Barriers to care for children diagnosed with malaria at José Macamo Hospital in Maputo, Mozambique



Master thesis in Medicine Helena Thiman

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# Master thesis in Medicine

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# 1. Abstract

**Background:** Malaria is a life threatening but treatable disease, affecting millions of people annually. In Mozambique, malaria is a major cause of morbidity and mortality, foremost among children. People suffering from malaria should have access to diagnosis and treatment within 24 hours from onset of symptoms according to a target set by the Roll Back Malaria Partnership. Yet, people in low-income countries often encounter barriers to care, hindering them from prompt treatment.

**Objective:** Determine socio-cultural, economical, geographical and health care related factors that have impeded access to malaria care for children diagnosed with malaria at a public hospital in Maputo and evaluate the general knowledge about malaria among caregivers of the children diagnosed with malaria.

**Methods:** Semi-structured, questionnaire based interviews with questions covering possible barriers to malaria care and knowledge of malaria were held with caregivers to children under the age of 15 diagnosed with malaria.

**Results**: 28 caregivers were interviewed. The majority of caregivers sought care with their ill child after 24 hours from onset of symptoms. We could not show that having received information about malaria prior to hospital visit, ability to associate correct symptoms to malaria, suspicions of malaria or previous episodes of malaria resulted in prompt care seeking. Main reason for waiting was thinking the disease would pass by itself. Most commonly experienced and perceived barriers to care were health care related factors. Few caregivers had been given information about malaria prior to coming to hospital or in connection with the hospital visit, and there is a lack of knowledge about malaria symptoms.

**Conclusion:** Incorrect perceptions of malaria, its symptoms and its potential risks seem to cause delay in seeking prompt diagnosis and treatment. More information about malaria symptoms, and foremost information about the importance of seeking prompt care, even with a child with vague or mild symptoms, needs to be provided.

Keywords: Malaria, treatment seeking behaviour, accessibility, knowledge, children,

Mozambique, attitude

# 2. Background

### 2.1 Mozambique

Mozambique is a post-conflict country in Southeast Africa with a population of approximately 26 million people. It was liberated from being a Portuguese colony in 1975 after a 13 yearlong war of independency and shortly thereafter suffering from an armed civil war up until 1992 [1]. After the declaration of peace Mozambique has had one of the highest economical growth rates in Africa, and the country has made great progress in terms of socioeconomic development in sectors such as education and health care [2]. But despite the economical growth, Mozambique is still one of the poorest countries in the world. The country's economy and prosperity has experienced major setbacks due to both natural disasters and international economic crises, and it remains dependent on economic aid from other countries [2]. In 2013 the gross domestic product (GDP) per capita (current USD) was 605 USD, in relation to the world average at 10,610 USD per capita and Sweden at 60,430 USD per capita [3]. In 2009, 54.7% of the population were living below the national poverty line, which is set at approximately 2 USD per day (PPP) [3, 4] and Mozambique is in the very bottom of the UN's Human Development Index [5]. The gap between different geographical regions and between rural and urban areas is great, with the poorest part of the population living on the countryside. Even though almost 70% of the total population live in rural areas [3] and more than half of the population reside in the north [1], almost all economic investments are concentrated in the capital of Maputo in the very south of Mozambique [3, 6].

In relation to the world average, Mozambique's health expenditure is very low, with only 37.2 USD is spent per capita. The correspondent world average in 2012 was 1030.4 USD per capita, and in Sweden 5319.4 USD per capita. The number of hospital beds remains constant since 2004 at 0.8 per 1.000 people, comparing with current 2.7 in Sweden

[3]. The fertility is high and almost half of the population is under 15 years of age [1, 3]. The life expectancy is 50.8 years for women and 48.9 years for men.

Regarding education, investments are done to increase school enrolment, but the primary completion rate is still low with almost half of the children not finishing grade 7. There is a slight majority of attending boys in primary school, but the gap has diminished during the last decade. In 2012, 51 % of the adult population were illiterate, and in 2009 the same number for young people between 15 and 24 years old was 67 %. It is mainly women who are analphabetic, with a total of 43 % illiterate women age 15-24 years between the years of 2005 and 2013, compared to 20 % of illiterate men. [3].

### 2.2 Malaria

#### 2.2.1 Epidemiology

Malaria is a treatable infectious disease affecting millions of people in the world, especially children under five and pregnant women. Approximately 80% of cases and 90% of deaths are estimated to occur in Africa. In 2013, approximately 198 million people were infected with malaria and 584 000 malaria deaths occurred globally [7].

The most common type of malaria in Africa is the one caused by P. *falciparum*, accounting for as much as 90 % of all malaria infections in Mozambique. This is the most aggressive form of malaria that can proceed rapidly into a life threatening condition, demanding early diagnosis and treatment [8].

In Mozambique, malaria is endemic but peaking during the warm rainy season stretching from November-March. The transmission rate is high, making the disease a major cause of morbidity and mortality. In 2013 there were 5.5 million suspected malaria cases in Mozambique, and 1.8 million probable and confirmed cases [9]. The same year, prevalence of laboratory confirmed malaria among children under the age of five was 46 % in rural areas and 16 % in urban areas [10]. Among children less than five years old, malaria accounted for 42% of the deaths, followed by AIDS at 13% [11]. According to the

Mozambican Ministry of Health, malaria is responsible for 40% of outpatient visits and 60% of pediatric hospital admissions [12], and it is the cause of approximately 26 % of all deaths occurring at hospitals in Mozambique, and 30% of registered pediatric hospital deaths [12, 13].

# 2.2.2 Risk groups

It is estimated that about 2.3 billion people reside in areas where there is a high risk of catching malaria [14]. In 2013, 97 countries and territories had on-going malaria transmission, Mozambique being one of them. Children under the age of five and pregnant women are the most vulnerable [15]. Higher risk of malaria and poorer prognosis is also associated with poverty. People living in poverty more often suffer from malnutrition, and the access to sanitation and clean water is often limited, which in turn leads to poorer health status with lesser ability to resist and fight disease [12, 16]. The higher risks of having severe malaria and develop complications is also due to the fact that poor people more often live in rural areas with less access to preventive measures and adequate health care [16, 17].

#### 2.2.3 Pathogenesis

Malaria is caused by different species of unicellular organisms called protozoa belonging to the genus *Plasmodium*. Those that primarily cause malaria in humans are *Plasmodium falciparum*, *P. vivax*, *P. ovale and P. malariae* [8]. Transmission of malaria occurs when a mosquito, carrying the protozoa in her salivary glands, bites a human host and injects the parasites into the blood stream. When another mosquito bites the infected host, the parasites are sucked up and thereby possible to transmit to another human [14].

#### 2.2.4 Symptoms and signs

The onset of severe malaria can be rapid, occurring in a matter of hours. Characteristic symptoms of malaria are intermittent fever and chills every second or third day. Other symptoms may include nausea, headache, and muscle aches. In case of *P*. *falciparum* malaria, the periodicity of fever may be continuous and there may also be accompanying cough, myalgia, jaundice, diarrhea, vomiting, convulsions and respiratory distress. The patient may rapidly become unconscious and develop shock and deep coma. The clinical picture of infection with other plasmodium species is much milder [18].

#### **2.2.5 Complications**

In the case of severe *P. falciparum* infection, the most common and important complications in children are cerebral malaria, severe anemia, respiratory distress (caused by metabolic acidosis) and hypoglycemia. Convulsions due to cerebral malaria occur in almost one third of severe cases of malaria in children, and 5-30% of these children will develop neurological sequelae [19]. The most common causes of death due to malaria among children are complications from acute infection or severe anemia caused by repeated malaria infections [20].

#### 2.2.6 Diagnosis

An early and correct diagnosis is essential for good malaria management. The WHO recommends immediate diagnostic testing for all patients with suspected malaria, either by a rapid diagnostic test (RDT) or microscopy, before the initiation of treatment. Treatment without diagnostics should be reserved for cases where no diagnostic means are available within two hours, or severe cases where the accuracy of the diagnostic test is unsure [21]. Even if the use of parasite-based diagnostics is increasing, most cases of suspected malaria in the world are not properly confirmed [22].

