and in the levels of adherence. A number of studies were identified which investigated adherence to LA (Kabanywanyi et al., 2010, Achan et al., 2009, Chinbuah et al., 2006, Bell et al., 2009, Fogg et al., 2004, Depoortere et al., 2004b, Gitonga et al., 2008, Rahman et al., 2008, Dunyo et al., 2011, Kangwana et al., 2011, Lawford et al., 2011, Simba et al., 2012, Watsierah et al., 2011, Barnes et al., 2005, Mace et al., 2011, Ajayi et al., 2008b, Akweongo et al., 2011, Lemma, Lofgren and San Sebastian, 2011). Adherence was found to differ considerably between studies; in household surveys or studies where participants were not aware of any follow-up, the majority of studies found 60% or more of participants to have adhered to the correct dosing schedule (Kangwana et al., 2011, Achan et al., 2009, Depoortere et al., 2004b, Simba et al., 2012, Mace et al., 2011, Ajayi et al., 2008b), and a number of studies found adherence rates of greater than 90% (Chinbuah et al., 2006, Fogg et al., 2004, Gitonga et al., 2008, Barnes et al., 2005, Akweongo et al., 2011). However a recent study conducted in Kenya found only 33% of individuals to have taken LA for the correct duration and 29% to have taken the correct dose (Watsierah et al., 2011). Adherence rates also varied in studies where participants were aware that there would be some sort of follow-up; ranging from 64% to 98% (Kabanywanyi et al., 2010, Bell et al., 2009, Rahman et al., 2008, Dunyo et al., 2011, Lawford et al., 2011). A recent study conducted in Ethiopia where participants were recruited in clinic found only 39% of participants to be probably adherent; it is unclear whether participants were aware of followup (Lemma, Lofgren and San Sebastian, 2011). The low level of adherence found in this study may be attributed to the strict definition of adherence used; details regarding timing of dose administration were gathered and participants were only considered adherent if medication was taken within two hours of the recommended timing. Three studies were identified which investigated adherence to LA in Malawi. Studies conducted in urban areas of Malawi found high levels of reported adherence: a study conducted in the Blantyre district found 100% of individuals to state they had adherence to the medication, while 92% of a subgroup who had been given electronic pillboxes were found to have adhered (Bell et al., 2009); in Lilongwe 99% of participants stated they adhered (Akweongo et

al., 2011). By contrast a study conducted in the rural Phalombe district of Malawi found a lower proportion (65%) of individuals to have adhered to treatment (Mace et al., 2011).

Similar levels of adherence have been seen for other ACTs. Adherence to artesunate-amodiaquine was found to be 48% in a study conducted in Sierra Leone (Gerstl et al., 2010) and 77% in Tanzania (Beer et al., 2009). Greater adherence (94%) was found in a study which did not distinguish between participants receiving artesunate-amodiaquine and those receiving LA (Ajayi et al., 2008a). However this study was part of an intervention in which CHWs were requested to visit caregivers on each day of treatment and give reminders. High adherence (93%) to artesunate-amodiaquine was also seen in a study where participants were required to participate in follow-up appointments (Asante et al., 2009). Adherence to a combination of artesunate and mefloquine ranged between 77% and 100% (Yeung et al., 2008, Shwe, Lwin and Aung, 1998, Na-Bangchang et al., 1997, Congpuong et al., 2010), with the highest levels of adherence (100%) coming from studies where participants were informed of follow-up (Shwe, Lwin and Aung, 1998, Congpuong et al., 2010). Adherence to artesunate and SP was found to be 75% in Tanzania (Kachur et al., 2004), but only 39% among a refugee population in Zambia (Depoortere et al., 2004a).

The high level of reported adherence in many of these studies should be interpreted with caution considering the challenges of measuring adherence described above (section 2.4.2). Data on reported adherence must also be supplemented with an understanding of why individuals use medications the way they do (Williams and Jones, 2004). Such information is necessary for the development of any interventions to improve adherence (Yeung and White, 2005).

Table 2.1 Studies investigating adherence to ACT drugs

Reference	Location	Study period	Drug	Sample size	Reported adherence	Package inspection	Notes
(Fogg et al. 2004)	Mbarara, Uganda	July - October 2002	LA	210	90% probably adherent	Results do not distinguish between those reporting adherence with empty blister packs and packs unavailable	Patients recruited in clinic but not informed of follow-up adherence visit on day three.
(Depoortere et al. 2004b)	Kajo Keju, Sudan	August – September 2002	LA	93	59% probably adherent	Results do not distinguish between those reporting adherence with empty blister packs and packs unavailable	Individuals not informed of day three follow up.
(Barnes et al. 2005)	KwaZulu- Natal, South Africa	February and March 2001	LA	228	96%	-	Reports of fever in the previous four weeks. Household survey.
(Chinbuah et al. 2006)	Dangme- West, Ghana	August 2004 – May 2005	LA	334	100%	Packages available in 239 (72%) of cases, 3 not empty	Caregiver reports 4-14 days after consultation. Household survey.
(Rahman et al. 2008)	Chittagong, Bangladesh	June 2006 – March 2007	LA	160 (unsupervised)	93%	Available for 140, 8 not empty.	Patients recruited in clinic and followed up at home on day three. Paper does not report whether patients were informed of visit; however they were required to return for later follow-up appointments.

(Gitonga et al. 2008)	Greater Kisii, Kwale and Makueni, Kenya	August 2006 – June 2007	LA	37	95%	-	Reported fever in previous two weeks. Household survey.
(Bell et al. 2009)	Blantyre, Malawi	May 2004 - April 2006	LA	Questionnaire: 185, MEMS: 87	Questionnaire: 100% MEMS: 92%	-	Patients randomised to one of three study drugs. Patients informed of follow up on day seven.
(Achan et al. 2009)	Kampala, Uganda	Sep 2007- April 2008	LA	85	88%	Packages inspected, number not stated	Children randomised to LA or quinine. Caregivers not informed of follow up visit. Follow up on day three (day after expected completion of treatment) where possible, or day seven.
(Kabanywanyi et al. 2010)	Ulanga and Kilombero, Tanzania	March- April 2008	LA	552	98%	Available in 548 (99%) of cases, all corresponded with reports	Individuals informed of follow-up. Follow up after one of the prescribed doses
(Dunyo et al. 2011)	The Gambia	October- December 2004	LA	600	67% stated they took all doses at home, 32% took some and 1% to none.	591 packs available, 31% with the medication remaining	Patients recruited in clinic and followed up at home on day three. Paper does not report whether patients were informed of visit; however they were required to return for later follow-up appointments.

(Kangwana et	Kusia,	(July-	LA	Control arm =	Control arm: 72%	-	Intervention involved
al. 2011)	Butere-	August		89	received correct		providing subsidised
	Mumias and	2008) July-		intervention	dose from		paediatric LA, training of
	Tesco, Kenya	August		arm = 221	provider; 50%		retail staff and community
		2009			consumed correct		awareness. No intervention
					number of doses.		in control arm. Caregivers
					intervention arm:		report of fever episode in
					77% received		previous two weeks.
					correct dose; 67%		Household survey.
					consumed correct		
					number of doses		
(Lawford et al.	Tigray,	August-	LA	155	39% probably	Participants with	Patients recruited in clinic
2011)	Ethiopia	November			adherent; 35%	tablets remaining in	and followed up on day
		2008			probably non-	blister packs were	three, not clear whether
					adherent; 27%	classed as non-	patients informed of follow
					definitely non-	adherent (27%)	up.
					adherent		
(Lawford et al.	Bunyala and	September	LA	918	64% (588) probably	76% (697) had blister	Patients recruited at the
2011)	Garissa,	and			adherent; 32%	packs available. Of	clinic and asked to keep
	Kenya	December			(291) definitely	the 588 reported	blister packs although not
		2009 and			nonadherence;	adherent 69%	told why. Patients followed
		July and			4% (39) probably	(407/588) presented	up on day three.
		August			non-adherent	empty blister	
		2010				packets. 32% (291)	
						had tablets	
						remaining. Those	
						who reported non-	
						adherence without	
						corresponding blister	
						packs were	
						considered probably	
						non-adherent.	

(Mace et al.	Phalombe,	October-	LA	386	65% completely	65% accurate recall	Recruited in clinic but not
2011)	Malawi	November			adherent, 22%	and empty pill pack	informed of follow up on day
		2009			missed ≥1 dose, 2%		three.
					took the wrong		
					number of pills per		
					dose.		
(Simba et al.	Kilosa,	June 2008-	LA	444	88%	-	Children aged 3-59 months.
2012)	Tanzania	May 2009					Children were followed up on
							day seven after the first dose
							of LA. No participants not
							informed about follow-up.
(Watsierah et	Kisumu,	Not stated	LA	127	Correct duration:	-	Reports of febrile episodes in
al. 2011)	Kenya				33%		the previous two weeks.
					Correct dose: 29%		Household survey. Any
							household member included.
(Akweongo et	Five African	2006-2009	Ghana:	1213	Ghana:	-	Caregivers report of fever
al. 2011)	cities in		artesunate		Kumasi 167 (93%)		episode in previous two
	Ghana,		and		Bolgatanga 53 (50)		weeks. Household survey.
	Burkina Faso,		amodiaquine		Ethiopia: Jimma 32		
	Ethiopia and		(AS-AQ)		(100)		
	Malawi		Burkina Faso:		Malawi: Lilongwe		
			LA and AS-		796 (99)		
			AQ		Burkina Faso:		
			Ethiopia and		Ouagadougou 73		
			Malawi: LA		(76)		
					Overall: 1123 (93%)		

(Ajayi et al. 2008b)	Ejisu-Juaben and Ho, Ghana; Badeku and Ojoku/Ajia, Nigeria; Bugiri and Iganga,	Not stated	AS-AQ and LA	1289	85% overall ASAQ = 350/382 (92%) LA = 746/907 (82%)	-	Caregivers report of fever episode in previous two weeks. Household survey.
(Ajayi et al. 2008a)	Uganda Ejisu-Juaben, Ghana; Badeku and Ojoku/Ajia, Nigeria; Bugiri and Iganga, Uganda	Not stated	AS-AQ and LA	240	94%	-	In Ghana and Nigeria instructions given for administration at home. In Uganda first dose given under supervision and CHWs instructed to make home visits on subsequent days. Caregivers report of fever episode in previous two weeks. Household survey.
(Beer et al. 2009)	Zanzibar, Tanzania	November 2006- January 2007	AS-AQ	174	77%	-	Children less than five years of age. Age-specific packaging not used. Caregivers followed up on day three (the day after expected completion of the medication). Health workers obtained patient details during the clinic visit however health workers were unaware of the study aims and participants were not informed of follow-up.

(Gerstl et al.	Bo and	July-August	AS-AQ	118	48% (57) probably	23% (27) had	Participants followed up on
2010)	Pujehun,	2008			adherent (correct	available packaging	day three (the day after
	Sierra Leone				verbal account),	with tablets	expected completion of
					21% (34) probably	remaining	medication).
					non-adherent		Not clear whether
					(incorrect or		participants informed of
					incomplete verbal		follow-up, but detailed
					account of intake),		address taken on exit from
					23% (27) certainly		clinic.
					non-adherent		
					(tablets remaining)		
(Asante et al.	Kintampo	Not stated	AS-AQ	190	93%	Blister packages	Not clear whether
2009)	North and					assessed but results	participants were aware of
	South,					not provided	day three follow up but
	Ghana						further follow-up
							appointments were required.
(Na-	Thailand	November	Artemether	126	87% according to	-	Patients requested to return
Bangchang et		1994 and	and		day-two blood		for follow up on days two,
al. 1997)		May 1995	mefloquine		mefloquine		seven, 14, 21, 28 and 42.
					concentrations		
(Shwe, Lwin &	Myanmar	April –	Artesunate	380	100% ^a	Blister packs	Patients recruited in clinic,
Aung 1998)		October	and			assessed however	randomised to either
		1996	mefloquine			urine tests for	mefloquine or placebo
						marker drugs main	(blind) and aware of day 7
						assessment	follow-up.

(Yeung et al.	Anlong Veng,	2002	Artesunate	44	77%	-	Reported fever in the
2008)	Koh Kongt,		and				previous three weeks.
	Malai,		mefloqunine				Household survey. Stated
	Sampalouen						duration of treatment used
	and						as a proxy for adherence
	Sotnikum						where adherence was equal
	and Thmar						to taking treatment for at
	Bang,						least three days.
	Cambodia						
(Congpuong	Tak	March	Artesunate-	240	100%	-	Patients requested to return
et al. 2010)	Provinces,	2008-	mefloquine				for follow-up on days three
	Thailand	February					(the day after expected
		2009					completion of treatment)
							and for additional follow-ups.
(Depoortere	Maheba,	February	Artesunate	157 (142?)	39% probably	110 packets	Patients followed up in the
et al. 2004a)	Zambia	2002	and SP		adherent	available, 28 found	home the day after expected
						to have tablets	completion of treatment. Not
						remaining.	informed of follow up.
(Kachur et al.	Rufiji,	February-	Sulfadoxine-	253: 125 at 24	92% reported	90% adhered by	Patients less than five years
2004)	Tanzania	March	pyrimethami	hours, 128 at	adherence at 24	tablet count 24	of age were enrolled at the
		2003	ne and	48 hours	hours, 77%	hours, 82% adhered	clinic. Caregivers were aware
			artesunate		reported	by tablet count at 48	that they may be followed up
					adherence at 48	hours. Using report	at 24 or 48 hours. A no follow
					hours.	and count combined	up arm was included to
						90% adhered at 24	introduce uncertainty.
						hours and 75% at 48	
						hours	

^aRounded from 99.5%

2.4.4 Factors influencing antimalarial utilisation

The following sections describe factors which have been demonstrated to influence antimalarial utilisation. Section 2.4.4.1 outlines the importance of considering locally held beliefs and the development of theories regarding the appropriateness of medications. Section 2.4.4.2 discusses the role of adverse events; this includes an overview of reported adverse events to ACTs (section 2.4.4.2.1). Other factors found to be important in influencing antimalarial utilisation include caregivers' knowledge of the dosing schedule and the importance of adherence (section 2.4.4.3); the ease of administering antimalarials children (section 2.4.4.4); individual and household factors (section 2.4.4.5); and factors operating at the health facility level (2.4.4.6).

2.4.4.1 The influence of locally held beliefs on utilisation of antimalarials

It is essential to understand community held beliefs around and perceptions of antimalarial drugs. This is demonstrated by a study conducted in Malawi, which identified the belief that women should avoid bitter substances during pregnancy, an idea found to be supported by health workers - yet pregnant women were given bitter chloroquine at antenatal clinics (Schultz et al., 1994). Similar beliefs have been found elsewhere: the belief that chloroquine may cause abortion has been found in the Sudan and Guatemala (Elzubier et al., 1997, Ruebush, Weller and Klein, 1992). Previous studies have found communities to hold beliefs such as the perception that antimalarials are too strong (Beer et al., 2009, Tavrow, Shabahang and Makama, 2003), or do not 'match with the child's blood' (Agyepong, 1992). Such beliefs may impact on individuals' treatment-seeking decision-making and result in poor adherence. A number of studies investigating LA found participants to hold positive perceptions of LA (Barnes et al., 2005, Kamat and Nyato, 2010, Wijesinghe et al., 2011, Ajayi et al., 2008c). However perceptions may be context specific and it is only through the investigation of locally held beliefs that conflicting and confusing messages and ideas can be prevented or tackled.

2.4.4.2 The influence of adverse events on antimalarial drug utilisation

Adverse events have an important influence on individuals' perceptions of antimalarial drugs and have been seen to lead to lack of adherence (Gerstl et al., 2010, Reilley et al., 2002, Bloland, Ettling and Meek, 2000, Achan et al., 2009, Kolaczinski et al., 2006). Further, vomiting following consumption of the drug precludes adherence if the medication is not replaced (Beer et al., 2009, Kabanywanyi et al., 2010). This issue is worsened by the failure of health workers to advise on appropriate responses if doses are vomited, which has been demonstrated in several studies (Beer et al., 2009, Kachur et al., 2004, Zurovac et al., 2008b, Zurovac et al., 2008a). A Sri Lankan study found participants perceived side-effects of antimalarial drugs to be more debilitating than malaria

itself (Jayawardene, 1993). In Tanzania study participants perceived the efficacy of any drug to be linked to potential toxicity, such that the more efficacious a drug, the more toxic potential it was believed to have (Winch et al., 1997). However the opposite was found in a study conducted in the Solomon Islands; participants perceived that the lack of side-effects combined with large number of tablets required when taking LA indicated its lack of effectiveness or strength (Wijesinghe et al., 2011).

2.4.4.2.1 Reported adverse events to ACTs

In general, ACTs have been found to be well tolerated with only minor reported adverse events (Ogbonna and Uneke, 2008, Falade et al., 2005, Meremikwu et al., 2006, Ajayi et al., 2008c, Wasunna et al., 2008). A number of studies investigated adverse events during treatment with LA. Serious adverse events were uncommon, and where these occurred they were thought not to be related to the drug, but rather due to the malaria or other concomitant illness (Piola et al., 2005, Song et al., 2011, Dunyo et al., 2011, Staedke et al., 2008). Further many of the non-serious reported adverse events were the same or similar to the symptoms of malaria such as fever, headache, body aches and cough (Piola et al., 2005, Barnes et al., 2005, Dunyo et al., 2011, Kamat and Nyato, 2010, van Vugt et al., 1999). Other commonly reported non-serious adverse events included vomiting, abdominal pain, other gastrointestinal disturbances, loss of appetite, dizziness, rash, weakness and pruritus (itching) (Menan et al., 2011, Piola et al., 2005, Barnes et al., 2005, Sagara et al., 2009, Dunyo et al., 2011). In a study conducted in Tanzania 94% of caregivers reported they had not noticed any adverse events (Kamat and Nyato, 2010).

Similar findings were found in studies investigating other ACTs. Minor adverse events were reported following treatment with artesunate-amodiaquine (Faye et al., 2007, Barennes et al., 2004). These included headache, body and joint pains, weakness, itching, gastrointestinal disturbances, shaking chills, loss of appetite, uncontrollable body movements and fatigue - all mild or moderate (Oduro et al., 2008, Ndiaye et al., 2008, Beer et al., 2009, Asante et al., 2009). Adverse events reported following treatment with dihydroartemisinin-piperaquine were also non-serious (Rijken et al., 2008) and included gastrointestinal disturbances, dizziness, loss of appetite, abdominal pain, insomnia, itching, drowsiness/fatigue and anxiety (Grande et al., 2007, Smithuis et al., 2006). Similar adverse events were seen following treatment with artesunate-SP: fatigue, fever and dizziness (Kimbi et al., 2012). Some studies which investigated artesunate-mefloquine identified only non-serious adverse events (Congpuong et al., 2010, Faye et al., 2007, Smithuis et al., 2006, Oyakhirome et al., 2007); however other studies identified serious adverse events such as repeated vomiting, generalised

urticaria and cardiac disturbances (Ashley et al., 2006, van Vugt et al., 2000, Grande et al., 2007). Non-serious adverse events reported following treatment with artesunate-mefloquine include abdominal pain, gastrointestinal disturbances, palpitations, sleep disturbance, dizziness, anxiety, cough, skin infections and fatigue (Ashley et al., 2006, Grande et al., 2007, Smithuis et al., 2006, Oyakhirome et al., 2007). Studies comparing LA to other ACTs found LA to compare favourably: a multi-site trial conducted in Cameroon, Ivory Coast and Senegal found a larger number of patients in the dihydroartemisinin-piperaquine-trimethoprim (DPT) group experienced vomiting compared to the LA group (10.2% vs 3%, P = 0.004) and a greater number of patients experienced multiple adverse events following treatment with DPT compared to LA (22.8% vs 14.7%, P = 0.038) (Menan et al., 2011). Another multi-site study conducted in Cameroon, Mali, Rwanda and Sudan found gastrointestinal disturbances were slightly less frequent in those receiving LA compared to those receiving artesunate-sulphamethoxypryazine-pyrimethamine (LA: 2.2%; AS-SMP 24 hour: 7%:AS-SMP three-day 4.6%; P = 0.003) (Sagara et al., 2009).

2.4.4.3 Caregivers' knowledge of the correct dosing schedule and the importance of adherence Patients', or their caregivers', understanding of the treatment regimen and why they should adhere is essential for correct adherence to the recommended dosing (Yeboah-Antwi et al., 2001, Bloland, Ettling and Meek, 2000, Gerstl et al., 2010, Beer et al., 2009, Ajayi et al., 2008c, Winnick et al., 2005, Achan et al., 2009, Mace et al., 2011). Further, knowledge of the causes and prevention of malaria has also been associated with greater adherence (Khantikul et al., 2009). Thus the provision of clear information to patients/caregivers regarding dosing and the importance of completion of treatment has important effects on completion of treatment (Bloland, Ettling and Meek, 2000, Conteh, Stevens and Wiseman, 2007, Kofoed et al., 2003, Denis, 1998, Okonkwo et al., 2001). A study conducted in Sierra Leone found the main reason for correct adherence was being given correct instructions at the health facility (80.7%, 46/57), while 37.0% of those who did not adhere said they were given incorrect instructions (Gerstl et al., 2010). In Kenya the patient's ability to correctly give at least one correct statement related to taking the drug significantly improved the likelihood of adherence (67.0% vs 51.2%; Adjusted OR 1.76, 95% CI 1.32-2.35, P < 0.0001) (Lawford et al., 2011). Health education interventions designed to clearly communicate appropriate drugs and dosing, such as the use of posters and videos, have been effective in improving adherence (Denis, 1998). Training community drug distributors and shop keepers in communicating clearly with caregivers about drug dosages and using visual aids to demonstrate the correct administration of drugs also had positive effects on adherence (Kaona and Tuba, 2003, Winch et al., 2003, Marsh et al., 1999). High adherence has also been found when ACT was introduced alongside community engagement activities

(Chinbuah et al., 2006). Yet caregiver's knowledge of the treatment regime has often been found to be poor (Achan et al., 2009, Kamat and Nyato, 2010), even minutes after the drugs have been dispensed to them (Conteh, Stevens and Wiseman, 2007, Depoortere et al., 2004a, Gerstl et al., 2010, Mace et al., 2011, Mwenesi, Harpham and Snow, 1995). In addition, a study conducted in Kenya found 55% (n=468) of mothers did not understand the dosage instructions, but none asked for clarification because they feared the health workers (Mwenesi, Harpham and Snow, 1995).

Instructions should include an emphasis on the importance of completion of treatment. Adherence has been found to drop-off towards the end of the treatment regime, decreasing over even short-term courses (Simba et al., 2012, Beer et al., 2009, Achan et al., 2009). Qualitative and quantitative studies have found individuals to cease antimalarial treatment once the child appears to have improved or recovered (Ajayi et al., 2008c, Depoortere et al., 2004a, Baume, Helitzer-Allen and Kachur, 2000, Comoro et al., 2003, Falade et al., 2006, Beer et al., 2009, Kachur et al., 2004, Achan et al., 2009, Rahman et al., 2008, Lemma, Lofgren and San Sebastian, 2011), after which antimalarials may be saved for future use (Ajayi et al., 2008c, McCombie, 1996, Williams and Jones, 2004, Barnes et al., 2005, Lemma, Lofgren and San Sebastian, 2011). This pattern of ceasing treatment once symptoms disappear has been reported in Malawi (Helitzer-Allen and Kendall, 1992, Mace et al., 2011).

2.4.4.4 The influence of ease of administering antimalarials to children on utilisation

Two main factors have been found to influence the ease of administration of antimalarials to children. The first, discussed in section 2.4.4.4.1, is the acceptability of the formulation of the medication itself. The second is the design of the packaging within which the medication is delivered to caregivers (section 2.4.4.4.2).

2.4.4.4.1 Formulation

Various methods of enteral antimalarial administration are available; drugs may be in tablet, syrup or more recently dispersible formulation. The method of administration has important implications for adherence. For instance, lower adherence to chloroquine in syrup form compared to tablets was largely attributed to the absence of or lack of use of appropriate measuring devices (Ansah et al., 2001). Caregiver's felt that tablets were easier; one participant stated that 'what I need to give each day is clearly indicated. I don't have to worry about measuring' (ibid). Difficulty in taking medication also impacts on adherence (Achan et al., 2009, Beer et al., 2009) and caregivers have been found to dislike the required crushing of tablets for young children (Ansah et al., 2001). The colour and taste

of pills have been found to influence individuals' perception of efficacy (Williams et al., 1999). The bitter taste of antimalarials is a frequent complaint (Beer et al., 2009, Ansah et al., 2001, Lemma, Lofgren and San Sebastian, 2011) and the full course of medication may not be taken if the patient dislikes it (Depoortere et al., 2004a, Kolaczinski et al., 2006, Lawford et al., 2011). The large number of tablets required for treatment with LA (Lemma, Lofgren and San Sebastian, 2011, Wasunna et al., 2008), and tablets being too large have also been given as a reasons for non-adherence (Lemma, Lofgren and San Sebastian, 2011). In order to reduce the difficulty of administering tablet form antimalarials to young children, a dispersible form of LA has recently been developed (Abdulla and Sagara, 2009, Premji, 2009). This offers advantages over syrup and tablets since no measuring or crushing is required. The dispersible form has been shown to have a good safety and efficacy profile when compared to crushed LA tablets (Abdulla et al., 2008, Borrmann et al., 2010, Abdulla et al., 2010). The solution produced has a sweet flavour which may further increase the ease of administration, however this is yet to be investigated beyond the initial palatability study (Abdulla et al., 2010).

2.4.4.4.2 Blister packaging

Individuals may forget to give the medication or forget the correct dosing schedule (Ajayi et al., 2008c, Khantikul et al., 2009, Achan et al., 2009, Rahman et al., 2008, Depoortere et al., 2004a, Beer et al., 2009, Mace et al., 2011). The use of blister packaging has been one of the most successful interventions to increase adherence (Yeboah-Antwi et al., 2001, Orton and Barnish, 2005, Shwe, Lwin and Aung, 1998, Qingjun et al., 1998, Yeung et al., 2008, Smith et al., 2009). Blister packaging is now common, and is used for the delivery of LA in Malawi. Within these packages tablets are divided into doses and daily requirements, making the schedule easier to understand. Pre-packaging is now frequently combined with pictorial instructions which are intended to provide clear explanations and reminders to both literate and illiterate individuals and have been associated with improved adherence (Okonkwo et al., 2001). Blister packages with pictorial instructions are an adjunct to effective communication with the patient or caregiver, however pictorial instructions on blister packs have been found to be poorly interpreted without verbal explanation (Ajayi et al., 2008c), and forgetting or not understanding the regimen has been seen even with blister packaging (Dunyo et al., 2000). Verbal explanations have been shown to improve adherence, especially when the packaging is used as a visual aid whilst giving instructions (Mace et al., 2011). An additional advantage of blister packaging is that drugs are kept safe, clean and dry; something approved of by caregivers (Kilian et al., 2003, Ajayi et al., 2008c, Kolaczinski et al., 2006). Caregivers have been found to receive the incorrect dosage of antimalarials which further complicates adherence (Beer et al.,

2009, Chinbuah et al., 2006, Nsungwa-Sabiiti et al., 2007, Ansah et al., 2001). Therefore to achieve full benefits, pre-packaging should be age-specific (Beer et al., 2009) which has been shown to increase the proportion of children receiving the correct dose of antimalarials (Nsungwa-Sabiiti et al., 2007).

2.4.4.5 The influence of individual and household factors on antimalarial utilisation

Studies assessing the influence of educational level on adherence have differing findings. In some studies lower adherence was associated with lower levels of education (Fogg et al., 2004, Beer et al., 2009, Depoortere et al., 2004a), however in other studies education was not found to be a factor (Rahman et al., 2008, Kachur et al., 2004, Yeboah-Antwi et al., 2001, Simba et al., 2012, Asante et al., 2009). It is possible that the relative importance of educational level varies according to other factors such as the quality of information received and type of drug and dosing. Similar results were found for socio-economic status, which in one study was not found to be associated with adherence (Kachur et al., 2004), while in other studies children from less poor households were more likely to adhere compared to those from poorer households (Simba et al., 2012, Watsierah et al., 2010). Greater adherence was found among individuals from households where the husband was the household head (Watsierah et al., 2010). In an area where health messages regarding malaria prevention and control were broadcast on the radio, possession of a radio was positively associated with adherence (Lemma, Lofgren and San Sebastian, 2011). Adherence was greater among younger patients in some studies (Lawford et al., 2011, Watsierah et al., 2010), whilst in Malawi children were less likely to adhere than adults (Mace et al., 2011).

2.4.4.6 The role of health facility related factors on antimalarial utilisation

Acceptance of ACTs by health workers is critical to the effective rollout of these drugs. However, poor adherence to treatment guidelines has been demonstrated in Kenya, Zambia and Uganda (Yeka and Harris, 2010). Higher adherence has been associated with obtaining drugs from government institutions or pharmacies/chemists rather than other sources (Watsierah et al., 2010). Adherence is also improved when the first dose is administered within the facility (Beer et al., 2009, Mace et al., 2011). However, the first dose is often not taken until the individual returns home, delaying essential treatment and losing an opportunity for demonstration of how the medication should be taken (Conteh, Stevens and Wiseman, 2007, Depoortere et al., 2004a). Greater adherence has been found when those giving the medication also attend the hospital and receive the instructions (Ansah et al., 2001), however these roles are sometimes taken by different individuals (Beer et al., 2009, Ansah et al., 2001). Recent studies found conflicting results regarding the influence of prompt attendance at a

health facility on adherence; one study found prompt attendance was associated with improved adherence (Lawford et al., 2011), while another found greater adherence among those who delayed health facility attendance (Lemma, Lofgren and San Sebastian, 2011).

2.5 Conclusion

This chapter began by setting the context of the thesis by providing a brief background to Malawi. Malaria was presented as a major cause of morbidity and mortality in Malawi. An overview of the health system structure was presented, and some challenges highlighted. The brief political and economic background was then presented.

This chapter summarised the literature on treatment-seeking for malaria and antimalarial utilisation with a specific focus on Malawi. The importance of understanding local perceptions of malaria was highlighted and an overview of perceived causes and symptoms of malaria within Malawi was presented. A limited number of studies were identified which investigated perceptions of malaria or fever within Malawi. Furthermore, the majority of studies identified were limited to an investigation of perceived causes of malaria and therefore may have failed to capture information regarding perceived causes of alternative local illness concepts, the symptoms of which overlap with malaria. This has implications for our understanding of treatment-seeking, as responses to alternative perceived illness concepts may differ greatly from responses to illnesses considered to be malaria. Those studies which did investigate responses to perceived causes of fever other than malaria highlighted the role of traditional treatments. Within-country variation in use of local terminology was identified; however no studies investigated illness concepts related to fever within the Chikhwawa district.

Gaps in the literature on responses to childhood fever were highlighted. Limited qualitative research has been carried out into treatment-seeking for childhood fever within Malawi; in addition the majority of quantitative data collection was conducted prior to the introduction of ACTs as first line treatment for malaria in Malawi. This change in drug policy may have had important influences on treatment-seeking decision-making and associated costs. In fact, data from the MDHS and malaria indicator survey conducted in 2010 suggests a higher proportion of recently febrile children to have received an antimalarial drug. However, less than half of recently febrile children under the age of five years were found to have received an antimalarial, considerably lower than the target 80% receiving and appropriately using treatment within 24 hours. This highlights the importance of

improving our understanding of treatment-seeking behaviour in this context in order to develop appropriate health intervention strategies. Reports from these surveys do not provide data on health facility attendance.

Distance, travel costs, transport and indirect time costs act as barriers to health facilities attendance. The definition HTR is used in Malawi for health system planning, however no studies were identified which specifically investigated the impact of living in HTR village on the decision-making process, access to care or associated costs. Limited evidence from the international literature suggests costs of treatment-seeking vary according to season; however none of the identified studies investigated the impact of season on costs within the Malawian context. Intra-household relations have been shown to have an important influence on the treatment-seeking in the international literature. Intra-household relations have been seen to be important in access to treatment for other (non-malarial) illnesses in Malawi, and for malaria in pregnancy. However little has been done to explore the role of such relations on treatment-seeking for childhood malaria generally, and especially within the Malawian context.

A good understanding of factors influencing ACT drug utilisation is essential for effective delivery. Adherence to antimalarial drugs has been investigated in a number of studies. However measuring adherence is challenging, and generally relies on self reports. Beliefs around medications have been previously found to influence utilisation within Malawi, yet perceptions of newer antimalarial drugs have not been fully investigated in this context. A number of studies in the international literature have been conducted to investigate the influence of medication specific factors, such as formulation and packaging, and factors related to administration, such as patients' or guardians' understanding of the correct dosing schedule and quality of instructions received, on antimalarial utilisation. However, little has been done to investigate how antimalarials are utilised within the household. In addition a new formulation of LA has recently been introduced and acceptability has not been fully investigated.

The following chapter describes the methodological approach to the current study, designed in light of the critique presented in this chapter. Chapter 6 reviews the approach taken and considers the contributions of the findings presented in chapters 4 and 5 with consideration of the literature presented here.

Chapter 3 Methods

Chapter 3 Methods

3.1 Introduction

This chapter presents the study methodology. It is divided into five main sections: Section 3.2 situates the thesis within the context of the research environment within which it took place and provides justification for the choice of study site. Section 3.3 briefly outlines the methodological background and the reason for choosing a mixed-methods approach. Sections 3.4 and 3.5 describe and justify the methods used and discuss the potential limitations of each. Section 3.4 describes the quantitative methods and section 3.5 describes the qualitative methods. Finally section 3.6 considers the ethical issues associated with conducting the study and how these were dealt with.

3.2 Situating the research

Throughout the period of the research I was based at the Malawi-Liverpool-Wellcome Clinical Research Programme (MLW) in Blantyre, Malawi. However this PhD was situated within a community-based study based in the Chikhwawa district of Malawi. The ACTia (ACTs in action) study was investigating the programmatic implementation of ACTs in Malawi (Clinical Trial ID No: NCT01038063). Specifically it was comparing the safety and effectiveness of LA with dihydroartemisinin-piperaquine in children aged 4-48 months with repeated treatments for uncomplicated malaria over a three year period. ACTia provided a framework for this PhD, and a number of other research projects. All data collection for this thesis was based out of the Chikhwawa field site.

3.2.1 ACTia and the Chikhwawa district

The Chikhwawa district is in southern Malawi, approximately 50km from Blantyre. It is located in the Rift Valley, 500m above sea level where temperature ranges from 16 - 43°C. There were a number of reasons for selecting the Chikhwawa district as the site for this study. The district suffers from a high burden of malaria cases; malaria is endemic with perennial transmission. The Shire River, the main outlet of Lake Malawi, travels through the district making large areas prone to flooding. This was of particular significance to the study design as it allowed comparison of easy and limited access areas. Several community-based MLW studies have been conducted in this area; as a consequence a research unit is maintained within Chikhwawa district hospital (CDH), staffed with clinical, laboratory, data entry and field research personnel. Finally, the geographic layout of the district was

also considered; the study site was within the catchment area of CDH. This area, of approximately 100 square kilometres and a population of around 120,000 is demarcated by natural borders - in the north east by the Rift Valley escarpment, in the west by the Shire River, in the south by Nchalo sugar plantation and Lengwe national park; these demarcations decrease population migration, aiding follow-up of participants.

3.3 Methodological background

This thesis draws on a mixture of qualitative and quantitative methodologies. These methods are used to investigate different phenomena; quantitative methods are concerned with measurement whereas qualitative methods are used to investigate meaning. The mixture of methodologies used in this thesis were chosen to complement one another, each being selected on the basis of its suitability for investigating a particular issue (Sale, Lohfeld and Brazil, 2002). Quantitative methods were used to provide an overview of the extent of the challenges experienced by caregivers. The results of the quantitative investigation prompted questions which were further investigated through the use of qualitative research methods. Qualitative methods were used to investigate the reasons why individuals behave the way they do. The combination of qualitative and quantitative methods allowed both a broad and in-depth investigation of the issues surrounding access to treatment for febrile children that would not have been possible through using a single method (Lingard et al., 2008).

3.4 Quantitative methods

Quantitative methods were used to evaluate utilisation of formal and informal healthcare for childhood fever, and the associated household economic costs. Data collected using quantitative methods was used alongside those using qualitative methods to fulfil objective 1 - Evaluate the use of a mixed-methods approach to investigate access to appropriate malaria treatment. This combined approach is demonstrated in chapters 4 and 5, and the benefits discussed in chapter 6. The utilisation data gathered through quantitative methods was also used alongside qualitative data to fulfil objective 3 - Describe patterns of treatment-seeking within the Chikhwawa district, the results are described in chapter 4; and objective 4 - Explore differences in barriers and enablers to appropriate malaria treatment between those living in hard-to-reach villages and those living near-the-hospital, presented in chapter 5. A household survey was chosen in order to collect standardised responses on individuals' behaviour across a large sample of subjects (Patton, 1990). These

standardised responses enabled the use of statistical techniques to assess differences between according to geographic location and season.

3.4.1 Quantitative methodology

Quantitative data collection was conducted through two descriptive cross-sectional household surveys. The first survey was conducted during the dry season (June-July 2009), the second during the wet season (January-February 2010). The data were collected by a team of fieldworkers, all of whom were of Malawian origin and whose first language was Chichewa. The Chikhwawa district is made up of a mixture of ethnicities, although Chichewa is the language in most use. The questionnaire was translated into Chichewa prior to piloting.

3.4.1.1 Inclusion criteria for the household survey

The following inclusion criteria were applied:

- The respondent must be the caregiver of a child under the age of 10 years who has experienced a febrile event in the past 2 weeks;
- Both child and caregiver must be resident within the catchment area of the CDH; and
- Fully informed consent must be obtained and the relevant form signed or thumb printed.

3.4.1.2 Household survey sample size and selection

This study was powered to detect a minimum difference in attendance at a formal health facility for a recent febrile illness, in children aged less than 10 years, of an estimated 40% of those living within 5km of CDH and 20% of those in HTR areas (power = 90% and α =0.05 two-sided). We estimated a design effect of 2, giving a total sample size of 478 recently febrile children in each survey.

A total of 13 villages were included in the survey: seven were NTH, defined as 5km or less from CDH. These were randomly selected from 13 eligible villages. The remaining six villages were chosen from a list of villages defined as HTR by the MoH in Chikhwawa. Under this definition villages were regarded as HTR if they were located more than 8km from a health facility or were difficult to access due to the presence of rivers or hills.

This survey was designed as part of the preliminary investigations for a study investigating the role of CHWs; as such sampling was based on the aims of the main study. The HTR villages were selected according to their fulfilling the following inclusion criteria:

- Classified as HTR by the MoH in Chikhwawa;
- Accessible by study team all year round;
- Village allocated a CHW;
- CHW actively treating children;
- CHW willing to participate in the study; and
- Village elders willing to participate in the study.

A list of HTR villages with CHWs in the Chikhwawa district was provided by the MoH. The district has 75 areas defined as HTR, 26 of which were listed as having operational health posts, six fulfilled the study criteria. HTR villages selected for the study are therefore representative of villages defined by the MoH as being HTR which also have an operational health posts. These villages may however have greater ease of accessibility compared to other HTR villages. This issue is discussed further in chapter 6.3.5.

Within each village, households were randomly selected by fieldworkers finding a central point in the village, spinning a bottle and then walking in the direction the bottle pointed, visiting all houses between the central point and edge of the village. It was emphasised to the fieldworkers that they must visit all houses to the very edge of the village regardless of whether they have already achieved their quota for that village. This was in order to ensure that selected households did not cluster around the central point of the village but were representative of all members of the village. This process was repeated if insufficient houses were visited. Each day the fieldworkers attended the allocated village together and worked in pairs visiting alternate houses. This enabled the fieldworkers to refer to one another in case of uncertainty.



Figure 3.1 Health post from which CHWs operate in a hard-to-reach village

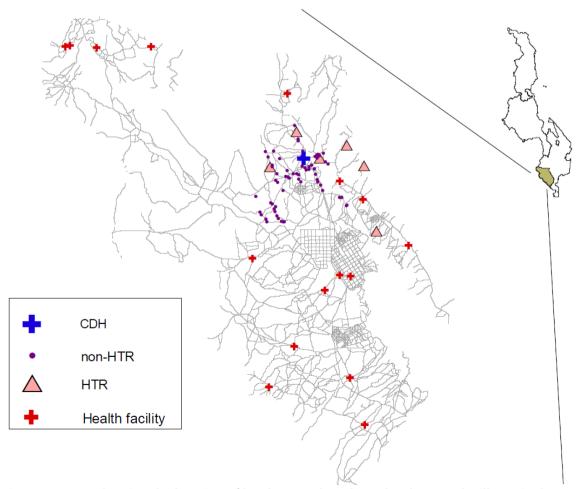


Figure 3.2 Map showing the location of hard-to-reach and non-hard-to-reach villages in the ACTia catchment area relative to Chikhwawa District Hospital (CDH)

3.4.1.3 Collection of quantitative data

Fieldworkers administered a structured questionnaire to the primary caregivers of eligible children in the local language (appendix 1 and 2). The questionnaire had three modules; the first collected details relating to the child and caregivers' demographic background and the child's illness experience. The second module was administered in those instances when care had been sought and included questions on the sources of care, medication utilisation and household direct and indirect costs experienced as a result of the child's illness. The final module collected data relating to socio-economic status; household asset ownership data was collected using questions from the MDHS 2004 (NSO, 2005b). The questionnaire was tested during field-staff training and then piloted in two villages; one before each round of the survey, after which minor modifications were made to the questionnaire.

3.4.1.3.1 Quantitative data capture

The data were collected using touch screen Personal Digital Assistants (PDAs). A user friendly questionnaire interface was developed using the mobile database software Visual CE® 11 (appendix 3). A variety of advantages were considered in the decision to use PDAs. The use of PDAs ruled out the need for manual data-entry thereby saving time and removing the potential for data-entry errors. The software used allowed checks and skips to be programmed into the questionnaire. Checks were programmed to improve the accuracy of data collection by avoiding accidental skipping of questions by the fieldworkers and detecting the input of invalid data, alerting the data-collector to revisit their answer. Skips ensured only relevant questions were provided depending on previous answers. Skips were also used to develop loops which allowed the user to revisit sections of the questionnaire where the same questions applied to different circumstances, for example when questions were repeated for each source of care visited. Finally electronic data collection removed the need for fieldworkers to carry large quantities of paper based questionnaires. The main disadvantages considered when choosing this method were the skilled technological support and time required for the programming; the extent of training required by fieldworkers in order to ensure they were proficient with the software; and potential unknown issues involved in using new technologies. Fortunately a computer programmer was found who could carry out the programming within the necessary time. The fieldworkers recruited for the study all had some level of previous IT experience and few problems were encountered either during training or during the course of the survey.

3.4.1.4 Pre-survey training and piloting

The field-staff for this study were drawn from among the pool of fieldworkers recruited for the ACTia study. A total of eight fieldworkers were involved in data collection, all of which were involved in quantitative data collection. The fieldworkers had previously received an introduction, IT training, training on communication skills and approaching communities sensitively. I then provided further training regarding the study specific objectives and methods, obtaining consent, dealing with distressed participants and encouraging caregivers of sick children to attend a health facility if they had not already done so.

Training and piloting of the questionnaire was carried out over four-day periods before each of the surveys. The training followed the same format for each of the trainings. Initially a paper version of the questionnaire with English and Chichewa translations was used. This was carried out to ensure a good understanding of the questions and methods involved. Following this, three days were committed to the use of PDAs programmed with the Chichewa version of the questionnaire. The fieldworkers practiced using the questionnaire as a group and individually; interviewing each other and staff based at the MLW field site. Ensuring that all the checks, skips and loops within the PDA software were working properly was the most challenging part of the questionnaire development. I met regularly with the computer programmer to check the questionnaire was functioning properly. I also spent one day with the fieldworkers and computer programmer testing the questionnaire using different response options so changes could be made in real-time. The fieldworkers then took the PDAs to a nearby village (not selected for the inclusion in the survey) and recruited volunteers for piloting the questionnaire. During training and piloting, minor modifications to questions were made. Mostly these related to the inclusion of additional answer options specific to the Malawian context and minor adjustments to wording where the fieldworkers felt the translation used may not be understood by village members in the way intended.

3.4.1.5 Management of quantitative data

Data was uploaded daily from the PDAs using Microsoft Access©. It was then stored on a central computer kept at the MLW field site at CDH from where it was collected on a weekly basis. In order to prevent duplication of ID numbers, each PDA was programmed with a different variant of the questionnaire software using a different set of ID numbers. Data tables were transferred into STATA version 10 (StataCorp, Stata statistical software: College Station, TX: StataCorp LP) and cleaned and merged weekly.