RDT's detect antigens produced by the malaria-causing parasites present in an infected persons blood stream. Since RDT's are still more expensive than microscopical microscopy remains the primary diagnostic method in most health care centres and hospitals. Through microscopical examination of a blood smear, the different kinds of malaria-causing parasites can be identified and quantified [21].

#### 2.2.7 Treatment

Malaria is a preventable and treatable. If treated promptly and appropriately, even *P. falciparum* infection follows a relatively mild course. However, without effective therapy it can rapidly become life threatening. For the individual, the main purpose with malaria treatment is to eradicate the plasmodium from the blood stream in order to prevent the progression from uncomplicated malaria into a life threatening condition, or to prevent the malaria from becoming chronic, causing negative long-term health effects such as anemia. In terms of public health, the main purpose with malaria treatment is to reduce the transmission within a population and to prevent the development of resistance to anti-malarial drugs [23].

#### **3.1** The right to health

The UN states that "Health is a fundamental human right indispensable for the exercise of other human rights" [24]. WHO declares that right to health means that everyone has the right to enjoy the highest attainable standard of physical and mental health [25]. In order for people to attain the best possible health, access to adequate health care is an absolute requirement. The right to health contains four elements, condensed into the abbreviation "AAAQ" in the General Comment no.14 of The UN Economic and Social Council. AAAQ stands for *Availability, Accessibility, Acceptability* and *Quality* [24]. The term *availability* implicates that functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. It comprises the type, range, and quantity of health care services, trained medical professionals, necessary drugs and opening hours, as well as the ability and willingness of health care providers to serve the population. The term *accessibility* is defined as every citizen's right to the available public health without discrimination, meaning that health care facilities, goods and services should be physically accessible and affordable, and information regarding health and health care should be in reach for

everyone. *Acceptability* means that the available treatment and all health services should be acceptable for the patients, being respectful of medical ethics as well as sensitive to gender, culture and religion. *Quality* denotes that the health facilities, goods and services must be scientifically and medically appropriate and of good quality. Factors occurring at the different dimensions of AAAQ interact to influence access to health care, and obstacles within these four elements pose a significant threat to safety and health of the population [25, 26].

Even though health is a fundamental human right, people in low- and middleincome countries often encounter barriers to care. Poor and disadvantaged groups in society often bear an unreasonably large proportion of health problems, suffering from more illness and dying sooner than the more privileged. Poor populations and socially excluded people face greater exposure to many health threats, and when they fall sick they are less likely to receive care. Social factors including the effects of poverty account for the majority of the global burden of disease and death, as well as for the largest share of health inequalities between and within countries [27].

# 4.1 Barriers to care

Barriers to care can be considered as obstacles or factors inhibiting the *availability*, *accessibility*, *acceptability* or *quality* of health care [24]. Barriers to *accessibility* of care are defined and divided by the WHO into these four following categories:

- economic (e.g. charges for health service, transport, loss of income),
- geographical (e.g. distance to clinic),
- socio-cultural (e.g. stigma, lack of knowledge and education, traditions), and
- health system-linked factors (e.g. how patients are being treated by health service staff, long waiting time at hospitals or pharmacies) [27].

#### **4.1.1 Economic barriers**

Poverty is the greatest impediment to human and socioeconomic development. In the health sector, poverty represents a principal barrier to health and health care, and each year 100 million people globally are pushed below the poverty line as a result of health care expenditure. Hence, the importance of integrating the promotion of equity and subsidized health care for the poor when addressing the right to health is evident [27]. In Mozambique, even though the Poverty Reduction Strategies have contributed substantially to reducing the number of poor, approximately 54% of the population lives below the poverty line, and access to basic social services remains low [28]. Many people are unable to afford proper treatment, especially since health care and medication can be expensive. In Mozambique, 46 % of visitors at primary health care units find it difficult or very difficult to raise the money for payment related to a single visit, and residents of rural areas are more likely to have difficulties raising the money needed [29].

#### 4.1.2 Geographical barriers

Geographical distance poses a major barrier to accessing general health services. Traveling to health care facilities is especially burdensome in settings where roads are inconvenient and/or public transport is lacking, for instance in most rural areas in low income countries, including Mozambique. In the rainy season some roads may be closed, compounding the problem of distance. Additionally, long distances mean more out-ofpocket costs for patients as well as loss of time spent working, which affect low-income groups more than others [27].

In Mozambique, 65% of the population has access to a health unit within 45 minutes of walking. Accordingly, more than a third of the population has to travel great distances to reach a care facility. However, there has been a positive trend since the beginning of the 21<sup>st</sup> century, when the number was only 55%. The greatest gains have occurred in rural areas (especially in the north of the country), compared to urban areas, where the ratio actually declined as a result of rapid urban expansion [6].

#### 4.1.3 Socio-cultural barriers

Evidence show that socio-cultural barriers are often major and underestimated causes to delayed visits to health care units in case of malaria. Incorrect perceptions of malaria, its symptoms, risks, way of transmission, methods to prevent it and its treatment, have implications for care seeking behavior as it often leads to delay in seeking prompt diagnosis and appropriate treatment at health facilities [30, 31]. The socio-cultural barriers are a complex network of everyday decision-making influenced by matters concerning gender issues, belief in traditional medicine, distrust in modern medicine, stigmatization of illness as well as family arrangements, perceptions of family hierarchy and organization of household economy [32, 33]. For example, preference in traditional medicine is seen in areas where the cause to malaria is believed to be spirits or witchcraft. In some African countries, a major barrier to care is the perception and fear that children with convulsions will die when given an injection or taken to the hospital, rather than of severe malaria [34]. Furthermore, fear of being mistreated by medical professionals as well as the lack of confidentiality is an issue, since distrust in medical staff causes delay in prompt treatment seeking. Also, the matter that malaria often is viewed as a mild, "ordinary illness" in many endemic countries [35, 36] rather than considered severe needing urgent attention, as well the fact that caregivers have their own way of categorizing child fever into mild and severe [37], leads underestimation the potential harm of child febrile illness and may contribute to the continued high mortality and morbidity due to malaria.

#### 4.1.4 Health-system linked barriers

Prompt access to effective malaria treatment is central to the success of malaria control worldwide [9]. Effective malaria case management, meaning early diagnosis and prompt treatment of malaria patients, is one of the fundamental pillars of malaria control.

A target set by The Roll Back Malaria partnership was that 80% of those suffering from malaria would have prompt access to affordable and appropriate treatment within 24 hours from onset of symptoms, by the year of 2010 [38]. Yet, most African countries are still far below these targets, with only a minority of fevers being treated effectively and in a timely manner [39, 40]. Between 2006 and 2007, only 38% of fevers caused by malaria reported among children under five were treated with anti-malarials, and only 3% were treated with artemisin-based combination therapy (ACT), the official first-line anti-malarial for uncomplicated malaria in over forty African countries, including Mozambique [41].

The responsibility for provision of drugs and treatments adjusted to fit patients' needs and difficulties lies on the health services. In low- and middle-income countries the available amount of basic medical supplies and number of educated health care personnel is often insufficient, leading to impaired diagnosis and treatment that is also significantly delayed due to work overload [40]. In addition, there is an existing problem with procurement and usage of fake, ineffective anti-malarials in several African countries. The high costs and shortage of the recommended malaria therapy provide a favorable platform for the spread of fake medications, putting the lives of malaria-infected individuals at great risk [42, 43].

## 4.1 Malaria care in Mozambique

#### 4.1.1 The health care system

Mozambique's health care system is composed of public, private for profit and nonprofit private sectors. The public sector is the main provider covering about 60 % of the population. It comprises health posts (located in less populated areas and served by trained paramedic staff), health centres (which provide ambulatory and basic hospitalization care), and public hospitals [29].

In Mozambique, microscopy of blood smear remains the primary diagnostic method in most health care centres and hospitals. But the use of rapid tests (RDTs) is beginning to be widely spread. In southern Mozambique, the method of rapid tests is well implemented. RDTs are beneficial because they are easy to use, require little training and provide a result in less than half an hour. Most RDTs used in Mozambique are certified by the WHO, meaning that they have a high specificity and sensitivity, making them a reliable diagnostic source [21].

#### 4.1.2 Barriers to malaria care in Mozambique

In Mozambique, effective treatment and equity in access to malaria services is a concern. As stated above, many of the major barriers to care in low- and middle-income countries are linked to an insufficient health care system; the available number of health care facilities and medical professionals is insufficient, the level of training is generally low and there is also a lack of medical resources [44]. The fragile situation affects people in several ways, e.g. poor knowledge at community level, overcrowded clinical practices and long waiting time for test results and treatment. In many cases necessary tests are not even performed [45]. Misdiagnosing malaria causes delay in receiving proper treatment and creates an unnecessary economical burden due to expenses put on ineffective therapy. Lack of medication at the public pharmacies forces people to buy medication at private pharmacies, charging substantially more than the governmentally funded option. Since poverty is widespread and the health insurance system is inadequate, both direct and indirect charges when seeking health care and costs of malaria treatment constitute a barrier to malaria care [12, 44]. Also, the lack of confidentiality is an issue, since illness in some cases is considered socially stigmatizing [44].

The Mozambican government aims to retrench patient expenses by funding malaria testing and standard treatment at public health care facilities, lowering the costs for everyone with suspected malaria to minimum fee of less than 0,2 USD for both consultation, testing and treatment of malaria [46]. But despite these governmental efforts with only modest charges for public sector health care, people in Mozambique often face high costs when seeking care and requiring hospitalization due to malaria, not uncommonly exceeding catastrophic payments (payments exceeding 10 % of monthly

income or 40% of non-food expenditure) for a single malaria episode, with largest expenses being on transportation and medicine [45].

# 3. Objectives

# 3.1 Overall objective

To determine factors that impede access to malaria care for children under the age of 15 attending at the public hospital José Macamo Hospital in Maputo, Mozambique.

# **3.2 Specific aims**

- Determine the time period between onset of malaria symptoms and attendance at hospital
- Evaluate the general knowledge about malaria and its manifestations among the caregivers of children diagnosed with malaria at José Macamo Hospital
- Identify socio-cultural, economical, geographical and health care related barriers to malaria care for children diagnosed with malaria at José Macamo Hospital

# 4. Methodology

# 4.1 Study description

This study was based on semi-structured interviews, conducted at the public hospital José Macamo Hospital in Maputo, Mozambique between 3rd November 2014 and 28th November 2014.

#### 4.2 Description of the study location

José Macamo Hospital is a public hospital in the outskirts of Maputo City. The catchment area of José Macamo Hospital is around 52 square kilometers and includes districts and villages of different character and various living standards. The hospital has a capacity of 303 hospital beds, of which 62 are pediatric. The average number of pediatric

consultations is 575 per month (35). According to working health staff, the number of pediatric admissions due to malaria per day can be as high as 10 during the rainy season and about 1 per day during winter. The average time of in-patient care at the pediatric department is 1-2 days.

# 4.3 Study population and sample size

The focus of the study was caregivers with at least one child under the age of 15, diagnosed with malaria at José Macamo Hospital in Maputo, Mozambique. Caregivers of non-admitted children at the outpatient department were directed to us by the nurse in charge, after the child had received the diagnose malaria through a diagnostic test. Caregivers of admitted children at the department of pedriatics were recruited by speaking to the treating health care personnel who had knowledge about which children were admitted due to the diagnosis malaria. A positive malaria diagnosis was defined as a positive rapid diagnostic test (RDT) and/or microscopy.

The study included participants who attended to the hospital within the time period of November 3rd to November 28th. The number of new malaria cases per day during this period of the year was between 1 and 4.

# 4.4 Inclusion criteria

- Caregiver attending the triage of Centro da Saúde, triage of Banco de Socorros (outpatient child) or the department of paediatrics at José Macamo Hospital (inpatient child) with at least one child under the age of 15
- Child having a malaria diagnosis at the time of the interview (positive RDT and/or microscopy) at José Macamo Hospital
- Child presenting at the hospital during the date of the interview

# 4.6 Study procedure and data collection

First, a pilot study was conducted. After the pilot studies only small changes were made in the questionnaire, and the pilot interviews were included in the final analysis of this study.

The interviews were held in privacy and conducted face to face after informed consent (Appendix 1) from the interviewee. If the participant orally agreed on participating but was unable to sign the informed consent sheet, participation was still approved. An assistant trainee, who works at the Faculty of Medicine, held the interviews in Portuguese or local language Xichangana by using a standardized questionnaire (Appendix 2). If accepted by the participant, both study researchers were present during the interview to answer questions if needed.

The questions were read out loud and explained if necessary, and the answers of the interviewee were put down on the questionnaire by ticking the corresponding boxes or writing comments on the questionnaire sheet. The questions aimed at mapping factors around the caregiver and the child diagnosed with malaria, referring to:

- caregiver factors/socio-demographic characteristics,
- duration of symptoms before attendance at hospital,
- knowledge about malaria and its manifestations,
- occurrence of previous malaria episodes,
- if participant sought care somewhere else before coming to hospital,
- transportation and time spent on travelling to hospital,
- perceived social/cultural acceptance of malaria and reactions from surroundings,
- barriers to malaria care, and
- perception/experience of the hospital procedures.

If the interviewee did not understand the question about what possible barriers to malaria care they could think of, the investigator gave an example of a possible barrier, since there is a difference between not seeing any barriers and not understanding the question. "Distance to clinic or not being able to afford transport" was used as an example. If the participant at that point did not understand the question, it was noted.

If the participant did not want to answer a question, the question was skipped and a note was put in the margin of the questionnaire that the participant did not want to answer.

No information regarding the identity of the child or the caregiver was documented during the interviews. The interviews were held in a separate room to secure privacy and confidentiality.

# 4.7 Data analysis and statistics

The quantitative data were collected, entered and analyzed using IBM SPSS Statistics 22. Patient demographics and clinical characteristics of the cohort were summarized using descriptive statistics. Correlations between patient factors, knowledge about malaria transmission and prevention and utilization of preventive measures were described using cross tabulations. Some answers from the open-ended questions were entered as citations in the results section to further illustrate recurring or interesting themes of answers.

Due to the homogenicity and limited size of the cohort the variables *age of child, age of participant* and *participant's educational level* and *monthly income* were dichotomized into groups of age less and over five years, age less and over 30 years, education of more or less than five years and income below and above public minimum wage at 3000 MZN (90 USD at current rate).

# 4.8 Ethical considerations

The project, the questionnaire and the informed consent sheet were approved by the Medical Scientific Committee of Eduardo Mondlane University and the Committee of Bioethics and Health at the Faculty of Medicine and Central Hospital in Maputo, Mozambique. Participants needed to provide informed consent before interviews were conducted. Information about the study and the conditions was given to the participants both orally and in writing. The interviews were held in privacy and all answers were handled strictly confidentially. No information regarding the identity of the caregiver or the child was documented during the interview, and participants were designated a number in order to secure anonymity throughout the study. Participation was completely voluntary, refusal to participate did not affect the child's treatment in any way, and participants were not given any payment for completing the interview. Contact with a counselor (HIV counselor) employed at the hospital was established before the collection of data started in order to be able to offer professional support to participants who might express concerns after the interview was finished. This was however never needed. None of the researchers received any payment for conducting this study. There are no conflicts of interest.

# 5. Results

Twenty-eight people consented to participate in the study. No interview was excluded from the analysis. Two caregivers were excluded from the study due to only being available during already on-going interviews, and one caregiver declined to participate. Two participants declined the researchers' presence in the interviewing room.