3.4.2 Quantitative data analysis

After the dataset was fully merged and cleaned, recoding and analysis was carried out using STATA 10. An analytical plan was drawn up prior to the analysis. All analyses were adjusted to account for clustering at the village and household level in the design of the survey.

3.4.2.1 Definitions of quantitative research outcomes

The quantitative outcome for the description of patterns of treatment-seeking was the proportion of children attending each source of care utilised in the first and second instances (chapter 4.3).

Sources of care included public health facilities, private health facilities, community health workers and shops.

Differences in barriers and enablers to appropriate malaria treatment between those living in HTR villages and those living NTH were explored using the following outcomes:

- The proportion of children less than 10 years old who had experienced a febrile episode in the previous two weeks and were taken to a health facility. Health facilities were defined as public, mission, private or NGO hospitals, clinics or health centres (chapter 5.2.2). A second analysis was conducted to assess the proportion of children taken to a health facility within 24 hours of fever onset (chapter 5.2.3). CHWs were not included in the initial analysis as CHWs do not stock antimalarials and are instead instructed to refer all febrile children to a health facility, in order for them to access appropriate treatment. A third analysis was conducted to assess attendance at any formal healthcare including CHWs (chapter 5.2.4).
- The direct and indirect costs. These were calculated as costs incurred per visit for each source of care utilised (chapter 5.3.1) and total household cost associated with the recent febrile episode among those children for whom formal care was sought (chapter 5.3.2). Direct costs included travel, consultation, laboratory tests and treatment costs. Indirect costs measured the lost productivity of the caregiver associated with caring for the child during the illness episode (Liljas, 1998). For the calculation of individual visit costs per source, indirect costs included the cost of travel time and time spent at the source of care. Travel time and time at the source of care were measured in days, hours or minutes.

The total household cost associated with the recent febrile episode among those children for whom formal care was sought included the total cost of attending any source of care during the course of the child's illness, including attending a heath facility. Indirect costs

included travel time and time spent at the source of care as above, but also included time lost from productive activities to care for the sick child at home, which was valued as days or half days. It would have been impossible to separate time spent caring for the sick child at home in the calculation of individual visit costs per source of care. By comparison for the calculation of total household costs experienced by those who attended a health facility costs were not separated according to source and time lost from productive activities was calculated across the duration of the child's illness.

Lost productivity was assigned a monetary value based on the Malawi minimum wage for an individual with no professional training and living in a rural area at the time of the 2009 survey (MK129 per day). All costs were converted from Malawi Kwacha (MK) to US Dollars (USD) using the exchange rate at the time of the 2009 survey (MK139 to 1USD) (National Bank of Malawi, Accessed: 17 July 2009). For the analysis of costs incurred per visit for each source of care utilised adjustment was made for clustering at the level of the child in addition to the household and village levels; this was to take multiple visits to the same source of care by a single child.

3.4.2.2 Participant characteristics

In order to adjust for differences between those living NTH and those in HTR villages, information on the following participant characteristics was collected:

- Child sex
- Child age: age as given by the caregiver was found to be unequally distributed, with most children said to be less than five years old, or 10 years old. This was likely to have arisen as a result of recall issues (3.4.3.3). It was therefore decided to categorise child age as those under the age of 5 years and those 5 years of age or greater.
- Maternal education: none, any primary, any secondary or greater
- Severity of illness: perceived by primary caregiver as either mild, moderate or severe
- Socio-economic status was measured using the DHS wealth index methodology (NSO, 2005b, Rutstein and Johnson, 2004). This method involved using principal components analysis to compute asset indices (Vyas and Kumaranayake, 2006, O'Donnell et al., 2008). Each household was scored according to possession of durable goods (such as bicycles), housing quality and sanitary facilities. Households were then ranked and divided into wealth quintiles.

3.4.2.3 Logistic regression

A logistic regression model was used to calculate odds ratios for the association between the explanatory variable geographic location and the following outcomes as listed above: proportion of children less than 10 years old who had experienced a febrile episode in the previous two weeks and were taken to a health facility, taken to a health facility within 24 hours of fever and taken to any source of formal healthcare including CHWs.

Participant characteristics thought likely to affect the outcome (e.g. child sex, child age) were tested for significance in a univariate model. Those characteristics found to be significantly associated with attendance at a formal health facility at the p<0.1 level in the univariate analysis were included in the multivariate analysis. Socio-economic status was not found to be associated with the outcome, however it was strongly associated with the explanatory variable (geographic location), and it was felt that it may still have contributed to an underlying confounding effect, and was therefore also included. Before adjustment, each of the a priori confounders were assessed for any interaction using an adjusted Wald test, none were found to interact and so adjustment was made. Results are presented in chapter 5.2.

3.4.2.4 Mean and mean differences

Mean costs were calculated for each source of care utilised. Sources of care included public health facilities, private health facilities, CHWs and shops. A limited number of visits were made to private pharmacies or petty traders and therefore these were grouped together under the heading 'shops'. Mean costs were calculated separately for direct and indirect costs, and each of their constituent parts, in addition to total mean costs (see above). The results are presented in chapter 5.3.1.

The differences in mean total household costs according to the explanatory variables (geographic location and season) were assessed for those children who attended a formal health facility using a censored-normal linear regression model. This approach was taken in order to take account of incomplete febrile episodes at the time of interview. Costs were adjusted for the same a priori confounders as in the logistic regression model. Interaction was assessed as previously described. The results are presented in chapter 5.3.2.

3.4.3 Methodological limitations of the household survey

3.4.3.1 Limitations of using a questionnaire

There are a number of potential pitfalls of using a questionnaire. These can be minimised through careful questionnaire design, but they may not be altogether avoided. Such issues come under two main categories: placing excessive mental demands on participants (Streiner and Normal, 2003) and biased responses (Green and Browne, 2005). The first describes situations where participants experience difficulties in answering questions, due mainly to the standardised nature of the questions. This may include problems with recall, or situations where it is difficult for the participants to match their answer to the possible response options (Streiner and Normal, 2003). There are a number of reasons questionnaire responses may be biased; a common example is where individuals alter their responses in order to be perceived a certain way (Green and Browne, 2005). The structured nature of the interview questionnaire may lead to challenges in developing good rapport with the participants and as a result they may not feel free to divulge information that they think may be perceived negatively. For instance this may also have influenced responses regarding sources of care visited by caregivers — individuals may have altered their responses if they considered the sources of care they attended would be viewed negatively by members of the study team, such as attendance at traditional healers.

Another issue specific to this questionnaire was its length; for individuals who had more than one sick child, or who attended more than one source of care the questionnaire was long. This may have led to response fatigue. It is possible that participants opted to withhold information about later sources of care, or illnesses experienced by additional children in order to reduce the duration of the questionnaire. Further, fatigue during the questionnaire may have led to inaccuracies in recall and responses.

3.4.3.2 Generalisability of findings

This study was limited to one district only; formal health facility attendance rates and costs of childhood fever may differ between districts. However, the relationships between these outcomes and village accessibility are not expected to differ greatly in other districts. It was initially anticipated that a larger number of HTR villages in the Chikhwawa district would be recruited for the household survey. However only six of the villages on the list provided by the MoH met two of the most essential criteria: accessible all year round and presence of an active CHW. It was planned that the wet season household survey would be conducted during the peak rains, however during pre-survey visits some HTR villages could not be accessed due to flooding. In order to ensure that villages could

be visited during both seasons, within the allocated timeframe, only those villages with year-round accessibility were included. The HTR villages recruited for the study are therefore unlikely to fully represent the majority of HTR villages. It would be expected that those living in less accessible villages make less contact with formal health facilities and may experience greater costs, particularly in the form of transport costs. It should therefore be anticipated that the actual differences between NTH and HTR villages, in terms of health facility attendance and associated costs, may be greater in more typical HTR villages.

3.4.3.3 Data collection issues

It was initially intended that only children under the age of 10 be included in the survey, during data cleaning however it was found that 10 year olds had been included. A seemingly disproportionate number of recently febrile children were said to be 10 years old compared to those said to be between the ages of 5 and 9 years. Commonly in Malawi the ages and years of birth are not well remembered (NSO, 2005b); it is therefore likely that caregivers rounded the ages to the nearest whole number and some of the children included may in fact have been greater than 10 years old. Equally if '10 year olds' had not been included, some children under the age of 10 may have been wrongly excluded. Other data collection issues included challenges associated with relying on participants' recall and challenges associated with the costing approach. All data was collected retrospectively and therefore may have been subject to recall bias. For this reason a short recall period of two weeks was chosen to minimise errors. Even so, it is possible that errors may have occurred. Short-term costs only were included in this study, which may therefore have underestimated the true costs experienced by households. Collection of household asset and indirect cost data required respondents to quantify the length of time they were engaged in particular activities, such as the length of time it took them to travel to the health facility. Many participants found estimating length of time difficult which may have reduced the validity of the findings. These issues are discussed in greater detail in chapter 6.3.

3.5 Qualitative methods

I initially entered into this PhD as a quantitative researcher. However I had taken modules in qualitative research during my MSc in public health and while analysing the household survey data I developed an interest in exploring treatment-seeking and antimalarial drug use more deeply. I decided to use qualitative research methods to explore individual and household level factors influencing decisions around and ability to seek care and use antimalarial drugs. Qualitative methods

allow an in-depth and detailed investigation and therefore can generate rich data about the topic under study (Patton, 1990). The more flexible approach to data collection taken in qualitative research allows for greater development of rapport between those collecting the data and participants. It also allows the direction of data collection to be influenced by emerging findings. Such an approach would have been too laborious and time consuming to be conducted for a large sample, such as that used for the household survey. However using these methods for a smaller number of participants supplemented the findings of the household survey and provided a clearer picture of the range of issues at stake.

The overall aim of the qualitative research was to investigate factors influencing the suitability and acceptability of antimalarial drugs provided through the formal health service. As described above data collected using quantitative methods were used alongside quantitative methods to fulfil objectives 1 - Evaluate the use of a mixed-methods approach to investigate access to appropriate malaria treatment; 3 - Describe patterns of treatment-seeking within the Chikhwawa district; and objective 4 - Explore differences in barriers and enablers to appropriate malaria treatment between those living in hard-to-reach villages and those living near-the-hospital. In addition, qualitative research methods were used to fulfil objective 2 - Explore interpretations of fever within the Chikhwawa district; the results are presented in chapter 4.

3.5.1 Qualitative data collection tools

Qualitative data was collected through the use of focus group discussions (FGDs) and in-depth interviews (IDIs). Flexible topic guides were used to maintain a balance of ensuring repport was maintained, whilst meeting the objectives of the research.

3.5.1.1 Focus Group Discussions

Two rounds of FGDs were conducted. The first round of FGDs was conducted during the early explorative phase of qualitative data collection. FGDs used early in data collection can help develop definitions of the topic being explored (Barbour, 2007, Lichtenstein and Lichtenstein, 2005). These FGDs were used to gather information about community definitions of malaria and other causes of fever and norms around appropriate responses to each of the perceived causes. This included discussions around knowledge and perceptions of known antimalarial drugs. FGDs provide a more naturalistic setting than an individual interview; they allow participants to explore their ideas and understandings through interaction with others as is done in everyday life (Kitzinger, 1994). In addition, disagreements and debates among participants enable the researcher to identify extreme

views or experiences that differ from the majority and the range of views commonly held (Patton, 1990). The FGDs were used to explore the distribution of decision-making authority within the household with regard to treatment-seeking and in utilising antimalarials. Discussions included challenges experienced in carrying out responsibilities, including the processes of negotiating with other household members, especially in relationships marked by gender or generational differences. All of the groups were then re-visited for repeat FGDs. These were used to discuss the findings of the earlier data collection and to clarify and probe further into the issues that were arising. After the first round of FGDs all of the audio files were transcribed and translated into English and these were studied with the fieldworkers as part of their ongoing training. The repeat FGDs proved invaluable in ensuring the accuracy of the data collected. For instance on one occasion the participants appeared to be describing castration of small boys as a traditional treatment, this was initially unquestioned by the fieldworker, however during the repeat FGD it was clarified that this had been misinterpreted. There were many other examples that demonstrated the advantages of this method, for instance in the discussion of who has responsibility in administering medication to children. During one of the initial FGDs it seemed to be clear that it was under the joint responsibility of the husband and wife:

Interviewer: Yes, do you assign a particular person to bear the responsibility of administering the drug to the child?

Respondent 6: The onus rests with the husband and the wife to ensure that the child takes the drug.

Interviewer: *Either of them?*

Respondent 6: Yes, both the man and the woman have the duty to administer the drug to the child.

(Younger women's FGD, HTR, 08/10/10)

The repeat FGD provided an opportunity to follow up this issue. It was found that whilst the responsibility was to some degree shared and to a large extent the man was considered responsible, it was the woman who performed the practical task of delivering the medication and the final onus was on her if anything went wrong:

Interviewer: Alright, sometimes the child doesn't take the drug properly; everything is messed up, who is usually blamed for it?

Respondent 9: The woman.

Interviewer: The mother, why the mother?

Respondent 9: *She has the greater responsibility over the child.*

(Younger women's FGD, HTR, 14/01/11)

Another advantage of conducting repeat FGDs was that it allowed the fieldworkers to build upon relationships with the participants and develop greater rapport, allowing a more in-depth discussion of the issues raised.

During the first round of FGDs participants were given short vignettes (appendix 4), these were used to introduce commonly occurring scenarios around childhood fever. The participants were then asked to role-play what they thought might happen next. This was followed by discussion of other possible outcomes, and why participants thought these outcomes would occur. The use of vignettes and role-plays was intended to promote participant engagement with each other and the research topic (Kitzinger, 1994, Khan and Manderson, 1992). When reading transcripts from the first round of FGDs it was noticed that the fieldworkers had not taken the opportunity to fully explore issues that had arisen during the role-plays. This was another example of the usefulness of the follow-up FGDs. During training with the fieldworkers, we discussed how the issues could be explored in more detail during the second round of FGDs. During the second round the fieldworkers provided a short recap of the role-plays, after which the participants appeared to have good recall of the issues and in some cases the participants took over the role of retelling the role-plays. Time was then spent exploring the issues that had been raised.

3.5.1.1.1 Recruitment for focus group discussions

As part of the ACTia study, community advisory groups (CAGs) were set up within the study population. These were the main point of contact between the researchers and the community. There was one CAG per village, or cluster of villages where a large village has been sub-divided into a number of smaller ones. CAGs were used in the selection of individuals to participate in FGDs. The decision was made to use CAGs to select participants rather than village leaders, in order to avoid village leaders selecting only family members, friends, or the elites to participate. However it was established early in data collection that most CAG members were elite members of the community. The fieldworkers were working across a large area (50 villages) and did not have a good enough local knowledge to be able to select individuals from the villages. It was therefore decided to continue with the initial design and use the CAGs to carry out the selection.

3.5.1.1.1.1 Selection of villages for focus group discussions

Maximum variation purposive sampling was used to select study participants, ensuring that a range of perspectives was included (Patton, 1990, Mays and Pope, 1995). FGDs were conducted in two village clusters, representing two diverse sub-sets of the population in the Chikhwawa district. In

keeping with the quantitative data collection, one was a group of villages defined by the MoH as HTR, the other was NTH. The earlier quantitative work had shown differences in health facility attendance between these two groups. The HTR community was made up of three villages and the NTH community was made up of two villages. The HTR villages selected were Supuni 1, 2 and 3 as they are the only villages in the ACTia study area defined as HTR⁹. The NTH villages, Julius 1 and 2, were selected due to their being of average size and accessibility for villages within this area.

3.5.1.1.1.2 Composition of focus group discussions

FGDs can be useful for approaching sensitive topics, especially where participants share similar experiences or more confident individuals encourage the less confident to speak (Kitzinger, 1994, Richie, Spencer and O'Connor, 2003). For this reason groups were made up of individuals who were relatively homogenous in terms of experiences. Gender and generational factors have been shown to have an important role in the position of women in the household and their decision-making authority. It was felt that because of this it might have been more difficult for women to contribute to the discussion if men were present, and also for younger women to contribute in the presence of older women. For this reason separate FGDs were held with groups of younger and older women. Since women are generally more involved in the care of children than men, I was particularly interested in hearing their views. A smaller number of FGDs were conducted with men, and men were not separated by age group. It is possible that as a result younger men's views were not as clearly expressed as those of older men.

The fieldworkers met with CAGs to discuss which factors were considered to be important determinants of underlying differences within the population and identify issues which may make it difficult for any sub-groups to speak within a group setting. I was initially concerned that those of different ethnic origins might have required separate FGDs. I was also concerned about whether the differences between those of patrilineal and matrilineal backgrounds may have made it difficult for them to participate in the same FGD. The Chikhwawa district is relatively mixed, however those NTH tended to be of matrilineal heritage whilst those in HTR of patrilineal. The CAGs however felt that it was unnecessary to hold separate FGDs for these different sub-groups of the population, as they felt participants would be able to talk freely about their different practices. This was seen to be the case in FGDs, as participants would at times describe the different practices in turn.

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⁹ The HTR villages included in the household survey were later excluded from the ACTia study due to their involvement in another study.

The selection process was conducted with fieldworkers present and strict selection criteria were provided. These included an emphasis that individuals should be selected on the grounds of their representativeness of the underlying population. For instance the CAG members were encouraged to select individuals they did not know very well, rather than just selecting friends or families. They were encouraged to select individuals that lived further away from the centre of the village in addition to those living nearby and those of different ethnic backgrounds. It is possible that despite these efforts the CAG members selected unrepresentative members of the population, such as family and friends. CAGs also selected a suitable place to conduct the FGD. These varied according to the village, but as far as possible a quiet, private area was used. In some instances they were held in unused buildings but in others they were held under trees in open areas surrounding the village.

Together the CAGs and fieldworkers selected 10 individuals for each FGD. Combined FGDs were held across the villages in each area, such that individuals from each of the separate villages were represented in a single FGD for that cluster of villages. Similar numbers of individuals from each village were represented in each FGD. The fieldworkers visited each of the selected individuals to invite them to participate in the FGD, carry out the consenting process (section 3.6.2) and inform them of the date, time and location of the FGD.

Table 3.1 Overview of focus group discussions

	Number of FGDs			
	Near the hospital	Hard-to-reach		
Group characteristics ^a				
Young women	2	2		
Older women	2	2		
Men	2	2		
Total	6	6		

^a8 to 10 participants per group



Figure 3.3 Example focus group discussion¹⁰

3.5.1.2 In-depth interviews

IDIs took the form of narratives through which individuals gave their account of their child's illness from the time they first noticed that something was wrong to the time of recovery or the interview. The narratives were used to describe how the caregiver initially recognised the child was ill, the perceived causes of the illness, what action was taken and how these factors changed throughout the course of the child's illness. Reasons for seeking care as they did were discussed, including belief systems, intra-household negotiations and financial implications. Caregivers were asked about any methods used to negotiate with their children over drug taking and challenges experienced. They were probed on their memory and understanding of the recent treatment schedule, the extent to which the medication was completed according to the schedule and barriers and enablers to adherence. Caregivers were asked about their perception of the medicine they had received and any perceived adverse events and responses to these were discussed.

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 $^{^{\}rm 10}$ Photograph included with participants' permission

3.5.1.2.1 Recruitment for in-depth interviews

By the time of planning the qualitative data collection ACTia had set up a rolling Multiple Indicator Survey (MIS) throughout all ACTia study villages. This survey included questions about whether any of the participant's children had experienced fever in the previous two weeks, whether they sought care and if so where from and what treatments they received. All children participating in MIS were finger pricked and a malaria rapid diagnostic test (RDT) was conducted. Children with a positive RDT result who had not already been treated with an antimalarial were treated with dispersible LA by the survey team. It was decided to recruit individuals to take part in the IDIs from among those participating in the MIS. Children with a positive RDT, or those who had received recent malaria treatment from a health facility were considered to have had probable malaria. It was therefore possible to compare the treatment-seeking process for those with recent probable malaria among those who attended a formal health facility and those who did not. It also provided an opportunity to compare perceptions of the original and dispersible formulations of LA. At the time of the survey participants were asked whether they would be willing to participate in a more detailed interview regarding their experiences.

3.5.1.2.1.1 Selection of villages for in-depth interviews

The rolling MIS was stratified; there were two surveys being conducted concurrently: one in villages near the hospital, defined as being less than a 15 minute walk away, the other in villages 15 minutes or greater walk from a health centre. In fitting with the methodology used throughout the study it was decided that half of the IDIs would be conducted with individuals living nearer the hospital while the other half with those living further. Due to their being only three MoH defined HTR villages within the ACTia study it would not have been possible to recruit sufficient numbers of individuals identified by the MIS as having suffered from a recent febrile episode. Instead selection of individuals for IDIs depended on the stratification being used by MIS. For the purposes of the IDIs the definition of HTR was extended to include all villages more than a 15 min walk from a health facility. IDI participants defined for the study as living in HTR villages therefore represent villages with a broader range of accessibility. Chapter 5.4 discusses how this less strict inclusion criteria may have influenced the way in which these villages represent the underlying cultural differences of those living in HTR villages compared to those living NTH.

3.5.1.2.1.2 Selection of individuals for in-depth interviews

IDIs were conducted with caregivers of recently febrile children. To ensure a range of perspectives was included and to fulfil the aims of the study, selection included both individuals that had and

those that had not attended a formal health facility. Individuals who were mid-way through a course of LA at the time of the survey were not included, since participation in the survey may have resulted in changes in drug taking or treatment-seeking behaviour. Those who had not attended a formal health facility were selected if the caregiver had recognised that the child had been febrile for more than 24 hours, the child tested positive for malaria by RDT and was given dispersible LA. Selection was restricted to those who had recognised their child was febrile as the intention was to explore the reasons why care had not been sought, other than lack of recognition of illness. This was limited further to those with fevers of more than 24 hours, since a shorter period may not have given sufficient time for individuals to seek care. Further, it is recommended that febrile children receive treatment within 24 hours of fever onset (WHO, 2005, RBM, 2008). Only those with a positive malaria RDT or those who received the first-line antimalarial treatment from a health facility were included. This was in order to ensure the comparability of those who sought and did not seek care by only including those with probable uncomplicated malaria in both groups. This also enabled the comparison of perceptions and ease of use of original LA and dispersible LA. All IDIs were conducted between day 3 (the day after the expected completion of LA) and day 14 after receipt of LA; the time period was restricted in order to minimize recall errors.

The IDIs were conducted with primary caregivers, defined as the individual who spends the most time caring for the child. Primary caregivers were selected since these were the individuals who were expected to know most about the events surrounding the child's illness. At the time of the IDI the primary caregiver was identified, the study purpose was explained and the consent process carried out (see section 5.1.2). Interviews were conducted in a quiet area near the individual's house in order to limit disturbances and provide as much privacy as possible. The principle of saturation was used; data collection continued until the research team was confident that no new information (categories and themes) was emerging and they understood the issues being expressed (Sandelowski, 1995, Patton, 1990). The background characteristics of the IDI participants are presented in Table 3.2 below.

Table 3.2 Background characteristics of in-depth interview participants

Attended a health facility

	Child sex	Child's age	Marital status	Income generating activities	Husband's income generating activities	Number of own children	Number of other children cared for	Total number of children living at home
Near the hospital	-	-	Married	Farmer	Bicycle taxi	6	1	6
	-	-	Married	Farmer	Farmer	4	0	3
	Female	4	Married	None	Vendor	4	0	4
	Male	4	Married	Farmer and vendor	Farmer	6	2	3
	Male	2	Divorced	Piecework and farmer	Not Applicable	4	3	5
	Male	4	Married	Piecework and vendor	Piecework	2	0	2
	-	-	Married	Farmer and vendor	Builder	2	0	2
Hard-to-reach	Female	1	Married	Farmer	Piecework	2	0	2
	Male	1	Married	Farmer	Farmer	2	2	4
	Female	2	Unassigned	None	Bicycle taxi	2	0	2
	-	-	Married	Piecework and farmer	-	6	1	7
	Male	1	Married	Farmer	Farmer	6	0	4

Did not attend a health facility

•	Child sex	Child's age	Marital status	Income generating activities	Husband's income generating activities	Number of own children	Number of other children cared for	Total number of children living at home
Near the hospital	Female	3	Married	Piecework and farmer	Piecework and farming	4	0	4
	-	4	Divorced	Piecework and farmer	Not Applicable	4	1	4
	Female	1	Married	Piecework	Piecework	5	0	5
	Female	4	Married	Farmer	Builder	1	0	1
	Male	1	Married	Piecework and farmer	Bicycle repairs	4	0	4
Ą	-	-	Married	Farmer	Farmer	3	1	4
Hard-to-reach	Male	3	Divorced	Farmer and vendor	Not Applicable	1	0	1
Harc	Male	4	Married	Farmer and vendor	Farmer and business man	2	3	5
	-	-	Married	None	Piecework	4	3	7
	-	-	Married	Piecework	Piecework	3	0	3

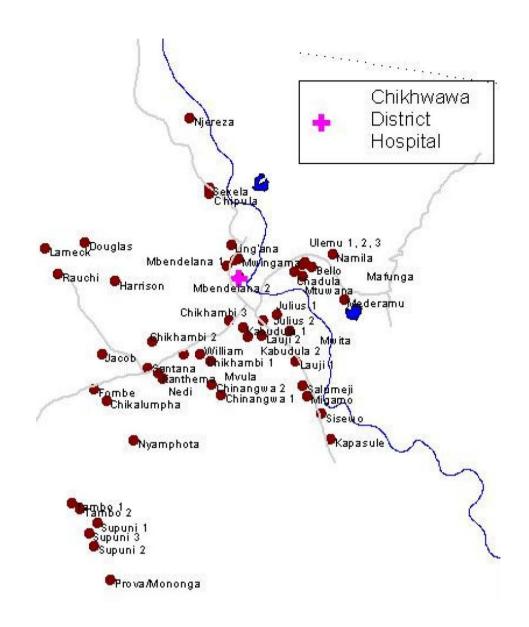


Figure 3.4 Map showing study population for qualitative data collection

3.5.1.3 Qualitative data collection

As for the household survey, all qualitative data collection was conducted in Chichewa. IDIs and FGDs were recorded using a Digital Voice Recorder (DVR). One fieldworker was assigned as facilitator whilst the other was responsible for note-taking and managing of recording equipment. Following the introduction the note-taker recorded the following (Appendix 5 and 6):

- Participant or FGD ID number (PIN)
- Date and time
- Location
- Number of participants (for FGDs)
- Age or age-range
- Sex
- Names of the facilitator and note-taker

3.5.2 Training of field staff in qualitative methods

Four of the fieldworkers who had previously taken part in household survey were selected to conduct the IDIs and FGDs. Two of the fieldworkers were male; they conducted FGDs with male participants only. The remaining two fieldworkers were female; both were present during the FGDs. One of the female fieldworkers was selected to become the primary fieldworker for the study, responsible for conducting all of the IDIs. None of the fieldworkers held formal qualifications in qualitative data collection, although all of them had previous experience in conducting IDIs and FGDs. In general this had been as part of work for NGOs rather than in a research setting and they had little knowledge of qualitative research more broadly. A series of training sessions were held with those fieldworkers taking part in the qualitative research. Members of the MLW Qualitative Research Department conducted sessions providing an overview of qualitative research methods, with specific sessions on conducting IDIs and FGDs. I conducted training sessions exploring issues around treatment-seeking and antimalarial drug use. I initially found it difficult to explore situational factors which may influence treatment-seeking and use of antimalarial drugs with the fieldworkers. At the start of training they openly voiced their beliefs that most issues surrounding lack of attendance at a health facility and lack of adherence were due to the laziness of caregivers. To help the research team better understand the topic, I developed a series of vignettes for the fieldworkers to role-play. These were developed taking account of issues around treatment-seeking that had come up in conversation with the fieldworkers and others, and drawing on the literature. The fieldworkers role-played different potential outcomes of the vignette and we discussed each of these. These role-plays provoked a lot of discussion with the fieldworkers and became an important

part of both my and their learning about the research topic; we used them in around five of our training sessions. Given their initial comments about the laziness of caregivers, I was surprised by how easily the fieldworkers demonstrated and then discussed the kinds of challenges individuals experienced in seeking care. As the discussions continued it seemed the laziness they were expressing was their way of describing why some individuals do not manage to overcome the challenges they experience in seeking care. I am not sure of the extent to which the fieldworkers changed their views throughout the course of the research. However they all, and especially the primary fieldworker, demonstrated an understanding of the importance of a non-judgemental interviewing technique. The fieldworkers themselves worked on refining the vignettes and developing new ones which were then piloted and used within the FGDs.

I reviewed English transcripts of the pilot IDIs and FGDs with the fieldworkers during training. These sessions highlighted some challenges the fieldworkers experienced in conducting the interviews (also see section 3.5.2.1.1). It is common in Malawi for individuals to talk indirectly about issues, and in the pilot IDIs individuals were seen to respond in sentences describing 'what one does' in the given situation, rather than giving their narrative of what happened when their child was sick. The same was true of the fieldworkers, who were often asking questions in the general rather than personal sense. As an outsider it was difficult to know whether the individuals were providing desirable answers or talking about their experiences. I had some difficulty in explaining this issue to the fieldworkers and developing a solution. The problem was eventually resolved through the help of a Malawian qualitative researcher. The fieldworkers were trained in the importance of encouraging participants to personalise their responses and ask participants to explain their story, rather than talk about what most individuals do or should do. For each of the remaining IDIs, after piloting, I listened to the recordings with the primary fieldworker immediately following the interview. We listened to the recordings section by section with the fieldworker translating what had been said. As we listened we discussed issues that could have been probed in more detail and other factors relating to interview style. In this way training continued throughout the duration of data collection. This method also enabled me to make notes regarding the interview and enabled issues that had been raised in earlier IDIs to be followed up in later ones. Due to the length of the FGDs I discussed translated transcripts of the first round of FGDs with the fieldworkers, rather than reviewing recordings.

I also recruited a research assistant to take part in the qualitative data analysis. The research assistant had an undergraduate social science degree and experience of working on qualitative research studies. I provided training on the study aims and objectives, methodology, background to the study and the findings of previous research. The research assistant had previously been involved in the analysis of qualitative data; however did not have experience of using qualitative data analysis software which I also trained him in. The MLW social science journal club and forum provided opportunities for additional training through the presentation and discussion of recent and ongoing research.

3.5.2.1.1 Topic guides

A detailed topic guide was used to focus the IDIs and FGDs on the specific areas of interest and ensure all the relevant topics were covered (Patton, 1990) (Appendix 7-10). However the fieldworkers were encouraged to use the topic guide in a flexible way; questions could be answered in any order and additional questions added to gain more detail or explore topics of interest (Britten, 1995). All of the IDIs and FGDs were conducted in Chichewa; to ensure the fieldworkers used the correct translations the topic guides were also in Chichewa. I asked the fieldworkers to translate the topic guides and I sent both the English and Chichewa versions to the translator who checked the quality of the written Chichewa and highlighted areas where there were differences in meanings between the translations. I then reviewed these discrepancies with the fieldworkers. I did this because it had been previously found that the fieldworkers had difficulty writing in Chichewa and because I wanted to be sure that the fieldworkers and I were sharing the same understanding. Further training was held to discuss the purpose of each of the questions and what additional probes may be suitable. The topic guides were then pilot tested in a village and among individuals not selected for participation in the study. After piloting I met with the fieldworkers to discuss the usability of the topic guides.

The fieldworkers had not used topic guides before and found it quite difficult. During the pilot IDIs the fieldworkers were found to use the topic guides as a questionnaire, only asking the listed questions rather than probing the participant for further details. The transcripts from these IDIs were used to help the fieldworkers better understand what was expected from the IDIs. I went through the transcripts with the fieldworkers encouraging them to think about what alternative questions they could have asked and the purpose behind each of the questions.

The fieldworkers were also involved in the development of the topic guides to be used during the IDIs and FGDs. I initially developed a draft topic guide which the fieldworkers helped refine. They provided insights into local beliefs around disease causation and the kinds of challenges experienced during treatment-seeking. They highlighted ambiguous or irrelevant questions and we worked on refining them together. I had been worried that if I developed the draft topic guide the fieldworkers would provide few comments. However I had been working with the fieldworkers on and off for over a year by the time we were developing the topic guides and they were quite vocal in explaining problems with the guides. Whilst reviewing the transcripts from the first round of FGDs (section 3.5.2) we highlighted any questions arising from the data, areas requiring clarification and considered themes that were arising that required further investigation. I worked with the fieldworkers and research assistant to develop a specific topic guide for each repeat FGD in order to respond to the issues raised by that group in the first round, covering any areas requiring clarification (Appendix 11).

3.5.2.2 Qualitative data management

IDIs and FGDs were allocated a sequential identification number which was recorded on the consent form and notes sheet (section 3.6.2). On return to the MLW main offices the files were uploaded, backed up onto the main server and removed from the DVR. The numerical identifier was retained in the audio-file name. Files were audio-typed and the transcript was also saved under the participant identifier. Audio-typing is not a common skill in Malawi and writing in Chichewa is found to be very difficult by most. To ensure a high quality of the data collected within the short period of time available an experienced secretary with good written Chichewa was recruited to carry out the transcription of sound files. This method provided logistical advantages in terms of reducing the time between which data could be collected and the point at which it could be read and analysed. In addition typing the text first in Chichewa and then translating into English eased the quality assessment of translation. The final transcripts were presented in Chichewa with English translations underneath. This allowed checking back to the Chichewa throughout the process of analysis. This method also had disadvantages; the individual carrying out the transcription was not present during data collection and as such they were not able to draw on their memory of the interview in interpreting the audio file. Further, they were unable to annotate the transcript with situational factors surrounding the context of the interviews. As discussed in section 3.5.5 below, the Chisena language was used by participants in some of the FGDs. The transcriber was unable to transcribe these passages; since they represented relatively short lengths of conversation it was decided that the translator translate them directly from the Chisena audio into English text.

Individuals selected to participate in FGDs were not part of pre-existing groups, but were selected by the community advisory groups. It was not clear the extent to which individuals may have known each other prior to the FGD and it was considered a benefit that there may have been some anonymity within the group. For this reason it was decided that individuals would not introduce themselves during the FGD. In addition to prevent interfering with the natural gathering and conduction of the FGD it was decided not to spend time gathering individual demographic details before commencement. Instead broad demographic groupings were used to select individuals for each group. The transcriber made efforts to identify each of the different voices present on the FGD audios and each individual was assigned a number to represent them in the transcript. This allowed some analysis of the interactions between participants during FGDs. However the voices could not be linked to individual demographics and therefore data were analysed at the group rather than individual level. Further, the lack of accuracy of this method was demonstrated by the fact that in some of the FGDs the transcriber assigned more participant numbers than the number of individuals actually present.

3.5.3 Qualitative data analysis

An iterative approach was taken to data collection and analysis (Richie, Spencer and O'Connor, 2003). Analysis took place alongside data collection and was used to guide further collection of data according to the emerging themes. A team approach was used during data collection and analysis in order to ensure the quality and rigour of the analysis and interpretation of findings (Barry et al., 1999, Richards, 1999). The team met after each data collection to review transcripts and discuss any emerging themes. Transcripts were uploaded into and analysed using the qualitative analysis software QSR NVivo 9. Data analysis was based on a framework approach (Richie, Spencer and O'Connor, 2003). Following this method time was initially spent in familiarisation with the data with reference to the aims and objectives of the study. A variety of the NVivo functions were utilised: the software allowed notes to be made and attached to transcripts during reading, memos were also made to record any arising themes or ideas. All of the transcripts were grouped according to the demographic characteristics of participants enabling comparison of particular characteristics across themes later in the analysis. A table was also created with the background characteristics of IDIs participants (Table 3.2) this enabled easy cross-reference later on analysis.

The next stage was the development of the index, which I conducted with guidance from RT (appendix 12). Initially one FGD and two in-depth interviews were coded, during which a broad index was developed. These transcripts were then summarised using the memos feature and the

summaries compared to the index to ensure all themes were included. Nodes were developed to account for arising themes, with constant reference back to the study objectives and topic guides. These were arranged into family trees to represent their relationship to one another. The family trees had two levels, parent nodes were general categories covering each of the child node subcategories. Initially broad descriptive nodes were used, for example an "actions" parent node was developed under which any actions described such as "sexual intercourse" were coded. As the initial transcripts were coded and more meaning became attached to these nodes, they were redefined. For example "sexual intercourse" was redefined as "breaking sexual taboos" as a child node of "causes of childhood illness". Free nodes were also used for ideas or themes that arose, that appeared unrelated to other categories. These were usually re-coded into family trees once the relationships became clear. Once the index was well-established, the other FGDs and IDIs were coded. Minor changes to the index were constantly made throughout the coding of the later transcripts. However because broad categories were initially used, for the most part it was not necessary to read through all of the earlier transcripts in order to make changes - instead the information in the relevant nodes was read, and subdivided into more specific nodes as more data was generated. For instance under the tree node "treatment" there had been a child node "administer" under which all references to administering medication were coded. As analysis went on it became clear that "administer" was made up of a number of child nodes and it itself was turned into a parent node and renamed "delivery of medication", under which child nodes include "ease of delivery", "vomiting" etc. The index was developed in discussion with my research assistant and RT. Towards the end of coding half of the transcripts were selected and summaries of the key themes arising from these IDIs and FGDs were made and included as memos attached to the transcripts. The coding was then checked against the summaries to make sure that all key themes were covered in the index.

Towards the beginning of the second year of my PhD I developed a neurological condition affecting my arms. Although this was initially mild, by the end of the academic year I was having great difficulty in using a mouse or keyboard. It therefore became necessary for my research assistant to take over a substantial portion of the coding, as the process in NVivo is heavily mouse dependent¹¹. While my research assistant was largely responsible for actually coding the text, I spent a great deal of time reading through transcripts and checking his coding, and initially we sat together while he coded. This process was particularly challenging during a three-month period during which it was necessary for me to travel to the UK for medical assessments. My research assistant continued with

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 $^{^{11}}$ I was able to complete the written components of the thesis using the voice recognition software Dragon NaturallySpeaking 11, by Nuance.

coding while I communicated my comments through e-mails, Skype and the NVivo file was sent backwards and forwards between us. During this time my research assistant also took responsibility for overseeing the qualitative data management. RT read through the text as coded under each of the nodes and provided comments and feedback.

Once the data was indexed I 'charted' it through running queries in NVivo. This allowed all data under a particular index or combination of indexes to be recalled and viewed as a whole or according to individual or group. I used these charts to develop descriptive and then explanatory accounts which we discussed as a team and modified where necessary. Throughout data analysis and the development of descriptive accounts, the raw data and summaries were reviewed in order to ensure that the final descriptive and analytical accounts were a true reflection of the data. Developing explanations were compared across all of the data and were modified or abandoned in order to take account of both cases that fit the initial theory and negative cases. Data obtained from IDIs and FGDs were compared and triangulated in order to enhance trustworthiness and increase rigour (Patton, 1990). Where findings of different sources of data corroborate one another this can increase the credibility of the findings (Patton, 1990). However where the findings differ, an investigation of why may lead to a deeper understanding of the issues at stake (Patton, 1990).

3.5.4 Quality assurance of qualitative research

A documented systematic approach was used throughout all stages of data collection and analysis. Quality checking of transcribed data was conducted by a second transcriber who reviewed 10% of the transcripts. The quality of translation was conducted through back-translation of 10% of transcripts by a second translator. Initially small sections of the selected transcripts were back-translated with further back-translation if discrepancies were found. The translators and transcribers met with the PI regularly to review transcripts and to discuss any arising issues.

3.5.5 Limitations of approach to qualitative research

This study was limited to an investigation of factors that I predetermined as being of interest. My position as a white, British female with a biomedical background, working within a biomedical research environment clearly influenced my choice of research topic, the way in which the study was implemented and perhaps most importantly my analysis of the data. I tried to consider this positionality throughout the data collection and particularly in my readings of the data and subsequent analysis.

As someone with limited ability in the local language I was fully dependent on the fieldworkers for data collection. As a result the collected data would have been influenced by my relationship with the fieldworkers, the messages I put across to them, the perspectives of the fieldworkers and their interactions with the participants. My interactions with the fieldworkers were marked by clear differences in backgrounds. However I developed good relationships with all of them, particularly my primary fieldworker. However as a result of my position in leading this study, my greater education and my whiteness, our relationships were clearly hierarchical. This undoubtedly affected the research in many unknown ways, but was likely to influence the fieldworkers' ability to ask for clarification, give their views, make suggestions and use the topic guides flexibly. The fieldworkers' descriptions of traditional beliefs or practices were sometimes accompanied by what seemed to be embarrassed laughter. I tried to reassure the fieldworkers of my interest in these beliefs and practices. We also discussed the importance of talking openly and in a non-judgemental way about them with the research participants.

All of the fieldworkers had secondary level education and worked within the hospital setting (although none had any sort of medical training). Whilst they made efforts to dress appropriately for their field visits, such as wearing a local wrap (skirt), they clearly stood out from the majority of participants who were dressed much more simply and had little to no education. None of the fieldworkers came from or lived in the villages under study. The advantage of this is that it may have been easier for the participants to speak freely and honestly to someone they did not know. However differences in the local dialect and life experiences may have been barriers to communication.

The study was restricted to fitting with the interests of the main ACTia study and that of the funding organisation to which I applied. I was encouraged to focus on younger children, since these carry the heavier burden of malaria illness. For this reason, and the more complex ethics around child participants, no interviews were conducted with children. The findings of this study therefore relate only to the experiences of adults during childhood febrile events. This study was funded by the ACT consortium and as such there was a necessary focus on barriers and enablers to accessing ACT drugs specifically, rather than conducting a broader investigation of treatment-seeking and utilization. For instance, although traditional sources of care were discussed, they were not investigated in-depth and interviews were not conducted with figures such as traditional healers. Many community members rely on traditional healers as sources of knowledge, and not including these in the study

may have resulted in a less complete picture of community perceptions of disease causation and appropriate responses.

An unexpected complication was related to the local language. Prior to commencing fieldwork I held discussions with the fieldworkers about whether Chichewa was the main language used in the study site and whether all individuals would be comfortable with using it during FGDs and IDIs. I was assured that they would. However soon after data collection it was established that most of the participants were using Manjanga, a dialect of Chichewa which was mixed with Chisena. Chisena was only spoken by one of the fieldworkers and not used by the transcriber. During IDIs and the conversational parts of the FGD the fieldworkers asked for clarification where Chisena had been used. However during some of the role-plays held in the HTR villages individuals were found to speak entirely in Chisena. This perhaps demonstrates how fully the participants were entering into the role-plays, since they naturally reverted to the language that is used around the home. In order to maintain the richness of the collected data I decided not to restrict individuals to speaking in Chichewa. Although unplanned, this was possible since the primary fieldworker was Chisena speaking.

3.5.5.1 Working within a clinical trial

Working alongside the ACTia study provided a good deal of flexibility in terms of freedom to investigate areas of interest. As such logistical support was provided in order for me to conduct the household survey, despite this not being directly related to any of the ACTia objectives. However my interest in antimalarial drug use was mutually beneficial, as this was in fitting with one of the secondary objectives of the main ACTia study:

To determine obstacles to full adherence to the evaluated ACTs in real-life programmatic settings, such as acceptability, tolerability and user-friendliness.

I was able to harness support for research into this topic, but also broaden the scope to include areas of specific interest to me, in particular the treatment-seeking process. However, as discussed above there were some limitations to the level of flexibility afforded, and working within a clinical trial provided both advantages and disadvantages.

Through undergoing good clinical practice training and working within a large clinical trial I learnt much about how clinical trials operate. Delays in the start date for ACTia made fieldworkers and equipment such as PDAs available. Recruiting, relocating and retaining fieldworkers in a challenging environment such as the Chikhwawa district of Malawi is no easy task. These tasks were carried out

by the ACTia trial managers and PIs while I benefited from observing the potential challenges and pitfalls. Senior fieldworkers were passed on from a previous large study and as such were very familiar with the study area and logistical issues around carrying out field level research. There were however also disadvantages of this association; the fieldworkers were recruited according to the needs of the main trial. The fieldworkers also had to be shared with the main trial and as such the requirements of the trial had to be prioritised. Possibly however, the most significant factor was the potential influence of community perceptions of those working within biomedical research, in particular on the ability of participants to openly express their views. The fieldworkers were clearly associated with hospital care through the activities they participated in such as taking participants to and from the hospital. Participants' awareness of this association was demonstrated by the fact that during interviews, some participants mentioned having seen the fieldworkers at the hospital. In Malawi those working in the hospitals are frequently referred to a 'achipatala', or 'those of the hospital', and are seen by many as being more educated, possessing knowledge about healthcare and being of a higher social class. During training it was emphasised to the fieldworkers that they should think of themselves as the learner and the participants as the teacher and that they should avoid telling participants how things should be done. Even so it is possible that the social gap between the participants and the fieldworkers may have influenced both the way in which questions were put across by fieldworkers and responded to by participants. Further than a social class issue, participants may have been suspicious of the fieldworkers due to the wider ranging activities carried out by the ACTia study. Household surveys conducted under the ACTia study involved clinical procedures such as blood tests. The fieldworkers selected to take part in my data collection were not involved in these surveys, but were clearly associated through reputation and information sheets given out during the consenting process. The fieldworkers reported that frequently, when the DVR was not recording, individuals questioned practices such as blood taking, and were suspicious of why they had been selected to take part in the qualitative component.