Two caregivers declined to answer the question regarding their monthly income, and one did not want to answer the question to why he/she felt dissatisfied with the overall experience at José Macamo Hospital. The questions about experienced and general barriers to care required explanation to six participants, however none of those stated the same barriers as in the example given.

# 5.1 Socio-demographics

Table 1 describes the socio-demographic characteristics of the cohort.

Table 1.	Descriptive	demographics
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Category	Frequency (N=28)	%		Frequency (N=28)	%
Sex of participant			Partner with income***	· · · · ·	
Female	27	96.4	Yes	19	67.9
Male	1	3.6	No	9	32.0
Age of participant			Type of housing****		
15-20	4	14.3	Conventional house	1	3.6
21-30	15	53.6	Basic house	23	82.1
31-40	5	17.9	Hut	3	10.7
41-50	2	7.1	Schack/Improvised home	1	3.6
51-60	2	7.1			
Median	28.0				
Range	19-60				
Sex of child			Number of people in the household		
Female	11	39.3	Median	4.5	
Male	17	60.7	Range	3-12	
Age of child			Main source of drinking water to the		
0-4	21	75.0	household		
5-15	7	25.0	Piped water into house	6	21.4
Median	3,0		Piped water into yard	14	50.0
Range	1-11		Water from neighbor	6	21.4
			Water from public tap	1	3.6
			Water from well or borehole	1	3.6
Educational level			Main type of fuel used for cooking	-	5.0
No education	2	7.1	Firewood	16	57.1
Primary level, 1 <sup>st</sup> grade (year 1-5)	15	53.6	Charcoal	11	39.3
Primary level, 1 <sup>nd</sup> grade (year 6-7)	7	25.0	Electricity from grid or town gas	1	3.6
Secondary level, 1 <sup>st</sup> circle (year 8-10)	4	14.3	Electricity from grid of town gus	1	5.0
Income source	Į.	11.5	Type of toilet facility in the household		
income source			Flush toilet inside	1	3.6
Salary from full-time paid employment	7	25.0	Improved latrine or flush toilet outside	11	39.3
Salary from irregular employment	2	7.1	Latrine	14	50.0
Income from year round self-dependent	2	/.1	No toilet in the household	2	2.0
business*	8	28.6	No tonet in the nousehold	2	2.0
Income from irregular self-dependent*	0	28.0	Main type of fuel used for cooking		
business	1	3.6	Firewood	16	57.1
Do not earn an income	10		Charcoal	10	39.3
Do not earn an income	10	35.7			
Income per month**			Electricity from grid or town gas Time traveling to hospital	1	3.6
0-499 MZN	1	3.6	<30 min	13	46.4
500-999 MZN	2	7.1	31-59 min	9	32.1
1.000-2.999 MZN	7	25.0	1-2 h	3	10.7
3.000-4.999 MZN	5	17.9	>2 h	3	10.7
5.000-9.999 MZN	1	3.6	Type of caregiver interviewed		
Do not earn an income	10	35.7	Child inpatient at hospital	16	57.1
Declined to answer	2	7.1	Child outpatient at hospital	12	42.9

\*Self-dependent business includes selling fruits, clothes or other items or offering simple services such as hair braiding on the street, and not having a stable income.

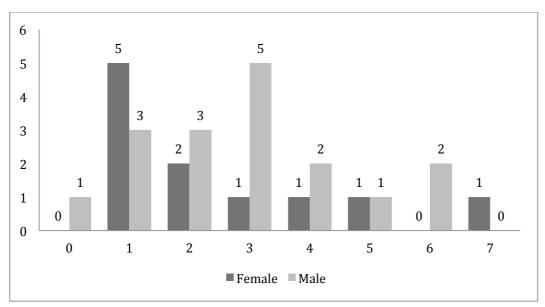
\*\*Public minimum wage in Maputo is at 3000 MZN (90 USD at current rate).

\*\*\*In all cases where the caregiver stated having a partner with an income, all partners earned more than minimum public wage at 3000 MZN.

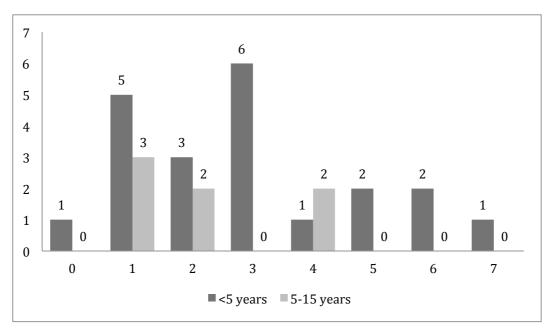
\*\*\*\*Basic houses have walls and roof made of conventional material such as bricks or concrete but lack toilet and kitchen inside as compared to conventional houses. Huts have walls or roof made of vegetable material.

# 5.2 Duration of symptoms

Figure 1 shows the distribution of number of days caregivers waited to seek hospital care after their child's onset of malaria symptoms (duration of symptoms). The majority sought care within three days of symptoms. Figure 2 shows the duration of symptoms by the child's age.



**Figure 1.** Distribution of days between onset of symptoms and attendance at hospital (duration of symptoms) divided sex. Median duration of symptoms for girls was 2 days (range: 1-7) and median duration of symptoms for boys was 3 (0-6). The difference is non-significant (p>0,05). Median time for all children was 2,5 days.



**Figure 2.** Distribution of days between onset of symptoms and attendance at hospital (duration of symptoms) in relation to age group. Median time for children under the age of five was 3 days (range: 0-7) and median time for children five years and older was 2 days (range: 1-4). The difference is non-significant (p>0,05). Median time for all children was 2,5 days.

As seen in table 2, the majority of caregivers sought hospital care after 24 hours from onset of their child's symptoms, foremost caregivers older than 30 years and caregivers who had studied more than fiver years of primary school (called 1<sup>st</sup> grade in Mozambique). The differences were however not significant. No tendency towards difference was seen on monthly income or having a partner with an income.

Because of the cohort's size and homogenicity in regards of markers of economic conditions (type of housing, main source of drinking water, main type of cooking fuel and type of toilet facility in household), no comparison with these economic markers and time of attendance at hospital was made. Similarly, time spent on travelling to hospital was not further investigated due to the absolute majority not travelling more than one hour to the health care facility.

	Symptoms <24	Symptoms >24	
	h N (%)	h N (%)	Total N
All children	9 (32)	19 (68)	28
Sex of child			
Female	5 (45)	6 (55)	11
Male	4 (24)	13 (76)	17
Age of child			
0-4 years	6 (29)	15 (71)	21
5-15 years	3 (43)	4 (57)	7
Age of caregiver			
15-30 years	4 (21)	15 (79)	19
31-60 years	5 (56)	4 (44)	9
Educational level of participant			
0-5 years	4 (24)	13 (76)	17
6-10 years	5 (45)	6 (35)	11
Monthly income of participant			
Below minimum public wage*	5 (35)	15 (75)	20
Above minimum public wage*	2 (33)	4 (67)	6
Partner with income			
Yes	13 (68)	6 (32)	19
No	6 (67)	3 (33)	9

Table 2. Socio-demographic factors and time until attendance at hospital from onset of symptoms

Distribution of children attended at the hospital within and after 24 hours from onset of symptoms. No significant differences were found between the groups presented in this table (all p-values >0,05).

\*Minimum public wage in Maputo is 3000 MZN (90 USD at current rate)

## 5.3 Knowledge of malaria

Only 11 caregivers (39 %) had received any formal information/education about malaria before coming to hospital, and 39% found it difficult to find information about malaria. Main sources of information were health care facilities (15 caregivers) and TV (7 caregivers), and speaking to friends and people in the community (7 caregivers). Table 3 shows the distribution of children attended at José Macamo Hospital within and after 24 hours from onset of symptoms dependent on if caregiver had received education/information about malaria before coming to hospital. No significant difference (p>0,05) in care seeking behavior dependent on the caregivers' previous experience of malaria information was found.

 Table 3. Caregivers seeking within 24 hours from onset of symptoms dependent on if caregiver been informed about malaria prior to coming to hospital

Received information	Symptoms <24h N (%)	Symptoms >24h N (%)	Total N
Yes	4 (36)	7 (64)	11
No	5 (29)	12 (71)	17

Number of caregivers seeking hospital care within and after 24 hours from onset of their child's symptoms of illness. The difference is non-significant (p>0.05).

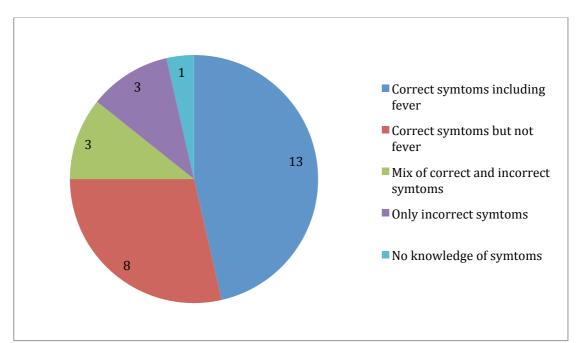
#### 5.3.1 Knowledge of malaria manifestations

Caregivers' knowledge of symptoms associated with malaria is shown in figure 3. Correct symptoms were defined as fever, chills, vomiting, weakness, stomach ache, head ache, muscle ache, loss of appetite, jaundice, confusion, sweating, diarrhea, convulsions, "feeling hot and cold", "feeling cold" and "to be warm". The most commonly mentioned symptoms associated with malaria were headache (15 caregivers), fever (13 caregivers), vomiting (8 caregivers), weakness and diarrhea (5 caregivers respectively). Symptoms mentioned regarded as incorrect were back pain, white eyes and "going into the shadow".

As figure 3 shows, a majority of the caregivers were able to associate one or several symptoms characteristic of malaria. However, a total of 15 caregivers (54 %) did not mention fever as a symptom of malaria. Out of the 21 caregivers associating correct symptoms (including or excluding fever), 8 (29 %) did not suspect malaria and 13 (62 %)

had children with symptoms of malaria for more than 24 hours before seeking hospital

care.



**Figure 3**. Distribution of caregivers stating correct, mix, incorrect or no knowledge of symptoms of malaria. Since malaria is disease with many unspecific symptoms, but fever is considered main symptom, division is made regarding those caregivers who were able to associate symptoms characteristic for malaria including fever and those stating correct symptoms of malaria but not mentioning fever.

#### 5.3.2 Suspicions of malaria

Seventeen caregivers (61 %) suspected their child to have malaria before seeking primary or hospital care. Median duration of symptoms among the children whose caregivers suspected malaria was 2 days, comparing with 3 days among those who did not suspect their child to have malaria. The difference is however not significant. In total, the majority sought care within three days despite suspicions of malaria or not.

Table 4 shows the correlation between caregivers' suspicions of malaria prior to coming to hospital and the child being attended at hospital within or after 24 hours from onset of symptoms. Slightly more of the caregivers who suspected malaria sought hospital care within 24 hours from onset of symptoms comparing to those not suspecting malaria, although no significant difference were found and the majority in both groups waited more than 24 hours from onset of symptoms. However, only 3 (11 %) of the caregivers who suspected their child to have malaria sought hospital care within one day from starting to suspect it.

Table 4. Attendance at hospital withi	1 24 hours from or	nset of symptoms dependent	on if caregiver
suspected malaria			

	Symptoms <24h N (%)	Symptoms >24h N (%)	Total N	
Suspected malaria	6 (35)	11 (65)	1	17
Did not suspect malaria	3 (27)	8 (73)	1	11

The difference is non-significant (p>0.05).

Correlations between educational level of the caregiver and suspicions of malaria are shown in table 5. More caregivers with education of five years or less suspected malaria, and more caregivers who had received any kind of formal information about malaria before deciding to seek hospital care suspected malaria, however no significant difference were found (p>0,05).

Table 5. Caregivers educational level and suspicions of malaria

Educational level	Suspected malaria N (%)	Did not suspect malaria N (%)	Total N
0-5 years	12 (71)	5 (29)	17
6-10 years	5 (45)	6 (55)	11
Received education/information about malaria	10 (91)	1 (9)	11
prior to coming to hospital			
Had not received education/information about	7 (41)	10 (59)	17
malaria prior to coming to hospital			

#### 5.3.3 Previous malaria episodes

Eleven of the children had been diagnosed with and treated for malaria previously. Ten (91%) of these children had symptoms for more than 24 hours before coming to José Macamo, compared to 9 (53%) of the 17 children having malaria for the first time. The difference was however not significant.

# 5.4 Barriers to care

#### 5.4.1 Caregivers' reasons for seeking care after more than 24 hours of symptoms

Twelve caregivers (43 %) waited more than 24 hours before seeking primary or hospital care because they thought the disease would pass by itself. Two common reasons

for choosing to wait and see if the illness would pass by itself was thinking the illness was not very serious and being misled by the fluctuating symptoms of the disease.

"I thought it was simple fever that would pass, but when it did not pass I went to the hospital." – Mother, 42 years

"She only had fever in the end of the day, during the day time she was fine. I thought it would pass by itself." – Mother, 37 years

Three (11 %) caregivers waited because they thought it was fever caused by moon disease, not requiring hospital treatment but instead traditional treatment given by the mothers themselves at home.

"I thought it was "normal fever" caused by moon disease. Children have fever all the time." – Mother, 27 years

"I waited four days because I did not think it was malaria. I thought he was talking to his friend, the moon, because he was talking to himself." – Mother, 24 years

Other reasons for waiting more than 24 hours to seek primary or hospital care included having other responsibilities like work or taking care of family (two caregivers), not knowing where to seek care (1 caregiver), not finding any available transport (one caregiver), being afraid of maltreatment from the health staff (one caregiver), and having to wait for permission from husband to leave home (one caregiver).

#### **5.4.2** Barriers to malaria care as experienced by the caregivers

When the caregivers were asked if they had experienced any barriers or difficulties when seeking care with their sick child at this time of illness, 12 (43 %) of the caregivers stated that they did not face any barriers. Six (50 %) of the children to these caregivers had symptoms of illness more than 24 hours before seeking hospital care.

The most commonly mentioned barriers that had impeded their child's access to malaria care were health care related factors such as lack of attention from and/or distrust in health staff (six caregivers), initially receiving wrong diagnosis or treatment (four caregivers) and transport related issues such as lack of transport or not having money for transport (three caregivers respectively). The barriers experienced when seeking care with the ill child at this time of illness mentioned by the caregivers are summarized in figure 4.

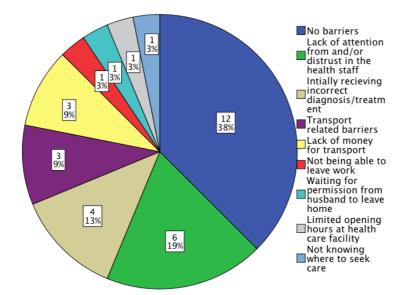


Figure 4. Main barriers as experienced by the caregivers when seeking care with the child ill with malaria at this time of illness

Following citations further illustrate these findings:

"When all mothers are laying in the same room, all with children with malaria and get different medications it is a problem. You wonder why you get different medications, but you are afraid to ask the nurses because you do not want to be a problem. But when you get different medicines for the same disease, you get doubts about the care." – Mother, 33 years

"The nurses that attended me at the health centre were a barrier because they came in very late and did not work as they should. They were hasty and did not pay attention, and when I wanted to talk, the nurse was writing a recipe and not listening. They did not make a test [at the health centre], they only gave the medication." – Mother, 24 years

"Not having money for transport to the hospital for me and my child was difficult." – Father, 54 years

#### 5.4.3 Caregivers' perceived barriers to care for children with malaria in general

When being asked about their perceptions about possible barriers to care for children with malaria in general, 10 caregivers stated that there are no barriers. The most common barriers mentioned were lack of attention from and/or distrust in health staff (8 caregivers), long waiting times at the hospital (5 caregivers), lack of medication at health care facility (4 caregivers), lack of money for medication (4 caregivers), transport related issues such lack of

transport or inconvenient traveling route (4 caregivers) and caregiver laziness (4 caregiver). Other barriers mentioned were lack of money for transport (2 caregivers) and caregivers giving the sick child traditional treatment at home instead of seeking professional care. The barriers mentioned by the caregivers are summarized in figure 5.