3.6 Ethical issues

Ethical approval was obtained from the College of Medicine Research and Ethics Committee, Malawi, the Liverpool School of Tropical Medicine Ethics Committee and the London School of Hygiene and Tropical Medicine Ethics Committee (Appendix 13-15).

3.6.1 Community engagement

Community engagement was conducted by the MLW communication department. This included setting up and regularly visiting CAGs in each of the study villages. In addition, two sensitisation campaigns were conducted. These were used to inform the communities about all aspects of the trial and affiliated studies and included the purposes and procedures of both the qualitative and quantitative aspects of this thesis. Before sensitisation village leaders were visited to request permission for the village to take part in the study. At the time of sensitisation all members of the village were invited and opportunities were given for any questions to be answered.

Feedback sessions were held in participating villages at various points throughout the study. These provided an opportunity for the research team to explain the main findings to the communities. These were organised by the communications department, in conjunction with the CAGs and village leaders. I met with the communications team prior to these feedback sessions, and provided written summaries of the study's progress. However the sessions themselves were conducted by the communications team, and covered aspects of the main ACTia trial and other sub-studies in addition to this study. There were a number of reasons for taking this combined approach: it helped provide continuity between the studies for the study population; prevented placing too many demands on the community; and had logistical advantages. This method also allowed all ACTia participants to receive feedback on all aspects of ACTia, rather than involving only those who participated in particular activities.

3.6.2 Individual consent

Fully informed written consent was obtained from all caregivers in the local language before recruitment into the study. Consent is a familiar concept in the study population. A standardised information sheet and consent form in the national language (Chichewa) was used (Appendix 16-19). The information sheet gave details of the study purpose, procedures, risks and benefits. The voluntary nature of enrolment was described alongside the right of the caregiver to refuse or withdraw at anytime.

The details provided on the information sheet and consent form were explained and the participant was offered the opportunity to read the information themselves (where possible) and ask any questions. Finally, participants were prompted on their understanding before being asked to sign the form. Where the individual was unable to read or write, the form was explained in the presence of a literate witness who was in no way connected with the survey; consent was then taken with a

thumb print and countersignature provided by the witness. A copy of the information sheet was kept by the participant. Each original signed informed consent was kept on file by the study PI.

3.6.3 Risks of participation

There were considered to be no foreseeable risks to either participants or investigators of participating in this study. There were two main ethical issues considered in relation to this study. The first was the potential distress to participants resulting from questioning into household illness and household economics. The narratives and questionnaires in this study were not intended to dwell on or explore in detail events or feelings surrounding the death of a child or other causes of severe grief. However it was possible that the topics covered might have resulted in distress to participants. The field workers were trained in appropriate interviewing techniques and in dealing sensitively with distressed participants. Interviewers involved in conducting the household survey were advised that if it was found that a child had died in the previous two weeks, the interviewer should break the questioning and ask if the respondent is willing to carry on with the questionnaire. If the participant did not want to continue the interviewers were instructed to finish and depart in an appropriate manner. Prompts for this behaviour were also built into the PDA questionnaire. Participants were informed of their rights to end the IDI or questionnaire, or leave a FGD at anytime. Study staff were trained to continually assess for any distress in participants throughout data collection, and respond accordingly through providing empathetic support or personal space where suitable. They were also trained to turn off any recording devices if it became apparent that recording of IDIs or FGDs was causing distress to participants. The second issue considered was the potential situation whereby a fieldworker discovered a sick child or children within a household that had not been seen by a health professional. Interviewers did not have a medical background but were advised to encourage caregivers to take any sick children to a formal health facility.

3.6.4 Adverse events

Adverse event reporting followed the protocol for the main ACTia study. In the event that a study participant described an adverse event experienced by their child following treatment with either formulation of LA a Pharmacovigilance reporting card was completed by the responsible fieldworker.

3.6.5 Confidentiality

Names of individuals were kept on consent forms only; a numerical identifier was used on data capturing forms and transcripts. Individuals and sub-groups of the population are not identifiable in any reports, publications or presentations.

3.6.6 Data management

Consent forms were stored in a lockable cabinet under the charge of the PI. These will be destroyed after a minimum of 3 years following completion of the study. Recordings of IDIs and FGDs were transcribed as soon as it was feasible and voice recordings destroyed within 6 weeks of transcribing.

Throughout the study hard and electronic copies of the data were only accessible to those within the study team, under the discretion of the study PI. Electronic data were password protected at all times and encrypted when being transferred between storage devices. Each member of the study team only kept copies of data being worked on at the time, and all files were removed from their system once work was completed. The data office kept a copy of all data collected on both the main and backup data management servers. After completion of the study the database was locked and the data office will retain a copy of the final database in CD format for a minimum of a further 3 years.

3.6.7 Benefits of participation

It is intended that communities benefit from participation through feedback to the MoH and the development of health intervention better targeted to meet the needs of the population. In accordance with the study protocol for the ACTia study participants did not receive reimbursement or gifts, however refreshments were provided to those participating in FGDs.

Chapter 4

Interpretations of childhood fever and patterns of treatment-seeking

Chapter 4 Interpretations of childhood fever and patterns of treatment-seeking

4.1 Introduction

This chapter draws on findings from both the qualitative and quantitative data collection. It explores how individuals within the study community interpret and respond to childhood febrile illness. Section 4.2 describes how febrile illness is interpreted by participants. Here the symptomatic presentations and perceived causations of various febrile illnesses are described and contrasted. Section 4.3 then presents the sources of care utilised by participants of the household survey. Section 4.4 compares these findings with the results of the qualitative data collection. This section describes how individuals make decisions about where to seek care based on the symptoms their child experiences, and their response to treatment. It also describes how this process changes over time as the child's illness continues. This final section is divided into three main parts which describe the treatment-seeking process in three phases: the assessment phase, seeking care outside the home, and later sources of care.

4.2 Interpretations of febrile illness

An individual's interpretation of their child's illness can influence their response. For instance, the perceived causative disease and disease aetiology may determine the source from which care is sought. Further, how an individual recognises that a child is suffering from an illness, and that a particular disease is responsible, may mediate what action takes place and when. In order to explore these issues, individuals participating in FGDs were asked to name each of the febrile illnesses they knew about, and describe the symptoms and causes of each. Those participating in IDIs were asked to describe the symptoms they recognised their child to have had, what they perceived the cause to be, and how these things may have changed throughout the course of the illness. Participants were able to provide clear descriptions of locally defined illnesses, and these are presented in the following sections (4.2.1 - 4.2.4). The process of recognising the cause of a particular febrile episode is more complex, and forms a major theme throughout the rest of the chapter.

In the local language, the phrase 'kutentha thupi', or 'hot body' was used by community members and fieldworkers to describe fever. A number of illnesses were described as causing kutentha thupi. The most frequently mentioned of which were malungo (4.2.1), mauka (also masungu) (section 4.2.2), nyankhwa (section 4.2.2) and (m)tsempho (section 4.2.3), which are described below. As can be seen in the following sections, there are many similarities between the symptoms of these illnesses, despite the perceived causes differing greatly. The similarities in the symptoms of these illnesses results in difficulties in differentiating the cause of illness, particularly during the early stages of illness. Later sections of this chapter describes how this impacts on sources of care utilised during the early stages of the child's illness (section 4.4.2), and decision-making following treatment failure (section 4.4.3.3).

4.2.1 Malungo (Malaria)

4.2.1.1 Symptoms of malungo

When the participants were asked to describe *malungo* in the abstract, it was said to consist of a complex of symptoms, similar to the clinical definition of malaria. Commonly mentioned symptoms included: fever, weakness, vomiting, diarrhoea and coughing. Less frequently mentioned symptoms included: sneezing, stomach ache, fainting, shivering, gnawing teeth, hallucinations, yellow or red eyes, headache, loss of appetite and aching body. However, when used during broader descriptions of febrile illnesses the terms *malungo* and *kutentha thupi* were not always discrete; at times 'malungo' was used to refer simply to fever. Despite this, the presence of fever (*kutentha thupi*) alone was not sufficient for the illness to be considered malaria and clinically treatable with antimalarials, but was considered to be a symptom of a variety of illnesses.

Severe malaria was not investigated in detail; however references were made to both anaemia and signs of cerebral malaria, but not to convulsions. Anaemia was described not as a sign that would let parents know their child had malaria, but rather a diagnosis that might be provided by doctors when the child has malaria. Fainting was reported in all the FGDs to be a sign of malaria, and that the illness was serious:

When the malaria is severe, the child faints (Younger women's FGD, HTR, 08/10/10)

In the older woman's group, cerebral malaria (*malungo ali mu ubongo*) was mentioned by participants in both the initial and repeat FGDs. It was described as causing the child to faint, hallucinate and talk nonsense. However elsewhere, the presence of some of these symptoms was

not interpreted as cerebral malaria. One of the individuals taking part in an IDI explained that they initially thought their child's illness, which involved fever and fainting, was epilepsy, rather than malaria, whilst another thought it was an illness similar to tetanus:

Respondent: No, he had fever all night till morning and in the morning, he collapsed...

Interviewer: ... What disease did you think it was?

Respondent: I thought it was epilepsy...

Interviewer: ... Didn't you think it could have been malaria, as the child had fever?

Respondent: No, I still thought it was epilepsy

(IDI, attended a health facility, HTR¹², 04/11/10)

Fainting though was not given as a symptom of the other frequently mentioned illnesses, *mauka*, *nyankhwa* and *tsempho*. In fact, in one FGD, fainting was given as a symptom which could help individuals differentiate between these illnesses and malaria:

Interviewer: Ooh, alright, what's the comment of others? How do we know that the fever

is caused by malaria, not tsempho, it is not mauka and it is nothing but

malaria; how do we know this?

Respondent: When fever develops

Interviewer: Eeh,

Yes

Respondent: The child can actually faint and when you take him to the hospital in that

state, he is tested and we are told that it is cerebral malaria

(Older women's FGD, HTR, 23/01/11)

4.2.1.2 Causes of malungo

Malungo (malaria) was widely understood to be caused by mosquitoes. To a lesser extent it was also thought to be caused by the weather, in particular the sun, and also by hunger and lack of hygiene. In one FGD poverty was extensively described as being the cause of malaria, mainly through the mechanism of causing people to work hard in the sun with little food.

4.2.2 Mauka (also masungu) and nyankhwa

4.2.2.1 Symptoms of mauka and Nyankhwa

Mauka (also masungu) and nyankhwa were other illnesses identified by the community as responsible for causing childhood fever. They are similar to one another in aetiology and

¹² For the purpose of the IDIs, villages were considered to be HTR if they were more than a 15 minute walk from a health facility.

presentation. There are also commonalities between the symptoms of these illnesses and those of *malungo*. For instance, in addition to fever, vomiting and weakness were frequently described as signs of *mauka*, and both *mauka* and *nyankhwa* were said to cause diarrhoea. The main distinguishing sign of these illnesses though, was the presence of symptoms in the mother - for one of these illnesses to be the cause the mother must be experiencing symptoms in addition to the child's fever. *Mauka* was said to cause flat rash-like sores inside the mother's vagina or anus (the condition can also affect men, but without consequences for children). *Nyankhwa* was described by some participants as a type of *mauka*. The main difference is that the mother suffers from growths rather than rashes, and these are located externally, generally between the vagina and anus, but also on the buttocks. Participants explained that if treatment is sought from a traditional healer *mauka* is scraped off using a razor blade, whereas *nyankhwa* is large enough to be held and cut off. A number of participants explained that when children suffer from *mauka* they close their eyes, or refuse to look at the mother during breastfeeding. At one point this was explained as being caused by the child's anger towards the mother, for having caused the illness.

4.2.2.2 Causes of mauka and nyankhwa

Mauka was described as emanating from the mother, who passes it onto her child through breastfeeding. The child develops fever through feeding on the infected milk. The women explained that they do not withhold breast milk if they are suffering from mauka or nyankhwa, but rather they treat the illness.

4.2.3 Tsempho

4.2.3.1 Symptoms of tsempho

Tsempho was also described as being similar in presentation to *malungo* with symptoms overlapping those of *mauka* and *nyankhwa*. Fever, coughing, weakness and diarrhoea were frequently reported signs, although later symptoms of *tsempho* are more distinct - the child was said to become thin, stunted and swollen. *Tsempho* was also thought to cause the child to suffer from anaemia.

4.2.3.2 Causes of tsempho

The cause of *tsempho* is well summarised in the following quote:

Tsempho occurs when we don't follow the customs and traditions as taught by our elders in our homes. Our parents teach us certain things that we must do in our houses when a man, a woman and their child share the same room.

(Younger women's FGD, HTR, 08/10/10).

The various taboos that were believed to result in illness, if broken, are complex; and a number of them were mentioned. They included the parents having sex before the end of the traditional process surrounding the funeral of a relative, having sex away from the family home, or before the elders gave permission for the parents to have sex following the birth of the child (after the six months period of abstention). The father having sex with another woman was also said to cause the child to develop *tsempho*. Participants described protective medicine that the child could be bathed in to protect them from *tsempho*. However participants explained that if this was not used, the child was at risk of developing the illness when the father returned from the other woman and touched the child. Infidelity of the mother was also mentioned as a cause, although less frequently. The women claimed that since they understood the difficulties of raising a child, they were less likely to take such risks with the child's health. Finally, there were important regulations regarding the positioning of the child in the bed (on the mat) which if broken were perceived to cause *tsempho*: the child should not be between the parents (specifically following sex), and neither parent should pull the child towards them.

4.2.4 Other perceived causes of childhood fever

In addition to the illnesses described above, children were said to suffer from simple fever, not attributed to any particular disease, and not requiring more than shop bought treatment. Causes of this type of fever included the weather (too hot or too cold), excessive crying, and teething. Parents look not only at the fever, but also for other signs that may help them ascertain the cause of the fever. For instance:

That's what I told you at the beginning, that we look at the way the fever began. It might be that the child has been in the sun for the whole day on a journey. We know that the fever is caused by the heat of the sun and we know that it is not a serious matter, so we just buy any other drug, not a malaria drug.

(Male FGD, HTR, 07/10/10).

and:

Interviewer: Ah ok. When you see that the child has fever, how do you know that the

fever is caused by teething?

Respondent: We know because when we make the child open his mouth, we find that the

gums are swollen.

(Younger women's FGD, HTR, 14/01/11)

Flu or cough and measles were also understood to cause fever.

Witchcraft (*ufiti*) was thought to be responsible for childhood fever. Witchcraft itself was not described as a disease nor said to cause specific diseases, but it was described as a mechanism through which individuals may develop sickness. Illness caused by malaria was said to differ from that caused by witchcraft. However participants explained that illness caused by witchcraft can mimic malaria; in such cases participants relied on the failure of hospital treatment to confirm the cause. For this reason treatment failure was often described as leading to the suspicion that someone was responsible for causing the illness (section 4.4.3.3). In all examples provided perpetrators of witchcraft were relatives; grandmothers (especially paternal) were usually mentioned as suspects but the uncle and less frequently the father were also mentioned. The following quote demonstrates how individuals begin to suspect bewitchment after attempts of health facility treatment have failed:

Still, the child does not recover, that is when we make a decision to look for help from elsewhere; sometimes we just go to the traditional doctor to seek assistance. We begin to suspect our grand-parents to have bewitched the child (Men's FGD, NTH, 17/01/11)

Suspicions of witchcraft were also said to arise in situations where hospital doctors find nothing wrong with the child.

4.3 Responses to childhood fever - results of the household survey

The first part of this chapter has described the various interpretations of childhood febrile illness. The remainder of the chapter describes how individuals respond to the signs of illness, and change their interpretation of illness as it progresses. This section presents household survey participants' responses to childhood fever; the following section compares this to the results of the qualitative data collection (section 4.4).

Primary caregivers taking part in the household survey were asked about the sources of care they utilised during their child's recent febrile illness. Figure 4.1 presents the results of sources of care utilised in the first and second instances. The majority of individuals participating in the household survey had attended at least one source of care, with only 13% (133/1040) not attending any source of care. Public health facilities were the most frequently utilised first source of care, attended by just over half of the participants (580/1040) of individuals. A small proportion of individuals went on to attend a second source of care. The majority of those who utilised a second source of care had initially attended either a public health facility or a shop, and the majority of switches were between

these two providers. Despite the number of individuals attending a second source being greatest for those initially attending a public health facility, the total proportion making a return visit or attending another source of care was small (5%).

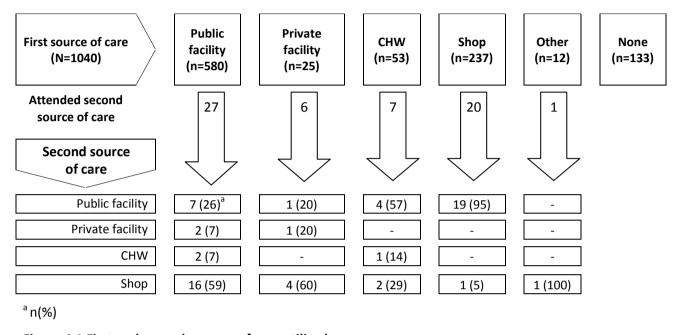


Figure 4.1 First and second sources of care utilised

4.4 Responses to childhood fever - Results of the qualitative data collection

Individuals' belief structures act as barriers or enablers to treatment; community perceptions around when it is appropriate to seek care, and from where, determine what action, if any, is taken. External factors, such as accessibility or finances, also promote or inhibit access. Both types of issues must be investigated in order to provide a complete picture of access to treatment. The remainder of this chapter focuses on beliefs around appropriate responses to childhood illness, while the latter issues are described in chapter 5. The first step in examining belief structures around treatment-seeking is to establish how individuals decide whether it is necessary to seek care. In order to investigate this, FGD participants were asked to describe signs that would prompt them to seek care outside the home. This was supported with data from IDIs, where participants were asked why they decided to attend or not to attend a source of care during their child's recent febrile episode. The FGDs and IDIs were then used to explore how caregivers' responses changed throughout the course of an illness episode, and why.

The analysis of these data led to the development of a three-phased overview of the treatment-seeking process, presented diagrammatically in figure 4.2 below and presented in the following sections. Initially caregivers use the assessment phase to establish whether care seeking is necessary (section 4.4.1). If deemed necessary they then go on to seek care outside of the home (section 4.4.2). After this caregivers must assess whether the treatment has been successful and respond accordingly if not (section 4.4.3). This apparently linear and well-defined treatment-seeking pathway is in fact a complex and dynamic process which may be confusing for caregivers who are constrained by external factors (section 4.4.4).

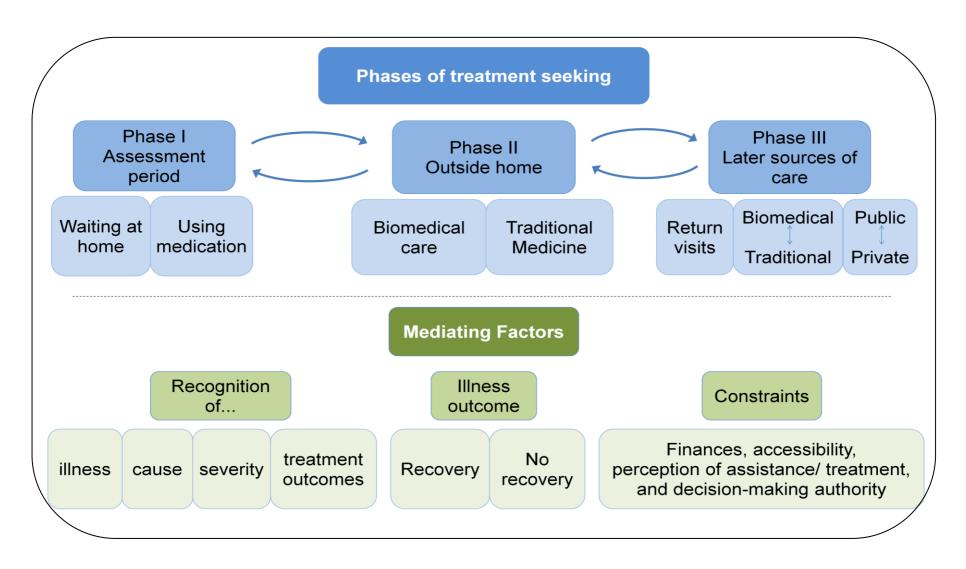


Figure 4.2 Diagrammatic representation of the treatment-seeking process

4.4.1 Phase 1: Assessment period

The usual first step after recognition of illness is to assess its severity. This assessment period is presented in figure 4.2 as Phase 1 of treatment-seeking. Participants frequently differentiated between mild forms of illness, which could be treated using home remedies, and severe forms requiring hospital assistance:

Yes, the extent of the sickness. If he is very sick, we rush to the hospital because a child can be sick and be able to play. Yet another child would be too sick to eat or play; he just sleeps. It won't help to buy drugs from a shop; we'd better take the child to the hospital. (Younger women's FGD, NTH, 22/01/11).

This finding is supported by the results of the household survey which showed that children suffering from illness considered to be more serious were more likely to be taken to a health facility (chapter 5.2.2).

At times the process of assessing illness severity was described as a period of waiting. More often however, waiting was combined with some form of action such as using purchased drugs or bathing the child in an attempt to cool them. Participants from all of the FGDs described a period of waiting and using shop bought drugs before deciding to take the child to the hospital if there was no improvement. Some individuals explained that at times various types of shop bought drugs are used in a single episode, and that the assessment period may continue for several days. It is when symptoms fail to resolve, or worsen that hospital care is sought:

We try to see, as I said before, whether or not it is real malaria. When he starts in the evening, we wait till morning to see how he will spend the night and in the morning when we see that the fever is still there, we will try some small drugs like children's **cafenol**¹³ or **panado**¹⁴ so that if it is ordinary, simple fever, then the drugs will work and the fever will cease. When we try the children's **cafenol** and the fever does not stop it or it increases, then we think of taking the child to the hospital.

(Men's FGD, HTR, 07/10/10)

And:

In this village we have a **grocery**, where some drugs are sold. When the child has fever, we don't just rush to the hospital. Sometimes we buy **panado** from the **grocery** and administer it to the child; but then when we administer it in the morning and again in the afternoon without any change, then the following morning, we decide to go to the hospital.

(Younger women's FGD, HTR, 08/10/10)

¹⁴ Panado is a South African brand of paracetamol

¹³ Cafenol contains paracetamol and caffeine

Recognition of illness severity was found to be challenging for participants. All of those who had taken part in an IDI had observed that the child had fever, and in some cases other symptoms, and all of the children had received positive malaria test. The majority of those who had not attended a hospital reported having not done so because the child's illness did not appear serious; in most cases the fact that the child was still playing was taken as a sign that illness did not require hospital intervention. Waiting to see how the illness progressed was given by others as a reason for not yet attending a health facility. A number of those who had not taken their child to a health facility had used shop bought drugs, with some commenting that they would have taken the child to the hospital if the illness persisted.

Recognition of illness severity, and recognition of malaria as a cause are particularly challenging at the onset of illness; these were reported to be issues in all the FGDs. Caregivers therefore rely on lack of recovery after the initial period of assessment as an indicator that malaria is the cause, and this prompts attendance at the hospital. Caregivers explained that it takes them between two and five days to recognise their child has malaria, and in some cases longer. This period of waiting and testing means that at times the illness is quite serious by the time they attend the hospital. Other reasons for not attending a health facility until the illness is serious include the fact that at times caregivers are not aware that the child is unwell until the illness has progressed, and that the illness may develop so rapidly that it becomes serious before the caregiver has chance to respond.

It happened to me once. I have a child aged seven. When he is in trouble, sometimes I don't realise that he has malaria but I just realise that he has fever, perhaps he is vomiting and at the same time, I realise that the child has collapsed. Then I know that it must have started long ago but I didn't know. I just see a sudden attack. Sometimes I just carry him on my back and rush him to the hospital.

(Young women's FGD, NTH, 22/01/11)

Caregivers described that in most cases this period of assessment was carried out, however they also stressed that in situations where an illness was recognised to be severe they would go straight to the health facility rather than waiting:

Interviewer: Oh, so it all depends on the manner in which the malaria develops?

All: Yes

Interviewer: When it's serious?

Respondent 1: *The same night*

Interviewer: *Ok, when it's mild?*

All: We will start off the next day in the morning

Respondent 2: We will go tomorrow

(Older women's FGD, HTR, 23/01/11)

4.4.2 Phase 2: Seeking care outside the home

If symptoms do not resolve after the assessment period, individuals move on to Phase 2 of treatment-seeking. This involves seeking care outside the home. Individuals must decide which source of care to attend. A large proportion (>60%) of individuals taking part in the household survey had attended a source of formal healthcare (public or private health facility, or CHW). It is perhaps unsurprising therefore that during qualitative data collection all of the symptoms described as those of malaria were given as signs that would prompt caregivers to seek formal healthcare. This included those symptoms overlapping with traditional causes of illness. Fever, particularly if high or combined with one or more another symptoms, and weakness were most frequently given as signs that would prompt attendance at a formal health facility. The hospital was considered to be the appropriate place to receive treatment for malaria:

When we see that the fever is actually malaria, we go to the hospital whether it is evening, afternoon or morning.

(Male FGD, NTH, 17/01/11)

A *sing'anga* (traditional healer - *asing'anga* plural) was perceived to be the appropriate place to receive treatment for illness caused by witchcraft, *tsempho*, *nyankhwa*, and for the most part *mauka*. Further a*sing'anga* were thought to be the only ones capable of identifying witchcraft as the cause. Despite this, some members of all the FGDs stated that if the illness does not resolve after the assessment period, then care will be sought from a formal health facility. Reasons for attending the hospital first, rather than visiting a traditional healer included the potential for malaria to progress rapidly, leading to death; difficulty in recognising traditional causes of illness (section 4.4.3.3); and the importance of biomedical diagnosis (chapter 5.5.2):

But first, it is important to rush to the hospital before going to the traditional healer because the traditional healer may tell lies since he doesn't have any **machine** for diagnosis, he will just give you lots of medicine and that may create many problems. That's why it is really important to first of all rush to the hospital for diagnosis.

(Men's FGD, NTH, 06/10/10)

IDI participants who had sought care from a health facility did so for similar reasons: they understood the child's illness to be caused by malaria, and this to be treatable in a hospital and not

by a traditional healer; and because delays caused by attending a traditional healer may otherwise have lead to the loss of the child's life if the illness was cerebral malaria. However, participants described situations where it was possible to recognise that an illness required assistance from the sing'anga in the first instance, rather than from a health facility. The main example of this was when the child suffers fever and the mother 'an itch' at the same time (mauka and nyankhwa).

4.4.3 Phase 3: Later responses to childhood fever

This section concludes the chapter by exploring how individuals decide that further care seeking is required (section 4.4.3.1). Changes in the way different sources of care are utilised as the illness progresses are presented, with descriptions of how this is influenced by changes in beliefs about, and understanding of the illness (section 4.4.3.3). Finally section 4.4.4 attempts to highlight the complexity of the treatment-seeking process and describe 'negative cases' that do not fit neatly into the three-phased overview.

In the household survey only a minority of children were found to have attended a source of care outside the home more than once (section 4.3). However repeat visits and switching between providers was commonly described in FGDs and IDIs (sections 4.4.3.2 and 4.4.3.3). Attendance at a second source of care is not necessarily a sign of treatment failure. IDI and FGD participants explained that they are frequently advised to obtain shop bought paracetamol to take with LA. In some cases individuals outlined their belief that LA cannot work properly unless combined with paracetamol. Treatment failure was however a major theme arising from the qualitative data collection, and has important consequences. Failure of the first source of care may lead to progression of the severity of the illness, cause both time related and out-of-pocket costs, result in reinterpretation of the cause of illness associated with moving from biomedical to traditional sources of care (section 4.4.3.3), and may impact on perceptions of treatment and assistance received (chapter 5.5).

4.4.3.1 Recognition of treatment failure

Caregivers rely on lack of resolution of, or increased severity of symptoms as indicators of treatment failure. In contrast participants described reduced fever, increased strength, eating and playing as signs of recovery. The treatment-seeking process was not linear and caregivers described how after attending a source of care outside the home they would return to the assessment stage (Phase 1), where a period of waiting would be used to assess whether the treatment was successful. This was described after using shop bought drugs, hospital treatment and treatment by traditional healers. In

several of the FGDs, individuals explained that it was not appropriate to return to the hospital before completion of the medication. Some individuals felt that repeat visits were appropriate as soon as medication was completed, whilst others felt a number of days should be waited after completion.

4.4.3.2 Return visits

Repeat visits to the health facility were a major theme in the FGDs. Some members of all the FGDs indicated that they usually try repeat visits before trying other methods. Participants emphasised that they may make several trips to the hospital before searching out other methods. In addition four out of the 12 IDI participants who had attended a health facility made a repeat visit. A minority of individuals mentioned switching from public to private health facilities if treatment was unsuccessful. Various reasons were given for returning to the hospital, rather than seeking care from elsewhere. These included getting another opinion, because hospital treatment is free, so others can see you did all you could, to get another (compatible) drug, and so the doctors realise the severity of the illness. A minority of individuals suggested that they would switch to the traditional healer rather than make a return visit. Reasons for not returning to the health facility included: receiving a negative malaria test at the first visit, which some considered to indicate a traditional illness; fear of receiving the same drug (LA) again (chapter 5.5.1.4), and; no improvement upon completion of medication, felt to indicate a traditional cause. The majority of references to repeat visits described such visits taking place before attending a traditional healer. However this was not always the case; sometimes repeat visits were described as occurring after visiting a traditional healer. It should be noted that repeat visits were not limited to health facilities only, but repeat visits to shops and traditional healers were also described.

Return visits to the health facility were commonly described in FGDs, and a number of times such references were volunteered before probing into responses to treatment failure. In addition return visits were described by IDI participants. However in the household survey only seven out of 580 individuals who had attended a public health facility made a return visit (figure 4.1). It is difficult to interpret why so few individuals who participated in the household survey reported making a return visit to the health facility given that this was such a major topic in FGDs, however there are several possible explanations: Firstly it may be that the negative perception of care received from the hospital is more based on rumour than experience, in other words treatment failure may be less common than perceived. Secondly illnesses may be infrequently perceived to have traditional causes; discussion of treatment failure and repeat visits frequently followed probing into the recognition of traditional illnesses. This may have led to an over emphasis of treatment failure and

repeat visits. Thirdly participants may have been concerned that attendance at a traditional healer would be looked at negatively, and chosen to describe this as behaviour they only undertake after attending a health facility. The following quote may demonstrate a sense of embarrassment related to attending a traditional healer:

Respondent 1: We go to the hospital again.

Interviewer: Alright, how about my mother over there?

Respondent 2: We go to the traditional healer.

Interviewer: Mmm mmmh, so we push **LA** aside since it is not effective?

Respondent 2: (Speaking in low voice)

Interviewer: What did you say? Please would you raise your voice?

All: (Laughing)

Respondent 2: When we administer drugs from the hospital and we don't see any

improvement, we try our traditional medicine.

(Young women's FGD, HTR)

The fact that only one individual in the household survey described seeking care from a traditional healer, whilst such practice was commonly described in FGDs, adds further strength to this argument. It is known that it is easier for participants to divulge perceived negative behaviour in a group rather than individual setting. Fourthly, at times participants appeared to refer to repeat visits as a way of shifting the conversation when they felt that they were being accused of irresponsible behaviour, and instead highlighting the effort they go to in order to ensure their child receives appropriate treatment. For instance, in the following quote the participant appears to be avoiding a question they perhaps felt implicated them in the receiving of delayed treatment by children:

Interviewer: How long does it take us to realise that perhaps our child has malaria?Participant: Sometimes he has fever and vomits and so we know that perhaps it is

malaria. When he is tested, sometimes he is given ${f LA}$ and when we see that

LA is not good for the child, we go back and explain and the treatment is

changed and then he begins to improve.

(Young women's FGD, NTH, 22/01/11)

A final possible explanation is that repeat visits to health facilities may have been under-reported in the questionnaire due to fatigue (chapter 3.4.3).

4.4.3.3 Reinterpretation of illness

As mentioned above, treatment failure results in individuals re-evaluating the illness and considering other causes. Individuals do not base their interpretation of illness cause solely on the symptoms seen in the patient. Treatment outcomes were described as being highly valuable in the process of

recognising the cause of an illness; individuals arrive at their final perceived causes of illness through a process of reinterpretation, or trial and error. If treatment is successful there is no need to reassess the illness, as the cause has been found. The following quote demonstrates how the failure of home treatment combined with the success of hospital treatment enabled the participant to recognise malaria as the cause:

Interviewer: Alright, how would you know that the fever is caused by malaria?

Respondent: ...Well, when we apply medicine, sometimes it doesn't yield anything,

therefore, we take the child to the hospital and the doctors know, they test him and give him medicine. When the doctor tells us to administer the drug

in the morning, at noon and in the evening, we just realize that the

following, the child has started recovering.

(Older women's FGD, HTR, 08/10/11)

When hospital treatment is unsuccessful individuals begin to doubt malaria as the cause. The recognition of *mauka* was a frequently given example of this reinterpretation process. Following the failure of biomedical treatment the mother may be asked whether she is suffering from vaginal illness. This may be done either at the hospital, within the village or alternatively she may herself link the two illnesses. If she is found to have such illness then the next stage is to treat the mother, either with biomedical or traditional treatment. Treatment failure was described as being particularly important in the process of recognising witchcraft or *tsempho* as the cause, as these illnesses were not considered to be readily identifiable during the initial stages of illness.

When it's fever, we can't tell whether it is caused by witchcraft or just mere fever. (Younger women's FGD, NTH, 22/01/11)

It was frequently described that it is only after treatment at the hospital fails that these are recognisable. Individuals suggested that when hospital treatment is successful these illnesses, along with *mauka*, are not considered; failure of biomedical treatment signals that it is time to attend a traditional healer.

Interviewer: Alright, how can we know that it is witchcraft that has caused fever in the

child?

Respondent: Ah, we realize this after visiting the hospital. When the child is given **LA** or

panado, we go back home and administer the drug. At times, the drugs worsen the illness and the father decides to take the child to the traditional

healer who casts lots to find out who bewitched the child. Sometimes the

magician is able to tell that it is not malaria but witchcraft. He may mention the uncle or the father as the wizard who bewitched the child. In this case, he makes a plan to cure the child.

(Older women's FGD, HTR, 08/10/11)

And:

Interviewer: You mentioned various things that cause such things. I therefore, wanted to

say that among the various causes of fever, you mentioned fever, nyankhwa,

mauka. How do you know that the fever is caused by malaria and not mauka

or nyankhwa?

Participant: When the child has fever, we take him to the hospital and when he is tested

and found to have malaria, he is given treatment. When he's treated, he

recovers but there are cases whereby the treatment doesn't work. When it

is the case, we go back for further treatment and this time when it doesn't

yield anything, we consult the elders and tell them that the child is unwell.

Then we go to traditional doctors to do that.

(Younger women's FGD, NTH, 22/01/11)

Treatment failure brings with it the suspicion that somebody is to blame for the child's illness, either through their unfaithfulness (a parent) or through engaging in witchcraft (usually a relative). However, as for malaria, it was frequently cited that proof that either *tsempho* or witchcraft was the cause comes from successful treatment, in this case by the traditional healer.

4.4.4 Additional complexity

The three-phased process of treatment-seeking as described in this chapter involves some simplification. The process of treatment-seeking is not clear-cut, neither is it the same for all individuals. As previously hinted, caregivers experience a number of constraints which influence the treatment-seeking process; these are described in more detail in chapter 5. For instance, the involvement of other community members also impacts on the treatment-seeking process - relatives and village elders can be influential (chapter 5.4). Moreover caregivers are not the sole individuals following a process of trial and error. The process of reinterpreting the illness following treatment failure is also carried out by healthcare staff, who may try different treatments, such as switching from an antimalarial to an antibiotic. The following paragraphs attempt to address some of the complicating factors which are not fully accounted for in earlier descriptions within this chapter. They attempt to highlight the chaotic nature of the process individuals go through.

4.4.4.1.1 A process driven by constraints

External constraints to access force caregivers to make treatment-seeking decisions that minimise associated challenges. The assessment phase was described as the period during which caregivers attempt to establish the illness severity and the need for care. Shop-bought drugs may be used during this phase. However at times shop-bought drugs were used as a result of negotiating challenges of access, rather than as a purely strategic method to assess illness severity. For instance a number of references were made in FGDs to the use of shop bought drugs at night-time to control the fever until the child can be taken to a health facility. This was also described by IDI participants who had attended a health facility. A further example that shop-bought drugs are not only used as part of the assessment of illness severity comes from references which highlight that caregivers do not always appear satisfied with their use; similar comments about the use of expired shop-bought drugs were made in both male FGDs:

Respondent 1: Especially at the **grocer's** in our villages, we are just given drugs which perhaps **expired** long ago, and sometimes these drugs are kept in hot places,

not good for drugs.

Interviewer: So we just buy?

All: *Yes!!*

Respondent 2: We just buy them. By the time we go to the hospital, it means we have failed. Let's be honest, before we reach the hospital, we try all ways available and when we fail, it's when we go to the hospital.

(Men's FGD, HTR, 07/10/10)

During Phase 3 of treatment-seeking individuals respond to treatment failure, which may involve reassessing the cause of illness and switching providers. However it is an oversimplification to imagine that when treatment fails, individuals simply change their beliefs about the cause of the illness. Individuals work through their treatment options in an order that attempts to minimise costs experienced, as well as making decisions based on which source of care is perceived to be most suitable. At times a source of care becomes more suitable because they have given up on the previous one, rather than because they have reinterpreted the illness:

We go again and when we are given **LA** again and there is no change then we make **plans** to see other people to help us. At the hospital we are told that the only available drug is LA, so, as beggars, we do not have anything to say.

(Men's FGD, NTH, 17/01/11)

4.4.4.1.2 Traditional versus biomedical illnesses: are the distinctions really clear?

In the majority of cases it seems clear that the choice between traditional and biomedical sources of care depends on the interpretation of illness cause, however this does not fully account for the pluralism seen. Individuals may switch between traditional and biomedical sources of care and do not categorise all illnesses as only having a traditional or biomedical cause. The following quote demonstrates the use of both traditional and biomedical sources and the development of explanations of illness which combine both:

When the mother has mauka removed, what remains is just ordinary malaria that is treated using **LA** and if the child doesn't recover, all the mother does, is to go to the hospital for change of treatment or to get another **dosage**.

(Younger women's FGD, NTH, 22/01/11)

Another example of such syncretism was the belief that children may require hospital treatment for anaemia after receiving traditional treatment for *tsempho*. Further evidence that the division of illnesses into traditional and biomedical may not be relevant came from one of the male FGDs. The men suggested that biomedical researchers should do more to develop cures for illnesses with traditional names.

There was disagreement among the participants about the appropriate treatment of mauka; some individuals argued it could only be treated by a traditional healer, while others stated that it could also be treated at the hospital. The following quote demonstrates the blurring of boundaries between biomedical and traditional theories, with regard to *mauka*, and how healthcare workers' interpretation and management of childhood fever may further complicate matters:

Sometimes when the child has fever, we can't tell if it is mauka and we go to the hospital for the treatment of the fever. There, we are given **treatment** depending on their findings. We may be told to administer the drug for **3 days** and at the completion of the dosage, we find that there is no improvement. Usually, we go back to the hospital and explain that the medicine has not been effective.

The doctors then, tell us that there is nothing wrong with the child and usually they ask if the mother doesn't feel itching in the private parts and they suggest a certain sickness other than mauka and so they administer some pills to be applied in the private parts.

(Younger women's FGD, NTH, 06/10/11)

This quote demonstrates support of traditional beliefs by some biomedical personnel. In fact there were references to biomedical staff actually referring individuals to traditional healers, such as in the following quote which refers to illness caused by witchcraft:

When we take him to the hospital, nothing changes and some loving doctors will tell us that there is nothing they can do and they give us a choice to stay on in the hospital or to go back home and seek assistance from the traditional healers.

(Younger women's FGD, NTH, 06/10/11)

4.4.4.1.3 Ending the process

Phase three of treatment-seeking is possibly the most complicated to understand and the most challenging for caregivers. It involves making return visits to, and switching between providers. Caregivers must decide when to make further visits and when these are no longer necessary. Most challenging of all, individuals must decide what to do in the case of prolonged illness. As previously outlined, many individuals claimed they would make (perhaps several) repeat visits to the health facility if initial treatment fails, followed by attending a *sing'anga*. In a number of FGDs individuals stated that if they had been to the hospital with no success and then the traditional healer had failed, then they would give up:

Interviewer: So when you go to the hospital for the first time and it doesn't help, you go

again and it fails again-

Respondent: Then we go to the traditional healer.

Interviewer: You go to the traditional healer, and when he fails?

Respondent: We become stranded, we really don't have a solution.

Interviewer: Where do you go?

Respondent: Whatever happens, we give in (Laughter).

(Men's FGD, HTR, 07/10/10)

There were surprisingly few references to religion throughout the data collection. The majority of references to either turning to prayer or depending on God were following failure of both biomedical and traditional sources of care. These references seem to contrast to the idea of giving up. Individuals stated that when all else has failed they would depend on God, this would give them hope and they would still be actively trying to do all for their child by praying:

No. I wanted to just add that we do not just give up, but we commit everything in the hands of God, whether or not we sinned against him. We expect anything to happen.

(Men's FGD, NTH, 17/01/11)

Although severe illness was not investigated, it is without question that not all individuals will recover after Phase three of treatment-seeking. It is notable therefore that despite probing into treatment failure, there were few references to death. *Mauka, tsempho* and *ufiti* were described as potentially leading to death and in two of the FGDs (both with younger women) individuals stated that death may result from attempting to treat these illnesses at the hospital. Equally though delays caused by attending a traditional healer were said to potentially lead to death if the child had severe malaria:

Whereas the witchdoctor will tell you to cut incisions all over the body of the child; in fact you just delay yourself and if the child has cerebral malaria, you might as well lose the child (IDI, attended a health facility, HTR, 06/01/11)

The process of reinterpreting illness following treatment failure was discussed above (section 4.4.3.3). An example that treatment failure does not always lead to a reconsideration of the cause of illness is the case of witchcraft (*ufiti*) - illnesses caused by *ufiti* may not be successfully treated by a traditional healer, even if bewitchment is the cause of illness. This occurs if, for instance, the traditional healer is a fake, or if the spirits decide the child will not recover. In this way *ufiti*, in particular, may provide a kind of fall back on explanation for unsuccessful treatment.

4.5 Conclusion

An accurate understanding of individuals' perceptions of the causes of malaria symptoms is essential to our understanding of why individuals respond the way they do. This chapter has explored perceived causes of and appropriate responses to childhood febrile illness. It has also used complementary data from the household survey to demonstrate how individuals respond during actual febrile episodes. Together this provides a foundation to our understanding of the barriers and enablers to accessing appropriate treatment, which are explored in the following chapter.

The disease *malungo* was described as closely fitting the clinical definition of malaria. It was understood, for the most part, to be caused by mosquitoes. However the word *malungo* was at times used interchangeably with the phrase *kutentha thupi* to simply mean fever, a symptom of various illnesses. Other illnesses which were reported to cause childhood fever included *mauka* and *nyankhwa*, diseases of the female reproductive organs said to be passed through infected breast milk; *tsempho*, childhood illness perceived to be caused by breaking cultural taboos; measles; and cough and flu. Participants also perceived witchcraft (*ufiti*) to be responsible for childhood febrile illness. In general participants had a good understanding of the signs, symptoms and causes of malaria. Further, attendance at a formal health facility was considered by most to be the appropriate response to febrile illness, which was frequently perceived to be *malungo* at the early stages.

The majority of individuals who participated in the household survey had attended a source of care outside the home during their child's recent febrile illness. Public health facilities were the most frequently attended. A small number of visits were made to a second source of care, and the majority of switching was between public health facilities and shops. These results correlated well with the findings of the qualitative data analysis, with the exception of two main findings: Firstly household survey participants made very few repeat visits to a public health facility, whereas this was frequently described during qualitative data collection. Secondly, only one participant in the household survey said they had visited a traditional healer, whereas this was commonly described during qualitative data collection. Potential explanations for these discrepancies were highlighted and are discussed in more detail in chapter 6.

The qualitative data demonstrates a three-phased process of treatment-seeking (figure 4.2). Recognition of illness is followed by an initial assessment period (Phase 1). This involves waiting at home and using shop bought drugs and other methods to reduce the fever. Illness considered serious, or which fails to resolve is generally taken to a health facility (Phase 2). Caregivers return to the assessment phase while they establish the outcome of treatment. If the illness continues or progresses caregivers move to Phase 3. This usually involves returning to the health facility; however, continuation of the illness may lead caregivers to consider alternative causes of illness, such as *mauka*, *nyankhwa*, *tsempho* or *ufiti*, for which care is usually sought from a traditional healer (*sing'anga*). The decision to switch from one phase to the next is mediated by the treatment outcome, i.e. whether or not the child recovers; the ability of the caregiver to recognise whether the child has recovered; and changes to the recognised cause of the illness, or reinterpretation, based on observed symptoms and the outcome of the earlier phases of treatment.

The process of treatment-seeking is not always so well-defined; it is often a complex and dynamic process, involving switching between multiple sources of care, both biomedical and traditional. Individuals develop theories which combine biomedical and traditional beliefs in a syncretistic manner. Health facility staff contribute to this syncretism through suggesting traditional causes and treatment. At times individuals appear to try all of their available options, driven by external constraints and a need to find a solution, rather than by changes in the perceived cause of illness. Decision-making becomes more difficult as the available options become exhausted. Failure of both biomedical and traditional sources of care causes some individuals give up and sit at home, while others turn to God and trust everything to him.

This chapter has summarised individuals' interpretations of and responses to febrile illness. There are a number of reasons why it is important to understand how caregivers respond to illness: an understanding of current behaviours is necessary for monitoring the appropriateness of health interventions; to aid in the design of new interventions; and as a foundation to any exploration of external constraints to accessing appropriate treatment.

Chapter 5

Barriers and enablers to appropriate treatment

Chapter 5 Barriers and enablers to appropriate treatment

5.1 Introduction

The previous chapter described individuals' interpretations of and responses to febrile illnesses. However an accurate understanding of the biomedical model of malaria, or other febrile illness, is not sufficient to ensure individuals attend a health facility promptly, or use the treatment they are given. This chapter draws on findings of both the qualitative and quantitative data collection to explore how accessibility of formal health facilities, finances, treatment-seeking decision-making and perceptions of health facility care influence the responses described in chapter 4, and act as barriers or enablers to access to appropriate treatment.

Section 5.2 explores how geographic location influences attendance at a formal health facility. Section 5.3 presents the costs experienced by households during the course of childhood febrile events, and how these are influenced by location and season. It also goes on to explore decision-making regarding the use of finances at household level. Section 5.4 describes how decisions regarding treatment-seeking are made at household level. This section focuses on the influence of gender and generational roles. Section 5.5 concludes the chapter by describing participants' perceptions of health facility care, as a potential determinant of whether individuals choose to attend the health facility and make use of medications provided.

5.2 The accessibility of formal health facilities

A household cross-sectional survey was used to quantify the influence of living in a village deemed by the MoH to be HTR, on attendance at a formal health facility. The results are presented in the following sections. Section 5.2.1 presents an overview of the background characteristics of the household survey participants. Sections 5.2.2 and 5.2.3 then explore how distance influences attendance at a formal health facility. Section 5.2.4 responds to the question of whether the presence of CHWs in HTR villages improves access to formal healthcare? Finally section 5.2.5 presents qualitative data relating to the influence of access on attendance at a formal health facility.

5.2.1 Background characteristics of household survey participants

Data collection was carried out during July 2009 (dry season) and February 2010 (wet season). A total of 1,181 households were surveyed in the dry season and 1,397 in the wet season. None of the eligible households refused to participate. Forty-one percent (482/1181) of households in the dry

season and 35% (484/1397) in the wet had at least one child under the age of 10 years who had experienced a febrile event in the two weeks prior to the survey and for whom a suitable caregiver could be found. At the time of the surveys, 47 children in the dry season and 60 during the wet were suffering from reported fever on the day of the survey. Forty-five percent (186/416) of individuals taking part in the survey during the wet season had previously taken part in the dry season survey.

Table 5.1 shows the participants' background characteristics. Dry season and wet season data are shown separately for those living NTH and those living in HTR villages. However there were no statistically significant differences according to season, therefore dry season data only is summarised in the following paragraphs. The proportion of children of each sex did not differ by area; 51% percent (138/169) of recently febrile children living near the hospital and 53% (139/262) of those living in HTR were female. The majority of children sampled in both areas who had suffered a febrile event in the previous two weeks were less than five years of age: In the dry season 61% (160/262) of those in HTR villages and 65% (176/269) of children living in NTH villages were less than five years of age. Mothers of those living in HTR villages had attained lower levels of education compared to those in NTH villages (Dry: P=0.06). In the dry season survey, 33% (87/262) of mothers living in HTR villages had no education, 56% had primary education and 10% had secondary or greater. Twentythree percent (63/269) of mothers in NTH villages had no education, 57% had primary education and 20% had secondary education or greater. Those living NTH tended to occupy the higher wealth quintiles, whilst those living in HTR villages tended to occupy the lower wealth quintiles (Dry: P=0.002). Twenty-nine percent (76/262) of those in HTR villages were in the lowest wealth quintile, 25% in the second and third, 15% in the fourth and 6% in the highest. This compared to 11% (29/269) of those living in NTH villages in the lowest wealth quintile, 15% in the second and third, 25% in the fourth and 34% in the highest.

Caregivers' perceptions of the severity of the child's illness were recorded as mild, moderate or severe. No differences were seen in perceived severity of illness according to geographic location. Fifty-one percent (134/262) of children living in HTR villages suffered a mild illness, 30% a moderate illness and 19% a severe illness. Fifty-eight percent (155/269) of children living in NTH villages suffered a mild illness, 30% a moderate illness and 12% a severe illness. Only one death occurred from reported recent febrile illness (wet season data available only). Among children who attended a health facility, mean illness length was longer for those in HTR villages than for those NTH (Dry: 5.8 vs. 4.9 days, P=0.09; Wet: 5.6 vs. 4.8 days, P=0.03). However illness length did not differ between seasons.

Table 5.1 Association between participant background characteristics and village of residence

	Dry season			Wet season			
Background characteristics	≤5km from Hospital (%) n=269	Hard-to-Reach (%) n=262	P ^a	≤5km from Hospital (%) n=263	Hard-to-Reach (%) n=246	P ^a	
Child Sex							
Male	131 (49)	123 (47)		138 (52)	126 (51)		
Female	138 (51)	139 (53)	0.57	125 (48)	120 (49)	0.75	
Child Age							
<5 years	176 (65)	160 (61)		175 (67)	157 (64)		
5-10 years	93 (35)	102 (39)	0.12	88 (33)	89 (36)	0.48	
Maternal Education							
None	63 (23)	87 (33)		68 (26)	87 (35)		
Primary	153 (57)	148 (56)		159 (60)	145 (59)		
Secondary +	53 (20)	27 (10) ^b	0.06	36 (14)	14 (6) ^b	0.03	
Wealth Quintile							
1 (Lowest)	29 (11)	76 (29)		31 (12)	68 (28)		
2	41 (15)	66 (25)		47 (18)	51 (21)		
3	41 (15)	65 (25)		48 (18)	63 (26)		
4	68 (25)	38 (15)		57 (22)	44 (18)		
5 (Highest)	90 (34)	17 (6)	<0.01	80 (30)	20 (8) ^c	0.01	
Severity of Illnes	ss ^b						
Mild	155 (58)	134 (51)		132 (50)	111 (45)		
Moderate	81 (30)	78 (30)		93 (35)	88 (36)		
Severe	31 (12)	49 (19)	0.11	38 (15)	46 (19)	0.24	

^aF test for heterogeneity or trend based on logistic dose response, with adjustment for clustering in survey design; ^bMissing data - four individuals did not know or remember the severity of the illness; ^cValues add up to greater than 100% due to rounding errors

Table 5.2 shows the breakdown of the asset ownership data. There were some notable differences between seasons; use of piped water among those living NTH decreased during the wet compared to dry season. This was found to be due to intermittent electricity supply during the wet season and therefore lack of ability to pump water. The largest differences between the two areas was also in water supply; a much greater proportion of those living NTH used piped water than those living in HTR villages, who mainly relied on water collected from a well. During the dry season 86% of those living NTH used piped water, which dropped to 51% during the wet season. By comparison 95% of those in HTR villages used water from a well in dry season, decreasing slightly to 87% in the wet season, when a few more used surface water (Dry: 3%; Wet: 8%), perhaps due to access issues. The district suffers from annual flooding during the wet season which impacts on the ease which individuals can travel. This is demonstrated by the increase in time to collect water experienced by both groups during the wet season. The Chikhwawa district is a predominantly rural farming area however ownership of agricultural land differed between the two areas; 76% of those living NTH and agricultural land compared to 97% of those living in HTR villages (dry season data). It is unsurprising therefore that a greater proportion of those living in HTR villages were farmers (86%) compared to those living NTH (64%) (wet season data available only).

Table 5.2: Household characteristics by village location and season

_	Dry se	ason	Wet season		
	≤5km from Hospital n=243 (%)	Hard-to- Reach n=239 (%)	≤5km from Hospital n=263 (%)	Hard-to- Reach n=221 (%)	
Sanitation			_		
Piped water	208 (86)	3 (1)	133 (51)	10 (5)	
Water from a well	35 (14)	228 (95)	130 (49)	193 (87)	
Surface water	0	8 (3)	0	18 (8)	
Time to collect water (mean minutes)	11	19	23	46	
Flush toilet	4 (2)	0	0	0	
Household own pit latrine	103 (42)	82 (34)	120 (45)	98 (44)	
Shared pit latrine	123 (51)	124 (52)	122 (46)	96 (43)	
No toilet facilities	13 (5)	33 (14)	21 (8)	27 (12)	
Household possessions					
Cell phone	105 (43)	40 (17)	100 (38)	42 (19)	
Table and chair(s)	74 (30)	33 (14)	55 (21)	35 (16)	
Bed with mattress	59 (24)	10 (4)	42 (16)	11 (5)	
Bicycle	111 (46)	105 (44)	130 (60)	87 (40)	
Floor material					
Cement ^a	76 (31)	18 (8)	41 (16)	10 (5)	
Livestock (mean number)					
Goats	0.8	1.1	0.5	1.1	
Pigs	0.3	0.1	0.4	0.1	
Cattle	0.2	0.3	0.2	0.6	
Chickens	4.1	4.4	3.4	4.3	
Agricultural land	Agricultural land				
Ownership	185 (76)	231 (97)	220 (84)	219 (99)	
Acres owed (mean) ^b	2.32	2.63	1.87	2.26	

^aAll other household floors were earth/sand

^bIncludes only households owning agricultural land

5.2.2 Influence of distance on attendance at a formal health facility

Table 5.3 shows the influence of distance on the likelihood of attending a formal health facility for a recent febrile illness during the dry season. In the dry season 69% (185/269) of those living in NTH villages attended a health facility compared to 48% (126/262) of those living in HTR villages. In the univariate model those living in HTR villages were significantly less likely to attend a health facility (OR 0.42, 95% CI 0.22-0.79, P=0.01) and the strength of this relationship increased after adjusting for the a priori potential confounders of child age, maternal education, socio-economic status and perceived severity of illness (Adjusted OR 0.35, 95%CI 0.18-0.67, P=0.004).

Children aged 5-10 years were less likely to be taken to a health facility for a febrile illness compared to those less than 5 year old in both the univariate (OR 0.49, 95%Cl 0.32-0.77, P=0.005) and multivariate models (AOR 0.49, 95%Cl0.31-0.79, P=0.007). Higher maternal education was associated with an increased likelihood of attending a health facility in the univariate model (Primary education: OR 1.17 95%Cl 0.82-1.67, P=0.36; Secondary: OR 1.63, 95%Cl 1.03-2.56, P=0.05). However this relationship was not found in the multivariate model. The more severe the child's illness, the more likely they were to be taken to a health facility in both the univariate (Moderate illness: OR 1.68, 95%Cl 1.25-2.26; Severe illness: OR 3.10, 95%Cl 1.66-5.80, P=0.001) and multivariate (Moderate illness: AOR 1.80, 95%Cl 1.26-2.57; Severe illness: AOR 3.97, 95%Cl 2.25-7.02, P<0.001) models.

Table 5.3: Factors associated with attendance at a formal health facility for a recent childhood febrile event during the dry season

Background characteristics	n (%)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI) ^a
Village of residence			
≤5km from Hospital	185 (69)	1	1
Hard-to-Reach	126 (48)	0.42 (0.22-0.79)*	0.35 (0.18 - 0.67)*
Child Age			
<5 years	218 (65)	1	1
5-10 years	93 (48)	0.49 (0.32 - 0.77)*	0.49 (0.31 - 0.79)*
Maternal Education			
None	82 (55)	1	1
Primary	176 (58)	1.17 (0.82 - 1.67)	1.09 (0.74 - 1.62)
Secondary +	53 (66)	1.63 (1.03 - 2.56) [†]	1.32 (0.69 - 2.44)
Socio-economic Status			
Poorest quintile	59 (56)	1	1
Quintile increase	252 (59)	1.03 (0.85 - 1.24)	0.90 (0.75 - 1.10)
Illness Severity			
Mild illness	147 (51)	1	1
Moderate illness	101 (64)	1.68 (1.25 - 2.26)	1.80 (1.26 - 2.57)
Severe illness	61 (76)	3.10 (1.66 - 5.80) [‡]	3.97 (2.25 - 7.02) [‡]

All analyses adjusted for survey design. a Odds Ratios adjusted for a priori confounders; child age, maternal education, socio-economic status and illness severity. * P \leq 0.01; † P=0.05; † P \leq 0.001

Table 5.4 shows factors influencing attendance at a formal health facility during the wet season. In the wet season those living in HTR remained less likely to attend a health facility compared to those NTH (AOR 0.46, 95%CI 0.27-0.80, P=0.01). However age was no longer significantly associated with health facility attendance. As in the dry season, maternal education and socio-economic status were not associated with health facility attendance. There remained a strong relationship between severity of illness and attendance at a health facility in the wet season (Moderate illness AOR 3.08, 95%CI 2.03-4.67; Severe illness AOR 4.49, 95%CI 2.33-8.65, P<0.001).

Table 5.4: Factors associated with attendance at a formal health facility for a recent childhood febrile event during the wet season

Background characteristics	(n/%)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI) ^a	
Village of residence				
≤5km from Hospital	184 (70)	1	1	
Hard-to-Reach	133 (53)	0.48 (0.29 - 0.79)*	0.46 (0.27-0.80)*	
Child Age				
<5 years	218 (65)	1	1	
5-10 years	99 (56)	0.69 (0.45 - 1.06) [†]	0.69 (0.40-1.20)	
Maternal Education				
None	83 (53)	1	1	
Primary	200 (66)	1.74 (1.03 - 2.92)	1.32 (0.77-2.28)	
Secondary +	34 (67)	1.85 (0.82 - 4.17) [†]	1.29 (0.54-3.08)	
Socio-economic Status				
Poorest quintile	56 (56)	1	1	
Quintile increase	261 (64)	1.11 (0.97 - 1.28)	1.03 (0.90-1.18)	
Illness Severity				
Mild illness	117 (48)	1	1	
Moderate illness			3.08 (2.03 - 4.67)	
Severe illness	66 (79)	$4.00(2.11 - 7.61)^{\ddagger}$	4.49 (2.33 - 8.65) [‡]	

All analyses adjusted for survey design

^aOdds Ratios adjusted for a priori confounders child age, maternal education, socio-economic status and illness severity. *P≤0.01; $^{+}$ P< 0.1; $^{+}$ p<0.001

5.2.3 Influence of distance on attending a health facility within 24 hours of fever onset

Time between onset of illness and attendance at a health facility was also examined. Table 5.5 shows the influence of distance from health facility on attendance within 24 hours of fever onset. In the dry season those living in HTR villages were less likely to attend a health facility on the day of fever onset or the next day compared to those living NTH (32% vs. 55% AOR 0.32, 95%CI 0.16 - 0.62, P=0.003). This relationship was also true in the wet season, however the strength of this relationship was decreased (43% vs. 57% AOR 0.53, 95%CI 0.32 - 0.88, P=0.02).

Table 5.5: The influence of village of residence on attendance at a formal health facility within 24 hours of fever onset according to season

		Dry season	Wet season		
Village of residence (n/%)		Adjusted Odds Ratio (95% CI) ^a	(n/%)	Adjusted Odds Ratio (95% CI) ^a	
≤5km from Hospital Hard-to-Reach	147 (55) 83 (32)	1 0.32 (0.16 - 0.62) [*]	151 (57) 109 (43)	1 0.53 (0.32 - 0.88) [†]	

All analyses adjusted for survey design

5.2.4 Do community health workers in hard-to-reach villages improve access to formal healthcare?

All of the HTR villages selected for inclusion in the study have a health post from which a CHW operates. The CHWs use a locally adapted version of the IMCI. They use a small range of medications which enable them to treat some common childhood illnesses but do not stock antimalarials, and are therefore required to refer all febrile children to the health facility for treatment. For this reason earlier analyses considered attendance at a health facility to include attendance at a public or private clinic or hospital only, and did not include attendance at a CHW. In order to investigate whether the presence of CHWs improves access to any formal healthcare, a second analysis was conducted: The influence of distance on attendance at either a health facility or a CHW was assessed; the results are presented in Table 5.6. After including CHWs in the analysis, those in HTR villages were still less likely to attend any formal healthcare compared to NTH in both the dry (AOR 0.53, 95%CI 0.25-1.11, P=0.09) and wet (AOR 0.60, 95%CI 0.37-0.98, P=0.04) seasons. However, including CHWs in the analysis decreased the strength of the relationship between location and use of formal healthcare, particularly during the wet season. This is because, although a relatively small number of the total individuals attended a CHW, a high proportion of those who did attend a CHW

^aOdds Ratio adjusted for a priori confounders child age, maternal education, socio-economic status and illness severity. *P≤0.01; [†]P<0.05

did not go on to attend a formal health facility. Ninety-two percent (49/53) of individuals across both seasons who sought care from a CHW in the first instance did not go on to attend a formal health facility¹⁵.

Table 5.6: The influence of village of residence on attendance at a formal health facility or community health worker according to season

Dry season				Wet season		
Village of (n/%) Adjusted Odds Ratio (95% CI) ^a		(n/%)	Adjusted Odds Ratio (95% CI) ^a			
≤5km from Hospital	187 (70)	1	184 (70)	1		
Hard-to-Reach	155 (59)	0.53 (0.25-1.11)*	151 (61)	$0.60~(0.37-0.98)^{\dagger}$		

All analyses adjusted for survey design

5.2.5 Access to formal health facilities: Qualitative data

The issue of distance from health facility occurred frequently throughout qualitative data collection, in both FGDs and IDIs. Three of the IDI participants explained that they had decided not to seek care from a health facility, or delayed care seeking because of the distance they would have to travel. Distance was particularly described as being a problem by those living in HTR villages, and even those living NTH described how the problem affected the villages on the other side of the river (the HTR villages). Time of day was also a major issue when deciding whether to seek care. Travel to a health facility at night was considered dangerous, as it put the caregiver at risk of murder or mugging. Participants also expressed their concerns about receiving trouble from night police who may accuse them of crimes if they are travelling at night time, although the child's health passport could be used as evidence of the reasons for their trip. Participants stated that an extremely sick child would be taken to the hospital even at night, but the caregiver would require accompanying by the husband or neighbours.

Distance from the health facility was linked to problems with illness occurring at particular times of day; those who live in HTR villages not only have to consider the time at which they travel, but whether they can feasibly travel to the hospital, receive treatment and travel back again before it

 $^{^{}a}$ Odds Ratio adjusted for a priori confounders child age, maternal education, socio-economic status and illness severity. * P<0.1; † p<0.05

¹⁵ Two individuals attended a CHW after visiting a formal health facility, it is unclear why but it may have been for paracetamol.

gets dark. For this reason they prefer to wait and leave early the following morning, unless the child is severely ill:

Not many people will rush to the hospital in the first place, mostly when we consider the distance to be covered. Supposing the child is sick now, I can't go to Chikhwawa and come back. It will be too late. Usually, we wait first because we think about the long distance. That's our problem here.

(Men's FGD, HTR, 07/10/10)

In this way distance delays health facility attendance not only through the greater length of time it takes to travel to the hospital, but also through restricting the times at which it is feasible to make the journey.

Members of all the FGDs explained that children suffer from illnesses which are more serious, such as malaria and cholera, more frequently during the wet season. However women living NTH also described an increase in childhood illnesses such as coughing and pneumonia around June (the time of the dry season survey) due to the colder weather, and described this as a reason for increased hospital attendance at this time of the year.

5.3 Finances

The costs associated with treatment-seeking are a potential determinant of access to appropriate treatment. The household survey was used to gather data related to the costs experienced by households during recent childhood febrile events. The costs associated with attending the various sources of care utilised are presented in section 5.3.1. Detailed costs associated with attending a formal health facility are then presented in section 5.3.2. This includes descriptions of the influences of geographic location and season on costs experienced. Qualitative data is then presented in sections 5.3.3 and 5.3.4, which describe strategies related to the provision of money when required for treatment-seeking, and responsibilities for financial decision-making within the household.

5.3.1 Costs per visit of attending various sources of care

Costs per visit were calculated for each source of care utilised (Table 5.7). Direct costs, or out-of-pocket costs, included the costs of travel, consultation and treatment. Indirect costs included the cost of time spent travelling to and waiting at the source of care. A minimum wage method was used to calculate indirect costs (chapter 3.4.2.1). Costs of attending a private pharmacy or petty trader were grouped together with the costs of attending a shop. The majority of visits were made to public

health facilities (611), followed by shops (261), CHWs (56) and private hospitals (28). CHW attendance was associated with the least cost; there were no direct costs and mean indirect costs were USD0.05. Private facilities were associated with the highest costs (USD1.43), the majority (USD1.17) of which were direct costs. By contrast the majority of costs associated with attendance at a public health facility were in the form of indirect costs (USD0.87), and the majority of this was due to time spent at a facility.

Table 5.7: Mean cost of seeking care from various sources of care

	Public health facility (n=611) (USD)	Private health facility (n=28) (USD)	Community Health Worker (n=56) (USD)	Shop (n=261) (USD)
Direct Costs ^b				
Travel	0.32	0.83	-	0.07
Consultation	-	0.10	-	-
Treatment	-	0.24	-	0.14
Total Direct Costs	0.32	1.17	-	0.21
Indirect costs ^c				
Travel time	0.10	0.09	0.03	0.03
Time at facility	0.76	0.17	0.02	0.01
Total Indirect Costs	0.87	0.26	0.05	0.05
Total costs	1.19	1.43	0.05	0.26

All analyses adjusted for survey design

5.3.2 Total mean household costs of a childhood febrile episode among children who were taken to a formal health facility

The relationship between reduced accessibility of health facilities (living in HTR villages) and cost of attending a health facility was examined. Total costs of a childhood febrile event were calculated for those households where the child had been taken to a formal health facility. In order to demonstrate variation according to time of year, the results are presented separately for each season (Table 5.8).

In the dry season, the mean total cost of a childhood febrile episode was significantly greater for those living in HTR villages compared to those living NTH (USD5.24 vs. USD3.45, P=0.03). Significant differences were seen in both direct and indirect costs. Direct costs made up the smaller proportion of total costs, and the difference between the two groups was due to costs arising from the increased travel time experienced by those living in HTR villages (USD0.31 vs. USD0.17, P = 0.03).

^bOut-of-pocket expenses. ^cCost of time losses.

Indirect costs represented the main economic burden for households. This was predominantly due to time spent caring for the sick child at home, which was greater for those living in HTR villages than those living NTH (USD4.01 VS. USD2.40, P=0.02), perhaps due to the more delayed care seeking seen in this group.

In the wet season the difference in cost experienced by those in HTR villages compared to those living NTH was of borderline significance. Mean total cost was USD5.60 for those in the HTR villages and USD4.46 for those NTH (P=0.12). Indirect costs remained the largest contributor to costs, but did not differ significantly according to geographic location in the wet season. As in the dry season, the majority of indirect costs were due to the cost of time associated with caring for the sick child at home; however, unlike in the dry season these costs were no longer significantly greater for those in HTR villages. This may be due to increased pressure on caregivers to engage in farming activities during the wet season rather than caring for their child (see chapter 6.3.6.1). Indirect costs associated with time spent travelling to and from the health facility were significantly greater for those living in HTR villages compared to those living NTH during the wet season (USD0.08 vs. USD00.16, P<0.001).

Direct costs increased in both groups in the wet season compared to the dry season. For those NTH total direct costs increased from USD0.20 in the dry season to USD0.40 in the wet season (P=0.061), for those in HTR villages direct costs increased from USD0.38 in the dry season to USD0.95 in the wet (P=0.051). The largest increase in direct costs was due to increased costs of travel, which were considerably greater in the wet season compared to dry for those living in HTR villages (USD0.31 vs. USD0.89, P=0.035).

Table 5.8: Mean cost of a febrile episode among those who attended a formal health facility according to village of residence and season

	Dry Season			Wet Season		
	<5km from Hospital (n=269) (USD)	Hard-to-Reach (n=262) (USD)	P ^a	<5km from Hospital (n=263) (USD)	Hard-to-Reach (n=246) (USD)	P ^a
Direct Costs ^b						
Travel	0.17	0.31*	0.03	0.28	0.89*	0.03
Consultation	0.01	0.02	0.43	0.05	0.00	0.18
Treatment	0.02	0.05	0.24	0.07	0.06	0.72
Total Direct Costs	0.20^{\dagger}	0.38 [‡]	0.04	0.40^{\dagger}	0.95 [‡]	0.08
Indirect Costs ^c						
Travel time	0.07	0.15	0.11	0.08	0.16	<0.001
Time at facility	0.78	0.69	0.58	0.86	0.67	0.27
Time caring at home	2.40	4.01	0.02	3.13	3.82	0.12
Total Indirect Costs	3.25	4.86	0.07	4.06	4.65	0.32
Total costs	3.45	5.24	0.03	4.46	5.60	0.12

All analyses adjusted for survey design

^aT test for the difference in means using censored linear regression with adjustment for clustering in survey design and confounding of child age, maternal education, severity of illness and socioeconomic status. ^bOut-of-pocket expenses. ^cCost of time losses. ^{*}P=0.035 for the difference between seasons for those living in hard-to-reach villages. [†]P=0.061 for the difference between seasons for those living <5km of district hospital. [‡]P=0.051 for the difference between seasons for those living in hard-to-reach villages.

5.3.3 Provision of money

Women and men in all areas agreed that it was the man's responsibility to provide money, if required, for treatment-seeking. The men may need to borrow money in order to be able to provide it for their wives. However, since this does not always happen and is not always possible, the women described a variety of strategies that they used to access finances when required: this included hiding some of the change when given money for purchases; selling vegetables from the garden, from which they have access to the revenue; and borrowing from friends, family members and grocery store owners. Both men and women described giving clothing as a pledge to either traditional healers or money lenders in exchange for treatment or cash, for which they would pay later. Although, both male and female participants were unanimous that if funds were not available for transport the mother would carry the child to the health facility on foot:

We usually walk, not everyone will **hire** a bike, most people walk because of financial constraints. Let's imagine you only have K200 in the house and you have neither flour nor relish and the child falls ill, if you take a bicycle and go to the hospital, what will the child eat when you come back from the hospital? Where are you going to find porridge or flour? That's why most of us go on foot, not all of us **hire** a bicycle.

(Young women's FGD, NTH, 06/10/10)

However, as the respondent continued, women may take the risk of spending money on transport if the case is serious, in the hope they will receive it back from the husband or be able to earn sufficient to cover the cost:

When the sickness is very **serious**, we spend the money to go to the hospital simply because it is a **serious** case... We know that the husband will do his best to bring money home.

There are several ways in which the restriction on finances could result in delayed health facility attendance: delays could be related to the longer length of travel as individuals will walk rather than take a bicycle if sufficient funds are not available. This is especially important for those living in HTR villages due to the relationship between journey length and the restriction on the time at which it is feasible to travel to the health facility. In addition caregivers may wait longer, until they are sure the child requires hospital treatment, in order to avoid unnecessary costs associated with travelling.

5.3.4 Responsibility for decision-making regarding the use of finances

When conducting the household survey it was found that many of the women said that they did not engage in any work or income generating activities. With probing it was apparent that the majority of these women were involved in cultivating crops for consumption and for selling. The fieldworkers

explained that since the farm was considered to be owned by the husband, or family if they were unmarried, women had no ownership over either the farm or the work they did in it. The same issue was found to be true in some of the IDIs:

Interviewer: Let's start with you what do you do here at home to make money?

Respondent: Ah, there is nothing I do...

Interviewer: Alright, do you do anything that helps you to feed your family?

Respondent:

Interviewer: How about farming?

Respondent: Indeed I farm

(IDI, attended a health facility, HTR, 06/01/11)

The majority of the women stated that the husband had full control of budgeting and decisionmaking when it came to finances. Some of these women explained that they had no right to contribute in decisions over finances; they were just beneficiaries of their husbands, who were the income generators:

Ok, what if you realized that your husband misused the money? Interviewer:

Respondent: There is nothing I would do. I am just a beneficiary...

Interviewer: What do you mean by "beneficiary"?

Respondent: Well, it's my husband who makes the money. Interviewer:

He makes money; so do you just obey anything?

Respondent: Yes

(IDI, attended a health facility, NTH, 03/11/10)

and

Interviewer: Why don't you take this responsibility?

Respondent: The law is greater than power/authority.

Is there a law? Interviewer:

Respondent: Yes

What does that law say? Interviewer:

Respondent: When he decides that the money is supposed to be used in such and such a

way, I just have to obey what he says.

(IDI, attended a health facility, HTR, 04/11/10)

Whilst it is true that more of the men did piece work than the women, the women contributed considerably to income generation through farming and the selling of produce. Yet the following quote demonstrates how unfamiliar the concept of the women having responsibility over budgeting is:

Interviewer: How about you, don't you take part?

Respondent: [laughs]

Interviewer: What role do you play?

Respondent: [laughs]...

...My role [laughs]

Interviewer: Perhaps you don't take part?

Respondent: Honestly, I don't play any role.

(IDI, did not attend a health facility, HTR, 04/11/10)

It should be borne in mind that this relationship does not necessarily mean that the husband refuses money that is required; husbands having provided the necessary money for drugs or transport during their child's recent febrile episode was more commonly described in the IDIs than situations where money was not provided. Some men took steps to ensure that their wife had access to money in the case of unexpected events. For instance some members of male and female FGDs described that if the husband went away he would leave money for emergencies, this was confirmed in one of the IDIs. In addition, a number of the IDI participants stated that, despite the husband having the responsibility for budgeting, they would discuss with their husband any issues they had over the way he used available finances. It is clear however that the holding of decision-making responsibility by the husband may have serious consequences on treatment-seeking in situations where the husband is not concerned about the child's best interests:

Some husbands wouldn't produce a penny even if he had the money. They will act as if the child is a step-child and yet he is their own child.

(Young women's FGD, NTH, 22/01/11)

Indeed, one of the IDI participants had not attended a health facility for their child's recent febrile illness because the husband would not provide money for a health passport¹⁶, which the child required in order to access treatment.

¹⁶ A health passport is a book containing medical notes which is issued at the time of the child's birth.

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A small number of women stated that they and their husband conducted the budgeting together. It was notable that all of these women also had a source of income of their own, such as from working as a vendor. Further evidence of the benefits of women having an independent source of income comes from an IDI with a woman who sought care for her child on the day of the illness started. She was able to use a bicycle taxi to take the child promptly to the hospital, which she funded from the proceeds of a small business she runs.

5.4 Treatment-seeking decision-making

Gender roles and generational hierarchy were seen to be important influences on the treatmentseeking process and this influence varied according to location. In order to understand these variations, differences in the social structures of the two populations studied must first be understood. Those living in the centre of the Chikhwawa district (NTH) are mainly of the Chewa and Mang'anja ethnic groups, however because this is a trading area a mixture of people from different ethnic groups now reside here. In the HTR villages selected for this study the majority of individuals are of the Sena ethnic group. This was true of the locations in which the HTR FGDs were conducted, however some of the IDI participants who were classed as living in HTR villages were slightly closer to the centre of the district and therefore some other ethnic groups may have been represented. One major difference between these ethnic groups is that the Chewas and Mang'anjas traditionally form a matrilineal and matrilocal society, whereby the husband leaves his home area to live with his wife's family; whereas the Sena practice a patrilineal and patrilocal system (Mudeka, 2011, Mandala, 1978, Phiri, 1983). The practising of a matrilineal or matrilocal system does not mean that the mother becomes the head of the family; traditionally her brothers take on this role, and her eldest brother is considered the head of the family and assumes responsibility over his sisters' children. These days however the child's father takes over more responsibility, while the role of maternal uncle is still respected. The people in the central area of Chikhwawa are mixed; therefore these different practices occur alongside each other. Further, the people in this area are more exposed to external influences and ideas; by comparison those in HTR villages are more secluded. Villages from these two different areas were selected for study, in part, because it was believed that these different social structures may lead to important differences in the decision-making process. In fact, it was in the area of decision-making that some of the biggest differences were seen between these two regions. The gender dimensions of these decision-making processes are discussed below.

The men and women in both areas described a chain of communication, whereby the child's mother usually identified that the child is suffering from an illness and then informed the father. Members of all the FGDs placed great importance upon this system, and were unanimous that it is necessary for the child's mother to inform the father if their child is sick. A number of reasons were given: in order to receive advice; for the father to make a decision about how they should respond; because the child belongs to both parents; so the husband is not surprised to find the wife gone; because it is the role of the woman to inform the husband; because the husband is the head of the family; it would be disrespectful not to, and; so that the husband can assist with transport or money. Some of the women explained that there would be consequences of not informing the husband:

Respondent: Yes, as a woman in the family, there are bound to be problems.

Interviewer: *Like what?*

Respondent: He may ask about the wife's whereabouts and the reason for not telling him

that the child was sick... Yes, it becomes a big issue.

(IDI, did not attend a health facility, 27/01/11)

There was a strong opinion among all groups of those living in HTR villages that, in the absence of the husband, women were expected to inform their mother-in-law of the child's illness. While women in general were said to have little responsibility for decision-making (see below), the opinion of the mother in-law was highly respected, and mothers-in-law were said to have the ability to make treatment-seeking decisions. The child's mother was also said to be able to make treatment-seeking decisions in the absence of the husband, as long as the mother-in-law was made aware of the situation, and therefore had the opportunity to intervene should she wish to. In-laws were considered to have a level of ownership over the children and therefore the right to know what is happening and contribute to the decision-making process:

We tell them so that they should be aware, because our customs here require that the wife should live at the husband's home and we believe that the husband's parents and relatives are the owners of the children.

(Young women's FGD, HTR, 14/01/11)

In HTR villages there was a clear difference between the level of authority that men and women possessed with regards to making treatment-seeking decisions. The men living in HTR villages explained that it is necessary for a woman to inform their husband, or if not present, their in-laws, before seeking care. They also explained that, as men, they do not need to be concerned about informing others:

Interviewer: What would happen if she didn't inform people?

Respondent: This could also cause a fight when the child is sick... Sometimes it becomes a

big issue...

Interviewer: ...You, yourself... will you just leave for the hospital by yourself?

Respondent: Ah, yes I can just go, you know.

Interviewer: Without telling anybody?

Respondent: Ah, well, I am a man.

All: (Laughter and discussions from participants)

(Men's FGD, HTR, 07/10/10)

The moderator probed further as to what would happen if there was nobody around to inform, and the child was seriously ill. The men explained that the woman would have to wait, or send a message:

Respondent 10: Suppose the woman leaves without informing anybody because the

child is ill and perhaps the child dies or on the way the child dies, in our tradition it is a big issue, she has a case to answer. The question will be: why did she have to go without informing anyone? She must

have done something bad to the child – this may cause a row.

Interviewer: Do you all agree?

All: Yes, we agree entirely.

Respondent 9: Really, it becomes a big issue; those from the husband's family can

even boycott the funeral and disown the dead child.

All: [Laughter and comments from participants]

Respondent 8: They don't know what happened since the husband, the in-laws and

the neighbours were all away.

Respondent 9: And a **neighbour** is not a relative; they have to look for at least one

relative.

Despite this, some members of all of the female FGDs stated that if the husband or extended family were not around, they would inform neighbours, or find some way of sending a message to the family and leave for the hospital. It is possible that it is rare for women to be left with children in

situations where there are no other relatives around to inform, and indeed such a situation was not found to have occurred during any of the recent febrile events discussed in the IDIs. Most of the women participating in IDIs had informed the husband of the child's illness before taking any action. In total, six of the married women had not informed their husbands; two had informed in-laws, because their husbands were away; three had taken no action and did not consider the illness serious enough to inform anyone; one had been unable to inform her husband because he was drunk.

Those in HTR villages explained that after informing others that the child is sick, the mother makes little contribution to the decision-making process. Younger women in HTR villages role-played scenarios where they discovered the child was sick and informed the husband and in-laws. In one case the opinion of the relatives differed from the mother's, yet after informing the relatives the mother said no more. When discussing this issue, the women explained that their role was to deliver the message and await a decision to be made. This idea was supported throughout the FGDs in HTR villages. Elderly people, especially experienced mothers, were seen to possess knowledge and be able to advise as to the appropriate response, such as whether a traditional remedy or hospital treatment should be sought. Younger women said they would take the advice of the mother-in-law even if it differed from their own opinion:

I am just beginning to experience what she knows already, therefore, I just submit to what my [mother-] in-law says.

(Younger women's FGD, HTR, 14/01/11)

Men in HTR villages also showed a great deal of respect for the advice of elders. They also explained that they would go along with the elders' advice, even if it was contradictory to what they had initially believed would be appropriate. The men however, unlike the women, were not required to seek the advice of elders before acting.

The requirement of women to inform their mother-in-law of the child's sickness should not be seen as a purely negative structure; since there are benefits for women. The mother-in-law takes the role of mediator in case of a disagreement between the husband and wife. The woman can also call upon the husband's extended family members, who were said to "look after" them, and can intervene if the husband fails to provide necessary assistance. This strategy may not always be effective; for example one of the IDI participants whose husband had not provided money for a health passport¹⁷, sought help from her mother-in-law, who supported the husband's decision. There are also a

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¹⁷ The cost of a replacement health passport is around USD0.40.

number of roles which are required of in-laws, and they need to be informed about the illness in order to carry these out. Their roles include: looking after the house if it is empty overnight; providing childcare for other children in the home; sorting out arrangements, such as organising transport and providing money, while the mother is busy with the child. If the mother does not return, informed relatives will know that the child has been admitted. In this case it is also necessary for another relative, usually the mother-in-law, to attend the hospital in order to take responsibility for activities such as cooking, so the mother is free to care for the child. The women stated that if relatives were not informed they may be left at the hospital with no assistance.

Women in HTR villages explained that in some cases they were required to inform a number of elders, not only the mother-in-law, of the child's sickness. This was particularly true in the case of serious illness, when the village headman may also be informed. Older women were more mixed in their views of the importance of informing and getting advice from elders and husbands. In discussing the situation where the husband does not provide assistance, some of the older women explained that this would not affect them as they 'don't really mind about the husband'. One older female participant stated that she would be willing to disobey the husband and mother-in-law and "be shouted at" if that meant the child would get the right treatment. Another expressed frustration about delays caused by informing others:

When the child is sick, we leave him in the house to inform the village chief so that the chief may decide what to do and then the child is taken to the hospital. Let's be frank, let's just take the patient to the hospital.

(Older women's FGD, HTR, 08/10/10)

In general though the older women were respectful of elders and agreed with younger women that the ownership of the child lies with the husband's family.

As in HTR villages, women living NTH were expected to inform their husbands of the child's illness. Members of both the male and female FGD's NTH expressed respect for elders, and the insight they provide. The younger women described their inexperience, and reliance on elders for advice, while the men described the merits of involving others in the decision-making process. However the wisdom of elders was mainly described in the context of illness arising from problems in the household (*tsempho*) and their advice was particularly considered relevant in the case of failure of hospital treatment. More emphasis was put on attending the hospital in the first instance and informing family members at a later stage. Informing family members was described by some male

participants NTH s a cause of delay, as friends and family may advise that a particular person is to blame for witchcraft, when in fact the child needs hospital treatment:

Instead, when you see that the child has fever, don't mind whether they are your in-laws or not, you tell yourself that the child is yours, you just have to go to the hospital and later on you can tell them what happened and if the in-laws are intelligent enough, they will be very grateful for your action.

(Men's FGD, NTH, 06/10/10)

There were other marked differences between the views of those living in HTR villages and those NTH with regard to treatment-seeking process. There were no references to seeking advice specifically from the mother-in-law in any of the NTH FGDs. They agreed that the husband has responsibility for making decisions, and should be informed of the child's sickness. Some also agreed that relatives are particularly influential for women, as there may be disagreements if she takes the child to the health facility without informing them. However the men in villages NTH had a very different attitude towards women's ability to make decisions compared to those in HTR villages; they considered the woman able to make decisions in the absence of the husband:

Respondent 2: It is the husband, but it might happen that a child falls sick when the husband is at work in Nchalo¹⁸ and the wife decides to wait for the husband to take the child to the hospital; now can we say that the woman is wise? When a child is sick, it is the responsibility of the one who is present to take the child to the hospital.

Respondent 1: I can say that it is a question of responsibility.

Respondent 4: Yes, both have the responsibility over the child. (Men's FGD, NTH, 17/01/11)

The pace of change may be slower for those living in HTR villages, however there are indications that health education messages are getting through and that the importance of hospital care is being recognised. Whilst younger women in HTR villages are still very dependent on the involvement of elders in decision-making, there are signs that hospital treatment is beginning to be prioritised:

Our generation depends much on the hospital, therefore we go to the hospital first and when we come back from hospital, we seek advice in order to discover the real problem. So we have some elders who tell us about life in this world.

(Young women's FGD, HTR, 08/10/10)

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¹⁸ Nchalo is another town in the Chikhwawa district; it is home to a large sugar cane growing estate, which is a major local employer.

5.5 Perceptions of health facility care

Chapter 2.4.1 described the potential impact of perceptions of antimalarial drugs on utilisation and the consequences of inappropriate utilisation on treatment failure and the development of antimalarial drug resistance. Section 5.5.1 explores perceptions of LA within Malawi. During data analysis, the availability of diagnosis at health facilities, perceptions of the general assistance provided, and comparison of care available from alternative sources also developed as themes related to individuals' perceptions of health facility care; the results are presented in sections 5.5.2, 5.5.3 and 5.5.4 respectively.

5.5.1 Medication

Within each of the FGDs there were some participants who had a positive perception of LA and others who said that it does not work. In general participants in the male FGDs were more negative about LA whereas female group comments were more positive. In particular there were few negative comments from the younger women's FGDs in HTR villages, who were generally positive about the drug. Some of the young women from HTR villages stated that they have never heard of anyone having problems with LA. A number of men by contrast questioned the efficacy of the drug:

Let's be frank, **LA** is not a strong drug.

(Men's FGD, NTH, 06/10/10)

The following sections cover a range of issues related to giving LA to children. The initial section discusses adverse events experienced by participants' children. The following section then describes the issue of compatibility of medication; participants explained how they believe that the effectiveness of medication is determined by its suitability for a particular child. Participants' understandings of the importance of following the instructions given at the health facility are then described. Concerns about the frequency with which their children take LA are then outlined. The final section explores practical aspects of administering LA to children and includes discussion of participants' experience of using the dispersible compared to the original formulation.