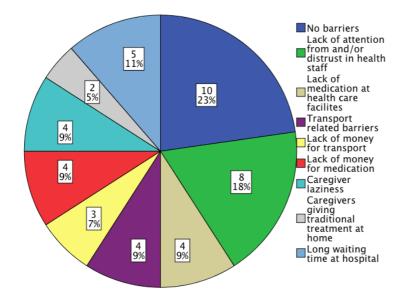


Figure 5. Barriers for children with malaria in general as perceived by the caregivers

Following citations further illustrate these findings:

"The nurses don't pay attention or treat you good, and that makes people not want to go to the hospital. They stay at home and give traditional medicine. For example, some people use Cacana because they have been told that it can cure malaria." – Mother, 24 years

"Some people wait a long time at the hospital to get treatment, and during that time the child gets worse. And sometimes there is no transport available to get a sick child to the hospital. Then you have to search for transport while your child is getting seriously sick." – Mother, 42 years

"Having trouble getting your child to the hospital, trouble getting transport or affording transport. Having to wait for a very long time when it is crowded at the hospital. Lack of some medicines at the pharmacy so that you have to buy it at a private pharmacy where it is very expensive, much more than at the hospital." – Father, 54 years

"We people are different. Some of us can think it is better to go first to a traditional healer to get treatment, and some might go to hospital. Some might be afraid of the hospital and that the nurses would kill their child. I don't know why, but maybe the nurses would give the wrong treatment or bad treatment." – Mother, 27 years

#### 5.4.4 Socio-cultural perceptions

All of the participants answered 'yes' or gave an affirmed response to the question whether malaria is socially accepted or not. Out of 17 participants suspecting their child to have malaria, 12 had chosen to tell someone else about their suspicions. The main reaction from people told was advising the caregiver to go to hospital. Among the five caregivers not telling anyone, four stated concern about someone making the child's illness worse by witchcraft as the reason for not telling, and 1 stated concern about being advised to use ineffective traditional remedies. Following citations further illustrate these findings:

"No, I would not tell. I do not like it. The one you tell, maybe your neighbour, will make the disease worse by witchcraft. A disease is not a party that you tell others about." – Father, 54 years

"If you tell other people, they might tell you to do this and that, like give the child home made remedies, and then the child does not get better." – Mother, 29 years

#### 5.4.5 Health care related barriers

#### 5.4.5.1 Seeking care somewhere else before coming to hospital

Twelve caregivers sought care at another health care facility before coming to José Macamo. Only six of them were able to state how many days the child had been sick before seeking care at the first health care provider, but among those who answered the median time from onset of malaria symptoms to first health care visit was 2 days (range: 1-4), with three having symptoms of malaria more than 24 hours before seeking care at José Macamo Hospital.

No caregiver stated traditional healer as first choice of care provider, 10 went to a health centre or a health post, and two chose to go to another hospital other than José Macamo. Everyone stated proximity to home as reason to why they chose to go to the first caregiver instead of José Macamo. Ten out of ten caregivers turning to a health post or a health centre as first health care provider thought their child's illness to be moderate or less. When turning to José Macamo Hospital, 14 out of 28 (including the group first going to a health post or centre) thought their child's condition to be serious. However, the

caregivers own estimation of illness severity did not correlate with the child being admitted or not to José Macamo Hospital.

Going to a health care provider that did not do a malaria test was mentioned by three caregivers as a reason for going to hospital instead. The children to these caregivers were either given the wrong diagnosis or no diagnosis at all, causing delay in receiving correct treatment and possibly worsening or symptoms (all 3 children were admitted to José Macamo Hospital compared to 5 out of 8 children whose caregivers sought care somewhere else before going to José Macamo and did not face this problem at the first care provider). All three of these caregivers did also suspect malaria and all three of the children had fever when turning to the primary health care facility that did not do a test for malaria. Following citations further illustrate these findings:

"I went to the health centre first because it was close to home. They gave us medicine and we went back home, but when I noticed that the child was not getting better, I went to the hospital the next day. --- Before I came to the hospital I did not know what kind of illness my child had because they did not make an analysis at the health centre, they only gave me paracetamol and amoxicillin to give to the child. I gave the child the medicine because I wanted to see if she got better, but because the health centre had not tested the child, they did not know what illness she had and the treatment they gave was ineffective. I lost time on giving the medication, trying to see if it got better." – Mother, 24 years

"I went to the health post yesterday where they gave her paracetamol. I asked them to make a test for malaria, but they did not do one." – Mother, 23 years

"I went to them because my child was constipated and was shaking because he was cold. They told me to give him orange to make him poop. But while we were there he got convulsions and they understood that he had fever, so they gave him a paracetamol and made a malaria test. Then we were transferred to José Macamo in an ambulance, but they did not tell me why." – Mother, 23 years

#### 5.4.5.2 Procedures at José Macamo Hospital

Only one caregiver stated having to wait for a nurse or doctor's attendance more than 2 hours at José Macamo Hospital. 17 children (61 %) got tested within 2 hours after arrival at the hospital and 8 (29 %) had to wait 3-5 hours. The test result was provided to the caregivers within 1 hour in 71 % of the cases. Every child got treatment within 5 hours from arriving at the hospital, 8 (29 %) within 1 hour.

	All children		Inpatients		Outpatients	
	(N=28)		(N=16)		(N=12)	
	Yes	No	Yes	No	Yes	No
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Received information about the	24 (86)	4 (14)	13 (81)	3 (19)	11 (92)	1 (8)
intention of the malaria						
diagnostic blood test						
Received information about the	25 (89)	3 (11)	14 (86)	2 (14)	11 (92)	1 (8)
test result						
Received information about	5 (18)	23 (82)	8 (50)	8 (50)	3 (25)	9 (75)
malaria from the health staff						
Have gained knowledge about	4 (14)	24 (86)	3 (19)	5 (81)	3 (25)	9 (75)
malaria symptoms during/after						
hospital visit						
Would have wanted more	13 (46)	15 (54)	7 (44)	9 (56)	6 (50)	6 (50)
information about malaria from						
health staff						

Table 6. Characteristics regarding information about malaria given at the hospital

Table 6 summarizes how the caregivers stated in regards of information given to them during the hospital visit for all children and separated by if the child was admitted to the pediatric ward or non-admitted receiving treatment for use at home.

"They (the health personnel) have not told me it is malaria, they only brought us to the malaria room, that is how I know it's malaria." – Mother, 34 years

"I do not know if a blood test was done for malaria. They took blood but I do not know what they did with it, they have not told me. They have also not told that my son has malaria or why we are in the malaria room." – Mother, 23 years

"I would like to know more about the treatment of malaria. My child has malaria a lot so I would also like to know more about prevention and how to treat a child with malaria." – Mother, 28 years

# 6. Discussion

Due to the limited study population, no general conclusions should be drawn from the findings in this study. Nevertheless, the study does highlight some interesting occurrences among the caregivers interviewed.

The majority of the study participants waited more than 24 hours before seeking care with their children ill with malaria, meaning that most of the children did not receive timely care (consistent with the Abuja target of treating malaria within 24 h of illness onset Abuja Roll Back Malaria Target). The main reason for this seems to be incorrect perceptions of the severity of malaria and the importance of prompt treatment.

A basis in knowing when to bring your child to the hospital for a malaria test is recognizing what symptoms malaria can present with and when to suspect malaria [47]. In our study, a fourth of the population stated incorrect or no knowledge of associated symptoms with malaria and more than half did not mention fever as a symptom of malaria, implying that the knowledge of the manifestations of malaria is not sufficient. Also, even among the participants suspecting that their child had malaria, the number of caregivers seeking care in a timely manner was low, in fact, almost equally as low as among caregivers not suspecting malaria. Consistent with previous studies [37, 48], this indicates that malaria is not considered a serious illness, and that there is a lack of knowledge of malaria having a potentially rapid and life-threatening disease progression. This is further indicated by our findings that almost two thirds of the participants waited more than 24 hours before seeking hospital care did so because they thought that the child was not seriously ill and that the illness would pass by itself. Also, the need for greater recognition of malaria manifestations is further stressed by the fact that several caregivers stated that fluctuations in the disease had tricked them into thinking the illness was about to pass since the child sometimes was feeling better, being able to play. In all, these findings suggest that incorrect perceptions of malaria, its symptoms and its potential risks cause delay in seeking prompt diagnosis and appropriate treatment. Thus, more information about the

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manifestations of malaria, and foremost information about the importance of seeking prompt care, even with a child with vague or mild symptoms, needs to be provided.

The lack of information is made even clearer by the fact that very few of the participants stated ever having received any kind of formal education or information about malaria, its symptoms or the need of treatment. This among a population of mostly mothers, of which many had recently been in contact with the health care through antenatal- or maternity care. Also, out of the children having received previous treatment for malaria, a greater part had symptoms for more than one day before seeking care than among children having their first malaria episode. This implies that participants having sought care for malaria at a previous occasion had not been informed at the health care facility about malaria and the need for early treatment. Further, very few of the caregivers stated that they had gained any greater knowledge of malaria when seeking care this time at José Macamo Hospital, showing that a very good opportunity for the health staff to inform about malaria is not taken advantage of. Especially since almost half of the participants considered health staff providing information about malaria being the most effective way of spreading knowledge about the disease. Also, even though the participants did not ask for any information themselves, a great share of the participants stated that they would have wanted to learn more about malaria from the staff. This suggests that informing about malaria among caregivers should be made a routine, rather than information being provided when asked for. Moreover, since many participants mentioned talking to people in the community as an important source of information, one could assume that information provided to one caregiver at the hospital might lead to the spread of knowledge among more households in the caregiver's community.

More than informing at health care facilities, an effective way of informing about malaria according to the caregivers was having meetings in the communities. This requires some kind of initiative from people active in the community, a suitable location to hold the meetings and commitment to arrange meetings on a regular basis. One way of achieving

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this might be targeting local decision-makers with power in the communities, like the community leaders, requesting regular health education accessible for all community members. Doing so has been mentioned as the main solution to knowledge-related barriers to care, when interviewing caregivers to children ill with malaria, pneumonia or diarrhea in Kenya, Nigeria and Niger [47].

In addition to the health staff at José Macamo Hospital not informing about malaria in general, some participants also experienced a lack of information about the procedures at the hospital, their child's diagnosis or the reason for their child being admitted to the pediatric department. Similar results have been seen in Gambia where over half of caregivers seeking care with a child ill with malaria did not know what was wrong with their child when leaving the health care facility [49]. Not being informed about why blood is drawn from your child, not being informed about the results of tests made or about treatment given, as well as not being told why your child has to be admitted to receive treatment could be very traumatizing [49]. It creates insecurity and is a probable reason for future distrust in the health care facilities and their staff. As stated above, health staff taking the opportunity to inform about malaria is important in achieving timely care for all children affected. But in order for the information to be truly accepted and assimilated by the caregivers, a sense of trust must be established between them and the health care staff. Further, Thiede [50] stated that "...while trust enhances communicative interaction, it is the process of communicative interaction that generates trust in the first place" highlighting that the issues of communication, information and trust are highly interrelated. Building trust is essential not only in providing acceptable care, but also in creating a platform for successfully informing about malaria and other diseases.

Apart from a lack of trust affecting the interaction between health staff and caregivers present at the hospital, it is also a cause of delaying, or even preventing, people from visiting a health care facility [47, 51]. The same is indicated in our study since the most commonly mentioned barriers to malaria care, both as experienced by the participants

and as their general perception, was in fact lack of attention from and/or distrust in health staff. This further points out that efforts directed towards improving the relationship between health care personnel and the caregivers are of great importance in order to establish a preference for, and a habit of, going to a health care facility when someone is ill. One suggestion could be creating, and providing health staff with treatment guidelines also sensitive to patients' rights, in order to remind the staff about measures needed to provide acceptable care. But even more important is ultimately strengthening the resources of the health care facilities, since high workload, staff shortages and low salaries play a big part in affecting provider-patient relationships [52].

Some of the participants mentioned long waiting times as a perceived barrier to malaria care for children, but our findings at José Macamo Hospital were that the children were attended to and appropriately tested for malaria in a timely manner. Especially inpatient children with severe malaria had in many cases been taken care of, and administered treatment, very quickly. The caregivers interviewed at the triage of the health centre had at the time of the interviews not yet collected the medication from the hospital pharmacy, why we do not know how long time it took for their children to receive treatment. What we can say is that the pharmacy queue was always very long and that people were often observed waiting outside the pharmacy, telling us that they could not collect all of the malaria medication prescribed since the pharmacy had run out of it.

Restrictions in malaria testing were found among some of the participants that had been to a primary health facility before going to José Macamo Hospital. The children that did not receive a malaria test were all presenting with fever when visiting the primary health facility, making the fault of not testing even greater. Receiving no diagnosis or an incorrect diagnosis delayed the children's access to appropriate treatment, possibly worsening their illness, especially since all of them ended up being admitted to José Macamo Hospital. Caregivers' estimate of the severity of their child's illness was in general lower among those who chose to seek care elsewhere before coming to José Macamo Hospital. Still a great majority of these children ended up being admitted to hospital, compared to only 38% among children going directly to José Macamo Hospital. This could either be a consequence of the caregivers underestimating the severity of their child's illness, or the child having a rapidly proceeding illness. But it could also suggest that children going to a primary health facility first were delayed in receiving efficient treatment causing them to have more severe symptoms when coming to José Macamo Hospital. It has been shown that in 2001-2002, only 34% of patients being diagnosed with malaria in Maputo Province received their diagnosis through a blood test [45]. Even though some years have passed, this could suggest that health care facilities in the areas outside of Maputo City, where José Macamo is situated, might lack sufficient RDTs and other diagnostic equipment.

None of the participants went to a traditional healer before seeking care at a health care facility, making the preference for traditional medicine lower than expected, since previous studies in Africa have shown that traditional medicine is often considered first line treatment for malaria [34]. However, some caregivers tried to give the child traditional remedies at home, but none of them due to suspecting their child to have malaria. The remedies were given to treat moon disease (fever caused by the moon) or constipation, thus no one in our study tried any traditional remedy to treat malaria, which further indicates that the use of traditional treatment for malaria in this area is low.

Stigma does not seem to be a problem linked to malaria. All participants answered that malaria is socially accepted, and most participants that suspected their child to have malaria chose to tell someone about their suspicions, and no one stated receiving any judgmental or disrespectful reactions. Out of the caregivers that chose not to tell about their suspicions, no one did so because of any stigma related concerns. There were however several caregivers that expressed concerns about telling other people of their child being ill since this would risk having others affecting the child's illness by witchcraft, causing the illness to aggravate.

As mentioned in the results section, the limited study population does not allow conclusions to be drawn on whether transport possibilities, time spent traveling to clinic or lack of money are barriers to malaria care. But since some of the participants stated having faced problems raising money for transport or finding suitable transport, and even more caregivers mentioned transport problems and lack of money for medication and transport as possible general barriers to malaria care, these ought be considered as probable reasons for people not coming to hospital in time. Not least, these barriers are important to regard especially if considering that people lacking money for transport, having no transportation possibility or lacking money for medication might not come to the hospital at all.