5.5.1.1 Adverse events

There were some reports of problems with taking LA in all FGDs, apart from those with females living in HTR villages. Problems included itching, rashes, loss of appetite and worsening of symptoms. In a couple of the FGDs references were made to children babbling and hallucinating after treatment, this was believed to be due to the LA fighting the malaria. By comparison, in several of the FGDs,

worsening of symptoms such as increased temperature and vomiting were said to be a sign that LA is either not suitable for the child or for the illness. One of the IDI participants stated that she believed it is normal for LA to result in increased temperature, but this should later drop. In the case of this participant's child, however, the higher fever continued so she returned to the hospital. Overall, problems of treatment failure (chapter 4.4.3) were much more commonly described than adverse events, which were infrequently described despite probing into this topic. By comparison quinine was considered to be a fast acting and effective drug, but there were a number of complaints about its effect on hearing and it causing itching. Quinine was reported to have the advantage of avoiding the problem of vomiting which was associated with taking LA.

Vomiting was described as being a problem in administering drugs to children in all of the FGDs. There was a mixed response in terms of the appropriate action after vomiting. Infrequently mentioned responses included a minority of individuals who felt that if the child vomits they should not be made to take any more of the medication. Some mentioned that if the vomiting takes place a period of time after taking the medication, such as around 15 minutes, then there is no problem as the medication has done its work. There was one comment that if the child vomits they should be taken straight back to the hospital. Most frequently, individuals explained that if the child vomits or spits the medication, then another dosage should be given as instructed at the hospital. There was general agreement that there was no need to replace this dose, as the child will have recovered by the time the course is finished. There were some references to the fact that if the child continues to vomit after each dose they should be taken to the hospital. None of the IDI participants had experienced their children vomiting after any of the doses.

5.5.1.2 Compatibility of the medication

As described in the previous chapter, treatment failure, or recurring illness was a common complaint. It was frequently claimed that this recurring illness is due to the drug not suiting the child. Participants in all of the FGDs mentioned that the effectiveness of LA is dependent on its compatibility with the child's body, or blood. The following comments were given as responses to questioning about FGD participants' perception of LA:

For some, it is not a suitable drug because when you administer LA to them, the fever gets worse, for others it is a suitable drug. When we see that the fever has risen higher, we rush to the hospital and ask for change of drugs.

(Young women's FGD, NTH, 11/10/10)

and

Sometimes the efficacy of the drug depends on one's blood. (Men's FGD, HTR, 07/10/10)

Across all the FGDs, except those with the young women living in HTR villages, there were participants who suggested that LA either works or does not work well consistently in their particular child. This was also mentioned by some of the IDI participants. The focus of these comments was that the drug either always works or never works in that particular child, rather than the function of the drug being determined by the cause of illness. Although, as described in chapter 4.4.3 participants also interpreted successful treatment and failure or as signs that the correct cause had or had not been identified. Compatibility was also suggested to be an issue for other drugs, including traditional medicine.

5.5.1.3 Importance of following instructions

Another reason given for treatment failure was not following the instructions correctly.

When you don't follow the instructions [for LA), then you tend to think that the drug isn't powerful enough, but when you are told to take the drug in the morning, at noon and in the evening, you must do so, if not, you won't be cured.

(Men's FGD, NTH, 06/10/10)

Skipping doses, taking tablets at the incorrect time and failing to take LA with food were all felt to result in treatment failure. Despite this in one FGD participants described that they sometimes attempt to speed up the process by taking the tablets three times a day.

Respondent 9: You may be told to give one tablet of LA and half a tablet of Panado in the morning and in the evening but only Panado at noon. We are clearly told how to do it and yet when we come back home, we think it is a joke and we

just administer LA in the morning, at noon and in the evening.

Respondent 5: To do it fast...

Interviewer: ... What do you mean by doing it fast?

Respondent 9: To heal fast.

(Older women's FGD, HTR, 08/10/10)

Taking the tablets in a shorter period of time than recommended was mentioned in both IDIs and FGDs. As in the above two quotes there were a number of references throughout the FGDs to taking LA morning, noon and evening, rather than the recommended twice daily schedule. In addition two of the IDI participants said they gave LA to their child three times a day. Another IDI participant said they gave the tablets twice a day, but for six days. Despite references to the fact that tablets are sometimes taken at the incorrect dose, participants seem to have a general understanding of the importance of the correct dose and of continuing until the medication is completed:

We are advised to administer the drug as soon as we return home, so when we reach home, we take the drug and administer it to the child and we don't stop it when we see that the child is rejoicing but we administer the entire dosage as instructed by the doctor. It isn't proper to give the drug to another child. He has to complete the dosage prescribed to him. Each patient must have his own dosage.

(Older women's FGD, HTR, 08/10/10)

There was also a general understanding that the dosage of medication varies according to the age of child.

Participants gave a mixture of responses in terms of the length of time they would expect to have to wait before they see benefits of taking the LA. Some said they would expect to see benefits the day treatment commences, others expected to wait longer. The general consensus was that treatment should be continued until all of the tablets have been taken, especially if the child has not yet recovered.

5.5.1.4 Frequency of illness and of taking LA

Treatment failure and adverse events were not the only concerns related to taking LA. Some individuals felt that children appear to get sick with malaria a short period of time after treatment with LA.

When we go to the hospital and the child is given LA to take right away as first **treatment**, we realise that the child is better soon after arriving home. **At least** he feels better. However,

we get surprised to see that the child is alright just that one **week**. The following **week** or **after** two weeks the sickness recurs.

(Men's FGD, HTR, 07/10/10)

Other concerns included the frequency with which LA is being taken, both in terms of it being received for all ailments, and it being given repeatedly after treatment failure:

At the hospital, we are tested for malaria and whether one is complaining of stomach pains or pneumonia, we are told that it is malaria and we are given **LA**, a drug that may not cure pneumonia.

(Men's FGD, NTH, 17/01/11)

and

I don't know what is happening now with LA, but one thing is certain: it's being taken far too frequently.

(Men's FGD, HTR, 07/10/10)

As described in chapter 4.4.3.2, some individuals stated that they would avoid returning to the health facility in the case of treatment failure for fear of receiving a repeat treatment with LA.

5.5.1.5 Ease of administering LA to children

There was general agreement that the nature of the child determines whether it is easy or difficult to give the drug. Some children tend to take medication easily, whereas others refuse and are difficult:

The difference comes in depending on the child's mind because there are some children who dislike drugs and there are some who easily receive drugs when they are sick. Indeed, there is a difference among people though they may be the same age, because most people are afraid of drugs.

(Younger women's FGD, HTR, 08/10/10)

However it was widely stated that the bitter taste of LA was responsible for children refusing to take medication. Other reasons included a total loss of appetite, even for water, due to the illness and being tired of taking so many tablets.

In general very young children were said to be unable to discern whether medication tastes bad and therefore do not refuse it. The methods available to manage a difficult child vary according to the age; for this reason it was thought to be generally easier to give medication to younger children,

who can be physically overpowered and forced to take the drugs more easily. Young children can also be breastfed immediately after to soothe them and prevent vomiting:

Respondent: As a mother, she will perform 'bzade' [laughs].

Interviewer: What is 'Bzade'?

Respondent: The mother gives the drug and if she just stops there, the child will throw up,

so what she does is to immediately offer the breast to the child.

(Men's FGD, HTR, 07/10/10)

The mother alone can easily overwhelm an infant by holding them firmly between her legs, holding their noses or arms and force-feeding the drug if necessary. As the child grows larger one or more other individuals may be needed to help physically restrain the child. It was frequently mentioned that older children might hold the drug in their mouth and later spit it out. Between the ages of around five and 10 many children could be bribed with small gifts in exchange for taking the tablets, but children of this age can also easily run away and hide to avoid taking medicine. Older children were said to not be easily bribed as they are too wise.

Male and older female FGD participants tended to describe using physical methods, such as restraint, to ensure that both younger and older children take their medication. The younger women tended to favour the use of threats for older children. Although others described threats, the women from HTR villages were particularly dramatic in their descriptions and many threats were described, such as:

"I will hit you, if you don't take the medicine you'll die". So, the child is scared because she knows that if she doesn't take the medicine, she'll either die or be whipped.

(Young women's FGD, HTR, 08/10/10)

It is apparent from the severity of the threats, and references to the use of physical force, such as binding children, that the struggle between caregivers and children may contribute to greater difficulty with medication adherence longer term. This was infrequently recognised, but a minority of participants highlighted that the aggravation between caregivers and children leads to the child fearing hospital treatment generally. This relationship is further demonstrated by the following quote, where hospital treatment itself was used as the threat:

Yes, "I will whip you, come on, swallow the drug or else, I will tell the police to arrest you or the doctor will vaccinate you".

(Young women's FGD, HTR, 08/10/10)

Not all caregivers agreed with using force or threats; a small number of caregivers suggested talking nicely to children, reasoning with them, and using other positive methods such as mixing the medication with porridge or sugar to mask the taste. The range of different views is demonstrated in the following responses where participants explain how children can be encouraged to take medication:

Respondent 7: We'll win him over by talking to him nicely.

Interviewer: Do you mean persuading him?

Respondent 7: Yes, persuading him by telling him that the drug isn't bitter, that it is like a

sweet, that he will be cured if he refuses to take the drug, that the sickness will go on if he doesn't swallow the drug and that he will be well again if he

just swallows the drug.

Respondent 5: It works when you keep the drug away.

Respondent 3: *Direct violence; take it, swallow! Swallow!*

(Men's FGD, HTR, 07/10/10)

5.5.1.5.1 The dispersible versus original formulation of LA

Individuals who received dispersible LA and who had ever previously received non-dispersible LA from the health facility were asked to describe any differences in experiences between the two formulations. Few differences were described; most individuals described the medication as being the same. Despite this a number of children who received the non-dispersible formulation either struggled and refused to take the medication, or cried as a result of taking it; by comparison no such comments were made by mothers of children who received dispersible LA. A minority of participants who received the non-dispersible formulation stated that their child had spat out some of the medication and others had taken steps to prevent spitting it out; this was not reported to be a problem for the dispersible formulation. Half of the IDI participants who had received the nondispersible formulation of LA used physical force to ensure their child took the medication, whereas none of those who received dispersible LA used force. Two commented that their children did not complain about the taste of the dispersible formulation, whereas they usually complain that LA is bitter. One mother remarked that although her child never causes a problem with taking drugs, this one smells so sweet that even a difficult child 'could cry for it'. Also one participant who received the dispersible formulation found that their child spat out other medication taken alongside LA, but did not spit out the LA. It is clear that improving the taste of the drug may have widespread advantages, for children of all ages and their families. Stress and aggravation associated with administering

medication would be reduced, and in turn fear arising from the association of medication with harsh treatment would be impacted.

The advantage of dissolving the dispersible formulation, as opposed to crushing the original formulation, rarely featured in the comments. Some caregivers gave their children the dispersible tablets to chew or swallow whole, as for the original formulation. However there were a couple of individuals who, once probed, described the dispersible formulation as easier to dissolve. Overall, none of the children were considered extremely difficult and all took the medication.

5.5.2 Availability of laboratory diagnosis

There were many references to diagnosis and testing for malaria throughout the study and diagnosis became a major theme during the analysis. Participants saw receiving a test result as an important step in the treatment process. During questioning about how participants recognise the cause of childhood illness, a number of participants stated that it is through diagnosis in the laboratory that they can know what is wrong with the child. The availability of testing for malaria and receiving a test result was given as a reason for attending government health facilities by some IDI participants.

Really, we cannot tell that the fever is malaria or anything else. We know when we go to the hospital and we are tested at the **laboratory**. Then we can tell what the problem is.

(Men's FGD, NTH, 17/01/11)

Some caregivers felt that by diagnosing the problem, doctors were able to use this information to establish what treatment is appropriate. There was an understanding that whether the drug works or not is determined by it being used for the correct cause of illness:

When the doctors diagnose the patient, they know exactly what medicine to administer to the child depending on the results of the diagnosis. If the doctors find that LA won't work, it will be a waste to administer LA to the child.

(Young women's FGD, HTR, 08/10/10)

The following quote is similar to a number of quotes from women who had attended a health facility whose child had not received a malaria test. It demonstrates the importance placed on laboratory diagnosis; the mother felt the child did not received the best treatment, because he did not have a test:

Interviewer: Alright, when you explained that the child had fever and diarrhoea, was he

tested-?

Respondent: (Overlaps) He wasn't tested...

Interviewer: ... How did you feel when you saw that the child was not tested?

Respondent: I was scared because he was just given drugs without establishing what was

wrong with him.

(IDI, attended a health facility, HTR, 06/01/11)

Not all participants placed as much importance on biomedical testing however. For a minority it was enough to receive treatment:

Respondent: No, he wasn't tested...they just looked at him and gave him some medicine.

Interviewer: When they just looked at him and gave him some medicine, how did you

feel?

Respondent: I was happy because I received some medicine.

(IDI, attended a health facility, HTR, 01/12/10)

In addition, malaria testing was not always described positively. Some FGD and IDI participants expressed confusion and frustration over children showing signs of malaria despite receiving a negative test result, experiencing treatment failure following a positive test result, or receiving malaria treatment despite having a negative malaria test. In one case a participant whose child received a negative test requested to receive antimalarial treatment:

Respondent: He was tested...I was told he had no malaria... As far as I was concerned, I

saw that indeed the child had signs of malaria... Therefore, I didn't see any

other option... Instead, I asked for malaria treatment...

Interviewer: ...What treatment did you receive?

Respondent: I was given LA

(IDI, attended a health facility, NTH, 07/01/11)

5.5.3 General assistance

Issues related to the general assistance available at health facilities, such as opening hours and staff attitudes were not investigated in detail but they were mentioned occasionally by participants. Health facility opening hours, and services such as blood tests, are limited to certain times and days of the week. This was given as a reason for delaying health facility attendance, particularly at night, and for children not receiving malaria tests. Waiting at a health facility was also a complaint; a number of the participants who had not attended a health facility expressed their appreciation for being brought medication by the MIS team, as this helped them avoid long queues and waiting times at the health facility. A few participants complained about the manner in which patients are received at the hospital; patients are not always received respectfully and in some cases doctors may shout at

patients. By comparison it was said that at private hospitals the doctors may be poorly qualified, but they are courteous. At times participants appeared not to recognise that they have a right to an opinion about the quality of care received. In general participants appeared to accept poor quality treatment, if that was what is available:

Interviewer: Were you satisfied with drug you were given?

Respondent: ...We just received it since it's the hospital

(IDI, attend a health facility, HTR, 06/01/11)

and

Interviewer: Alright, so how did you feel [about not receiving a malaria test]?

Respondent: *I was annoyed...*

Interviewer: ...So, what did you do about it?

Respondent: I just went and collected the drug because I was given a prescription.

(IDI, attended a health facility, HTR, 06/01/11)

Many participants spoke positively about government health facilities, explaining that it was there that a correct diagnosis could be obtained. The staff were described as being better trained than at private facilities. Doctors and nurses at government health facilities were said to possess knowledge that enabled them to find the cause of the child's illness and to prescribe the correct medication. One participant also described that doctors were able to give medication to children in a way that meant they wouldn't vomit. A number of IDI and FGD participants explained that they either attended or would attend a government health facility for childhood illness because they know that is where they will receive assistance:

[The hospital is] where we usually get assisted. It's where we find proper diagnosis. I chose to go to the hospital so that my child could be examined to find out the exact problem in his body. (Older women's FGD, NTH, 03/11/10)

5.5.4 Comparison with other sources of care

The availability of free treatment at the government health facility was a major positive feature. Participants explained that the same treatment and tests were prohibitively expensive in private facilities, and therefore they preferred government health facilities. Participants also explained that the government health facilities provide better services than can be obtained in shops, as proper diagnosis is obtained, drugs are provided in the correct dosage and expired drugs are not used.

5.5.4.1 Traditional healers

Traditional healers were considered important, as they have a role in treating illnesses not curable through biomedicine. It is notable that the importance placed upon diagnosing illness is not a new thing restricted to biomedicine; diagnostic methods were described as playing an important role in traditional medicine. Various methods of traditional diagnosis were described in detail by the younger women living in HTR villages, particularly for identifying whether tsempho was the cause, and who the culprit was. Methods included placing a small quantity of grass in front of a spider's hole whilst saying a short chant. If the spider takes the grass, tsempho is believed to be the cause. Alternatively flour may be placed at two spots on an anthill; a short chant would be said whilst placing each pile - on one asking whether the mother was to blame, on the other the father. The culprit could be identified according to which pile of flour was eaten by the ants. Both male and female FGD participants felt that identifying the culprit was an important part of the treatment process; this was true of witchcraft and tsempho. The women explained that traditional methods of diagnosis are taught to them by elders at the time they have their first child. They enable the women to avoid relying on traditional healers for diagnosis. They accused traditional healers of creating trouble within the family by assigning blame for the illness to family members, such as the child's grandmother. They also explained that conducting their own diagnosis reduced the costs of visiting traditional healers:

So instead of taking our children to these diviners, we use the divination that our fathers taught us like the spider one or we go to an ant hill. The latter is another type of divination. We'd rather do our own divination than to waste our money... We try our own ways and when we fail, then we go to these people who eat our money.

(Young women's FGD, HTR, 08/10/10)

5.6 Conclusion

This chapter has explored accessibility of formal health facilities, finances, treatment-seeking decision-making and perceptions of health facility care as potential barriers or enablers to accessing effective treatment.

Those living in HTR villages were less likely to attend a formal health facility for a childhood febrile event and were less likely to attend promptly (section 5.2). FGD participants explained challenges experienced as a result of distance from health facility. However participants were unanimous that, regardless of distance and lack of transport, a child requiring treatment would be carried to the

health facility. CHW attendance was infrequent, despite their proximity to community members and the low costs of attending. Further, the majority of those who attended a CHW did not go on to attend a health facility.

Despite free healthcare provision at public health facilities, residents of the Chikhwawa district experienced considerable costs in accessing these facilities, and costs were greater amongst those in HTR areas (section 5.3). The majority of costs were indirect; predominantly due to time spent caring for the sick child at home. Direct costs increased in both groups in the wet compared to dry season, largely due to increased travel costs, which for those living in HTR villages were considerably greater in the wet compared to the dry season. In general men were responsible for income generation, budgeting, and provision of money in the case of childhood illness.

In HTR villages women were expected to inform their husband or mother-in-law of childhood illness (section 5.4). Women in HTR villages were found to benefit from the involvement of their mother-in-law, who might act as a mediator and provide practical assistance during a child's illness. Women living NTH were also expected to inform the husband of the child's illness; however no references were made to the mother-in-law. In addition men NTH felt that, in the absence of other relatives, women are able to make the decision to take the child to the health facility.

Perceptions of LA were mixed; women tended to be more positive than men (section 5.5). Adverse events were described as being less common than treatment failure, which was frequently perceived to arise as a result of lack of compatibility of the medication with (the blood of) particular children. In general participants had a good knowledge of the importance of taking the correct dose of LA for the correct duration; however this did not always result in appropriate action. Participants expressed concerns about frequently receiving LA due to repeated episodes of malaria and the provision of antimalarials at health facilities for all ailments. The bitter taste of the original formulation was reported to be largely responsible for difficulties in administering LA to children. Caregivers described a variety of methods used to ensure children take the medication, some, including physical force, may be detrimental. Most caregivers who received dispersible LA did not recognise any differences between this and the original formulation. Despite this, none of those receiving the dispersible formulation used physical force to ensure their child took the medication, whereas half of those who received the original formulation did.

The availability of laboratory diagnosis was highly regarded, and was given as a reason for attending government health facilities. However participants expressed frustration over the apparent lack of correlation between symptoms, test results, treatment, and treatment outcomes. There were also a number of complaints regarding other aspects of health facility care. Despite this the majority of participants expressed a preference for public health facility care, which was perceived to be a source of free assistance, with properly qualified staff who are able to identify the cause of children's illnesses, and where non-expired drugs are provided at the correct dosage.

This chapter has highlighted the way in which multiple factors act together to determine access to appropriate treatment for young febrile children. Intra-household factors and perceptions of available care promoted health facility attendance where perceptions were positive and family structures supported health facility attendance. By contrast women's lack of financial resources and decision-making responsibility, and negative perceptions of available care led to delayed or absent health facility attendance. Those living in HTR villages experienced considerable challenges in accessing treatment, not only was travel more difficult and costs greater, but women in HTR villages also experienced greater restrictions throughout the decision-making process. Once an appropriate drug has been obtained appropriate treatment may still be inhibited by experience of adverse events, incorrect dosing and challenges associated with administering antimalarials to children.

Chapter 6

Discussion and Conclusion

Chapter 6 Discussion and Conclusion

6.1 Introduction

This chapter presents and discusses the study findings detailed in chapters 4 and 5. Section 6.2 discusses the ways in which the current findings complement and build upon previous findings that were reviewed in chapter 2. The importance of in-depth context specific investigation is highlighted. This section is concluded by a discussion of the strengths of the methodological approach. Section 6.3 discusses the study limitations in light of the methodological approach described in chapter 3; data collection challenges are outlined and criticisms of the methodological approach are discussed. Section 6.4 makes recommendations for future research with consideration to the limitations outlined. Section 6.5 considers the study findings overall and outlines the implications for policymakers.

6.2 Strengths of study

Barriers to accessing appropriate treatment are experienced at each step in the treatment-seeking process; context specific studies are required to investigate the processes by which these barriers prevent progression through each stage in the process (Smith et al., 2010). This study contributes to the literature by providing detailed descriptions of illness perceptions and treatment-seeking decision-making within the Chikhwawa district of Malawi. Many of the study findings broadly correspond with previous studies conducted both within Malawi and within the international literature discussed in chapter 2, indicating the reliability of the data collected. Section 6.2.1 compares the study findings with previous research, and highlights additions to the existing body of knowledge. Section 6.2.2 discusses the strengths of the mixed-methods approach in investigating the broad range of factors influencing access to appropriate treatment.

6.2.1 Contributions to the literature

6.2.1.1 Interpretations of febrile illness

Knowledge of local illness categories is essential to our understanding of why individuals respond the way they do to febrile illness and for developing effective health education interventions that target context specific barriers to accessing appropriate treatment. This study responded to that need, providing details of local disease categories relating to childhood febrile illnesses within the Chikhwawa district (chapter 4.2). The literature review highlighted that a limited number of studies

have previously investigated perceptions of malaria, and even fewer have investigated alternative local illness concepts, the symptoms of which overlap with malaria. Ongoing health education interventions and other factors may contribute to changes in understanding among communities over time; this study provided an update to the literature available on local classifications of febrile illnesses (chapter 2.3.1). Summaries of the contributions are provided in the following paragraphs.

6.2.1.1.1 Definition of malaria

In support of previous work conducted in Malawi, a corresponding one-to-one relationship between local disease conceptions and those of allopathic medicine was not found (Morris, 1985). McCombie (1996) described that malaria-like illnesses may be grouped under a broader illness category or alternatively there may be several illness categories with malaria-like symptoms. Within the Chikhwawa district this distinction does not appear to be so clearly defined. The local term malungo was used to describe an illness with a specific set of symptoms which corresponded well with the biomedical definition of malaria; however this term was also used to refer to the symptom of fever, which is associated with a variety of other illness categories (e.g. tsempho and mauka). A previous study conducted in Malawi described the term malungo as a broad term encompassing a number of illnesses with different aetiologies (Helitzer-Allen and Kendall, 1992). However during FGDs, participants' descriptions of each of the specific illness categories indicated that these other illnesses were not considered to be a subset of malungo. The multiple ways in which this term is used perhaps reflects the long-standing influence of biomedicine in Malawi, which has led to the development of some consistency between biomedicine and the traditional concepts of disease, but has not completely overridden the original meaning of the term, which was used to describe febrile illnesses in general, with a focus on joint weakness (Morris, 1985). Descriptions of the symptoms of malungo were found to match well with the biomedical definition of malaria despite its continued use to broadly describe fever. Severe malaria was not investigated in detail; however the findings were consistent with earlier studies. The study identified a lack of recognition of the signs of severe malaria; there was a lack of clarity regarding the link between anaemia and malaria (Muula and Chimalizeni, 2004) and participants attributed convulsions to causes such as epilepsy and witchcraft (Chibwana et al., 2009). These findings indicate the need for health education interventions targeted at increasing knowledge of signs of severe illness.

6.2.1.1.2 Causes of malungo

The perceived causes of *malungo* identified broadly concur with the previous studies; however there were some differences in the details. A previous study conducted in the Mangochi area of Malawi

identified perceived causes of *malungo* to include: a form of malaria perceived to be caused by spirits or witchcraft; a subtype of *malungo* referred to as *kulipuka* which is associated with *mauka* in the parent; and airborne methods (Helitzer-Allen and Kendall, 1992). FGD participants stated that witchcraft did not directly cause *malungo*, and considered fever arising as a result of witchcraft to be different. There were no references to *kulipuka*, and airborne methods were not mentioned as a cause of *malungo*. These discrepancies are likely to be due to local differences in belief structures, and highlight the importance of conducting local, context specific research. Research concerning local classifications of illnesses cannot be assumed to be generalisable beyond the immediate setting of the research, even to other areas of the same country.

6.2.1.1.3 Mauka

Mauka was described as an illness affecting the reproductive tract of the mother passed through infected breast milk and causing malaria-like symptoms in the child. The descriptions of mauka identified, broadly correlate with previous descriptions identified in the literature review. However, there were regional differences in terms of the terminology used. Some terms identified in the literature review as being synonymous with mauka, such as likango, liable, and kulipuka were not used by study participants. In addition, participants used terms not previously identified in the literature review, such as masungu, which was used interchangeably with mauka, and nyankhwa which was considered by some to be a different, but similar illness, and by others to be a subtype of mauka.

6.2.1.1.4 Tsempho

Tsempho was described as a childhood illness which causes malaria-like symptoms during the early stages of the illness, although later symptoms include weight loss, stunting and swelling. A limited number of studies have been conducted to investigate tsempho from a malaria perspective. In the literature this illness is more frequently referred to as mdulo. It was noticeable that my research assistant and a number of others whom I held discussions with in Blantyre had never heard of this concept; however it was immediately understood by the fieldworkers. The term mdulo was recognised by study participants, however was not used by them; in all FGDs when the interviewer introduced the term mdulo the participants responded with descriptions of tsempho. The fieldworkers were therefore encouraged to use the latter term. In fitting with the previously reported definitions of this illness, study participants described this illness as arising as a result of breaking sexual taboos. However there were differences between the study findings and previous reports. Hot/cold symbolism has been said to be intrinsic to the concept of mdulo, whereby a person

in a 'hot' state may inflict illness through interactions with a person in a 'cold' state (van Breugel, 2001, Morris, 1985). The mdulo concept has also been linked to the use of salt, for instance a woman who has had an extra-marital relationship is said to be in a 'hot' state, and can inflict mdulo through salting the husband's ndiwo (relish/side dish) (Morris, 1985, van Breugel, 2001). This hot/cold symbolism and importance placed on the use of salt were not emphasised by participants. There were a couple of brief, indirect, references to the importance of the 'hot' state in one of the FGDs: as part of the explanation of the influence of the position of the child in the bed one mother explained that if the mother pulls the child towards her in bed, this was said to cause illness through exposing the child to her 'hot' body, even though she may not physically be warm. Another participant went on to explain that should the father move across the child to have sex with the mother, this was said to blow 'warm air' across the child causing illness. There were a few references to the role of salt. There was one reference to illness occurring if the parents have sex during a forbidden period followed by the woman preparing ndiwo (relish) with salt for them to eat. However more frequent were references to the use of salt in the treatment of tsempho; salt may be added to medicines provided by traditional healers. In addition a salt-like treatment was said to be received from the hospital, which should be applied to the vaginal sores. During one of the role-plays the mother described that the child 'losing blood' was a sign that 'salt was dissolving', and that therefore the child's illness was caused by tsempho (the father's transgressions). These differences between the study findings and those previously reported in the literature may reflect regional differences, the impact of increased use of formal health facilities, the mixing of ethnicities, or the changing of cultural beliefs over time. This issue is discussed further in section 6.3.1. Health education interventions must keep up with changing beliefs in order to effectively target relevant issues and not to be dismissed as being outdated. This is particularly important as some changes may arise as a result of contact with health system.

6.2.1.1.5 Witchcraft (*Ufiti*)

Findings related to *ufuti* (witchcraft) were similar to those previously reported in Malawi. *Ufiti* was perceived to be a risk factor for childhood illness (Launiala and Honkasalo, 2010). Illnesses that become chronic and do not respond to herbal or biomedical treatments may be redefined as being attributable to witchcraft (Morris, 1985). Participants believed that when an individual suffers from an illness as a result of bewitchment, medical doctors may see nothing wrong with the body (Maroon, 2010). Illnesses resulting from witchcraft were perceived to require treatment from a traditional healer and are not perceived to be treatable at health facilities (Maroon, 2010, Helitzer-Allen and Kendall, 1992). Relatives, particularly mothers-in-law were considered likely perpetrators

of illness caused through witchcraft (Launiala and Honkasalo, 2010). These findings are also in agreement with reports in the international literature that the suspicion of witchcraft often arises after repeated failed visits to the hospital, or where hospital doctors failed to find the cause of illness (Ribera and Hausmann-Muela, 2011, Tanner and Vlassoff, 1998). Previous studies conducted in Malawi report differing findings on whether witchcraft is perceived to be a cause of *malungo*: as discussed above one study reported participants perceived witchcraft as a cause of *malungo* (section 6.2.1.1.2), however another found participants did not consider witchcraft to be a cause of normal or severe *malungo* (Launiala and Honkasalo, 2010). In the current study witchcraft was not perceived as a cause. This difference of interpretation may have arisen as a result of the complexity of the use of the term *malungo*, which is sometimes used to refer specifically to an illness similar to the biomedical definition of malaria, and at other times to mean fever (section 6.2.1.1.1).

6.2.1.1.5.1 The role of traditional healers

Traditional healers were perceived to be essential in the treatment of illness caused by witchcraft and other traditional causes of illness (chapter 5.5.4.1). However, FGD participants stated that they use their own methods of diagnosing the cause of illness in order to avoid the traditional healers 'eating' their money and causing problems between family members. This is similar to accusations previously made against traditional healers in Malawi: that they charge exorbitant prices and deceive individuals, particularly the vulnerable, into believing they are able to cure illnesses which they are unable to (Maroon, 2010).

The findings of previous Malawian studies differed regarding the role of traditional healers and traditional medicines. A previous study identified the perception that *malungo* from mosquitoes is untreatable by traditional medicines (Helitzer-Allen and Kendall, 1992), whereas another study found that although the majority of individuals also held this view, some felt that the choice between traditional healers and government health facilities is down to the individual and may be based on factors such as proximity (Maroon, 2010). FGD participants stated that traditional healers were used for illnesses of traditional causation and bewitchment, whereas *malungo* was said to require antimalarial treatment. There were no references to traditional healers being used due to ease of access.

6.2.1.2 Responses to childhood fever

In common with most previous studies in the international literature, the majority of individuals participating in the household survey had attended a source of care (McCombie, 1996, Williams and Jones, 2004); only 13% sought no care for their child's recent febrile illness. However, only a minority of individuals reported utilising more than one source of care, whereas a previous study in Malawi found the use of multiple sources to be common (Mota et al., 2009). This may be related to the fact that in the present study, public health facilities were the most frequently utilised first source of care. Health facilities have been seen to be more frequently used in the first instance in situations where it is difficult to obtain antimalarials through informal sources and where treatment from public health facilities is free (Williams and Jones, 2004), both of which are true in the Chikhwawa district of Malawi. The previous Malawian study found the majority of individuals to seek informal sources of care in the first instance, with many switching to formal sources in the second instance (Mota et al., 2009). This difference may be the result of changes in drug policy between the two studies; LA was introduced as first line treatment for malaria in Malawi between the two studies. Participants did raise concerns about LA, however adverse events were infrequently reported (chapter 5.5.1), and there was a general perception that the drugs available from health facilities were of better quality than those available from shops (chapter 5.5.4). SP, the first-line antimalarial at the time of the previous study was, and continues to be, freely available from shops. However, since the switch to ACT drugs, careful drug control has ensured that these highly efficacious drugs are not readily available from shops or small retail outlets in rural areas. The positive perception of LA, combined with its lack of availability outside of the formal health sector may have lead to the greater proportion of individuals attending formal health facilities in the first instance since the introduction of LA.

The findings of this study were used to develop a model of the treatment-seeking process in which three phases were defined: Phase 1 – the assessment period; Phase 2 – seeking care outside the home; and Phase 3 – later sources of care (chapter 4.4). This phased approach has similar characteristics to the treatment-seeking process reported in the literature: a generalised response to managing mild febrile illness proceeds to decision-making based on treatment outcomes (Williams and Jones, 2004), however the study results enabled the development of a novel model to represent this process. Caregivers usually respond to the initial stages of illness using some form of home treatment, such as tepid sponging and locally obtained drugs. They then work through a trial and error type approach - as symptoms change individuals alter their beliefs and explanations and try alternative forms of treatment (Haussman Muela, Ribera and Tanner, 1998, Oberlander and

Elverdan, 2000, Williams and Jones, 2004, Kamat, 2006). As previously reported, the absence of fever and ability to eat and play were used to as signs the child had recovered (Williams et al., 1999), whilst a combination of fever and other symptoms such as vomiting, fever that does not abate with home methods and high fevers were signs indicating care was required from outside the home. A previous study in Malawi identified the perception that less severe *malungo*, caused by rain, wind etc could be cured using shop bought drugs, whereas *malungo* from mosquitoes was perceived to require antimalarial therapy (Helitzer-Allen and Kendall, 1992). The qualitative and quantitative data collection corroborates the finding that less severe illness is frequently treated with shop bought drugs, whereas more severe illness is more likely to be taken to a health facility. In agreement with previous findings, caregivers explained lack of health facility attendance as resulting from the perception that the illness was not severe (Kamat, 2006). However the study findings add to this by describing how the decision-making process is not only based on the perceived appropriateness of a particular treatment for the illness; but is also determined by constraints. FGD participants explained that shop bought drugs may be used even when perceived to be inferior, in order to avoid the challenges associated with health facility attendance (chapter 4.4.4.1.1).

6.2.1.2.1 Traditional versus biomedical illnesses: are the distinctions really clear?

Participants' descriptions of *malungo* matched well with the biomedical definition of malaria and the perceived appropriate response was treatment from the health facility. On the other hand traditional illnesses such as *mauka* and *tsempho* did not have direct biomedical equivalents, and for the most part traditional healers were perceived to be the appropriate source of care. However, these distinctions were not always so clear (chapter 4.4.4.1.2). Some participants argued that *mauka* could be treated at the health facility. In addition participants developed illness explanations which incorporated both traditional and biomedical elements. This process has been termed medical syncretism (Muela et al., 2002) and has been previously demonstrated to exist in Malawi (Launiala, 2010). Further, as previously seen in Malawi health workers contributed to this blurring of boundaries through suggesting traditional causes of illness, and by referring individuals to traditional healers in the case of treatment failure (Maroon, 2010).

6.2.1.3 Factors influencing attendance at a formal health facility: results of the household survey Data from the household survey demonstrated factors influencing attendance at a formal health facility (chapter 5.2). The study findings support those of the international and Malawi literature that distance from a formal health facility, child age and perceived severity of illness are important determinants of health facility utilisation (chapter- 2.3.2 and 2.3.3). The study adds to these findings

by quantifying the impact of living in a HTR area on health facility attendance and associated costs. Those living in HTR villages were less likely to attend a formal health facility for a recent childhood illness than those living NTH in both the dry (AOR 0.35, 95%CI 0.18-0.67, P=0.004) and wet seasons (AOR 0.46, 95%CI0.27-0.80, P=0.01). There are a number of factors which may be responsible for the relationship between area of residence and health facility attendance. The association between distance from a formal health facility and costs is described in section 6.2.1.4 and the relationship between location and norms around decision-making and the influence of this relationship on health facility attendance is discussed in section 6.2.1.5.

Those living NTH were also more likely to attend within 24 hours of fever onset. The qualitative research provides supportive data for this finding; those living in HTR villages had to consider the length of the journey and the dangers of night travel in the decision to seek care. For this reason they prefer to delay health facility attendance until the following day, when they can leave first thing in the morning and complete the journey before dark. All of the HTR villages included in the study had a CHW responsible for treating selective childhood illnesses and referring febrile children to the health facility. Despite this, those living in HTR villages were less likely to attend a formal source of care, even after including CHWs in the analysis. This differs from previous Malawian studies which found uptake of treatment from CHWs to be good (Akweongo et al., 2011), and that in the Chikhwawa district those in villages with CHWs were more likely to state that they would take their sick child to a health facility (Masangwi et al., 2010). There are some potential explanations for the differences seen between this and the previous Chikhwawa study. The previous study used a household survey to ask caregivers about hypothetical responses to illness, whereas in this study caregivers were asked about recent febrile episodes. In addition, the previous study distinguished between villages with and without CHWs but did not describe whether villages were classified as HTR; it is possible that a number of villages in the previous study without CHWs were in fact in HTR. This would demonstrate a benefit of having CHWs in HTR villages. However as shown in the present study, the presence of a CHW does not remove differences in access to care between HTR and NTH villages. A discussion of the importance of assessing the acceptability of the current CHW program in Chikhwawa, and the potential benefits of strengthening this intervention is presented in section 6.5.1.

6.2.1.4 Finances

As with previous Malawian studies, residents of the Chikhwawa district experienced considerable costs associated with seeking treatment for childhood febrile events. Among those who attended a

health facility, the total cost of a childhood febrile episode was USD3.45 for those living in HTR areas and USD5.24 for those living NTH in the dry season, and USD4.46 for those in HTR villages and USD5.60 for those NTH in the wet season. In economic studies it is advisable to estimate the indirect as well as direct costs (Drummond et al., 2005). Indirect costs incurred as the result of an illness have been defined as: 'reduced paid production due to the individual's disease; reduced unpaid production due to the individual's disease; and indirect costs accrued by the family and/or friends for taking care of the individual due to his or her disease' (Liljas, 1998). Estimating indirect costs is not without challenges, particularly in non-wage settings such as this. The researchers must choose to either apply an equal value of time to all individuals, or to value the individual's time on some sort of scale relative to their loss of production (Attanayake, Fox-Rushby and Mills, 2000). The findings presented in chapter 5.3.2 demonstrate that the majority of costs experienced by households were in the form of indirect costs. This is consistent with the findings in the international literature (Sauerborn et al., 1991, Attanayake, Fox-Rushby and Mills, 2000, Morel et al., 2008). However a previous study in Malawi found the majority of costs experienced by households in the treatment of malaria to have been in the private purchasing of antimalarial drugs (Ettling et al., 1994). The differences seen between the two studies may have arisen as a result of differences in the approach taken to valuing indirect costs. The previous study used income and household productivity data to value household member's time (Ettling et al., 1994). Such methods may more accurately value individuals' time, however the consequence of such methods is that they apply a greater value to time for individuals with greater earnings. This method would have been inappropriate in this study, as it was designed to assess geographic equity. Such an approach would have undoubtedly assigned a greater value to time lost by residents living NTH than those living in HTR villages, rendering any comparison between the two areas misleading. Rather, an equal value of time was assigned to all residents using a minimum wage method. Another possible explanation for differences in findings between these two studies is possible changes in treatment-seeking practices with the introduction of LA as the first-line antimalarial in Malawi (section 6.2.1.2).

Direct (out-of-pocket) costs made up the smaller proportion of total costs. Total direct costs were greater for those living in HTR villages compared to those living NTH in both seasons (Dry: NTH USD 0.20, HTR 0.38, P=0.04; Wet: NTH USD0.40, HTR USD0.95, P=0.08). The majority of direct costs were experienced in the form of costs associated with travel to and from the health facility. As discussed above, those living in HTR villages were also less likely to attend a formal health facility. This complements previous studies conducted in Malawi which found: the majority of respondents (73%) cite distance or transport costs as the main obstacle to accessing the nearest health facility

(Masangwi et al., 2010); that financial implications, particularly in the form of cash for transport, impact on access to care (Launiala and Honkasalo, 2010); and that, of those who attend a health facility for an episode of malaria, those living further from health facilities experience a higher hospitalisation and in-hospital mortality rates suggesting delayed treatment-seeking (Kazembe, Kleinschmidt and Sharp, 2006).

6.2.1.5 Gender, finance and the treatment-seeking decision-making process

Women's contribution to the economic status of the household through farming and other income producing activities was largely unrecognised (chapter 5.3.4). In general men were the landowners and therefore work done on the land was attributed to them, rather than to women workers. Unequal access to land for women has been reported elsewhere in the literature (Ribera and Hausmann-Muela, 2011, Tolhurst and Nyonator, 2006). The majority of women had little responsibility for decision-making regarding the use of finances. According to Sen's theory of intrahousehold bargaining, an individual's ability to contribute to decision-making processes is determined by factors including their perceived contribution to the household (Sen, 1990). Women's contributions are often minimised, whereas their outside earnings may improve their bargaining position (ibid). This is supported by evidence that IDI participants who stated they and their husbands conducted budgeting together all had an independent source of income.

A limited number of previous studies have investigated the role of intra-household relations on access to treatment for childhood malaria generally, and especially within the Malawian context. The usual process of decision-making involved recognition of illness by the mother, followed by the mother's responsibility to inform the child's father/her husband, whose responsibility it was to make decisions regarding the appropriate form of action. Those living in HTR villages also emphasised the role of the paternal grandmother who may take responsibility for decision-making in the absence of the father, or who may mediate between the mother and father in the case of disagreement. This supports previous studies, which found that female elders in Malawi have an important role in treatment-seeking decision-making (Bezner Kerr et al., 2008, Launiala, 2010, Tolhurst et al., 2008b). As seen in a study conducted in Ghana, fathers and their families were reported to be the 'owners' of children (Tolhurst et al., 2008a). This pattern, whereby the mother's role is to inform others while males and other senior household members take responsibility for final decision-making, has been previously reported (Molyneux et al., 2002, Orubuloye et al., 1991, Tolhurst et al., 2008a, Williams and Jones, 2004). There were differences in attitudes towards women's decision-making authority between the two study areas. Those in HTR villages emphasised the requirement for women to

notify others of the child's illness and the consequences for the woman of taking action without having done so. It was clear that such a process may result in delayed treatment-seeking in the case of the father's/husband's - the ultimate decision-maker's - absence (Hildenwall et al., 2008, Tolhurst and Nyonator, 2006, Mwenesi, Harpham and Snow, 1995). Those living NTH demonstrated an awareness of the possible negative consequences for the child of such a hierarchy, and argued that women should make decisions in the husband's absence. It is possible that differences in the cost consequences of treatment-seeking contributes to the differing levels of responsibility assigned to women in the two study areas; however, male participants living in HTR villages made it clear that the main concern was the consequence of the decision made - the woman would be blamed if she acted without permission and the outcome was poor.

Previous studies have found that women may take responsibility for financing treatment costs, either because the husband is unable or unwilling to pay, or to assist the husband temporarily until he can refund the money (Ribera and Hausmann-Muela, 2011, Tolhurst et al., 2008a, Tolhurst and Nyonator, 2006). Whilst lack of control of finances may inhibit women's decision-making capability (Williams and Jones, 2004), in some cases women's ability to fund treatment-seeking may provide them with the authority to make treatment-seeking decisions (Asenso-Okyere et al., 1997, Tolhurst et al., 2008a). Within the Chikhwawa district it was clear that with the small amounts of money the majority of women are able to raise, they are only able to fund the purchasing of small quantities of tablets, such as paracetamol, from local sources, but are in general unable to raise the funds required in order to use transport to get to the hospital or to pay for larger items such as a health passport. Lack of financial support from the husband prohibited health facility attendance, whereas access to independently raised finances was demonstrated to positively influence prompt appropriate treatment-seeking; access to and control over resources has been previously identified as influencing the treatment-seeking process (Asenso-Okyere et al., 1997, Tolhurst et al., 2008a, Richards, 2011).

The above paragraphs demonstrate that both norms around decision-making and access to resources influence the treatment-seeking process. Women generally relied on men for the provision of finances; the participants were unanimous though, that absence of funds for transport would not prevent health facility attendance, since the mother would carry the child and walk to the health facility, where treatment is free. Direct costs of treatment-seeking therefore do not fully account for differences in health facility attendance between the two study areas. The interaction between access to resources and norms around the decision-making process has been previously

described, and resources may be non-financial, such as access to education (Richards, 2011). Improvements in women's access to resources may influence their position within the household and the application of currently existing norms.

It should be noted that the involvement of other individuals in the treatment-seeking process also had the potential to promote access to treatment; some men ensured finances were made available for treatment-seeking in the case of the illness during their absence. In addition, mothers-in-law in HTR villages were found to have a number of supportive responsibilities; they were responsible for providing logistical support for health facility attendance such as organising transport, child care and providing food.

6.2.1.6 Perceptions of health facility care

On the whole participants were positive about care available from public health facilities. The availability of free care, in particular, was valued. High quality of available medications and skilled staff were also described. As previously seen in Malawi, doctors' knowledge of diseases, and the availability of diagnostics were given as reasons for attending public health facilities (Maroon, 2010). However, as previously seen in the literature, limited opening times, particularly at night-time; rude staff and long waiting times were all described as leading to poor perceptions of available care (McCombie, 1996, Williams and Jones, 2004, Masangwi et al., 2010, Chibwana et al., 2009).

6.2.1.6.1 Perceptions of Medication

Participants had mixed views regarding LA; women in HTR villages were generally positive, whereas male FGD participants expressed concerns including that it is not a strong drug (chapter 5.5.1). As previously reported, a number of participants believed that LA does not match with particular children, sometimes described as not matching with their blood (chapter 2.4.4.1). As described by Williams and Jones (2004), participants made decisions about the choice of treatments based on the perceived effectiveness of the medication for a particular set of symptoms in a specific illness episode. Participants recognised the importance of establishing the cause of illness in order for the correct medication to be selected; however suitability of a medication was not perceived to be determined by the cause of illness alone. This is similar to previous findings in Malawi that individuals' perceptions of cause of illness were not predictive of their preferred treatment strategies (Ager et al., 1996). The process of interpretation is complex; individuals interpret treatment failure differently at different times, through a process that is determined by factors related to the context of the illness. For instance suspicions of bewitchment have previously been

described as mainly arising in contexts of pre-existing social conflict (Haussman Muela, Ribera and Tanner, 1998). In addition to issues of compatibility and failure to identify the correct cause, treatment failure was also felt to arise as a result of lack of effectiveness of the medication and poor adherence to the dosing schedule. Participants expressed concerns about the frequency with which they received LA, both in terms of frequency of malarial illness and the perception that treatment with LA is a default treatment given for all ailments even if not suitable.

As reported in previous studies investigating adverse events to LA (chapter 2.4.4.2), such events were infrequently reported and described as mild occurrences. Vomiting was the most frequently mentioned adverse event, and was described to be a problem in all of the FGDs, although it was not reported in any of the IDIs. Vomiting can lead to lack of adherence. In contrast to the studies previously described, the participants were generally aware of the importance of replacing a vomited dose; information which they stated was given at the health facility. However, the consensus was that there was no need to obtain additional tablets to make up for the loss, suggesting a need for education in this area. Further, vomiting and other adverse events were reported to be signs that the medication is not suitable for the child, which may have serious consequences for adherence.

The nature of the study design did not allow an investigation of the quality of instructions given at the health facility, which has been reported to be a problem in the international literature. The participants showed an awareness of the importance of following instructions received at the health facility and possible consequences of altering the schedule; however they described experimenting with the schedule in an attempt to speed the process up. There were also areas in which participants lacked knowledge of the appropriate dosing schedule. Some participants reported overdosing through taking all doses over a shorter period than intended, whilst others continued treatment for longer, both of which have been previously reported (Depoortere et al., 2004b, Beer et al., 2009, Kachur et al., 2004). Previous studies conducted in urban areas of Malawi found higher rates of reported adherence (Bell et al., 2009, Akweongo et al., 2011) than in a rural study (Mace et al., 2011). The adherence issues reported by participants may indicate that overall adherence to LA within the Chikhwawa district is in line with that reported in a rural area of Malawi. Regional differences in utilisation of antimalarials may be an area worth further investigation.

A number of participants described taking the tablets three times a day, which may be related to confusion over the pictorial instructions printed on the package, and indicate a lack of supportive verbal instruction. A Nigerian study found that a number of participants could not understand the instructions based on the drawings only: participants interpreted the youngest dosing schedule as one tablet required three times a day for two days or once daily for six days rather than twice daily for three days (Ajayi et al., 2008c). It is encouraging that participants were aware of the importance of correct dosing, and that many understood the dosing schedule and importance of replacing vomited doses. However lack of knowledge of certain aspects highlights the importance of the provision of messages at the health facility to clarify, and reinforce the importance of the correct dosing. Participants placed importance on following instructions given at the health facility which indicates the considerable potential impact of such messages.

The ease of administering medication to children is determined by the formulation (chapter 2.4.4.4.1). The study design allowed some comparison of the ease of administration of the dispersible and non-dispersible formulations of LA. The bitter taste of medications was said to be a general problem in administering drugs to children, causing children to refuse to take tablets. A number of participants experienced difficulties in administering the non-dispersible formulation; by comparison the dispersible, flavoured, formulation was associated with few problems. This may indicate the potential for improved adherence, and decreased risk of treatment failure and reinfection rates with this new formulation. However, the dispersible formulation is only currently available in doses suitable for the youngest age groups, whereas participants reported greater difficulty in administering medication to older children. This highlights the importance of considering the role of flavoured medication in increasing adherence rates among older children.

6.2.1.6.2 Perceptions of diagnosis

Participants demonstrated an expectation to receive malaria testing before being prescribed LA and dissatisfaction with receiving antimalarial treatment without such testing. Pressure by patients has previously been seen to be a contributing factor to inappropriate drug prescribing (Wasunna et al., 2008). In this study participants rarely expressed a desire to receive LA regardless of the test result, in keeping with other findings internationally, that individuals show preference for receiving antimalarial testing (Derua et al., 2011, Chandler et al., 2008b, Tarimo et al., 2000), and that patient-side pressure for overuse of antimalarials in health facilities is minimal (Derua et al., 2011, Chandler et al., 2008b).

6.2.1.6.3 Comparison of public and private health facility

Attitudes to medication available from formal health facilities differed from previous research conducted in the north of Malawi. Study participants perceived medications available from formal health facilities to compare favourably to those available from private health facilities. However in the north, study participants complained of lower quality drugs and lack of medication at public health facilities (Maroon, 2010, Munthali, 2005). None of the participants complained about drug shortages. There were a number of references to participants being instructed to purchase paracetamol, however this was taken for granted and not complained about. It is unclear why there appears to be a difference between the north and the south: it may be due to differences in the restocking systems between the two areas, or improvements in the process over time. As previously reported the high costs of treatment provided in private hospitals were reported to be prohibitive (Maroon, 2010). Benefits of private facilities were said to include better attention to patients, while disadvantages include attempts of private facilities to treat illnesses they are unequipped or unqualified to manage (ibid).

6.2.2 Strengths of the methodological approach

The previous sections have discussed the contributions of the study to the existing literature. Within this section I discuss the strengths of the methodology used. The mixed-methods approach allowed investigation of a broad range of factors which influence access to appropriate malaria treatment. It enabled the development of explanations that combined the findings of the quantitative and qualitative data collection; particularly in relation to differences between the two study areas. As previously discussed, differences were demonstrated in health facility attendance for recent febrile events between the two study locations (section 6.2.1.3). The combination of methodological approaches used enabled the development of explanations for this finding based on quantifiable factors, such as the difference in household costs of attending a health facility between the two study locations, and process related factors, such as differences in norms around decision-making.

Methodological approaches differ in their suitability to investigating particular aspects of behaviour (chapter 3.3). An advantage of the mixed-methods approach is that it allows the investigator to draw together the findings of data collected using different approaches. Aspects of the study methodology and question wording can have an important influence on study findings (McCombie, 1996). For instance, indirect questioning about treatment options may elicit very different responses from specific questions about the methods used by a particular individual (McCombie, 1996). For this reason this study utilised and triangulated various methods, drawing on the strengths of each in

order to develop a clearer picture of the issues. The FGDs allowed generation of information regarding general community perceptions, and comparison between the different groups, while the IDIs and interview questionnaires used in the household survey provided information regarding actual behaviour following episodes of illness. A particular strength of the recruitment strategy for the IDIs was the ability to interview caregivers of children who had experienced fever and were confirmed to have malaria parasites, yet had not sought care. The IDIs provided a flexible and open way of gathering in-depth information, whereas the survey design allowed analysis to be conducted on statistically representative data. Triangulation of data collected using different techniques enables validation as data gathered using different methodologies may reinforce or confirm findings (Patton, 1990, Helitzer-Allen and Kendall, 1992). Alternatively findings from each technique may differ, and validity may be increased by developing explanations for such differences (Patton, 1990, Helitzer-Allen and Kendall, 1992, Richie, Spencer and O'Connor, 2003). Triangulation is particularly useful in enhancing short-term, rapid research (Helitzer-Allen and Kendall, 1992). The advantage of the mixed-methods approach has been previously demonstrated in Malawi through a study which investigated perceptions of malaria prophylaxis in pregnancy (ibid). During the quantitative phase of the study low adherence to the prophylaxis was identified, however when asked whether there were any medicines that should not be used by pregnant women, the majority of participants (99%, n=265) did not mention the drug used for prophylaxis. During the qualitative arm of the research however, participants were unanimous that bitter tasting drugs, such as that used for prophylaxis, should not be used by pregnant women. It is not exactly clear why this discrepancy arose, it may have resulted from the setting of the quantitative questionnaire since interviews were conducted within the antenatal clinic as part of the clinical study. However it demonstrates the benefits of combining multiple methods in order to develop rich data.

Utilisation of traditional healers was infrequently reported in the household survey and was not reported by any of the IDI participants, yet it was frequently discussed in the FGDs. Frequent references to the use of traditional healers during FGDs has been previously reported in Malawi, and compared to low reported rates of utilisation in surveys (Chibwana et al., 2009). As discussed above, the IDIs and interview questionnaires provided an opportunity for investigating actual behaviour. However the one-to-one setup can be daunting for participants, who may be unfamiliar with discussing their behaviour with a previously unknown individual. This may have resulted in participants being inclined to withhold information about specific aspects of their behaviour, which they believed may have been perceived negatively. By comparison FGDs provided a forum for discussion of issues more broadly, in a safer and more naturalistic environment, which arguably led

to participants feeling freer to discuss issues more openly and honestly. This effect can be seen in the comparison of IDI and FGD transcripts; the IDIs tended to be brief, around 20 to 30 min long each, and in some cases the interviewer had to probe hard in order to elicit a deep explanation of events. The FGDs on the other hand tended to be long, around 2 1/2 hours and participants demonstrated a desire to explain and discuss issues. There are advantages of gathering data regarding actual recent behaviour, however where the topics covered are sensitive this may not be possible. The combination of methods used in this study allowed the strengths of methods investigating actual behaviour to be balanced against methods which facilitated the collection of sensitive information regarding cultural beliefs.

Another example of the strength of FGDs in collecting sensitive information comes from the investigation of reasons for delayed or absent health facility attendance. Perceived lack of severity was reported to be an issue in both IDIs and FGDs: it was reported to be responsible for delayed health facility attendance and was the main reason for lack of health facility attendance among IDI participants. By contrast, another issue - the use of health facilities as a last resort, despite perceived low quality of available alternatives - was only described in FGDs. The fact that recognition of illness severity was described as a challenge in both IDIs and FGDs suggests this was a serious issue for participants. However its importance may have been over-emphasised in the IDIs: problems with recognition may have been perceived by participants to be a more acceptable explanation for their lack of health facility attendance and the one-to-one setup of the IDI may therefore have encouraged participants to opt for this response. However within the security of the FGDs, participants may have felt greater freedom to present both the perceived acceptable and unacceptable aspects of their behaviour. The use of different data collection methods in this study has allowed this comparison of results and increased the validity of the findings.

6.3 Limitations of the study

The following paragraphs discuss the limitations of the study with reference to the methodological approach outlined in chapter 3.

6.3.1 Scope of the study

This study aimed to demonstrate how multiple factors interact to determine access to appropriate malaria treatment. However it was not possible to provide an all-inclusive description of factors influencing access, but rather it was necessary to focus on the study's initial objectives. For instance,

some of the factors known to influence the treatment-seeking process, such as educational status, household structure (eg female headed versus male headed, polygamous etc) and household wealth (chapter 2.3.4) were not investigated. In addition, health facility related factors were not investigated in detail.

The study design allowed the development of a detailed description of the treatment-seeking process; however, it was necessary to restrict the depth of investigation in order to demonstrate the role of multiple factors. This led to limitations in regard to how far underlying beliefs, values and perceptions of community members could be explored. The influence of this may be particularly pronounced in the investigation of perceptions of fever and local illness classifications. For example the locally perceived illness tsempho may not be fully described in all its complexity. This may be demonstrated by the fact that, where previous research highlighted the importance of belief in hot/cold symbolism and salt as a medium in this illness, these issues were infrequently raised, and may have been missed without the previous reading of the literature (section 6.2.1.1.4). As discussed above, these differences may reflect regional differences or changes over time. However they may be due to the deeply rooted nature of such beliefs, which are kept 'hidden' and not easily uncovered with the methods used in the study. This study may have provided a 'snapshot' of beliefs relating to this complex; whereas some of the more detailed descriptions arose out of extended periods of anthropological research (van Breugel, 2001). In addition, the study uncovered differences in treatment-seeking norms between the two study areas, however an in-depth investigation of underlying cultural differences would have required more extended research, beyond the scope of this study.

Participants explained that it was often easier to administer medication to younger children. Investigating the influence of child age on utilisation of antimalarials was beyond the scope of this study. Lower adherence to antimalarials among older children has previously been reported (Souares et al., 2008). This was explained in terms of older children returning quickly to their responsibilities such as school or farming once recovered and having greater freedom and less supervision from caregivers. Chapter 2.4.4.3 outlined the importance of patients', or caregivers', understanding of the treatment regime; older children's understanding may also be an important determinant. The importance of the three-way relationship between provider-caregiver-patient in adherence to medication has previously been expressed, and highlighted within the Malawian context (Sanz, 2003, Winnick et al., 2005, Weigel et al., 2009). A suggestion for future study would

be to investigate antimalarial utilisation by older children, in particular the extent of responsibility given to the child and the child's willingness to take the medication.

6.3.2 Limited qualifications of field-staff

The field-staff recruited to conduct the data collection had limited experience in qualitative research techniques. On some occasions this was seen to result in a lack of probing into the details of the treatment-seeking process. This was particularly noticeable in the IDIs, partly due to participants being less forthcoming with information in the IDIs than they were during FGDs. One noticeable issue was that at times participants lacked clarity about the ordering of events and in some cases actual events themselves were difficult to understand. Sound files of interviews were reviewed with fieldworkers immediately after each data collection. On several such occasions the fieldworkers stated that they had not understood what the participants meant, and attributed this to the participants' confusion. Despite emphasising the importance of following up points lacking clarity, at times the fieldworkers had insufficient experience and confidence to establish the rapport required to assist the participants to develop clear accounts of events.

6.3.3 The influence of research team members' positionalities in determining findings

The position and perspective of each member of the research team would have impacted on the way in which the research was designed, conducted, analysed and interpreted (chapter 3.5.5). The biomedical perspective from which this study was designed, and my position as European, trained in the UK would have dictated the underlying expectations and the areas selected for research. The pre-existing beliefs and expectations of the fieldworkers would have influenced their phrasing of questions and interviewing manner and in turn participants' responses. The fieldworkers were recruited to take part in the study from outside the local area; they had all completed secondary education; and had access to a private health insurance scheme through their employment. These factors will have impacted on the fieldworkers' perspectives of study participants, and may go some way to explain why at the start of the study the fieldworkers expressed the view that absent health facility attendance and poor adherence to antimalarials was due to laziness (chapter 3.5.2). A team approach was taken and interpretations drew on the perspectives of the various team members. The assistance of a Malawian research assistant proved useful in providing a local perspective on the analysis.

6.3.4 Reliance on caregivers reports

Reliance on participants' reports may have influenced a number of areas of the study. The study relied heavily upon retrospectively collected data, which may have been subject to recall bias. For this reason a short recall period of two weeks was chosen for both the household survey and IDIs to minimise errors. Even so, it is possible that errors may still have occurred. This is likely where the date of an illness was incorrectly believed to have been within the past two weeks when in reality it was longer ago. It is doubtful that the recall bias was differential between the two village locations and therefore it is difficult to establish in what way it may have affected results.

As is common in treatment-seeking studies, the household survey relied on caregivers' reports of fever – a proxy for malaria - in the identification of recently febrile children (Chuma et al., 2006, Attanayake, Fox-Rushby and Mills, 2000, Jayawardene, 1993, Sauerborn et al., 1996). However this was supported by the investigation of the underlying meaning of fever including recognition and perceptions. In addition, children of all caregivers participating in IDIs had received either a positive RDT for malaria or antimalarial treatment from a health facility, and were therefore likely to have experienced a recent malaria episode (3.5.1.2.1.2). The study relied on caregivers' reports of the perceived severity of illness. This may have limited the accuracy of adjustments made for severity of illness in calculations of the effect of distance, and other factors, on health facility attendance, although previous studies have shown caregivers to have a good ability to recognise both mild and severe signs of illness (Williams and Jones, 2004, Kallander et al., 2006).

The collection of indirect cost data required respondents to quantify the length of time they were engaged in particular activities. Many participants found estimating length of time difficult, and the fieldworkers informed me several times that participants were guessing in order to provide answers to these questions. This issue arises from the approach to the questionnaire design. The questionnaire was designed from an outsider (health economics) perspective rather than from the community's perspective. The advantage of this method was that it generated an internationally comparable measurement of indirect and total cost. The disadvantage was that the difficulty individuals had in responding to questions may have reduced the validity of the findings. In addition the value assigned to caregivers' time may have little meaning to the study population. Another challenge associated with relying on participants' recall of out-of-pocket costs and time is that participants' awareness of the study aims may have altered their responses. Participants may exaggerate economic hardships in the belief this may increase future benefits to themselves (Attanayake, Fox-Rushby and Mills, 2000). However, since this perception could operate among both

village groups it seems unlikely that this could have been responsible for the differences in findings between the two study groups.

Participants' reports were relied on for all aspects of the qualitative data collection. It cannot be assumed that participants provided a full and accurate account of events. It may have been difficult for participants to disclose information about their behaviour, or the behaviour of others in the household, where it was perceived to be at odds with local norms, or perceived expectations of the research team. This issue was discussed with reference to the use of traditional healers in section-6.2.2), but may have also influenced responses to other areas of the study.

6.3.5 Sampling

The sampling strategy had several limitations which may impact on the generalisability of the findings. The study was limited to one district and may not represent the experiences and perspectives of those living elsewhere in Malawi or internationally. The choice of district enabled the investigation of access to malaria treatment in a highly endemic area with high levels of poverty. In addition as highlighted in section 6.2 many of the findings broadly concur with those of studies previously conducted in Malawi and elsewhere. Further, detailed accounts of context specific elements require a restriction on the area of study. Quantitative factors such as formal health facility attendance rates and costs of childhood fever may differ between districts, however the relationships between these outcomes and village accessibility is not expected to differ greatly in other districts.

It was initially anticipated that a larger number of the HTR villages in the Chikhwawa District be recruited for the household survey. However only six of the villages on the list provided by the MoH met two of the most essential criteria: accessible all year round and presence of an active CHW. The HTR villages recruited for the study may therefore not fully represent the majority of HTR villages. It would be expected that less accessible villages make less contact with formal health facilities and may experience greater costs. We should therefore anticipate that the actual differences between nearby and HTR villages in terms of health facilities attendance and associated costs may be greater in more typical HTR villages.

A limited number of FGDs and no IDIs were conducted with male participants. This may have led to an underrepresentation of male views, which may have important consequences considering the significant role that men have in the decision-making process (chapter 5.4). In addition, no IDIs were conducted with mothers-in-law, who were also shown to share responsibility for decision-making.

Future research to investigate in detail the perspectives of other household members regarding their role in decision-making during responses to childhood febrile episodes in this context is warranted. Treatment-seeking and antimalarial drug use for older children was not investigated, in addition no children were recruited to participate in the study and therefore their perspectives are not represented; another possible area for future study.

6.3.6 Limitations of the costing approach

In many ways the most challenging aspect of the methodology used in this study was the allocation of a monetary value to the burden of malaria experienced by caregivers during childhood febrile events. Such measurements rely on the recall of caregivers, who are required to describe details of their everyday life which they may usually take for granted; recall issues were described above (section 6.3.4). The following paragraphs discuss additional challenges associated with the approach. Justification for the method used to assign a value to caregivers' time was presented in section 6.2.1.4; associated challenges are described in section 6.3.6.1. The methods used in this study to measure economic cost suffer from the cross-sectional design: costs associated with single febrile events were measured, rather than the accumulation of costs over time – the experience of multiple episodes and the contexts of such costs were not considered (section 6.3.6.2). In addition, only short-term costs associated with the febrile events were measured (section 6.3.6.3).

6.3.6.1 Valuing caregivers' time

Indirect costs formed the majority of costs experienced by households during recent childhood febrile episodes. The majority of indirect costs were associated with time spent caring for the sick child at home, and these were found to be significantly greater for those living in HTR villages compared to those living NTH during the dry season (NTH: USD2.40; HTR: USD4.01, P=0.02). However caring costs did not differ significantly by area of residence during the wet season (NTH: USD3.13; HTR: USD3.82, P=0.12), despite an increase in the strength of the relationship between living in a HTR village and mean illness length (Dry: HTR 5.8 days vs. NTH 4.9 days, P=0.09; Wet: 5.6 vs. 4.8 days, P=0.03). This may be due to the method used to value indirect costs. This study responds to an earlier call to consider seasonality in cost measurements: costs were calculated separately in each season (Chuma et al., 2006); however the monetary value assigned to time was constant, in order to allow comparability between areas. In reality, for agricultural communities the value of time differs considerably between seasons, being greatest during the wet season, when the majority of the agricultural activity of the year takes place (ibid). The impact of this may have been greater for residents of HTR villages since they were more likely to own agricultural land and engage

in farming activities. The consequences of such differences are difficult to quantify; the changes in the value of time between seasons may impact on individuals' perceptions of and responses to illness. A previous study investigated seasonal variations and household costs of all illness in a rural Burkina Faso (Sauerborn et al., 1996). During the wet season the opportunity cost of time was seen to increase; this was associated with a reduction in perceived severity of illness. A later paper detailed the results of an investigation of household coping methods and identified three main strategies: individuals modified their perception of the illness, continued to work regardless of the illness, and left illnesses untreated (Sauerborn, Adams and Hien, 1996). In the current context there may have been increased pressure on caregivers to engage in farming activities during the wet season, rather than caring for their child. This is an example of the challenge associated with using quantitative methods to describe complex behaviours. The methodological approach taken to value caregivers' time focused on ensuring comparability of costs according to geographic area. This simplification may have resulted in a failure to detect a true difference in the indirect costs experienced by households during the wet season. A suggestion for future research would be to investigate seasonal variations in the prioritisation and distribution of household roles and responsibilities, particularly in terms of caring for sick children.

6.3.6.2 The burden of malaria during the last episode or as an ongoing process

The approach taken for the household survey and IDIs was to collect data specifically related to the cost of the last, recent malaria episode. Such an approach has been criticised on the grounds of it detaching this last episode from the broader socio-cultural complexities which influence the accessibility of care, particularly for the vulnerable (Ribera and Hausmann-Muela, 2011). However, this study drew on a variety of methodologies and attempted to investigate contextual factors, such as the acceptability of the services provided, in addition to accessibility and cost. Further, the investigation of accessibility reached further than a simple investigation of quantifiable factors such as distance, and included a discussion of the position of women within the household and the intrahousehold decision-making process more broadly. Despite such efforts, as outlined below, the collection of cost data in particular suffered from this reductionist approach.

The cost data presented gives an indication of the considerable costs experienced by households during a single febrile episode. It does not however provide a picture of how such repeated costs of health problems accumulate and impact households. In particular it fails to take account of how the effect of these costs on households is determined by the context in which they take place, such as whether there are concurrent events within the household for example other illnesses, weddings

and funerals, or external events, such as the economic climate and environmental context (e.g. flooding, a regular occurrence in the Chikhwawa district); this context determines the available assets and strategies available during treatment-seeking (Ribera and Hausmann-Muela, 2011, Obrist et al., 2007, Chuma et al., 2006, Russell, 2005). Neither do the costs presented draw attention to the way in which costs, loss of income and coping strategies impact on the vulnerability of households and poverty (Chuma et al., 2006, Ribera and Hausmann-Muela, 2011, Russell, 2005). Even small, but frequent burdens may impact on the economic viability of the household (Russell, 2005). The intention of the cost data presented is to highlight the differences in costs experienced by those living NTH and those living in HTR villages which may explain some of the differences seen in treatment-seeking behaviour. A more detailed investigation of any differences between the two study areas in the way cost burdens accumulate and individuals adapt coping strategies may be warranted.

Individuals experience treatment failure in addition to repeated bouts of illness. This results in potentially costly and time-consuming repeat trips to the health facility occurring within a short period of time of one another. This may further impact on the economic burden of illness on the household and influence treatment-seeking, as caregivers consider the time and economic cost of further care-seeking and the long-term impact of these on the household. Such repeated visits to the health facility have been previously reported to inhibit adequate treatment-seeking behaviour (Ribera and Hausmann-Muela, 2011). Further, the impact of repeated bouts of illness or treatment failure may be greatest during the wet season when episodes of malaria are more frequent and households may be under greater financial pressure (Chuma et al., 2006).

6.3.6.3 Short-term versus long-term costs

Short-term costs only were included in this study, longer term economic costs include: reduce future productivity as a result of reduced educational attainment due to missed schooling and long-term effects on cognitive development; costs incurred as a result of longer term morbidity, such as sequelae resulting from severe malaria, and loss of quality of life due to such sequelae; and expenses associated with loss of life, such as funeral costs (Chuma et al., 2006, Sachs and Malaney, 2002, Chima, Goodman and Mills, 2003, Asenso-Okyere and Dzator, 1997). Only one household was found to have experienced recent childhood death due to fever, even so only including short-run costs the findings of this study may have underestimated the true costs experienced by households in this district due to childhood febrile illness. Since greater severity of illness and death are related to

delayed or absent care-seeking, and attendance at a formal health facility is lower among those in HTR villages, longer-run economic costs may also be greater in HTR compared to nearby villages.

6.4 Recommendations for future research

Based on the study findings and limitations, recommendations for future research include:

- Investigation of the perceptions of other community members, such as men and grandmothers, regarding appropriate responses to febrile illness, and determinants of the decision-making process;
- More in-depth qualitative work to explore the impact of additional factors on the treatmentseeking process, such as household structure and educational level;
- Assessment of antimalarial drug utilisation by older children including exploration of children's perspectives, and the potential role of dispersible LA among older age groups;
- Investigation of regional differences in utilisation of antimalarials (rural versus urban);
- Examination of reasons for the low levels of utilisation of CHWs and low proportion of referral visits;
- Detailed investigation of the way in which cost burdens impact on households. This should
 include exploration of any differences in the way accumulated cost burdens differ between
 the two locations and across seasons, and any differences in the use or avoidance of coping
 strategies which may influence the treatment-seeking process. Strategies that should be
 considered include selling assets; altering perceptions of illness; and re-prioritising and
 distributing household roles and responsibilities, such as when weighing the time costs of
 caring for sick children against the demands of farming;
- Household surveys investigating treatment-seeking frequently consider only the initial
 source of care. This study demonstrates the importance of considering the multiple stages of
 the treatment-seeking process. Individuals may not be able to attend the prioritised source
 initially and may rely on sources closer to the home until attending their preferred source
 becomes feasible.

6.5 Implications of study findings

The following paragraphs outline the main implications of this research. The study findings indicate the potential benefits of strengthening interventions to bring care nearer the homes of individuals; the role of enhanced community-based health education interventions; and, the need to strengthen appropriate diagnosis and treatment at health facility level. Chapter 4.4 described the phased

approach to treatment-seeking: initially individuals assess the severity of illness and consider what action needs to take place (Phase 1); if symptoms fail to resolve or worsen caregivers seek care outside the home, frequently from a public health facility (Phase 2); in most cases treatment failure leads to repeat visits to the health facility, however lack of resolution of symptoms results in caregivers reconsidering the cause of illness and seeking alternative sources of care (Phase 3). The first two issues described below target behaviours with the intention of improving actions, and promptness of health facility attendance during Phases 1 and 2 of treatment-seeking (section 6.5.1 and 6.5.2). Actions taken during Phase 3 of treatment-seeking are largely determined by responses to Phase 2 treatment, and may be better tackled through changes at the level of the health facility as described in the final issue (section 6.5.3).

6.5.1 The potential benefits of strengthening interventions to bring care nearer the home

CHWs are placed in HTR villages with the aim of bringing care closer to individuals' homes. This study found attendance at CHWs to have been infrequent, despite their proximity to community members and the low costs of attending. Further, the majority of those who attended a CHW did not go on to attend a health facility. Bypassing of lower levels of the healthcare system is a problem in Malawi (chapter 2.2.2). The essential healthcare package in Malawi is developed with the aim of providing a basic standard of care to everyone (2002). Services are rationed in order for high priority services to be delivered equitably (ibid). From both the perspectives of cost minimisation and equity prioritisation, it is essential that the current CHW referral programme be assessed in terms of establishing reasons for the low uptake of services, and lack of referral visits to health facilities. The inclusion of ACTs in the services provided by CHWs is being considered by the MoH. This may increase utilisation and improve access to appropriate treatment for the poorest and most at risk members of the population, whilst reducing the costs of accessing care. Concerns include the challenges associated with effective drug allocation and distribution, already reported to be a problem within the health system in Malawi (ibid). The following paragraphs discuss the potential benefits of strengthening the current CHW program.

6.5.1.1 Improved equity of access to appropriate treatment

Individuals living in HTR villages were less likely to attend a health facility for a recent febrile childhood illness compared to those living NTH. This suggests the potential role of bringing care nearer the homes of individuals in improving access to appropriate treatment. Treatment-seeking behaviour has been shown in the international literature to be influenced by the economic status of the household. This has been seen in studies using the same technique as this study (principal

components analysis – chapter 3.4.2.2) to measure socio-economic status (Onwujekwe, 2005, Schellenberg et al., 2003) and those using alternative techniques (Chuma et al., 2006, Chuma, Gilson and Molyneux, 2007). The results of this study however did not identify differences in the proportion of individuals attending a health facility according to socio-economic status in either season, in line with a previous study that used data from the MDHS 2000 (Mathanga and Bowie, 2007). The lack of association between socio-economic status and health facility utilisation in Malawi may be due to the availability of free healthcare at public health facilities acting to reduce inequities in access to health facility treatment according to household wealth. This should be looked upon positively, however it perhaps indicates that in the Malawian setting distance from health facility is of greater concern in reducing existing inequities in access to treatment.

6.5.1.2 Improved promptness of health facility attendance

Those living in HTR villages were less likely to attend a health facility within 24 hours of fever onset compared to those living NTH. This finding should be interpreted in light of the costs experienced by those living in HTR villages, and the phased approach to treatment taken by caregivers. Section 6.2.1.4 discussed the greater costs of health facility attendance for those living in HTR villages compared to those living NTH, and highlighted the role of distance and transport in the decisionmaking process. Phase 1 of treatment-seeking is the assessment phase, this was referred to as period of waiting to see how the illness progresses. Caregivers were more likely to seek care if they perceived the illness to be severe; however perceived lack of severity of illness was not the only reason for lack of health facility attendance at this stage. Caregivers also engaged a cost minimisation strategy and avoided unnecessary challenges associated with alternative treatment options if possible. This strategy helps families avoid pushing themselves further into vulnerability until they are sure it is necessary; other coping strategies available to households, such as selling assets, may undermine the economic viability of the household (Ribera and Hausmann-Muela, 2011, Chuma, Gilson and Molyneux, 2007, Chuma et al., 2006). Those living in HTR villages must consider greater costs associated with any travel to a formal health facility in the decision to seek care. It seems a logical conclusion that this additional burden acts to extend the assessment period, while caregivers establish whether action is really necessary, resulting in the observed later attendance at a health facility in this group. It is recommended that all febrile children are taken promptly to the health facility; however for caregivers this would place an unrealistic burden on the household (Ribera and Hausmann-Muela, 2011). The assessment period used to determine the necessity of treatment-seeking has been previously reported to be short (Ribera and Hausmann-Muela, 2011). In our setting however caregivers stated that it takes them between two and five days to recognise

that malaria is the cause of the illness and acknowledged that at times the illness is serious by the time it is recognised. Health education messages targeting the importance of prompt treatment are destined to fail while caregivers are forced to engage in treatment-seeking strategies to prevent potentially catastrophic burdens on the household. Bringing care nearer the home is essential in reducing geographic inequities and improving promptness of responses during Phase 1 and 2 of treatment-seeking among those living in HTR villages.

6.5.1.3 Reducing cost burdens on the community

Despite free healthcare provision at public health facilities, residents of the Chikhwawa district still experience considerable costs in accessing these facilities. In addition, children in the Chikhwawa district experience repeated febrile episodes, and costs of attending a health facility may be considerably greater if care is sought for each febrile episode. The link between malaria and poverty has previously been established (Chuma et al., 2006, Sachs and Malaney, 2002, Gallup and Sachs, 2001). The repeated economic burden of malaria experienced by households is therefore likely to be a contributor to the maintenance of poverty in this region. As implied above, the strengthening of interventions to bring care closer to the homes of individuals would act to reduce the burden of costs experienced by households. In addition to improving access to treatment, this may also lead to improvements in the overall wealth and development of the community.

6.5.1.4 Reduced time burden on women

Distance from health facility was strongly associated with health facility utilisation. However study participants described how if insufficient funds were available for transport, they would walk to the health facility. Section 6.2.1.5 discussed how this finding indicates the important role that differences in treatment-seeking norms between the two study communities have on health facility utilisation rates. A further potential contributing factor to the different health facility utilisation rates is the additional time demands that treatment-seeking places on women living in HTR villages. Women are usually responsible for attending the health facility with their child and as previously seen in Malawi, carry out the majority of caring activities (Simwaka et al., 2006). Heavy workloads reduce women's ability to seek care (chapter 2.3.4.4). There was an indication that indirect costs associated with travel time were greater for those living in HTR villages compared to those NTH in the dry season (USD0.15 vs. USD0.07, P=0.11), and this relationship was strongly significant in the wet season (USD0.16 vs. USD0.08, P<0.001). In addition differences in time allocation pressures for women in the two study areas may have arisen as a result of engagement in different income generating activities; a greater proportion of those in HTR villages were engaged in farming. Time

pressures associated with farming have previously been linked to reduced use of treatment (Ibrahim et al., 1994). In addition the lower standard of sanitation available to those living in HTR villages was seen to place additional demands on time (chapter 5.2.1). Enhancing interventions to bring care closer to individuals' homes would reduce the time burden associated with travel to and from the health facility, the benefits of which may include improved access to treatment and reduced consequences of lost farming time on household productivity. Benefits may extend beyond this to include a reduction in time burdens, which contribute to the time poverty of women (Richards, 2011).

6.5.2 The role of enhanced community-based health education interventions

Alongside their other tasks, CHWs living in HTR villages are also responsible for delivering health education messages. The isolated nature of these communities increases the importance of such programs. Individuals living in HTR villages make less contact with health facilities and therefore benefit less from education messages delivered at health facility level. Previous studies have demonstrated the benefits of education programs that strive to engage with communities within their own contexts (Rath et al., 2010, Aubel, Toure and Diagne, 2004, Richards, 2011). The lower rates of health facility utilisation among those living in HTR villages suggests a need to strengthen the delivery of education messages by CHWs. Chapter 5.4 highlights the roles of the various actors that take part in the decision-making process. Women are usually responsible for identifying illness, but it is then their role to inform the child's father or other elders. Despite women's lack of decisionmaking authority, in Tanzania women were found to be subject to aggressive health facility based education methods, which act to further undermine their status (Montgomery et al., 2006). In Malawi methods used to deliver health messages at antenatal clinics have been found to be dominant and teacher-centred (Launiala, 2010). Further, health education programs in Malawi rarely seek to involve grandmothers (Bezner Kerr et al., 2008). Community-based education programs should seek to involve the wider community, including men, in order to ensure that those responsible for making decisions are included (Montgomery et al., 2006, Richards, 2011, Bezner Kerr et al., 2008, Franckel et al., 2009). The role of older women should be harnessed in behaviour change strategies (Aubel, 2011); involving grandmothers in health education programmes has been seen to lead to improvements in the education messages grandmothers give to women, and women's actions (Aubel, Toure and Diagne, 2004). By involving all the relevant actors in context specific community-based health education programmes, such interventions may be used to address, rather than reinforce, the underlying gender (and generational) inequalities that dictate the

treatment-seeking process (Montgomery et al., 2006, Ribera and Hausmann-Muela, 2011, Richards, 2011).

6.5.3 The need to strengthen appropriate diagnosis and treatment at health facilities

Failure of health facility treatment has a number of potential consequences including leading to poor perceptions of health facility care and the utilisation of alternative treatment options.

6.5.3.1 Over-diagnosis of malaria and overuse of antimalarials

Participants were concerned about the frequency with which children are prescribed LA; concerns included LA being taken for repeated episodes of illness within short periods of time of one another, and being taken for a variety of complaints. IDI participants had experienced treatment failure following receipt of LA after which they received alternative medication during repeat visits, or in one case a second dose of LA. Such occurrences suggest an over-diagnosis of presumptive malaria and overuse of antimalarials. Previous studies in Malawi have demonstrated a lack of use of laboratory services and test results by clinical staff (Mepham et al., 2010, Chinkhumba et al., 2010). The issue of malaria over-diagnosis is well known, and potentially leads to under-treatment of other serious causes of childhood febrile illness (Reyburn et al., 2004, Amexo et al., O'Dempsey et al., 1993, Chandler et al., 2008a, D'Acremont et al., 2009). Over-diagnosis of malaria may hinder accurate reporting and monitoring of malaria cases, which is essential for developing appropriate control measures and appropriate resource allocation (Breman, Alilio and Mills, 2004). Treatment failure and repeat visits to health facilities associated with malaria misdiagnosis places additional costs on households, which may be higher if inappropriate diagnosis leads to death or disability (Amexo et al.). It may also lead to loss of faith in available medications and the health system more broadly if treatment is perceived to fail (Amexo et al., D'Acremont et al., 2009). This may explain the development of theories regarding the effectiveness of LA, such as the perceived incompatibility of the drug with particular children and the perception by some that it is not a strong drug. In addition, participants expressed frustration about not receiving a diagnostic test for malaria and confusion regarding the lack of correlation between test results, treatment given and treatment outcomes. Poor perceptions of care as a result of such challenges lead to altered treatment-seeking practices: perceived incompatibility of treatment may deter future health facility attendance, and fear of receiving a repeat treatment with LA was seen to lead to avoidance of return visits to the health facility as the illness progressed.

Inaccurate diagnosis and treatment during early stages of illness may also result in lost opportunities for appropriate prompt treatment of severe non-malarial illnesses. Several perceived traditional causes of childhood febrile illness were identified, such as *tsempho* and *mauka*. These illnesses were in general considered as causes after the failure of health facility treatment. The example of *tsempho* in particular highlights the importance of ruling out malaria where appropriate and considering alternative causes; symptoms during early stages of this illness mimic those of malaria. Later symptoms, such as stunting, loss of weight and swelling may better indicate one of the underlying causes described in the literature review (HIV, TB and severe malnutrition - chapter 2.3.1.2.2). However failure of (malaria) treatment early on in the course of the illness, when symptoms are broad and perhaps vague, may deter caregivers from returning to the health facility and instead lead them to seek traditional sources of care.

6.5.3.2 Education of health workers

Section 4.4.4.1.2 discussed the role of health workers in promoting traditional beliefs regarding the causes and treatment of illnesses. This highlights the importance of educating health workers in the range of illnesses which may be responsible for perceived traditional causes of the symptoms experienced. It also points to the importance of educating health workers in the diagnosis and treatment of non-malarial febrile illnesses, both initially and following treatment failure. The reduction in over-treatment of malaria and overuse of antimalarials discussed in the previous section will only be possible if health workers knowledge of alternative causes of febrile illness is strengthened. The potential role of health workers in communicating accurate information about the causes of and appropriate responses to treatment failure has been previously highlighted (Haussman Muela, Ribera and Tanner, 1998). Within the Malawian context however, health workers knowledge of these topics must first be strengthened.

6.5.3.3 Appropriate treatment includes effective communication

The need for health education messages targeting recognition of the signs of severe malaria and proper antimalarial dosing and responses to adverse events was discussed above (sections 6.2.1.1.1 and 6.2.1.6.1). In addition to this, the practical task of administering medication to children was challenging. Caregivers described using potentially detrimental methods such as threatening and physical force to ensure their children took the medication. Improvements in the ease of administration were seen with the dispersible formulation. However the study findings highlight the potential role of health education messages targeted towards teaching caregivers positive strategies for administering medication.

6.6 Final conclusion

Universal access to malaria treatment is essential to achieving international targets for malaria reduction. This requires an accurate understanding of factors influencing access, in order to develop locally appropriate health intervention strategies. Within this thesis I have demonstrated the multidimensional nature of access to appropriate treatment among children in the Chikhwawa district of Malawi. I have also explored how barriers to access differ among communities within the Chikhwawa district, and highlighted the need to develop interventions to target the specific challenges experienced by each.

This thesis responded to gaps in the existing literature; previous qualitative research into treatmentseeking behaviour for childhood fever in Malawi was limited. It has also updated the quantitative literature, as the majority of existing studies were conducted before the introduction of ACTs as the first-line treatment of malaria. Few previous studies have considered multiple dimensions of access within a single study. Access to appropriate treatment was found to be determined by a variety of inter-connected factors. One factor alone was not sufficient to determine responses, but rather responses were specific to each illness episode and its context. Sources of care utilised depended on the interpretations of symptoms. Participants were found to have a good understanding of the biomedical model of malaria; however this was not sufficient to ensure health facility attendance. Distance and out-of-pocket costs acted as barriers, although again not necessarily sufficient to prevent attendance. Despite long distances and associated travel costs, participants said they would carry the child and walk if necessary. Perceptions of available care were also important determinants of the action taken, which may explain why despite the low costs of attending and close proximity of CHWs, they were infrequently utilised. Participants expressed generally positive perceptions of health facility care, yet at times they opted for sources of care perceived to be of inferior quality, such as shops, to avoid the challenges associated with attending health facilities. This draws attention to the role of indirect costs. In addition to costs, distance and perceptions of care, norms around the intra-household process of decision-making influenced access to appropriate treatment. Support from husbands and mothers-in-law promoted health facility attendance, however women's lack of decision-making autonomy and access to resources acted as barriers, particularly for those living in HTR villages.

Attendance at a health facility did not guarantee access to appropriate treatment; treatment failure was a frequent complaint and barriers to utilisation remained. Adverse events, such as vomiting, led caregivers to stop administering antimalarials, and even where medication was continued, medication lost through vomiting may have impacted on the effectiveness. Lack of understanding of the correct dosing schedule also inhibited adherence. Caregivers used threats and physical force during administration of medication which may have led to loss of medication and problems with administering later doses.

The mixed-methods approach enabled the investigation of the different determinants of access described above. It also enabled validation of findings where results obtained using different methodologies supported one another and the development of explanatory theories where results differed. However the study methodology also had a number of limitations. It was necessary to restrict the scope of the study and focus on the initial objectives; as a result a number of potential determinants of access were not investigated. The field staff had limited qualifications and experience in qualitative research which had implications for the quality of the data collection process. The way in which the research was designed and implemented and the analysis conducted would have been influenced by the positions and perspectives of the various team members. It was necessary to rely on retrospectively collected information; as a result inaccuracies may have occurred as a result of poor recall, or where participants chose to present or withhold information according to its perceived acceptability. The generalisability of the findings may have been restricted by the need to investigate detailed context specific factors, and the underrepresentation of certain subgroups, such as men, may have led to gaps in the final results. In order to allow comparability of findings according to location a simplified approach was taken to measuring indirect costs; costs may therefore not accurately represented the value of time as experienced by caregivers. Finally, the costs provide a snapshot during one febrile episode, and do not take account of the burden of malaria as an ongoing process. Despite these limitations the findings broadly concurred with previous studies, suggesting their validity. In addition the methodological approach taken was suitable to achieve the objectives of the research and enabled the generation of detailed descriptions of the issues at stake.

The study findings had a number of clear implications. The strengthening of interventions to bring care nearer the home has the potential to lead to improved access to appropriate treatment, improved promptness of health facility attendance, reduced effects of malaria related costs on the community, and reduced time burdens for women. The strengthening of community-based health

education may contribute to improved access to treatment if decision-makers are involved. Involving the wider community members, such as men and mothers-in-law, in such education programs has the potential to assist in addressing underlying inequalities and ensure that those responsible for making decisions access knowledge. Finally strengthened diagnosis and treatment at health facilities may reduce the contribution of over-diagnosis of malaria to poor perceptions of antimalarials and improve antimalarial utilisation and treatment choices later on in the progression of the illness. The findings presented in this thesis have highlighted specific, targetable issues which suggest the considerable potential impact of strengthening existing interventions.