# 6.1 Strengths and weaknesses

This study has multiple limitations. The low number of interviews and consequently the insufficient data makes the external validity of this quantitative study highly limited. With the restricted time frame of data collection and limited number of malaria cases during this season, and in regard of the subject exploring treatment-seeking behavior and barriers to care from a micro perspective, using qualitative methods might have been more suitable. This would however have required assistance from an experienced translator, which we did not have access to. Distributing printed questionnaires would have made it possible to gather a few more participants, however at the time of data collection not many malaria cases were found and only very few caregivers to children diagnosed with malaria were waived due to us being occupied in other interviews. Using face-to-face interviewing, instead of handing out questionnaires, enabled participation in the study of people who were not able to or felt insecure about reading or writing – a group very likely to face barriers to care. In Mozambique were the illiteracy is high, this is an important aspect to consider.

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Studies based on interviews as this one are often affected by recall bias. The information about onset of symptoms, and hence the variable regarding time between onset of symptoms and health care visit, could therefore be somewhat inaccurate. The same applies to the caregiver's appreciation of time from arrival at hospital to the malaria test being performed and to receiving the test result and treatment. Since access to medical records would have required additional authorizations from the faculty of Medicine and the director of the hospital, data regarding hospital procedures were not controlled, i.e. only based on the information given by the interviewees. The caregivers who stated having gone to another health care provider before coming to José Macamo Hospital were not able to state for how long they had waited before going to the first care provider. Because of this, the time between onset of symptoms and seeking hospital care have been calculated based on when they arrived to José Macamo and not the first care provider, resulting in a falsely long duration of symptoms for these caregivers.

The fact that the study, which aims to map factors preventing people from seeking care, is conducted by interviewing caregivers presenting at the hospital is somewhat contradictory and could be considered as selection bias. Targeting caregivers presenting at the hospital, however, made it possible to explore the barriers actually faced when seeking care with an ill child, and not only barriers perceived. It also made it possible to some extent explore how the healthcare itself was experienced by the caregivers. Since Mozambique has large inequalities regarding household economics, the availability of private health care facilities in Maputo drives some people with higher income to those providers, leading to a misallocation of the Mozambican population within the public and private health care. Since a majority of people seeking care at public hospitals such as José Macamo represent the less wealthy, the results based on this study population are not generalizable on the population of Maputo. Because of the very limited number of participants, the results are not even certainly applicable on the clientele of José Macamo Hospital.

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As mentioned in Methods, the example "Distance to clinic or not being able to afford transport" was provided if the interviewee could not answer the questions about experienced and perceived barriers to malaria care. A risk with doing so is influencing the interviewee's answer and consequently receiving a false outcome for that variable. Fortunately, none of the participants provided the examples stated to them as barriers.

Similar studies on barriers to the care of malaria and other infectious diseases have been made in other low-income settings, but to our knowledge not about malaria care in Maputo, Mozambique. Also, most studies that explore access to malaria health care often focus on a single determinant of access, such as distance to health care facilities, availability of anti-malarials, or utilization of health care services. However, access to malaria care is far broader than these indicators, with a range of demand side barriers potentially hindering people from seeking prompt effective malaria treatment. This study aimed to explore a broader range of possible barriers, and with a larger number of interviews during a longer period of time, preferably including malaria peak season in January, it would have been feasible. Given the circumstances and our prerequisites, though, investigating a more limited range of variables would have been more reasonable.

# 6.2 Limitations regarding study conduction

This study became smaller than initially intended due to issues regarding the approval from the ethical committee in Maputo, Mozambique. Waiting for the approval delayed the start of the project and shortened the time for data collection.

# 7. Conclusion

According to our study, the most important barriers to malaria care are incorrect perceptions of malaria, its symptoms and its potential risks. Even after hospital visit, very few caregivers to the children diagnosed with malaria stated to have gained knowledge of malaria, showing that a very good opportunity for the health staff to inform about malaria is not taken advantage of. More information about the symptoms of malaria, and foremost information about the importance of seeking prompt care, even with a child with vague or mild symptoms, needs to be provided.

As many participants also stated health care related problems and distrust in the staff as experienced or perceived barriers to malaria care, those are existing problems that need to be addressed. Implementing measures such as providing health staff with treatment guidelines sensitive to patients' rights and ultimately strengthening the resources of the health care is important to create sustainable patient-relationships built on trust, and subsequently establish preference of seeking care when needed and founding a platform for successfully informing about malaria.

Due to the limited study population, no general conclusions should be drawn from the findings in this study. The study does highlight some interesting occurrences among the caregivers interviewed, however, other studies conducted on a larger scale are needed to get more accurate numbers and discover correlations between caregiver factors and possible barriers to malaria care for children with malaria.

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# 9. Populärvetenskaplig sammanfattning: Hinder till vård för barn diagnosticerade med malaria på sjukhuset José Macamo i Maputo, Mocambique

Malaria är en potentiellt livshotande men behandlingsbar infektionssjukdom, som varje år drabbar miljontals människor världen över. I Mocambique, där denna studie utfördes, är malaria den enskilt största orsaken till sjuklighet och dödsfall, främst bland barn. Här är den mest aggressiva formen av malaria vanligast, med hastigt insjuknandeförlopp som kräver behandling i tidigt skede för att förhindra uppkomsten av svåra komplikationer.

För att minska bördan av malaria i världen är omedelbar tillgång till effektiv behandling för drabbade centralt. Ett mål uppsatt av the Roll Back Malaria Partnership, ett samarbete mellan WHO, UNDP, Unicef och World bank, lyder att människor med malaria bör ha omedelbar tillgång till vård inom 24 timmar från symptomstart. Men i låginkomstländer är tillgången till sjukvård ofta begränsad och människor möter hinder som gör att de inte får den vård de behöver, resulterande i att 24-timmarsmålet för malaria inte uppfylls.

Denna studie syftade till att undersöka vilka möjliga hinder vårdnadshavare stöter på när de söker vård med sitt sjuka barn som sedan får diagnosen malaria samt utvärdera kunskapsläget kring malaria bland vårdnadshavarna. Studien utfördes på ett statligt sjukhus i utkanten av Mocambiques huvudstad Maputo. Vårdnadshavarna intervjuades med ett frågeformulär innehållandes frågor som berörde deras utbildning, arbete, inkomst och hemmiljö, hur de ansåg att malaria uppfattades av andra i samhället samt vilka hinder de upplevt och uppfattar att barn som har malaria kan stöta på när de söker vård.

Majoriteten av vårdnadshavarna sökte vård på sjukhuset senare än 24 timmar från att deras barn börjat uppvisa symptom på malaria. Även de vårdnadshavare som associerade korrekta symptom till malaria eller misstänkte att deras barn hade malaria sökte i majoritet sjukhusvård senare än 24 timmar. Studien kunde inte påvisa att man sökte vård fortare oavsett om man fått information om malaria eller om barnet tidigare haft malaria.

Enligt vårdnadshavarna själva var den främsta anledningen till att de väntade med att söka vård att de trodde sjukdomen skulle gå över av sig själv. En annan anledning var att de trodde febern var orsakad av "månsjukan", dvs. feber som behandlas på traditionella vis och inte på sjukhus. När vårdnadshavarna uppgav både sina genomlevda och sina allmänna uppfattningar om hinder till vård för barn med malaria var de vanligaste nämnda faktorerna hälsovårdsrelaterade, såsom att man inte blir bra bemött av sjukvårdspersonalen och att man inte litar på deras medicinska kompetens. Väldigt få deltagare hade blivit informerade om malaria både före ankomst till sjukhus och under sjukhusbesöket, och de allra flesta kände inte att deras kunskap kring malaria stigit i samband med det aktuella sjukhusbesöket.

Studien är för liten för att dra några långsiktiga slutsatser. Men resultaten pekar på att mer information om symptom på malaria och om vikten av att söka snabb vård, även med ett barn med vaga eller lindriga symtom, behöver tillhandahållas. Vidare är tydlig information till vårdnadshavare som söker med sjukt barn viktigt för att både öka kunskapen kring malaria och för att undvika och förebygga framtida misstro till sjukvården och dess personal.

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