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APPENDICES

Appendix 1 Household survey Questionnaire – English version

Background information

The following questionnaire is designed to establish the household costs involved in the care of sick children. Details are asked about direct costs such as the cost of buying necessary treatment and also about any loss of income the household may have suffered as a result of the child illness. [We are looking for households where a child under the age of 10 has lived in the past 2 weeks]

Part A Identification			
Interviewer:			
Date			
House identification number:			
Village:			
Details or comments from:			
Interviewer			
Supervisor			
Data entry person			
(Attempts should be made	e to find the m	nost sei	enior female in the household to interview)
Have any of the children in this	household		
suffered from fever in the past	2 Yes	No	
weeks?	1	2	
If yes how many?			
Please	fill in part B fo	r each	n child that has been sick

Part B Illness experience - You will now be asked about each	h of the child	ren in this h	nousehold
who have experienced fever recently.			
(Start with the youngest child that has been sick and move on to older c	hildren in age	order)	
Child ID	Α	В	С
What is your relationship to (name)?			
Other Mother Sister Aunt Grandmother (please specify)			
1 2 3 4 5 How old is (name)?			
Sex of child: Male Female 1 2			
6.What is the highest level of school (name) has achieved? None STD 1 STD 2 STD 3 STD 4 STD 5 0 1 2 3 4 5			
7. How severe was the child's illness? Mild fever Moderate fever fever fever Severe fever fever (specify) know 1 2 3 4 88			
8. Did they get better? Yes Still ill Died Don't know 1 2 3 88			
 If the child has died in the past two weeks please break the quecaregiver and ask them if they are prepared to carry on with the If the child has not recovered and hasn't visited a health facility How long did the illness last? Number of days or Don't know (88) Part C Accessing care – you will now be asked about the place 	e interviewing. - please refer.		
child.		-	•
10. Did you get treatment from outside of your Yes No			
house e.g. shop/clinic?			
11. If not what were the reasons for this? Not severe Got Too far No Family Would not Other			
enough better away transport let me (specify)			
1 2 3 4 5 6 (Go to question x)			
12. Who did you get treatment from?			
Please note all that apply, in the order of attendance			
Public/mission			
1 2 3 4 5			

shop/kiosk	petty	neighbour	traditional	HSA
	trader		healer	
6	7	8	9	10
other (specify) 11				

The following section is about the treatment the child(ren) received at each provider visited. A separate sheet should be used for each child and the child's id should be marked on the top right hand corner. Details of the first provider visited should be filled in first and then any subsequent visits in order of attendance.

Attendance Number							1st	2nd	3rd	4th
13. How many dathis provider?	ays after the	start of the	fever did y	ou go	to					
•	day Day	after next	More th	an 2 da	ys					
0 1 2 Write no. of days										
14. How far away	is this perso	on? – write ar	nswers in k	ilomet	res, if	less than				
1km write <1km, o	don't know (88)								
15. How did you travel there? Walk bicycle motorcycle										
		1	2		3					
private car	public taxi/bus	Boat donl	key/horse		her ecify)					
4	5	6	7		8					
16. How long did	it take you t	o get from yo	our home t	to the	provid	er?				
Hours/mir	nutes									
17. What was the	total cost o	f travelling to	and from	the p	ovide	r?				
18. How many pe	ople made t	he journey?								
Did you have to p	ay anything	for any of th	e followin	g servi	ces?		•	l .		
(Please ask wheth	er payments	were in cash	or kind ar	d reco	rd as s	tated)				
19. Consultation -	how much	did you pay?	nothing							
20. Tests – w	hat tests did									
you have?		RDT 1	Micros 2	сору	_	t know 88				
none										
21. What was the	result?									
		Positive	e Nega	tive	_	t know 88				
22. How much did	I the test co		<u></u>							
23. How many nig	hts did you	stay at the fa	ncility? wri	te num	ber					
24. What was the	cost of any	inpatient fee	s?							

Attendance Number		1st	2nd	3rd	4th
25. If the patient stayed overnight how many people from yo	our				
household stayed with the patient? Write number					
26. Drugs:					
Were drugs given or a prescription provided?					
Received Received No medicine or	Don't know				
medicine prescription prescription received 1 2 3	88				
(If no drugs received please go to question x)					
27. What drugs were given? SP/Fansidar LA	1 2				
Quinine	3				
Other (specify) Don't know	4 88				
28. How much did they cost?					
29. Did the child finish the course?	Yes No				
	1 2				
30. Is it possible to view any left-over packages?	Yes No				
(Mark name of drug if different and whether completed)					
31. Were any other treatments given?	Yes No				
	1 2				
32. (If yes) what treatments were given?					
33. How much did these treatments cost?					
34. What was the total period of time spent at this provider?	•				
(Hours/minutes)					
35. How many more visits did you make to the provider?					
give number or 0 for no more visits made					
36. Were there any other costs associated with visiting	Yes No				
this provider that you have not already described?	1 2				
37. Did the child take any supplements,					
nerbs or special foods during the time of	Don't Know				
their illness that have not already been	88				
mentioned?					
38. (if yes) what was the total cost of providing these supple	ments, herb	s			

Attendance Number			1st	2nd	3rd	4th
or special foods?						
39. Were there any other costs associated with this	Yes	No				
illness that you have not already described? (specify how much and what for)	1	2				

Part D Ot	her costs of c	are - you w	ill now be	asked a	about o	ther			
	ring for your chi	•					A	В	С
		id(i eii) aiid	IIOW LIIES	e arrect	eu youi		, ,		
household.									
40. What is	activity is carried	out by the cl	nild's main	carer d	uring thi	is			
time?									
Farmer		Shopkeeper/R	etail Bu	siness	Childca	re			
1	2 Civil	3	C	4 Other	5				
Student	Servant	No occupati	on (sp	ecify)					
6 41. How ma	ny days was the	8 child's main o	arer unab	9 le to car i	rv on th	eir			
	ies because of th				-				
		113 11111111111111111111111111111111111	tile past z	L WCCKS	i (tilis a	ocs			
not include	•		(00)						
	Days, Half days,								
Did any other	er children less th	nan 10 years (old who liv	e in you	r house	hold			
have fever i	n the past 2 weel	ks? If so pleas	e go back	to sectio	on x.				
Please an	swer the follo	owing que	stions fo	r all ch	nildren				
_	receive any outsi			g the co	sts of th	ie			
child(ren)'s	illness? If yes wh	o helped you	?						
Househo	=	ipport from	Insura	ance	Charit	v			
everyt 1	hing	employer 2	3		4	•			
43. What an	nount did you red	ceive?							
44. Did you	or members of ye	our househol	d have to l	orrow r	noney/s	sell			
assets to pa	y for this care? N	ote all that a	oply						
		Borrowed	-						
Sufficient	Borrowed from	from the	Sold	Sold	ç	old			
cash	friend/relative	healthcare	livestock	proper		our			
Casii	mena, relative	provider	HUCSTOCK	proper	cy iau	Jui			
1	2	3	4	5		6			
	ch did you borro		.						
-3. HOW IIIu	an did you bollo								

The following section will collect information about you and your household.

Informati	tion about the study participant	
46. What is	s your marital status?	
Married/ in union	divorced/separated widow/widower single	
1	2 3 4	
47. What is	s the highest level you have achieved in school?	
STD 1-5	STD 6-8 Secondary or more None	
1	2 3 4	
Informati	tion about the housing environment	
48. What is	s the total number of persons living in this household?	
49. What is	s the main source of drinking water for members of your	
household?	?	
Piped water	er	
Piped	l into dwelling 1	
Piped	l into yard/plot 2	
-	y stand pipe 3	
Water from	·	
	well in yard/plot 4	
	public well 5	
	n covered well or borehole	
	cted well in yard/plot 6	
	cted public well 7	
Surface wat		
· ·	g	
=	/stream 9	
-	/lake 10	
_		
	nter	
	ng does it take you to go there, get water, and come back?	
	ber of minutes, or on premises (99)	
	ind of toilet facilities does your household have?	
	t	
Pit toilet/la		
	ditional pit toilet	
	/bush/field 4	
• -		
	-	
	share these facilities with other households? Yes No 1 2	
-	our household have any of the following?:	
-	1 A bed with a mattress 6	
=	lamp 2 A sofa set 7	
	n 3 A table and chair(s) 8	
-	phone 4 A refrigerator 9	
A telephone	ne (landline) 5	

54. What type of fuel does your household mainly use for o	noking)	
Electricity 1 Charcoal	5	•	
LPG/natural gas	6		
Biogas 7 Dung	8		
Paraffin/kerosene 3 Other (specify)	9		
Coal, lignite	_		
55. Main material of the floor			
(record observation)			
Natural floor Finished floor			
Earth/sand 1 Parquet or polished wo	od	6	
Dung 2 Vinyl or asphalt strips		7	
Rudimentary floor Ceramic tiles		8	
Wood planks 3 Cement		9	
Palm/bamboo 4 Carpet		10	
Broken bricks 5 Other (specify)		11	
56. How many rooms in your household are used for sleepi	ng?		
Number of rooms			
57. Does this household own any agricultural land?	Yes	No	
•	1	2	
58. How much agricultural land does this household own?			
No. Acres or Don't know (88)			
59. Does this household own any livestock?	Yes	No	
•	1	2	
60. How many of the following types of animals are owned	l by this		Number
household?			
			Goats
			Pigs
			Cattle
			Sheep
			Chickens
61. Does any member of your household own:	Yes	No	
A bicycle?	1	2	
A motorcycle or motor scooter?	Yes	No	
Attractor of the construction of the construct	1	2	
A car or truck?	Yes	No	
	1	2	
62. Is there an active community health worker (HSA) in	Yes	No	
your village?	1	2	

Thank the family for their time.

Appendix 2 Household survey Questionnaire – Chichewa version

MAWU AZOFUNIKA KUZIDZIWA KOYAMBIRIRA

Mafunso akafukufukuwa akonzedwa kuti zimene mawanja amataya posamalira ana odwala ziikidwe pambalambanda. Zenizeni zokhudza chuma chogulira thandizo lawodwala komanso zotaika pabanja potsatira kudwala kwa mwana zidzafunsidwa.

[We are looking for households where a child under the age of 10 has lived in the past 2 weeks]

Part A Identification	
Ofunsa mafunso:	
Tsiku, Mwezi ndi Chaka:	
Chizindikiro cha nyumba yofikiridwa:	
Ndemanga zochokera kwa:	
Mudzi:	
Ofunsa ı	mafunso
Oyang'anira ofunsa i	mafunso
Osonkhanitsa zopezeka pakafuk	ufukuyu
(Kuyesetsa kudzikichitika pakafukufukuyu kuti mal	unso adziyankhulidwa ndi mayi wachikulire wa
pabanja lofik	iridwali).
1. Alipo mwa ana abanjali amene Inde Ay	i
avutika ndi kutentha thupi _{1 2}	
mwezi wangothawu?	
2.Ngati inde, ndi angati anavutika ndi kutentha thupi?	
Dzadzoni shigowo B zakhudza mwana aliyonsa s	mono anaduvala ndi kuika sikalata namadsi
Dzadzani chigawo B zokhudza mwana aliyense a	·
(Muyambirire ndi wotsiriza kubadwa amene ai	·
anadwal	awa).

Gawo B - zokł	nuza kadwa	alidwe-	You will no	w be a	sked about	each o	f the chi	ldren in t	his hous	<u>ehold</u>
who have experie	nced fever re	cently. (S	tart with the	e young	est child and r	move o	n to older	children ii	n age ord	<u>er)</u>
Mwana:								Α	В	С
3. Ubale wanu nd	(dzina) ndi v	votani?								
	Ndi ma	ayi Cher	nwali Adz	zakhali	Agogo akaz	71	apena ena?			
	1	,	2	3	4		5			
4. Ali ndi zaka zing	gati (dzina)?									
5. Ndi mwamuna	kapena mkaz	i			Mwamu	na	Mkazi			
					1		2			
6. Adaphunzira m	•		a)?							
Sad	aphunzire	Kalasi 1	K 2	К3	K 4		K 5			
	0	1	2	3	4		5			
7. Anadwala mota	ıni?									
kutentha thupi komverera	kutentha thupi kofikapo	kutentha kopatsa n	=	foto	alidwe ena, okozani ne zidaliri	Simuk	udziwa			
1	2	3			4	8	8			
8. Anapeza bwino	?	inde 1	akudwa l 2	labe a	namwalira 3	simukı 8				
Ngati mwa	na womwaliray	u sipadapi	ite masabata	a ochulu	ıka, lekezani n	nafunso	owa, pere	kani maw	a achipep	eso
kenaka afu	nseni amene m	ukucheze	rana nawo n	gati mu	ıngapitirire.					
Ngati mwa	na akuvutikabe	ndipo san	apite kukap	eza tha	ndizo la kuchi	patala,	alimbikits	eni kutero).	
9. Anavutika ntha	wi yaitali bwa	anji? Leml	bani kuchulu	ıka kwa	masiku, simu	kudziw	a (88)			
Gawo C – Kap	ezedwe ka	thandi	zo la ma	nkhw	ala a kute	entha	thupi			
- Mudzafunsidwa	za malo ame	ne mukuf	una mwan	a wanı	u akasamalir	idwe				
10. Munapeza tha	ndizo kwa wi	na aliyen	se chitsan	zo kwa	а	Inde	Ayi			
malaonda kapena	kuchipatala?	•				1	2			
11.Ngati sidzinali	chotero, ziful	wa zake	ndi zotani?	?						
kwenikweni	asintha achit ana	/lalo handizo li kutali	Vuto lakayended	dwe S	Apabanja langa anandiloreze	njira fotot	pena i zina (kozani zotani)			
1 (ngati sizotero, pitar	2 ni kufunso x)	3	4		5		6			

Chipatala cha boma kapena cha mpingo	Malo ongolandirako thandizo	order of attendance Chipatala cha munthu	Chipatala cha bungwe Iosati la boma	Malo ogulitsirapo mankhwala
1	2	3	4	5
Malo awogulitsa malonda	Munthu wa pamsika	Woyandikizana naye nyumba	Sing'anga	HSA
6	7	8	9	10
Kapena	a njira zina			
(fototkoza	ani ndi zotani)			
	11			

Chigawo chotsatira chidzafunsa za chithandizo cha mankhwala chimene mwana kapena ana analandira ku Chipatala chomwe anapitako. Peala la padera ligwiritsidwe ntchito kwa mwana aliyense ndipo chipjaso cha mwana chsisindikizidwe pa mwamba pa pepalalo kudzanja la manja . Zotsatira za ku chipatala choyamba zilembedwe koyambirira kenako ma ulendo enawo

Ma ulendo a	mene mwapi	tako				1st	2nd	3rd	4th
13. Mudaka masiku ang		o la mankhwala	a kutentha th	upi mut	tadwala				
Tsiku Iomwelo	M'mwawa mwake	Patapita masiku awiri	Kapena atatu kapena angati?						
0	1	2	Lembani kuchuluka kwa masiku						
14. Ulendo v	wake ndowota	arika bwanji kufi	ka kumalo am	iene mi	ınakapeza				
thandizolo?	– <u>makilomita</u>	angati? Kuchepe	ra pa Kilomita	<u>lemba</u>	ni <1km <u>,</u>				
simukudziwa	a (88)								
	15. Mudayenda pa mudayenda panjinga njinga yamoto mayendedwe otani? pansi								
		1	2		3				
galimoto	minibasi	bwato / ngalawa	nyama zokwera monga bulu	foto	na njira zina (tkozani ndi zotani)				
4	5	6	7		8				
16. Mudater	nga maola ang	gati paulendowu	? Maulo/N	Лрhindi					
17. Mudagw	riritsa ntchito	ndalama zingati	kupita ndi kul	bwera?					
18. Mudali a	nthu angati?								
19. Mudalip	ira chirichons	e pa zinthu zotsa	tirazi?			1	I	I	
•		nents were in casl		ecord a	s stated)				
Nanga pakul	kambirana nd	i Dokotala muda	lipira zingati?	,					
20. Zoyezaye	eza za mthupi	-							
mudayezets	a chiani?	<u>F</u>	RDT Micros		Simukudziwa 88				

21. Nanga zotsatira zake zinali		
zotani?	Positive Negative Simukudziwa	
	1 2 88	
22. Ngati munalipira munalipira zin	gati?	
23. Kodi ndi mwangonekedwa kang	ati ku Chipatala?	
24. Mudalipira zingati pogonera ku	chipatalako?	
25. Anamudikirira ndi anthu angati	pamene odwala anali mchipatala?	
26. Mankhwala:		
Mudalandira kapena anakulembera	ıni kuti mukagule?	
mudalandira chikalata		
mudalandira chosonyeza mankhwala? pogula mankhwala?	padalibe chimene simukudziwa adakupatsana	
1 2	3 88	
(ngati simunalandire mankhwala pit	_	
27. Mudalandira mankhwala amtur	or / ransidar immini	
wanji?	LA 2 Quinine 3	
	Zina (Longosolani) 4	
	Simukudziwa 88	
29. Mwana wodwalayo adatsiriza k	•	
	1 2	
30. Zingatheke kuona mankhwala a		
(Lembani dzina la mannkhwala ngat ngati anamaliza kumwa mankhwala	· · · · · · · · · · · · · · · · · · ·	
31. Padalinso thandizo lamtundu w		
	1 2	
	1 2	
32. Ngati inde ndithandizo lanji?		
33. Zinatenga ndalama zochuluka b	wanji?	
34. Mudakakhala nthawi yotalika b	wanji kumalo achithandizowa?	
(Maulo/Mphindi)		
35. Mudapita kungati kumalo a chit	andizowa? <u>Kapena simunapitenso?</u>	
36. Padali ndalama zina mudaonon	ga zimene simudazionetse	
kale?	•	
	1 2	

37. Kodi mwana odwala adalandira thandizo						
lina lowonjezera, zitsamba kapena zakudya	Inde	Ayi	Simkud	dziwa		
zapadera?	1	2	88	3		
38. Ngati zidaperekedwa, zidatenga ndalama zing	gati?					
20. Poli indologia nina mudaucana ganca (fataka	.a.:\2		Indo	Avi		
39. Pali ndalama zina mudawononganso (fotokoz	anı)?		Inde	Ayi		
			1	2		

Part D Othe	er costs of ca	<u>re</u> – Tsopano	mudzafunsid	wa za ndalama z	omwe			
zawononged	wa posamalira	mwana/ana r	ndiponso m'm	ene zimenezi		Α	В	С
zakhudzira b	anja lanu.							
40. Wosamalir	a mwana odwala	a amachita chia	ni panthawi yo	dwazika matenday	ıi?			
ulimi 1 wantchito	wogwira ntchit kwa ena 2 wongokhala	ko kugulitsa malonda 3 Other	kusamalira mwana 4	vophunzira 5				
wa boma	_	(specify)						
6 41 Wosamalii	7 ra wodwala anal	8 khala masiku ar	ngati wosatha l	kuchita ntchito zin	nene			
	nwezi wangotha				iieiie			
Did any other	children less tha	n 10 years old	who live in you	ır household have	fever in			
the past 2 wee	eks? If so please	go back to sect	ion x.					
•	•			•• •				
	wer the follo			<u>nildren</u>	T			
42. Mudathan	dizidwa ndi nda	lama kuchokera	a kwa ena?					
Adakuthandiz ndani?	•	idadzilimbira Iokha	Akuntchito adathandiza	Inshulansi				
1		2	3	4				
43. Mudaland	ira zochuluka bv	vanji?						
44. Mudangor	ngola kapena ku	gulitsa katundu	wa mnyumba	?				
Note all that a			•					
Mudalinzao	Mudangongola	Mudasiya						
	kwa abale	ngongole	Mudagulitsa	Mudagulitsa	C-11			
ndalama	kapena	kumalo a	zifuyo?	ziwiya?	<u>Ganyu</u>			
zokwanira?	anzanu?	chithandizowa?	•					
1	2	3	4	5	6			
45. Mudangor	ngola zingati?							
-	-							

Ndime yotsatirayi isonkhetsa maganizo wokhudza banja lanu (you and your family).

Zokhudza wot	enga mbali pak	afukufukuyi:		
46. Muli ndi banja	kapena ayi?			
Wokwatiwa 1	wopanda banja	lidatha kapena kusiyana 3	wa masiye	
	mpaka kalasi yanji?		·	
P	, , , , , , , , , , , , , , , , , , , ,			
Kalasi 1-5 K	6-8 sekondale k	-	aphunzire omwe	
1	2 3		4	
Zokhudza mal	o amene muma	khala:		
48. Banja lanu mu	li anthu angati?			
49. MADZI AKUM\	WA MUMATUNGA KU	JTI?		
Madzi amu Mpope	1			
	yumba	1		
	, poloti			
	malo adela lonselo			
Madzi apa chitsime				
	akhomo kapena papolo			
	anthu onse			
	hotoetezedwa kapena			
	oloti kapena pakhomo. tetezedwa xha anthu o			
Madzi oyenda pam		150 /		
• •		8		
·	ena mtsinje			
	a nyanja			
· · · · · · · · · · · · · · · · · · ·				
Madzi amvula	a	12		
	a pagalimoto/ Thankala			
-	wa m'mabotolo			
_	thawi yotalika bwan			
	ndi kapena ndipamalo d		(99)	
_	ntchito chimbudzi ch			
		1		
Dzenje Chokumba na	di kumangira	າ		
	di kumangira cholola mpweya kuma:			
		_		
	be chirichonse			
	ntchito chimbuzichi		Inde Ayi	
		wanga mia.	1 2	
53. Banja lanu liri	ndi:			
Magetsi	1 K	ama ya matilesi	6	
Nyali ya mafuta		lipando ya sofa		
Wailesi ya kanema		ome ndi mipando		
Lamya ya m'manja		hoziziritsira zinthu (f	iliji) 9	
Lamya ya mnyumb	5			

54. Mumaphika pogwiritsa	ntchi	to chivani?			
Magetsi	1	Nkhuni	6		
Mpweya wa chilengedwe	2	Zinyalala ndi udzu	7		
Mafuta anyali	3	Ndowe	8		
Malasha	4	Njira zina (fotokozani zota	_		
Makala a mtengo	5	Njira ziria (10t0k0zarii zota	1111) 3		
55. Pansi pa nyumba ndipo		dwa ndi chiyani?			
(record observation)	Ū	•			
<u>Dothi</u>		Finished floor			
Mchenga	1	Parquet or polished wo	ood	6	
Ndowe	2	Timaphathi ta phula		7	
Rudimentary floor		Mapale		8	
Matabwa	3	Simenti		9	
Njedza kapena nsungwi.	4	Chinsalu choyala		10	
Njerwa zowotcha	5	Njira zina – fotokozani		11	
56. Zipinda zingati zimagwi	itsid	wa ntchito pogona?			
(chiwerengero chazipindazi)				
57. Banja limeneli liri ndi m	alo ol	ima?	Inde	Ayi	
, and the second			1	2	
58. Malo ndi okula bwanji?					
Mayekala angati? Simukudziwa	(88)				
59. Banjali liri ndi zifuyo?	<u> </u>		Inde	Ayi	
,			1	2	
60. Zifuyozo zilipo zingati?					Zingati?
					mbuzi
					nkhumba
					n'gombe
					nkhosa
					nkhuku
61 Alino wanahania lasu a	i nd:	zinthu izi2	Inde	Ayi	Intraka
61. Alipo wapabanja lanu a	illul	ZIIIUIU IZI?	1	Ay i 2	
Njinga yakapalasa?			1		
Njinga yamoto / yopalasa			Inde	Ayi	
			1	2	
Galimoto loyendera/ Galimo	to lo	nyamula katundu?	Inde 1	Ayi	
62 Muli ndi wantahita		(a (IICA) malara lanco	1 Inde	2	
62.Muli ndi wantchito wa za	umo	o (nsa) maera ianu?		Ayi	
			1	2	

Thank the family for their time.

Appendix 3 First five screens of PDA questionnaire interface

HOUSEHOLD SURVEY	Interviewer & Village 1. Alipo mwana wa banjali amene	Child childletter 3. Ubale wanu ndi (dzina) ndi wotani? O Ndi Mayi O Chemwali	5. Ndi mwamuna kapena mkazi? C Mwamuna C Mkazi	7. Anadwala motani? C Kutentha thupi komverera C Kutentha thupi kofikapo C Kutentha thupi kopatsa nkhawa C Simukudziwa
(Kuyesetsa kudzichitika pakafukufuku kuti mafunso adziyankhulidwa ndi mayi wachikulire wa pabanja lofikiridwali)	avutika ndi kutentha thupi masabata awiri angothawa? C Eligible household Not eligible 2. Ngati inde, ndi angati anavutika ndi kutentha thupi? Back Next	C Adzakhali C Agogo Akazi C Bambo C Kapena ena 4. Ali ndi zaka zingati (dzina)? C under 1 year C over 1 year Back Next	6. Adaphunzira mpaka kalasi yanji (dzina) C Sadaphunzire C Kalasi 1 C Kalasi 2 C Kalasi 3 C Kalasi 4 C Kalasi 5 Back Next	Madwalidwe ena, fotokozani Nanga pano akupedza bwanji? Bwino Akudwalabe Anamwalira Simukudziwa Back Next

Appendix 4 Example Vignette

Women's group

A woman discovers that her child has fever; she thinks it might be caused by malungo...

What might she do....? (Role play)

Who might she tell? How might each of the people respond? What decision is made?

....ask what other alternatives might happen?

Appendix 5 Focus Group Discussion Notes Pages

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malawi

OBJECTIVES

- To explore beliefs around causes of malaria in children
- To determine factors affecting decisions to use biomedical or other sources of care
- To explore the intra-household process of decision-making around treatment-seeking and using medicines

FGD PIN:	Sex:
Village:	Age-range:
Date and time of	Facilitator:
FGD:	
Location of FGD:	Assistant:
First round or	DVR Folder
repeat FGD:	and file
	number:

Appendix 6 In-Depth Interviews Notes Pages

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malawi OBJECTIVES

- To explore in detail the experiences surrounding treatment-seeking and using medicines
- To explore the intra-household process of decision-making around treatment-seeking and using medicines
- To better understand the challenges of delivering anti-malarial drugs to children
- To gather information about the experiences of any adverse events to antimalarial drugs

Participant PIN:	Facilitator:	
Date and time of	Assistant:	
IDI:		
Date and time of	Sex:	
later interview if		
interrupted:		
Location:	Age-range:	
DVR Folder and		
file number:		
	I	

Appendix 7 Topic guide – Focus Group Discussions (English)

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malawi

OBJECTIVES

- To explore beliefs around causes of malaria in children
- To determine factors affecting decisions to use bio-medical or other sources of care
- To explore the intra-household process of decision-making around treatment-seeking and using medicines

INTRODUCTION

Introduce study, purpose of group, confidentiality

CHILDHOOD FEVER

1, What are the different things that can cause a child to have fever (kutentha thupi)?

Probe: Mauka (maternal mostly genitourinary illness), malungo (malaria), ufiti (witchcraft), tsempho/mdulo (transgression of sexual laws)...other...??

- a) How can you tell what's causing the child to have kutentha thupi?
 - Probe: Do the symptoms of the illness tell you what the cause is? How can you tell its Malungo or another cause like mauka?
- b) What are the main causes of malungo in children?

RESPONSES TO FEVER

Choice of treatment

2, What kind of treatment would you give for each of the causes of ku*tentha thupi* you have described?

Mauka?
Ufiti?
Malungo?

Etc etc

a) What do you think about the drugs you have mentioned for malungo?
Probe: If they respond 'LA is good because it's accessible' ask: What do you think about the drug itself?'

b) Are there times when you shouldn't give an antimalarial drug? Why?

TREATMENT SEEKING

3, How would you know that you should take the child to the health facility?

Probe: severity/symptoms

4, If you thought that the child might need to attend the health facility is there anyone you would consult before deciding what to do?

For each person - Why? What would be the consequences of not telling them? What if that person is not around?

What could you do if that person (people) doesn't agree with you? Or people you consult disagree among themselves? Is there someone else you could consult?

If it hasn't come up ask about where they get the money to attend the health facility

Can you role play for us what you do if your child has the symptoms of malungo? Who do you discuss it with? What advice do they give you or what decision do they make?

After the role play ask: Are there any other possibilities? Can you show us?

• Are there any other issues that may prevent you from attending a health facility or make it difficult to attend?

Probe: not enough money, busy with farming, other children to look after?

TREATMENT - Using antimalarial medication

5, Is there an individual or certain people in the household who are usually responsible for giving antimalarial drugs to a sick child?

What about if this person is away?

- a) When is a child (eg a sibling) ready to be responsible to give the drugs to another child?
- 6, When is a child ready to take responsibility for the drugs themselves?
- 7, Are there any problems with trying to get young children to take the tablets? (*children who need to be fed the drug*)

What problems? If responds 'child cries' or 'child doesn't like it' ask: Why do you think that is?

- a) What do you do to try to get the child to take the medicine? Are there times when you cannot manage? Is there anyone else who helps?
- b) What about older children? Are there different challenges? What kinds? How do these vary according to the age of the child?
- c) What can you do to encourage older children to take the medicines?
 - o Does anyone else get involved? Who? How well does that work?
- 8, Do you know any of the side-effects that LA has? What about quinine? *Other antimalarials* they have mentioned?

What? Any other problems?

9, If a child has received LA or any other antimalarial from the health facility how long do you need to wait before you know if it's working?

Probe: Are there other ways of deciding that the child isn't recovering?

a) If the child is not responding what would you do? Why?

Probe: other sources or care, traditional healer, returning to health facility

Appendix 8 Topic guide – Focus Group Discussions (Chichewa)

Treatment seeking and antimalatial drug use in the Chikhwawa district of Malawi

ZOLINGA

- Kuona zikhulupiriro zomwe zimayambitsa matenda a malungo.
- Kuona zinthu zimene zimapangitsa munthu kupeza njira za mankhwala kapena njira zina.
- Kufuna kuona kuti ndondomeko yopanga chiganizo pakugwiritsa ntchito mankhwala pakhomo.

INTRODUCTION

Introduce study, purpose of group, confidentiality

KUTENTHA THUPI MWA ANA

1. Ndi zinthu ziti zosiyanasiyana zimene zingapangitse mwana kutentha thupi?

Probe: mauka, malungo, ufiti, mdulo/tsempho ... zina...?

a) Mungadziwe bwanji chomwe chapangitsa mwana kutentha thupi?

Probe: kodi zizindikiro za matendawa zikukupangitsani kuti mudziwe chomwe chayambitsa matendawo? Mungadziwe bwanji kuti ndi malungo kapena vuto lina, monga mauka?

b) Kodi zinthu zomwe zimayambitsa malungo mwa ana ndi ziti?

THANDIZO /ZIMENE TIMACHITA MWANA AKATENTHA THUPI

Mtundu wa thandizo

2, Ndi thandizo la mtundu wanji limene mungampatse mwana pamene mwazindikira kuti chomwe chayambitsa kutentha thupiko ndi zinthu monga izi?

Mauka?

Ufiti?

Malungo?

Zina...?

- a) Mukuganizapo bwanji za mankhwala a malungo amene adza chifukwa cha zimene mwatchula pamwambapa?Probe: if they respond 'LA is good because it's accessible' ask: What do you think about the drug itself?
- b) Pali nthawi zina zimene mumaona kuti nkosayenera kupereka mankhwala othana ndi malungo? Chifukwa chiyani?

KAPEZEDWE KA THANDIZO

3, Mungadziwe bwanji kuti nkoyenera kuti mupite naye mwana ku chipatala?

Probe: modetsa nkhawa /zizindikiro

4, Mutaona kuti ndikofunikira kuti mwana alandire thandizo la mankhwala kuchipatala, alipo yemwe mungamufunse maganizo ake musanapange chiganizo?

Ndipo chifukwa chiyani (kwa wina aliyense?). Chingachitike chiyani mutapanda kumdziwitsa munthuyo? Nanga patakhala kuti munthuyo palibe?

Ndizotsatira zanji zingabwere chifukwa chosawauza? mungachite bwanji mutakhala kuti simunagwirizane ndi munthuwo kapena kuti anthuwo sakugwirizana pakati pawo? Aliponso wina yemwe mungamufunse?

If it hasn't come up ask about where they get money to attend the health facility.

Kodi mungationetse mongofanizira zimene mumachita ngati mwana wanu awonetsa zizindikiro za matenda a malungo? Nanga mumakambirani ndi ndani? Nanga mumagwirizana zotani kapena chisankhocho chimakhala chotani?

After the role play ask: Palinso njira zina? Nanga mungationetse?

• Kodi pali zinthu zina zimene zimakulepheletsani kapena zingathe kukulepheletsani inu kuti mupite ku chipatala?

Probe: not enough money, busy with farming, other children to look after?

CHITHANDIZO -kugwiritsa ntchito mankhwala a malungo

5, Pali munthu wina wapadera kapena ena m'nyumbamo amene ali woyenera kupereka mankhwala a malungo kwa mwana amene wadwala?

Nanga patakhala kuti munthu ameneyu kulibe?

- a) Ndi mwana wa msinkhu wanji amene angathe kumupatsa mnzake mankhwala?
- 6, Ndi ana a msinkhu wanji omwe amatha kumwa mankhwala pa iwo wokha?

Zimasiyana bwanji malingana ndi msinkhu wao?

7, Pali mavuto ena amene mumakumana nawo pamene mukufuna kuti ana aang'ono kwambiri amwe mapilitsi?

-ndi mavuto ati? If responds 'child cries' or 'child doesn't like it' ask: Why do you think that is?

a) Mumapanga bwanji kuti muyesetse kuti ana aang'ono kwambiri amwe mankhwala?

Pali nthawi zina zimene simungakwanitse? Palinso wina amene amakuthandizirani?

b) Nanga ana okulilapo? Palinso zovuta zina? Ndi ziti? Nanga mavutowa amasiyana bwanji poyerekeza ndi misinkhu ya anawa?

c) Mungapange bwanji kuti mulinbikitse ana okalilapowo kuti amwe mankhwala?

Aliponso ena amakhalapo? Ndani? Zimathandiza bwanji?

8, Mukudziwapo mavuto ena omwe amabwera chifukwa cha kumwa LA? -ndi ati? Palinso mavuto ena? What about quinine? What about any other antimalarials?

9, Ngati mwana walandira mankhwala a LA kapena ena a malungo kuchokera ku chipatala, kodi mumadikira nthawi yaitali bwanji kuti mudziwe kuti LA akugwira ntchito?

Probe: pali njira zina zimene mungadziwire kuti mwanayu sakuchira?

a) Ngati mwana sakupeza bwino atatha kumwa mankhwala a malungo, mumapanga bwanji?

Probe: njira kapena chisamaliro china, sing'anga, kapena kubwerera ku chipatala?

Thank them for their time

Appendix 9 Topic guide - In-depth Interviews (English)

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malawi

OBJECTIVES

- To explore in detail the experiences surrounding treatment-seeking and using medicines
- To explore the intra-household process of decision-making around treatment-seeking and using medicines
- To better understand the challenges of delivering anti-malarial drugs to children
- To gather information about the experiences of any adverse events to antimalarial drugs

INTRODUCTION

Introduce study, confidentiality

During introduction it may be necessary to ask the caregiver about the health status of the child – if very ill the caregiver should be advised to take the child immediately to the clinic

PRESENT CIRCUMSTANCES

- Age and gender of caregiver
- Marital status of caregiver
- How many children do you have? How many of these live in this house? How old are they?
- Who else lives in this household?
- 1, Could you tell me about the activities that members of this household carry out to generate money?

If carer earns money...what happens to the money that you earn? What kind of things can you use it for? Who can make decisions about how the money is used?

THE CHILD'S ILLNESS

During the past couple of weeks your household was visited by our colleagues doing a malaria survey.

During the survey you said that your child had suffered fever in the previous two weeks. Today we want to ask you more about that illness.

- 2, What did you first notice was wrong with the child?, What did you think was the cause?
 - Did you tell anyone about the illness?

Who did you tell? What prompted you to tell this person? What was their response? How did you feel about that?

3, Did you decide to go **anywhere** for treatment?

If **NO**, they did not seek care.....

why not? did you want to seek care from anywhere? Did you speak to anyone before deciding not to go? Who? What did they say? How did you feel about that?

If they respond that they didn't seek care because MIS came to them ask them: Why didn't you seek care before the MIS came to the house?

 If lack of permission was the problem, did you try to persuade the decision maker? How? How did they respond? What happened after that?

SKIP TO QUESTION 8

If YES, they sought care from anywhere...

4, Where did you go first/second/third? Why that place?

Did you discuss with anyone about going there? Who? Why each of them? Would there have been consequence of not telling them? What? How did you feel about going to that place (eg shop)?

5, Did you need money for treatment, transport or anything else? Where did this money come from?

If health facility or sing'anga (trad healer)

6, Was a diagnosis given?

What? How did you feel about that?

7, Did you receive any treatment?

What? How did you feel about that?

If DID NOT receive LA or quinine skip to question 11 -----

If received LA or quinine ask...

- 9, Did you have any discussions with any other household or family members about the treatment you received? What was discussed? What was the outcome?
- 10, Who kept the medicines?

If the child kept the drugs- was there a reason for this? Did anyone try to make sure the child took the medicine? How did they do that? How well did that work?

If carer responsible for giving the medicine...

Narrative of when each dose was taken – who gave, what time of day, were there any discussions about taking the medicines?

While going through the narrative ask about the child's signs and symptoms on each day – how did the caregiver feel about the child's recovery? What did they decide to do if recovery slow?

a) Did you have any problems getting the child to take the medicines? What problems? How did you cope with these? Did anyone else help? How well did that work?

If they received dispersible LA ask:

How easily did it dissolve?

Did you know how much water to add?

How did you find feeding it to the child?

Have you ever given your child the other type of LA? If yes, was there any difference with this one?

b) What did you think of this medicine?

Probe: Where there any problems with this drug? Do you think it worked?

END HERE IF NO TREATMENT SOUGHT

11, Did you seek further care?

If YES, further care sought skip back to question 4 with 2nd place...

If treatment was sought eg from shop, but not from health facility, ask:

Why not? Did you want to attend a health facility? How did you feel about not going?

 If lack of permission was the problem, did you try to persuade the decision maker? How? How did they respond? What happened after that?

"We would now like to ask you about the treatment you received from the survey team"

Skip to QUESTIONS 8-10

THANK THEM FOR THEIR TIME

NOTE – If specific adverse event experienced proceed to complete PV form at end of interview

Appendix 10 Topic guide – In-depth Interviews (Chichewa)

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malaria

OBJECTIVES

- To explore in detail the experience surrounding treatment-seeking and using medicines
- To explore the intra-household process of decision-making around treatmentseeking and using medicine
- To better understand the challenges of delivering ant-malarial drugs to children
- To gather information about the experiences of any adverse events to ant-malarial drugs

INTRODUCTION

Introduce study, confidentiality

During introduction it may be necessary to ask the caregiver about the health status of the child- if every ill the caregiver should be advised to take the child immediately to the clinic

PRESENT CIRCUMSTANCES

- Zaka za opereka chisamaliro
- Mamuna/ Mkazi
- Wapabanja/ Wopanda banja/ wamasiye/ lidatha
- Muli ndi ana angati? Ndi angati amene akukhala pakhomo pano? Ndipo ali ndi zaka zingati?
- Aliponso wina akukhala m'nyumbamu
- **1.** Mungatiuzeko ntchito zimene anthu apabanja panu amagwira kuti apeze ndalama ?

Ngati opereka chisamaliro amapeza ndalama ...mumapanga nazo chiyani ndalamazo? Ndi ntchito ziti zimene mungagwiritsire ndalamazo? Ndi ndani amene amapanga chiganizo cha kagwiritsidwe ntchito ka ndalama?

THE CHILD'S ILLNESS

During the past couple of weeks your household was visited by our colleagues doing a malaria survey.

During the survey you said that your child had suffered fever in the previous two weeks. Today we want to ask you more about that illness.

- 2. Choyamba chimene munazindikira kuti mwana sali bwino chinali chiyani? Munaganiza kuti chinayambitsa chinali chiyani?
 - Munauza wina aliyense za matendawa? Munauza ndani?
 Chinakupangitsani ndi chiyani kuti muuze munthu ameneyo?
 Adachitapo chiyani? Nanga munachimva bwanji?
- **3.** Munaganiza zopita kwina kukafuna chithandizo? *Ngati SICHONCHO*, chifukwa chiyani? Kodi munafuna kuti mukapeze chithandizo kwinakwake? kodi munayankhulapo ndi munthu wina musanapange chiganizo choti simupita? Ndani? Anakuuzani kuti chiyani? Munamva bwanji?

Ngati avomera kuti sanakafune thandizo chifukwa cha MIS: Chifukwa chiyani simunakapeze thandizo MIS isanakafike kunyumba kwanu?

 Ngati munalephera chifukwa sanakupatseni chilorezo, munayetsetsa kukambitsana ndi wopereka chilorezowo?
 Munakambitsana bwanji? Adachitapo chiyani? Chinachitika ndi chiyani pamapeto pake?

SKIP TO QUESTION 8 ----

Ngati ndi **INDE**, they sought care from anywhere.....

4. Munapita kuti koyamba/ kachiwiri/ kachitatu ? Chifukwa chiyani malo amenewo?

(what order, what timing – why)

Munakambirana ndi munthu wina za kupita kumeneko? Ndani?
Chifukwa chiyani iwowo? Pakanakhala zovuta zina zilizonse
munakapanda kuwauza? Chiyani? Munamva bwanji mutapita kumaloko?

5. Panafunika ndalama kuti mupeze chithandizo cha mankhwala, mayendedwe kapena zina? Ndalama zimenezi munazipeza bwanji?

If health facility or sing'anga...

- **6.** Kodi anakuyezani ndikukuuzani zotsatira zake? Zotani? Munamva bwanji?
- 7. Munalandirapo chithandizo?
 Chamtundu wanji? Munamva bwanji?

IF DID NOT RECEIVE LA OR QUININE SKIP TO QUESTION 11 ————

If received LA OR Quinine ask.....

 \triangle

8. Munauzidwapo za kamwetsedwe ka mankhwala? Munalangizidwa bwanji? Ndi ndani amene anapereka malangizo?
(The person who gave the medicine is not important if it was from the MIS)

Did they show you how to use the medicine? How did they show you? *ie did the child take the first dose at the hospital.*

- 9. Mudakambirana ndi wina aliyense wa mnyumba mwanu kapena wina aliyense wa chibale pa chithandizo chomwe munalandira?
 Munakambirana zotani? Nanga zotsatira zake zinali zotani?
- 10. Amene anasunga mankhwala ndi ndani?
 Ngati mwana ndi amene anasunga mankhwala chifukwa chiyani? Alipo anaonetsetsa kuti mwanayo wamwa mankhwalawo? Kodi anapanga

(Day by day)

bwanji? Ndipo zinathandiza bwanji?

Ngati wopereka chisamaliro ndi amene amayenera kupereka mankhwala...

Longosolani nthawi yomwe mankhwala amamwedwa - amene amapereka - panali zina zokambirana zokhudza kumwa mankhwala?
Atatha kulongosola zonse - patsiku lina lilironse mwana amaonetsa zizindikiro zotani?

Wopereka chisamaliro anamva bwanji ndi kuchira kwa mwana? Ataona kuti kuchira kukutenga nthawi anaganiza zochita chiyani?

a) Pakumumwetsa mwana mankhwala munakumana ndi vuto lina lilironse? Ndimavuto anji? Munathana nawo bwanji? Panalinso wina anathandiza? Ndipo zinathandiza bwanji?

If they received dispersible LA ask:
How easily did it dissolve?
Did you know how much water to add?
How did you find feeding it to the child?
Have you ever given your child the other type of LA? If yes, was there

b) Mankhwalawa mwawaona bwanji?

any difference with this one?

Probe: Were there any problems with this drug? Do you think it worked?

END HERE IF NO treatment sought

11, Munakapezanso thandizo lina?

If **YES** go back to question 4 with 2nd place, 3rd place etc...

Ngati **SANAPITE** kuchipatala (attended shop or other)...

Ndi chifukwa chiyani sanatero? Munafuna mutapita kuchipatala? Munamva bwanji posapitako?

 Ngati munalephera chifukwa sanakupatseni chilorezo, munayetsetsa kukambitsana ndi wopereka chilorezowo?
 Munakambitsana bwanji? Adachitapo chiyani? Chinachitika ndi chiyani pamapeto pake? "We would now like to ask you about the treatment you received from the survey team"

Go back to QUESTIONS 8-10 →

Thank them for their time

NOTE- If specific adverse event experienced proceed to complete PV form at end of interview

Appendix 11 Example Repeat Focus Group Discussion Topic Guide

Treatment seeking and antimalarial drug use in the Chikhwawa district of Malawi

OBJECTIVE

To gather information around topics arising in the earlier FGD and obtain deeper understanding of these issues.

INTRODUCTION

Introduce study, purpose of group, confidentiality

CHILDHOOD FEVER

- 1. During the previous FGD, you mentioned various causes of malaria which we would like to discuss. You mentioned that mosquitoes can cause malaria, you also mentioned:
 - That the sun can cause malaria What do you think about this?
 - O Does that kind of fever need treatment? What treatment?
 - Poverty was also mentioned as a cause of malaria What do you think about this?

A number of issues were mentioned in relation to poverty. Can you discuss how these things may impact on malaria...?

Mother too busy – how can this impact on malaria?

Lack of breast-feeding/food?

TREATMENT SEEKING

- 2. What is the first place you think of going when you see that the child has fever?
 - PROBE shop, neighbours, traditional healer
 - o Does the treatment differ if you feel that your child has malaria?
- 3. How do you know when your child has malaria
 - How do you differentiate that a fever is caused by malaria and not by other causes (e.g. Mauka, tsempho, witchcraft). Are there specific sign that it is malaria? Or that it is not malaria? How does the severity of the illness caused by malaria compare with that of other causes?

- 4. What are the specific signs that indicate you should go to the hospital?
 - In the last FGD high fever was mentioned as a sign what about severe headache and other serious signs?
- 5. Are there any challenges you experience in taking the child to the hospital?
 PROBE Is it ever possible to take a child to the hospital during the night?
- 6. Treatment what happens if the child does not recover after treatment from the hospital?

 PROBE

In the last FDG it was mentioned that sometimes you may go several times to the hospital for the same illness, each time being given different treatment. Is this something you can tell us more about?

- Is there a time when you attend the hospital with the child who has fever and you're told that this is not malaria? What happens?
- What about when you have visited a hospital several times what do you do next?
- What happens if both treatment from the hospital and traditional healer fail?
- 7. In the last FGD you prepared a role play. In it the man was found to be drunk when the woman was trying to get help for the sick child, what do you think about this situation?

 PROBE The women became frustrated and aggressive, what do you think about that? Does this happen?
- 8. Who usually notices that the child is sick? Who usually decides that the child should go to the hospital? Who will take them? Why that person?
- 9. Can the child's mother take the child to the hospital without consulting the father?

10. In the previous FGD you discussed that sometimes time is wasted in asking others for advice instead of going straight to the hospital. Is there a reason why others are consulted? Would there be a consequence if you go to the hospital without notifying anybody?

MUST ASK ABOUT MONEY!

If money is needed to attend hospital who provides the money?

- 11. How do you compare government and private hospitals?How do you find the reception at the hospital gov and then private?
- 12. Do you consider that there is time of year when if a child has fever that it is more important to go to the hospital? Or go more quickly? If so, when? Why?
- 13. Is there a time of the year when it's more difficult to take the child to the hospital?

TREATMENT

- 14. Can antimalarial drugs be found in the shops? Which ones?
- 15 Once La has been received from the hospital who is responsible for giving drugs to the child? Why that person? What exact role does the father play?
- 16. In the last FGD you mentioned a number of problems in giving the medication to the child can you tell us what happens if the child spits or vomits the medication? Is this common? What do you do?

Appendix 12 Index for coding qualitative data

Accessibility		
	B'	
	Distance	
	Time	
	Transport	
Causation		
	breaking sexual taboo	
	busy	
	cold	
	crying	
	feeding on infected milk	
	hunger	
	mosquitoes	
	poverty	
	sun	
	teething	
	lack of hygiene	
	witchcraft	
ocontext		
	government hospital	
	grocery	
	home	
	Private hospital	
	village	
	work	
0		
ODecision-making		
	based on diagnosis	
	Decision making based on symptoms	
	Decision making based on symptoms Decision making based on treatment	
	outcomes	
	Past experience	
	r ast experience	
delivering		
medication		
'		
	assistance (or none)	
	bad taste or smell	
	ease of delivering drugs	
	good taste or smell	
	importance of correct dose	
	responsibility to deliver	
	Side effects	

	strategies to deliver drugs	
	vomiting or spiting after treatment	
	worsening of symptoms	
diagnosis		
	diagnosis based treatment	
	ignoring test results	
	importance of biomed diagnosis	
	Traditional diagnosis	
Disease outcome		
	death	
	Improvement	
	No improvement	
	recovery	
Diseases		
	Malaria	
	cerebral malaria	
	cholera	
	Epilepsy	
	flue or cough	
	General illness	
	mauka	
	measles	
	Mtsempho (Mdulo)	
	nyakhwa	
	pneumonia	
	·	
	TB Tetanus	
Dosage		
	Dosage Completed	
	Dosage Conflicted Dosage Confusion	
	Dosage Instructions	
	Incorrect Dosage	
Feeling		
JI Celling		
	confused	
	feeling bad	
	Feeling good	
	hatred	
Finances		
pi ilialices		

	Expenditure
	Financial Strategies
	Income generation
	provision of money
	provision or money
good quotes	
Soou quotes	
Interactions	
•	
	advise
	avoiding conflict
	blame
	disagreement
	Inform
	Not informing anyone
medicine	
	aspirin
	bactrim
	Bruffen
	Cafenol
	Chloroquine
	drip
	fansidar
	Injection
	LA
	Liquid medicine
	ORS
	panado
	Quinine
	SUBFAB
	Traditional treatment
Narrative	
	avoidance
	Comparison
	Contradiction
	disagreement
	embarrassment perhaps
	· ·
People - Bio	
medical	
	doctors (Bio medical professionals)
	Health Surveillance Assistant (HSA)
	nurses

People - family		
, , , , , ,		
	Father (Husband)	
	In-laws	
	mother	
	Other children	
	other relatives	
	child	
_		
People - other		
	Elders	
	Landlord	
	1 1 1 1	
	neighbour	
	Peers	
	traditional doctor	
	village chief	
Perception		
	Compatibility of treatment with child	
	Perception of assistance	
	Perception of treatment Perception of own effort	
,	1 creeption of own enore	
recognition		
	diamonia based vecesiais v	
	diagnosis based recognition	
	outcome based recognition	
	Possession of knowledge	
	problems with recognition	
	rec of treatment outcomes	
	recognition of illness	
	symptom based recognition	
Relationship		
	father- child	
	mother - grandmother	
	mother - grandmother mother- child	
	mother- father	
	parent hospital staff	
	parent nospital stall	
roles		
roles	community responsibility	
roles	community responsibility Gender issues or roles	
roles	community responsibility Gender issues or roles other child responsible	

relatives
role of elders

Service quality

absent staff
aggressive staff
Opening hours
Waiting time

signs and symptoms

anaemic
blood from nose and mouth
closed eyes
cold then hot
complaining
coughing
crying
defecate blood
diarrhoea
fainting
fever
flue
gasps
gnaws teeth
growths
hallucination
headache
Heavy breathing
itching
looks pale
loss of appetite
Nausea
playing
puss discharge
rash
Red eyes
Refusal to feed
running nose
salty palms
severe pain
shivering
sleeping
sneezing
Sores
Startled
stomach ache
stunted growth

sweet palms
swelling
thin
vomiting
weak
Yellow eyes

Steps in treatment-seeking

Drug switching
from biomedical to religious
From clinic to a bigger hospital
Repeated treatments with la
return visits
switching from biomedical to traditional healthcare
switching from home to hospital treatment
switching from public to private hospital
switching from traditional to biomedical treatment
trying traditional medicine
using bought drugs
waiting at home

Treatment

Admitted
bathing
cut (from private part)
prayer
prepare herbs
Ritual
smear salt
vaginal tables
wearing string or garment
wet cloth or drinking water to cool

Appendix 13 Ethics approval: College of Medicine Research and Ethics Committee, Malawi



Principal

Prof. R.L. Broadhead, MBBS, FRCP, FRCPCH, DCH

Our Ref.:

Your Ref.: P.04/09/783

College of Medicine Private Bag 360 Chichiri Blantyre 3 Malawi Telephone: 677 245 677 291 Fax: 674 700 Telex: 43744

19th June 2009

Dr. Victoria Ewing Welcome Trust Blantyre 3

Dear Dr Ewing,

RE: P.04/09/783 - Treatment Seeking Behaviour and Household Economic Cost of Childhood Fever; a study in the Southern District of Malawi

I write to inform you that COMREC reviewed your proposal mentioned above which you resubmitted. I am pleased to inform you that your proposal was approved after considering that you addressed all the queries which were raised in an earlier review.

As you proceed with the implementation of your study we would like you to take note that all requirements by the college are followed as indicated on the attached page.

Yours Sincerely,

Prof. J.M.Mfutso-Bengo CHAIRMAN - COMREC

JMMB/ck

UNIVERSITY OF MALAWI COLLEGE OF MEDICINE

1.3 JUN 2009

COLMAND

P/BAG 366, CHICHIRLBLANTYRE 3



College of Medicine Private Bag 360 Chichiri

Blantyre 3 Malawi Telephone: 01 877 245 01 877 291

Fax: 01 874 700 Telex: 43744

Acting Principal

K.M Maleta, MBBS PhD

Our Ref.:

Your Ref.: P.10/08/707

6th September 2010

Dr Kamija Phiri College of Medicine Haematology Department P/Bag 360 Blantyre 3

Dear Dr Phiri,

RE: P.10/08/707 - Programmatic of ACTs in Malawi: Safety and effectiveness of combination therapies with repeated treatments for uncomplicated *P.falciparum* malaria over a three-year period

I write to inform you that COMREC reviewed your documents of the above mentioned proposal. I am pleased to inform you that COMREC **approved** the following documents:

1. English and Chichewa Consent Form

2. Topic Guides for interviews and Focus Group Discussions

As you proceed with the implementation of your study we would like you to take note that all requirements by the college are followed as indicated on the attached page.

Mulso

Sincerely,

Prof. J. M. Mfutso Bengo

CHAIRMAN - COMREC

JMB/ck

Approved by College of Medicine

(COMREC)
Research and Ethics Committee

Appendix 14 Ethics approval: Liverpool School of Tropical Medicine

Dr D Lalloo Liverpool School of Tropical Medicine Pembroke Place Liverpool L3 5QA

16 April 2009

Dear Dr Lalloo



Pembroke Place, Liverpool, L3 SOA, UK Tet: *44 (0)151 705 3100 Fax: *44 (0)151 705 3370 www.liv.ac.uk/lstm

Re: Research Protocol (09.07) Programmatic implementation of ACTs in Malawi: Safety and Effectiveness fo combination therapies with repeated treatments for uncomplicated P.faciparum malaria over a three-year period

Thank you for your letter dated 19 February 2009 responding to the points raised by the Research Ethics Committee. The committee accepted the responses to their original concerns. However, doubts were still expressed about the absence of the control groups and hence the problem of separating out the effects of different factors on the outcome measures. In this instance the committee felt that given that this is an observational study and that as the study had been scientifically reviewed by a funding body they would withdraw their objections to the study design whilst still retaining some concerns.

In addition the committee accepted the difficulties of providing definitive sample size and statistical analysis details at this time. Approval is therefore conditional on these being provided to the committee as soon as these are available.

The protocol now has formal ethical approval from the Chair of LSTM Research Ethics Committee.

The approval is for a fixed period of three years or for the duration of the grant, renewable annually thereafter. The committee may suspend or withdraw ethical approval at any time if appropriate.

Approval is conditional upon:

- · Submission of ethical approval from other ethics committees
- Notification of all amendments to the protocols for approval before implementation.
- · Notification when the project actually starts
- Provision of an annual update to the committee. Failure to do so could result in suspension of the study without further notice.
- Reporting of all severe unexpected adverse events to the Committee
- · Reporting of new information relevant to patient safety to the Committee
- Provision of Data Monitoring Committee reports (if applicable) to the Committee
 Continued/...

Service Services

Failure to comply with these requirements will result in withdrawal of approval. The Committee would also like to receive copies of the final report once the study is completed.

Yours sincerely

Dr B Faragher

Acting Chair, Research Ethics Committee



Victoria Ewing Liverpool School of Tropical Medicine Pembroke Place Liverpool L3 5QA Pembroke Place, Liverpool, L3 5QA, UK Tel: *44 (0)151 705 3100 Fax: *44 (0)151 705 3370

www.liv.ac.uk/lstm

Thursday, 10 June 2010

Dear Victoria Ewing

Re: Research Protocol (09.07) Programmatic implementation of ACTs in Malawi: Safety and effectiveness of combination therapies with repeated treatments for uncomplicated P. falciparum malaria over a three-year period

Thank you for your email dated 9 June 2010 informing the Committee of changes to your research protocol. These changes have been noted and accepted.

Yours sincerely

Acting Chair, Research Ethics Committee

Dr Brian Faragher

CC Prof David Lalloo and Dr Anja Terlouw

Appendix 15 Ethics approval: London School of Hygiene and Tropical Medicine

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

ETHICS COMMITTEE APPROVAL FORM FOR MSC RESEARCH PROJECT



Application number: \$08/231

Name of Principal Investigator Victoria Watkins Ewing

Course MSc Public Health in Developing Countries

Title Household cost of childhood fever: a study in a southern district

of Malawi.

Approval of this study is granted by the Committee.

Chair

Professor Tom Meade T.W. Meade

Date: 20 May 2009

Appendix 16 Information sheet for participants – Household survey (English)

Household cost of childhood fever: a study in a southern district of Malawi

Investigator:

The primary investigator for this study is Victoria Ewing who is carrying out this research through the Malawi-Liverpool-Wellcome Trust (MLW) research centre, at Queen Elizabeth Central Hospital in Blantyre.

Approval:

Approval for this study has been received from the College of Medicine Research and Ethics Committee, Blantyre and the London School of Hygiene and Tropical Medicine Ethics Committee in London, UK.

Why are we doing this study?

In Malawi, antimalarial treatment is freely available at Government health facilities. However many people still choose to obtain treatment from other sources, such as shops. The Malawi Liverpool Wellcome Trust Project would like to carry a study with the aim of gathering information on the current practices of treating children with fever in Chikwawa, Malawi and what costs are incurred by households because of this fever.

How are we going to do this study?

We will be visiting households within your area and inviting individuals to participate in an interview about childhood illness. For the sake of this study a child will be defined as a person under the age of 10 years. If you choose to take part in the study you will be asked questions about illness suffered by children living in your household in the past two weeks. Specifically you will be asked about the child's symptoms, where you sought treatment for the illness and what financial costs were incurred by your household as a result of the illness.

What are the risks of participating in this study?

There are no risks to either you or your child in taking part in this study. You will not be required to take any medication, or undergo any tests or give blood.

What are the benefits of participating in this study?

The results of this study may benefit people living in rural communities in Malawi. By identifying what costs are associated with accessing treatment it may be possible to improve the health system to reduce these costs. In particular it is hoped that the results will guide the design of a programme using community health workers to treat malaria.

What are your rights to participate in this study?

Your participation is this study is strictly voluntary; you have the right to refuse to take part or to withdraw at any time. If you chose to refuse to take part or to withdraw from the study you will not receive any penalty or loss of any benefits to which you are entitled.

Information you give in this interview will be kept confidential. Your name and any personal details about your household will not be made available.

If you have any queries about taking part in this study you can contact Paul Chipeta (Telephone: 0999941528).

If you have understood all of the above information and are willing to take part in this study please fill in the attached consent form.

Appendix 17 Consent form – Household survey (English)

Household cost of childhood fever: a study in a southern district of Malawi

Investigator:

The primary investigator for this study is Victoria Ewing who is carrying out this research through the Malawi-Liverpool-Wellcome Trust (MLW) research centre, at Queen Elizabeth Central Hospital in Blantyre. If you have any queries about taking part in this study you can contact Paul Chipeta (Telephone: 0999941528).

Consent:

ID number:

I have read the information concerning this study [or have understood the verbal explanation] and I
understand what will be required of me and what will happen to me if I take part in it.
My questions concerning this study have been answered by
I understand that at any time I may withdraw from this study without giving a reason and without
affecting my normal care and management.
I agree to take part in this study.
Signed/thumbprint Date
(Participant)
have read and understood all the information above and have witnessed the presentation of this
information to the participant.
Signed/thumbprint Date
(Witness)
Relationship with the participant

Appendix 18 Information sheet for participants – FGDs and IDIs (English)





THE COLLEGE OF MEDICINE
Malawi-Liverpool-Wellcome Trust
Clinical Research Programme

www.mlw.medcol.mw

PATIENT INFORMATION DOCUMENT

TITLE: TREATMENT SEEKING AND ANTIMALARIAL DRUG USE IN THE CHIKHWAWA DISTRICT OF MALAWI

WHO IS CARRYING OUT THIS STUDY?

This study is being carried out by the Malawi-Liverpool-Wellcome Trust (MLW) research centre at Queen Elizabeth Central Hospital in Blantyre, the College of Medicine, and Liverpool School of Tropical Medicine.

WHO HAS APPROVED THIS STUDY?

Approval for this study has been received from the College of Medicine Research and Ethics Committee, Blantyre and Liverpool School of Tropical Medicine Ethics Committee, UK.

WHY ARE WE DOING THIS STUDY?

Malaria kills many children in Malawi and we want to understand the challenges that individuals experience in accessing and using treatment for their children. We also want to find out about the opinions community members have of antimalarial medicines as this may affect how and when they use these drugs.

HOW ARE WE GOING TO DO THIS STUDY?

We will be visiting a number of people within their household and we will be inviting them to participate in an interview about their recent experience when a child in their house had malaria. We will ask them about going to a health facility and receiving and using antimalarial drugs. In some villages groups of men or women will be gathered together and asked about their experiences of malaria and antimalarial drugs. We may request to record interviews or group discussions and will make notes about topics that have been discussed. These tapes and notes will be kept securely so that only the research team have access to them and tape recordings will be destroyed within 6 weeks of typing them up.

WHAT ARE THE RISKS OF PARTICIPATING IN THIS STUDY?

There are no risks to either you or your child in taking part in this study. You will not be required to take any medication, or undergo any tests or give blood.







THE COLLEGE OF MEDICINE Malawi-Liverpool-Wellcome Trust Clinical Research Programme

www.mlw.medcol.mw

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

This is an opportunity for you to share your experiences of treating childhood malaria. These experiences will be used to guide the Ministry of Health in making decisions that may improve the issues you raise.

WHAT WILL WE DO WITH THE INFORMATION WE COLLECT?

We will share the results of this study with other people and groups including the Ministry of Health, so that they can benefit from the results. We will help others find out about the results through publishing them and presenting them at conferences. We will also provide an opportunity for those that take part in the study and their village elders to learn about what we find out.

WHAT ARE YOUR RIGHTS TO PARTICIPATE IN THIS STUDY?

Your participation is this study is strictly voluntary; you have the right to refuse to take part or to withdraw at any time. If you chose to refuse to take part or to withdraw from the study you will not receive any penalty or loss of any benefits to which you are entitled.

Any information you give will be kept confidential. Your name and any personal details about your household will not be made available.

WHO WILL ANSWER MY QUESTIONS?

If you have any queries about taking part in this study please ask a member of the study team, or you can contact Paul Chipeta (Telephone: 0999941528).

If you have understood all of the above information and are willing to take part in this study please fill in the attached consent form.

Appendix 19 Consent form – FGDs and IDIs (English)





THE COLLEGE OF MEDICINE Malawi-Liverpool-Wellcome Trust Clinical Research Programme

www.mlw.medcol.mw

Centre	Study Number	Patient Identification Number

PATIENT OR GUARDIAN CONSENT FORM

TITLE: TREATMENT SEEKING AND ANTIMALARIAL DRUG USE IN THE CHIKHWAWA DISTRICT OF MALAWI

Investigators:

This study is being carried out by the Malawi-Liverpool-Wellcome Trust (MLW) research centre at Queen Elizabeth Central Hospital in Blantyre, the College of Medicine, and Liverpool School of Tropical Medicine (LSTM). If you have any queries about taking part in this study you can contact Paul Chipeta (Telephone: 0999941528).

Consent:

i agi ce ioi oc	di discussions to be record	cu.		
Lagree for ou	ur discussions to be record	ed·		
I agree to tak	ke part in a group interview	v:		
I agree to tak	ke part in a one-to-one inte	erview:		
I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.				
My questions	s concerning this study hav	ve been	answered by	
		-		derstood the verbal d what will happen to me if I

Name of participant	Date	Signature
*Name of witness	Date	Signature

^{*}If participant cannot read or write.

Appendix 20 Malaria Journal publication



RESEARCH Open Access

Seasonal and geographic differences in treatment-seeking and household cost of febrile illness among children in Malawi

Victoria L Ewing^{1,2*}, David G Lalloo², Kamija S Phiri^{1,3}, Arantxa Roca-Feltrer^{1,2}, Lindsay J Mangham⁴, Miguel A SanJoaquin^{1,2}

Abstract

Background: Households in malaria endemic countries experience considerable costs in accessing formal health facilities because of childhood malaria. The Ministry of Health in Malawi has defined certain villages as hard-to-reach on the basis of either their distance from health facilities or inaccessibility. Some of these villages have been assigned a community health worker, responsible for referring febrile children to a health facility. Health facility utilization and household costs of attending a health facility were compared between individuals living near the district hospital and those in hard-to-reach villages.

Methods: Two cross-sectional household surveys were conducted in the Chikhwawa district of Malawi; one during each of the wet and dry seasons. Half the participating villages were located near the hospital, the others were in areas defined as hard-to-reach. Data were collected on attendance to formal health facilities and economic costs incurred due to recent childhood febrile illness.

Results: Those living in hard-to-reach villages were less likely to attend a formal health facility compared to those living near the hospital (Dry season: OR 0.35, 95%Cl0.18-0.67; Wet season: OR 0.46, 95%Cl0.27-0.80). Analyses including community health workers (CHW) as a source of formal health-care decreased the strength of this relationship, and suggested that consulting a CHW may reduce attendance at health facilities, even if indicated. Although those in hard-to-reach villages were still less likely to attend in both the dry (OR 0.53, 95%Cl 0.25-1.11) and wet (OR 0.60, 95%Cl 0.37-0.98) seasons. Household costs for those who attended a health facility were greater for those in HTR villages (Dry: USD5.24; Wet: USD5.60) than for those living near the district hospital (Dry: USD3.45; Wet: USD4.46).

Conclusion: Those living in hard-to-reach areas were less likely to attend a health facility for a childhood febrile event and experienced greater associated household costs. Consulting CHWs was infrequent, but appeared to reduce attendance at a health facility, even when indicated. Health service planners must consider geographic and financial barriers to accessing public health facilities in designing appropriate interventions.

Background

The link between poverty and malaria has been well established [1-3]. Countries that have successfully eliminated malaria have shown considerable economic growth when compared to other countries that have not [4]. Poor households living in malarious regions struggle

to meet the financial cost of repeated bouts of illness [5]. Direct and indirect costs of seeking appropriate health care result in households seeking treatment nearer the home [6]. This occurs in Malawi, where despite the free provision of healthcare through the formal health system, these services are under-utilized and home treatment is common using left over drugs or those obtained from vendors [7]. Consequences of private purchasing of drugs include inappropriate drug

Full list of author information is available at the end of the article



^{*} Correspondence: vewing@liv.ac.uk

¹Malawi-Liverpool-Wellcome Trust Clinical Research Programme, Blantyre, Malawi

selection and dosing [8] potentially leading to death and disability and the promotion of drug resistance [9].

There is considerable concern regarding inequities in health within Africa; improving the health of the population overall is inadequate if groups, such as the very poor, do not benefit [10-13]. In addition to the wealth of the individual, proximity to health facilities is an important determinant of uptake of health services [14,15]. The Malawi government has sought to bring care nearer to patients by establishing a Community Health Worker (CHW) scheme in some villages that have been defined as hard to reach (HTR) either because they are more than 8 km from a public health facility or have reduced accessibility due to rivers or hills [16]. These CHWs operate from small health-posts within the HTR villages. CHW programmes such as this have been advocated as an effective method of reducing barriers to care-seeking [17]. CHWs are involved in delivering health education messages and use a nationally-adapted version of the Integrated Management of Childhood Illness guidelines to treat children aged 2-59 months. However, due to logistical challenges and policies which have emphasized the strict control of ACT prescribing, anti-malarials have not been stocked at health-post level since the switch in first-line antimalarial from SP to ACTs. CHWs are, therefore, trained to refer all cases of childhood fever to the nearest health facility for treatment.

This study compares communities living in HTR areas with those near the hospital (NTH). The aim was to understand how physical barriers for access to health care and the consequent expenditure incurred by households influence utilization of health facilities.

Methods

Study site

This study was carried out in Chikhwawa District, in southern Malawi. This area experiences year round malaria transmission with a peak during the rainy season from December to May. Public health care is provided by the district hospital, 17 health centres and CHWs. There are also a number of private clinics throughout the district. Malaria is a major contributor to the high under five mortality in Malawi and a survey conducted in 2006 found that only 21% of febrile children under the age of five years received a recommended anti-malarial [18].

Data collection

Two cross-sectional household surveys were conducted in 13 villages: seven were located NTH, defined as within 5 km of the district hospital and six were among villages defined as HTR. To examine seasonal effects, data were collected during both the dry season (June

2009) and the wet season (February 2010). Fieldworkers administered a structured questionnaire to the primary caregivers of eligible children in the local language (Chichewa). Caregivers were eligible to participate in the survey if they had a child less than 10 years and the child had suffered a self-reported febrile episode in the previous two weeks.

The questionnaire had three modules; the first collected details relating to the child and caregiver's characteristics and the child's illness experience. This included questions on the duration of the illness and the caregivers perceived severity of illness, as either mild, moderate or severe. The second module was administered in those instances when health care had been sought and included questions on the sources of care and household direct and indirect costs of seeking care. Direct costs included the costs of travel, consultation, laboratory tests, and treatment, while indirect costs measured the caregiver's time lost from productive activities while caring for the child. The final module collected data relating to socio-economic status by asking about household asset ownership and was based on questions from the Malawi Demographic and Health Survey [19]. The questionnaire was tested during fieldstaff training and piloted in two villages before each round of the survey, after which minor modifications were made to the questionnaire. Data were collected using Personal Digital Assistants (PDAs) that incorporated internal consistency checks.

Sampling

This study was conducted as part of a larger study investigating the role of CHWs. Selection of HTR villages was determined by the criteria for the larger study; villages were selected if they were accessible by the study team during both the wet and dry seasons and had a CHW that was actively involved in disease management. A list of HTR villages with CHWs in the Chikhwawa district was provided by the MoH, six fulfilled the study criteria. There are 13 villages within 5 km of the hospital and seven were randomly selected to take part. Within each village, households were randomly selected by field workers finding a central point in the village, spinning a bottle and then walking in the direction the bottle pointed, visiting all houses between the central point and edge of the village. All households to the very edge of the village were visited to ensure that selected households were representative of the village. This process was repeated if insufficient houses were visited.

The study was powered to detect a minimum difference of 40% of recently febrile children in NTH villages attending a health facility compared to 20% of those in HTR villages (power = 90% and α = 0.05 two-sided)

during each survey. A design effect of two was estimated, giving a total sample size of 478 recently febrile children in each survey.

Outcomes

The primary outcome was the proportion of children less than 10 years old who had experienced a febrile episode in the previous two weeks and were taken to a health facility. For the primary analysis, health facilities were defined as private or public clinics and hospitals: CHWs were not included as all febrile children should be referred to a health facility. A second analysis was undertaken to assess attendance at any formal healthcare including CHWs. A priori potential confounders were age, maternal education, severity of illness and socio-economic status. The primary economic outcome was the household cost of seeking treatment at a health facility, for those children that reported a febrile episode in the past two weeks. Secondary outcomes included the differences in attendance at a health facility and costs of attending according to season. The proportion of children attending a health facility either on the day of fever onset or the following day and the proportion receiving anti-malarials either on the day of fever onset or the following day were also calculated.

Analysis of data

Data were cleaned and analysed using Stata version 10 (Stata Corp., College Station, TX). All analyses were adjusted for clustering in the survey design. Unadjusted odds ratios were calculated and then adjusted for a priori potential confounders using a logistic regression model. Mean costs were calculated and censored linear regression was used to assess for differences in costs taking account of incomplete febrile episodes. Values were considered significant if the P-value was less than 0.05 and borderline if less than 0.10.

Both direct and indirect costs incurred by households were included. Indirect costs measure the lost productivity of the caregiver in order to care for the child during the illness episode [20]. Time lost from productive activities to care for the sick child at home was valued as days or half days, while travel time and time at each source of care was measured in days, hours or minutes. Lost productivity was assigned a monetary value based on the Malawi minimum wage for an individual with no professional training and living in a rural area (MK129 per day). All costs were converted from Malawi Kwacha (MK) to US Dollars (USD) using a rate of MK139 to 1USD [21].

Socioeconomic status was measured using the DHS wealth index methodology [19,22]. This method involves using principal components analysis to compute asset indices [23,24]. Each household is scored according to

possession of durable goods (such as bicycles), housing quality and sanitary facilities. Households are then ranked into wealth quintiles.

Ethical considerations

Written consent was obtained from eligible participants in the local language. Consent was given either by signature or thumb-print. Only numerical identifiers were used on data capturing forms. Ethics approval was obtained from the College of Medicine Research and Ethics Committee, Malawi and from the London School of Hygiene and Tropical Medicine Ethics Committee.

Results

A total of 1,181 households were surveyed in the dry season and 1,397 in the wet season. None of the eligible households refused to participate. Forty-one percent (482/1,181) of households in the dry season and 35% (484/1,397) in the wet had at least one child under the age of 10 years who had experienced a febrile event in the two weeks prior to the survey and for whom a suitable caregiver could be found. At the time of the surveys, 47 children in the dry season and 60 during the wet were still suffering from reported fever. Forty-five percent (186/416) of individuals taking part in the survey during the wet season, had previously taken part in the dry season survey.

Table 1 shows the background characteristics according to distance to hospital and season. The distribution of age, sex and severity of illness was similar between HTR and NTH villages and across season. However, mothers of those living in HTR villages had attained lower levels of education compared to those NTH (Dry: P = 0.06; Wet P = 0.03). Households in HTR villages tended to occupy the lower wealth quintiles compared to those NTH (Dry: P = 0.002; Wet: P = 0.01). Eightysix percent (212/246) of the caregivers in HTR villages were farmers compared to 64% (168/263) of those NTH (wet season data available only). The proportion of recently febrile children who were less than five years were similar across seasons (Dry: 63%: Wet: 65%). Only one death occurred from reported recent febrile illness (wet season). In children seeking health facility care, mean illness length was longer for those in HTR villages than for those NTH (Dry: 5.8 vs 4.9 days, P = 0.090; Wet: 5.6 vs 4.8 days, P = 0.028). However illness length did not differ between seasons.

In general, those in HTR villages had access to lower quality sanitation and owned fewer possessions. Absence of toilet facilities was more common among those in HTR villages (Dry: 14%; Wet: 12%) compared to those NTH (Dry: 5%; Wet: 8%). However, more of those in HTR villages owned agricultural land (Dry: 97%; Wet: 99%) compared to those NTH (Dry: 76%; Wet: 84%).

Table 1 Association between participant background characteristics and distance to formal health facility

	Dry season			Wet season		
Background characteristics	≤ 5 km from Hospital (%) n = 269	Hard to Reach (%) n = 262	P ^a	≤ 5 km from Hospital (%) n = 263	Hard to Reach (%) n = 246	P ^a
Child Sex						
Male	131 (49)	123 (47)		138 (52)	126 (51)	
Female	138 (51)	139 (53)	0.57	125 (48)	120 (49)	0.75
Child Age						
<5 years	176 (65)	160 (61)		175 (67)	157 (64)	
≥5 years	93 (35)	102 (39)	0.12	88 (33)	89 (36)	0.48
Maternal Education						
None	63 (23)	87 (33)		68 (26)	87 (35)	
Primary	153 (57)	148 (57)		159 (60)	145 (59)	
Secondary +	53 (20)	27 (10)	0.06	36 (14)	14 (6)	0.03
Wealth Quintile						
1 (Lowest)	29 (11)	76 (29)		31 (12)	68 (28)	
2	41 (15)	66 (25)		47 (18)	51 (21)	
3	41 (15)	65 (25)		48 (18)	63 (25)	
4	68 (25)	38 (15)		57 (22)	44 (18)	
5 (Highest)	90 (34)	17 (6)	< 0.01	80 (30)	20 (8)	0.01
Illness Severity ^b						
Mild	155 (58)	134 (51)		132 (50)	111 (45)	
Moderate	81 (30)	78 (30)		93 (35)	88 (36)	
Severe	31 (12)	49 (19)	0.11	38 (15)	46 (19)	0.24

^aF test for heterogeneity or trend, with adjustment for clustering in survey design.

Treatment-seeking

Table 2 shows attendance to a health facility by background characteristics. In the dry season 48% of children in HTR villages were taken to a health facility compared to 69% of children living NTH. During the wet season this increased slightly to 53% of those in HTR villages and 70% of those living NTH. Children in HTR villages were less likely to attend a health facility for a recent childhood febrile event in both the dry (OR 0.35, 95%CI 0.18 - 0.67, P = 0.004) and the wet (OR 0.46, 95%CI 0.27-0.80, P = 0.01) seasons. Attendance at a health facility was less common among those over five years compared to those under five in the dry season (OR 0.49, 95%CI 0.31 - 0.79, P = 0.005), however this association was not significant in the wet season. Children suffering from more severe illnesses were more likely to be taken to a health facility in both the dry (moderate illness: OR1.80, 95%CI1.26-2.57; severe illness: OR3.97, 95%CI2.25-7.02, P < 0.001) and wet (moderate illness OR3.08, 95%CI2.03-4.67; severe illness OR4.49, 95% CI2.33-8.65, P < 0.001) seasons.

Time between onset of illness and attendance at a health facility was examined. In the dry season 32% (83/262) of those in HTR villages compared to 55% (147/269) of children living NTH attended a health facility on

the day of fever onset or the next day (P = 0.003). In the wet season 43% (109/246) living in HTR villages compared to 57% (151/263) of those living NTH attended a health facility either on the day of fever onset or the next day (P = 0.02). Children in HTR villages who attended a health facility were more likely to do so on the day of fever onset or the next day during the wet season compared to the dry season (OR 2.24, 95%CI 1.30 - 3.86, P = 0.01).

The data were also analysed to assess the relationship between village of residence and attendance to any formal health-care including CHWs. Those in HTR villages were still less likely to attend any formal health-care compared to those living NTH in both the dry (OR 0.53, 95%CI 0.25-1.11, P = 0.09) and wet (OR 0.60, 95% CI 0.37-0.98, P = 0.04) seasons. However, including CHWs in the analysis decreased the strength of the relationship between location and care-seeking. Eighty-nine percent (49/55) of individuals who sought care from a CHW did not go on to attend a formal health facility.

Household cost

Table 3 shows the mean costs of a childhood febrile episode among those who attended a health facility by distance to hospital and season. In the dry season, the

^bMissing data - four individuals did not know or remember the severity of the illness.

Table 2 Odds ratio for attending a formal health facility by background characteristics and season

		Dry Season	Wet Season		
Background characteristics	N (%) Odds Ratio (95% CI) ^a		N (%)	Odds Ratio (95% CI) ^a	
		ATTENDED FACILITY			
Village of residence					
≤5 km from Hospital	185 (69)	1	184 (70)	1	
Hard to Reach	126 (48)	0.35 (0.18 - 0.67) ^b	133 (53)	0.46 (0.27-0.80) ^b	
Child Age					
<5 years	218 (65)	1	218 (65)	1	
5 - 10 years	93 (48)	0.49 (0.31 - 0.79) ^b	99 (56)	0.69 (0.40-1.20)	
Maternal Education					
None	82 (55)	1	83 (53)	1	
Primary	176 (58)	1.09 (0.74 - 1.62)	200 (66)	1.32 (0.77-2.28)	
Secondary +	53 (66)	1.32 (0.69 - 2.44)	34 (67)	1.29 (0.54-3.08)	
Socio-economic Status					
Poorest quintile	59 (56)	1	56 (56)	1	
Quintile increase	252 (59)	0.90 (0.75 - 1.10)	261 (64)	1.03 (0.90-1.18)	
Illness Severity					
Mild illness	147 (51)	1	117 (48)	1	
Moderate illness	101 (64)	1.80 (1.26 - 2.57)	133 (73)	3.08 (2.03 - 4.67)	
Severe illness	61 (76)	3.97 (2.25 - 7.02) ^c	66 (79)	4.49 (2.33 - 8.65) ^c	
	ATTEN	IDED FACILITY WITHIN 24 HOUR	S		
Village of residence					
≤5 km from Hospital	147 (55)	1	151 (57)	1	
Hard to Reach	83 (32)	0.32 (0.16 - 0.62) ^b	109 (43)	0.53 (0.32 - 0.88) ^d	
	ATTENDED FA	CILITY OR COMMUNITY HEALTH	WORKER		
Village of residence					
≤5 km from Hospital	187 (70)	1	184 (70)	1	
Hard to Reach	155 (59)	0.53 (0.25-1.11) ^e	151 (61)	0.60 (0.37-0.98) ^f	

All analyses adjusted for survey design.

mean total cost of a childhood febrile episode was USD5.24 for those in HTR and USD3.45 for those NTH villages (P = 0.03). In the wet season, the mean total cost was USD5.60 for those in the HTR villages and USD4.46 for children NTH (P = 0.12).

Travel costs made the largest contribution to direct cost, and for those living in HTR villages these increased significantly between the dry and wet seasons (Dry: USD0.31; Wet: USD0.89, P = 0.04). Direct costs were greater for those living in HTR compared to NTH villages in both the dry (USD0.38 vs USD0.20, P = 0.04) and wet (USD0.95 vs USD0.40, P = 0.08) seasons. Direct costs were greater in the wet season for both those in HTR (P = 0.05) and NTH (P = 0.06) villages. Indirect costs represented the main economic burden for households. These were USD4.86 for those in HTR villages and USD3.25 for those NTH in the dry season and USD4.65 for those in HTR villages and USD4.06 for those NTH in the wet season. Most indirect costs were

due to 'time caring at home'. The cost of time spent caring was greater for those in HTR (USD2.40) compared to NTH (USD4.01) villages in the dry season (P = 0.02), but did not differ significantly by village in the wet season (P = 0.12).

Discussion

This study compares the utilization and household costs of attending health facilities for febrile illness in two geographically defined communities: households within 5 km of the hospital (NTH) and households that are 8 km from a health facility and considered hard to reach (HTR). Those in HTR villages were less likely to attend a health facility than those NTH and experienced greater costs in seeking treatment. Costs associated with travel to the health facility were significantly greater for those in HTR areas, and also increased markedly during the wet season. The costs associated with a febrile illness increase substantially when the indirect costs

^aOdds Ratio adjusted for a priori confounders; age, maternal education, socio-economic status and illness severity.

 $^{{}^{}b}P \le 0.01$, ${}^{c}P < 0.001$, ${}^{d}P = 0.02$, ${}^{e}P = 0.09$, ${}^{f}P = 0.04$.

Table 3 Mean cost of seeking care for a childhood febrile episode by distance to formal health facility

		Dry Season	Wet Season			
	<5 km from Hospital (n = 269) (USD)	Hard to Reach (n = 262) (USD)	P ^a	<5 km from Hospital (n = 263) (USD)	Hard to Reach (n = 246) (USD)	P ^a
Direct Costs ^b						
Travel	0.17	0.31 ^d	0.03	0.28	0.89 ^d	0.03
Consultation	0.01	0.02	0.43	0.05	0.00	0.18
Treatment	0.02	0.05	0.24	0.07	0.06	0.72
Total Direct Costs	0.20 ^e	0.38 ^f	0.04	0.40 ^e	0.95 ^f	0.08
Indirect Costs ^c						
Travel time	0.07	0.15	0.11	0.08	0.16	< 0.001
Time at facility	0.78	0.69	0.58	0.86	0.67	0.27
Time caring at home	2.40	4.01	0.02	3.13	3.82	0.12
Total Indirect Costs	3.25	4.86	0.07	4.06	4.65	0.32
Total costs	3.45	5.24	0.03	4.46	5.60	0.12

^aT test for the difference in means using censored linear regression with adjustment for clustering in survey design and confounding of child age, severity of illness and socioeconomic status.

associated with the caregiver's loss of productive activity during the illness episode are also taken into consideration.

These findings are based on the caregivers' responses to questions relating to a febrile illness episode, which is an accepted methodology in economic studies [5,25,26]. The measurement of severity of the illness was dependent on the caregiver's assessment, though previous studies have shown that caregivers are able to recognize both mild and severe signs of illness [27]. To reduce reporting error relating to the caregiver's account of the fever episode and the costs involved, the recall period was limited to the previous two weeks. In economic studies, it is advisable to estimate the indirect as well as direct costs [28]. This is not without challenges, particularly in non-wage settings such as this. In the absence of salary data, it is common practice to value caregiver's lost productivity using the minimum wage [26]. The inclusion criteria for this study included year round accessibility of HTR villages to the study team. Less accessible villages might make even less contact with formal health facilities and may experience greater costs, particularly in the form of travel costs and time.

Each of the HTR villages taking part in this study have been allocated a CHW. The CHW health posts are placed within the communities, so direct and indirect costs of attendance are minimal. CHWs working in HTR villages in Malawi treat a range of illnesses, but do not currently treat malaria. Instead all febrile children should be referred to a health facility. This study found attendance to CHWs to have been infrequent, despite their proximity to community members, and the majority of those attending a CHW did not go on to attend a health facility. The current CHW referral programme should be assessed both in terms of establishing reasons for the low uptake of services, and lack of referral visits to health facilities. The inclusion of Artemisinin-based Combination Therapy (ACT) in the services provided by CHWs is being considered by the MoH. The inability of CHWs to prescribe anti-malarials is recognized by communities and is likely to adversely impact attendance at CHWs. Making antimalarials available would increase utilization of CHWs and considerably improve access to prompt appropriate treatment for the poorest and most at risk members of the population, whilst reducing the costs of accessing care.

As previously found in Malawi, perception of severity of illness was associated with higher health facility attendance [29], and for those living NTH this was more marked in the wet than the dry season. Care-seeking delays were more common among those living in HTR villages during both seasons. However those in HTR villages that sought care, did so sooner during the wet compared to the dry season, despite poor accessibility due to the rains. This may be due to caregivers' knowledge that fevers during the wet season are more likely to be malaria. The balance of risks for those in HTR villages of the severity of the child's illness, the cost of

^bOut of pocket expenses.

^cCost of time losses.

^dP = 0.04 for the difference between seasons for those living in hard to reach villages.

 $^{^{\}mathrm{e}}P$ = 0.06 for the difference between seasons for those living <5 km of district hospital.

^fP = 0.05 for the difference between seasons for those living in hard to reach villages.

attending for care and the potential costs of not attending is complex and deserves in-depth investigation. The HTR villages taking part in this study were accessible to the study team and this pattern of increased promptness of treatment-seeking during the wet season may not be seen in less accessible villages.

Despite free healthcare provision at public health facilities, residents of the Chikhwawa district still experience considerable costs in accessing these facilities and costs are greater amongst those in HTR areas than villages located around the hospital. This study investigated single febrile episodes occuring in each of the wet and dry seasons. However children in the Chikhwawa district experience repeated febrile episodes and costs may be considerably greater if care is sought for each febrile episode. The definition of HTR is used in health system planning in Malawi, however this is the first study to investigate the impact of living in such areas on the household economic cost of childhood febrile illness. This study shows that even within a poor, rural population there are differences in wealth, access to formal health facilities and prompt treatment of childhood fever according to geographic location.

Conclusion

Those living in HTR areas were less likely to attend a health facility for a childhood febrile event and experienced greater associated household costs. Attendance to CHWs was infrequent but appeared to reduce attendance at a health facility, even when indicated. Since CHWs do not stock antimalarials this may have reduced the proportion of children receiving appropriate care. Health service planners must consider geographic and financial barriers to accessing public health-facilities in designing appropriate interventions.

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Authors' contributions

VE and MS designed the survey with assistance from LM. VE supervised survey conduction, undertook the data analysis and drafted the paper. LM, MS and DL provided study supervision. LM and MS assisted with data analysis. KP and AR provided guidance throughout the study process. All authors were involved in revising the paper for publication.

Competing interests

The authors declare that they have no competing interests.

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